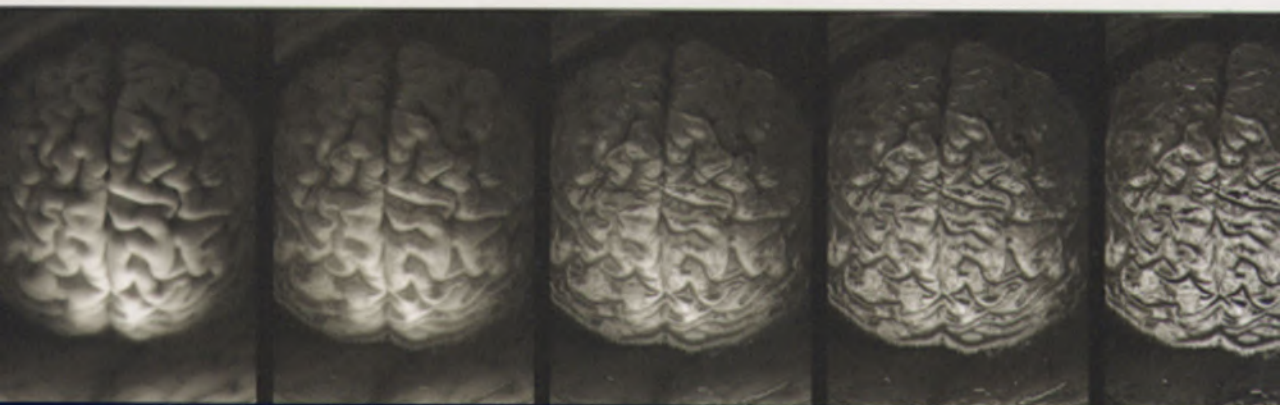


# THINKING ABOUT DEMENTIA



CULTURE, LOSS, *and the*  
ANTHROPOLOGY *of* SENILITY

EDITED *by*

ANNETTE LEIBING *and* LAWRENCE COHEN

# Thinking About Dementia

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# Thinking About Dementia



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# Introduction

## Thinking about Dementia

LAWRENCE COHEN

### Senility and Its Future

Our aims in bringing together the scholars assembled in this volume were threefold. First, we wanted to link a variety of research strategies and disciplinary vantage points in the human and social sciences in order to better understand the remaking—biological and clinical, economic and political, public and phenomenological—of the senile dementias today. Beyond the specificity of Alzheimer's disease or vascular dementia, many of us have been involved in research on what I have long termed *senility*. By senility, I mean *the perception of deleterious behavioral change in someone understood to be old, with attention to both the biology and the institutional milieu in which such change is marked, measured, researched, and treated* (Cohen 1998). For us, as social scientists and humanists of medicine, to organize our conversations around senility in this sense of the word, as opposed to organizing them around dementia, is simply not to presume in advance how perception, biology, and milieu are related. This reluctance to presume, as opposed to any shibboleth of naive social construction, is what makes us careful about terms and what makes our conversation anthropological. But far-ranging and systematic conversations *among* scholars of senility are few.

Second, we presume that the future of senility, and clinically of the dementias, is an open one. Much is changing: state- and corporate-funded pharmaceutical, genomic, and epidemiological initiatives; instruments and regimes of health-care funding and insurance; structures and strategies of treatment and of care and their associated forms of reason; modes of therapeutic and non-therapeutic practice challenging the limits to such reason; differences and inequalities across axes of difference we attempt to capture by terms such as *class*,

*gender, race, and nation*; and the larger frames of the structure of economies and institutions, generations and ethics, and bodies and persons. The perspective of the editors is not to presume that we understand what senility has been and must be—in the home, laboratory, clinic, chronic-care facility, regulatory office, or boardroom—and thus to offer an expert critique. It is rather to put our interpretive and critical tools to work to understand what senility might be becoming. In the case of the assembled chapters, our focus is on the dominant modern clinical form by which senility has been articulated—dementia—and what is happening to it.

Finally, we presume that thinking about dementia is not only a salutary but also a necessary practice to address broader questions: of language, selfhood, and sovereignty; of the structure of care both in general and in the clinic; and of the practices and forms of reason and of life. That is, we hope to begin to reanimate the relation of senility to creative understanding in the human sciences more broadly, to move beyond the solicitous and welfare-driven categories of contemporary gerontology.

We do not wish to claim that these chapters, or this introduction, singly or collectively accomplish all these objectives: such a claim would not do justice to the specific and contingent projects of the authors. But we do hope and expect that bringing these projects together will begin to suggest the contours of a field in the three ways we have outlined. Nor do we claim that we have been able to invite all or even most of the growing number of scholars thinking creatively about senility and dementia to participate in this volume. Our expectation is simply to frame a broader and more inclusive conversation.

Both editors have in earlier or ongoing work focused on what the dementia clinic looks like beyond Western Europe and North America and share as well a sense of critical distinctions in the making and management of dementia within the so-called West. We have asked for contributions from authors who have been trained or are working or doing research in and across a variety of national sites (Brazil, Canada, Germany, India, Japan, the Netherlands, and the United States). The tools and theoretical commitments of these authors differ from one another and from those of the editors, and we have encouraged these contradictions in service of a robust conversation.

The chapters in *Thinking about Dementia* are organized around a discrete set of problems, specific sites of the creative application of technical reason: (1) the emergence of new or reorganized forms of *clinical practice* in dementia given shifts in the dynamic of forces constituting clinical reality; (2) the role of *genomics* in Alzheimer's research and clinical practice, its reconstitution as a media object, and the popular reception and use of such media-driven understandings; (3) the organization of *voice, self, or personhood* in individuals with dementia across therapeutic and experimental milieus as well as the set of forces and forms that constitute both clinical and scholarly attention to "the

person” with dementia; and (4) *the relation between dependency and discipline* in the constitution of senility as what Steven Collier and Andrew Lakoff (2005) have termed a regime of life. Before we turn to a preliminary engagement with each of these sets of problems, we offer some general reflections.

### Senility as a Site for Thought

What do we mean by, as stated earlier, *reanimating the relation of senility to creative understanding in the human sciences*? Simply that the study of senility can and must set out to do more than improve the care and treatment of demented persons: it must use senility to understand the critical stakes in persistent and emergent forms of reason, memory, care, aging, medicine, and life itself. And inversely, we are suggesting that scholars with general commitments to these broad themes would do well to consider senility carefully. We are not dismissing the necessity or value of applied research: most of the authors of the essays collected here make direct or indirect claims upon the everyday structure and management of dementia as an area of pragmatic concern. But at their best they do so by troubling any division between “applied” work and social theory. At stake for the editors is the future of medical anthropology and its allied fields: we are as troubled by a persistent anti-intellectualism masquerading as public or applied research as we are by scholarship that presumes that academic excellence is inversely related to practical relevance.

We want to suggest that senility has had—at various moments and in reference to various kinds of human problems (Rabinow 2003)—this broader relevance for critical thought and application, though by the late twentieth and early twenty-first centuries it for the most part has been reduced to a medical problem.

Such an assertion is banal to the extent that it exemplifies a kind of speaker’s benefit: gerontological discourse has arguably long justified itself by claiming some sort of cataclysmic lack or fallen state it will redress (Cohen 1994, 1998). That senility has been “reduced” to a medical problem—in other words, rendered coherent only as dementia or in particular as Alzheimer’s disease—is not necessarily a bad thing. Several of the authors in this volume attend with extraordinary care to the future of dementia in itself. Others speak to what we might call the “personhood turn”—to the movement, within and among clinical, lay, and academic spaces, to rediscover the person “lost” within the logic of dementia diagnosis and care. And a few engage the conditions under which attention to dementia and to what may be lost in its wake can be conjoined.

Rather, then, than offering a generalized lapsarian account of the impoverishment of senility as an existential figure, we will attempt a partial and undeniably potted genealogy of earlier forms and forums of reason organized in critical relation to senility. These fragments are offered as provisional materials for understanding the present.

### Senility as a Matter of Voice

Of the three great figures of mental anguish that might be said to haunt European thought before the nineteenth century—melancholy, lunacy, and dotage or senility—the first two become central to the reflexive accounting of modernity, whether refigured as alienation and anomie or violence, disorder, and possession. Senility, despite an earlier centrality to figurations of emergent reason in its articulation as dotage or folly (think, for example, of the significance of Shakespeare's *Lear* at the boundaries of sovereignty and nature), comes to be less central to thinking modernity, with the exception perhaps of the imperial representation of colonized subjectivity as age-discordant to civilized norms, simultaneously too juvenile and too senile: the African or oriental despot as both infantile and doddering (Haggard 1887, 1905; Nandy 1983). Senility as the state of ancient civilizations gone to seed, within such fields of colonial representation, becomes a figure disjunctive from the self-understanding of European modernity.

It might have been otherwise. *King Lear* is not an incidental reference: the suffering old person and the quality of his or her speech is a frequent figure within the contest for reason in the Renaissance. When physicians begin to make claims of authority over this speech, they do so in relation to a proliferation of women's voices that are out of place (MacFarlane 1970). The problem of the old voice is feminized as the witch's curse. For the ideologies of the members of the Inquisition and other prosecutors of witches, the dangerous claims of older women's speech suggest devilry. The physicians Reginald Scot and Johannes Weyer—in their contest with the Inquisition for authority—hear the voices of accused witches not as devilry but as a natural process of dotage. The witches are but “doting old women.” Previously a general figure of *memento mori* in earlier medical literature, dotage in Weyer (1991) and in Scot (1964) becomes something more than a sign of the ephemeral condition of worldly life. For the physician, dotage is the epitome of unreason as a natural state, the epitome of Nature itself. Few of these persons would have been demented: the dotage of interest to the physician was both more capacious (older indigent persons in general) and narrower (primarily women) than much later articulations of senility.

Scot and Weyer's interest was primarily juridical: they were engaged in appeals to the prince in contestation with the church over the question of punishment for accused witches. Dotage materializes the stakes in Reformation struggle. There has been no Great Confinement (Foucault 1973): doting women, or men, do not form populations presenting problems of governance. When medicine in Europe will again make claims over senile bodies, much later, in the mid-nineteenth century, it will be to articulate the relation between confinement and norms. Although everything has changed, we again confront a proliferation of senile voices, and these are again feminized. The hospital marks

the age and quality of its population: it registers the shift from young women's hysteria to old women's senile dementia. In the Salpêtrière hospital in Paris, what is at stake is less Nature in itself than its normalization under physiology as an emergent science of life. Jean-Martin Charcot is interested in aging as a process that stands at the border of the normal and the pathological and that delineates the limits to each. In his *Leçons cliniques sur les maladies des vieillards*, Charcot examines the life of the old women of the Salpêtrière as material for the establishment of norms. The old body is critical to the stabilization of life itself as the object of the new biomedicine. But the old *voice*, central to Scot and Weyer's earlier practice of listening against church accusation, fails to awake the imagination here. Charcot's (1866) theater of clinical pathology comes to focus on a different age, that of the young woman, the voice of the hysteric. Later fin de siècle and modernist accounts of pathological modernity remain deeply invested in hysterical rather than senile form. Over the course of the twentieth century, both hysteria and senility become marked as disorders of memory. But senility fails, with a few exceptions, to anchor an inquiry in the relation of language, memory, and the self. For Charcot and his successors, senility stands as a problem of life but not of the subject: it no longer *speaks*.

### Senility and Geriatric Lament

Charcot's early-twentieth-century heir, I. L. Nascher, the coiner of the term *geriatrics*, as a distinct form of knowledge and practice, recognizes old age in general and mental debility in old age in particular as marginal sites within a reformulated clinic. The relevance of the aging body to the systematization of normal life has declined since the time of Charcot's clinic. Nascher revives the nineteenth-century focus on old age as a problem of the limit, but unlike Charcot, he frames old age's status as limiting case as an *ethical* problem for medicine. Nascher tells of his turn to the medicine of the aged: he was a medical student in New York, in an institution for the indigent, wondering why his preceptor seemed to be ignoring the repeated demands for attention of an old woman. When his preceptor notes her problem is nothing but old age, Nascher has his epiphany. Because we do not know how to distinguish the normal and the pathological in old age, we cannot listen. We do not know how to hear. The old voice returns as something that cannot be heard. This marginality demands an ethical response; thus, geriatrics, an inquiry into the norms of aging (Nascher 1914; Thewlis 1941). The new field is organized as a lament against silence, and it responds by analyzing the senescent voice into its discrete normal and pathological components. Senility, to be heard within the clinic, is split into the existential condition of "normal aging" and the purified (Latour 1999) pathology of dementia.

The project is progressive: the normal elder, split off from his or her



pathology, can be redeemed as the liberal subject. In practice, the location of the really old simply moves along the life course: for the “old old” or “the frail,” normality and pathology remain inextricably entangled. Yet the hopes of geriatrics fail to materialize for the ever older bodies constituting its subject population: the field becomes recognizable within biomedical culture as utopian and unrealistic. Yet this very utopianism undergirds the centrality of geriatrics and its sister discipline gerontology to the twentieth-century dreamworlds (Buck-Morss 2000) of planned development and state socialism.

With the Cold War emergence of modernization theory and planned development as instruments of state (and the parallel Soviet emergence of a socialist science of international welfare) aging returns as a normed index of modernity in nonclinical forums. Thus the social sciences (in the Western, nonsocialist variant) collaborate on the production of a binary and its resolution: “traditional” societies value the aged; “modern” societies currently and unfortunately do not, but future moderns will value them all the more through the beneficent welfare technology of gerontology (Katz 1996; Ballenger, this volume). Echoing the nineteenth-century colonial tableau of the senile elsewhere, gerontology as a signature apparatus of postcolonial internationalism extends the presumptive ethical project of Nascherian geriatrics as a set of norms for nation-building. The gerontologist Erdman Palmore could thus draw a hopeful “J-shaped curve”: it may look bleaker and bleaker for the elderly—the initial failure of utopia—but fund us professionals and things will get better (Palmore and Manton 1974).

Sociology, anthropology, and social history become of particular relevance to setting the new norms. The social turmoil of the 1970s brings a reaction in these fields against the adequacy of modernization binaries. More nuanced accounts of aging appear in the name of complexity and liberal relativism. But the emergence of a disciplinary apparatus around old age remains unchecked by such nominally critical gestures. On the contrary, the continuation of a debate over whether old age was better here versus there or now versus then extends the normative claims of even the most critical gerontologies (Cohen 1994).

Scholarly imagination is limited because of the massive expansion of the “aging enterprise” as a normative and disciplinary apparatus, as chronicled by Carroll Estes (1979), W. Andrew Achenbaum (1995), and in particular Stephen Katz (1996). With expansion come capital, a proliferation of new audit apparatuses to assess research value, and the increasing delimiting of legitimate gerontological practice by the more empiricist discourses of psychology, applied sociology, and social work. Debates in the human sciences that might have informed a rigorous engagement with age and voice—for example, 1970s and 1980s conversations over the narrative structure of experience—are translated into banal practices. In the case of narrative, social gerontology degenerates into computer-mediated word counts that look more operational and scientific, a putative “narrative analysis” that comes to stand in for serious scholarship.

Despite iterative calls for a critical gerontology, the subdiscipline relegates itself to the (relatively well-funded) margins of mainstream anthropology and sociology, in contrast to other fields predicated on the study of social difference: race, gender, and sexuality. This self-marginalization and effective cultivation of mediocrity allow the foundational lament of Nascherian geriatrics—*no one listens to old people*—to be maintained as disciplinary *ressentiment*.

### The Age of Alzheimer's

Until the 1980s, senility is not central either to a normalized gerontology or to the social sciences and humanities of medicine. Despite persuasive claims for the genealogy of the modern self as a melding of memory and will, senile dementia as a matter of memory loss understandably remains a more peripheral concern to the medical humanities than emergent nineteenth- and twentieth-century disorders of consciousness such as multiple or split personality and traumatic memory loss (Hacking 1995; Young 1995). At stake is a recurring tendency to exhaust the significance of senility in the social fact of old age, a pattern tracked by Jesse Ballenger in this volume. Where change occurs, given a postwar assemblage of norms and forms (Rabinow 1989, 1999) that powerfully links modernity to a crisis of the growing population of dependent elderly, it is in the emergence of an aging public whose members are organized around their independence from the demands of the labor force and the support of children. This independence, though mediated by practices of identification tied to market and electoral incitements, is naturalized as the category of the (progressively older) “young old,” who make up a population framed by its ability to avoid the stigma of physical and economic frailty. By the 1970s the market, more than the welfare apparatus, becomes critical to available forms and narratives of successful aging (Featherstone and Hepworth 1995): over time, what emerges is an assemblage of market and welfare forms.

“Alzheimer's disease” as both a clinical site and a popular citation appears at precisely this moment of naturalized independence and dependency, extending the effects of the constitution of old age as an instrument of welfare to an emergent “aging public” consuming Alzheimer's narratives as a form of dependency anxiety: the problem appears not as an adjudication of values, but as the increasing prevalence of an insidious disease. Ballenger, in this volume, troubles any reading of this shift as an effective conquest of stigma in his rethinking of the recent history of Alzheimer's disease. One of the dynamics of the age of Alzheimer's is its apparent total biologization of senility: internal disease processes become not only the necessary but also the sufficient ground of all reasoned conversation on the recognition of behavioral change in late life.

An example of such reasoned conversation in reference to senility's biologization is the writer John Bayley's (1998) series of memoirs about his late

wife, the well-known novelist and philosopher Iris Murdoch. Bayley deploys the irony of a beautiful mind felled by the unstoppable natural processes of dementia as both a touching art of remembrance and a perverse act of revenge against his sometimes wayward and inattentive and always far more successful spouse. We accede to Bayley's abject version of the end of Iris, as the invocation of "Alzheimer's" offers few other narrative possibilities.

But there are multiple possibilities for rethinking senility's reason, as the contributions in this volume indicate. Abjection may not be the only mode of thinking about dementia, and irony can be deployed in less punishing ways (Cohen 2003). The rise of "behavioral" and "personhood" turns in clinical practice and social science research, the emergence of new forms of literary production and theatrical experiment, the complexity with which the genetics of dementia is interpreted by experts and laypersons alike. These possibilities are rooted not only in what the dominant discourse fails to see but also in on-the-ground changes and the emergence of new social and biological forms. As many of the chapters in this volume differently reveal, changes in the making of demented persons in and out of the clinic both respond, often eloquently, to earlier and ongoing limits of practice, and in so doing generate new sets of problems for future research.

### Shifts in Clinical Practice

The chapters by Janice Graham; by Ladson Hinton, Yvette Flores, Carol Franz, Isabel Hernandez, and Linda S. Mitteness; by Sharon Kaufman; by André Smith; and by Jesse Ballenger address critical determinants in the transformation of clinical practice. Kaufman's chapter comes out of a multiyear study of the management of death on an intensive care unit in the western United States, and building on a set of powerfully delineated case studies, she defines as her object the status of what she terms *dementia-near-death*. This focus on hospital death allows Kaufman to locate dementia within what the sociologist Nikolas Rose has termed *the politics of life itself*. Kaufman notes that "dementia works [in the making of hospital death] in three ways: as a rationale for facilitating death, as a contested feature of what matters about the patient's identity, and as a moral-clinical designation of value when a frail life is perceived to hang in the balance."

That dementia has become a central if contested feature of situated practices whereby differential forms of life are valued and their cessation made comprehensible is one of the critical insights of this volume. Dementia becomes a limit case within a broader biopolitics through which technicians and experts, on the one hand, and citizens, consumers, and caregivers, on the other, struggle to constitute an ethics of life itself. "Dementia has entered the domain of the ethical because the 'fact' of the *person* can be questioned and because, often, death is a matter of a decision. One must choose," writes Kaufman.

Rose (2001), like Giorgio Agamben, Michael Fischer, Paul Rabinow, and several other contemporary thinkers, reworks the legacy of Georges Canguilhem and Michel Foucault to engage the politics of life and death today. Of this group, Agamben (1998) has been the most cited of late, perhaps because his evocation of the death camps of Nazi Germany and of more recent practices of defining brain death to ensure more organs for transplantation at first glance appear most evocative of the contemporary stakes in life itself. Yet dementia, which is complexly central, as Kaufman shows, to the constitution of hospital death as a problem, may be a more compelling, or at the least more generative, exemplar given the strong ambivalence that comes to haunt the value of severely demented life.

This ambivalence, and the structures, norms, and forms that both constitute and are constituted by it, are central to Kaufman's analysis. Less a bald "cultural value" in some vague anthropological sense, it is an effect of a proliferation of techniques and the normative demands they make. "Inescapable today," writes Kaufman, "is the fact that demented life (as all forms of *life itself*) is the object of debate about value; it must be accorded a value. . . . We can choose, and it is our responsibility to choose, because biomedical technique has extended choice to every aspect of existence, . . . including the timing of death. In the case of dementia-near-death, death in the hospital is facilitated or postponed according to a negotiated calculus about the value of a particular kind of vulnerable life in relation to assumptions about the nearness of that life to death."

Kaufman shows how nineteenth- and early-twentieth-century debates over normal versus pathological aging (Charcot, Nascher) are "supplemented" by "ethical, institutional, and economic imperatives about the classification of life-sustaining treatments as appropriate or not." Borrowing Rabinow's (1999) use of the term, one could speak of this mix of historical norms and forms that confront experts and caregivers today as an "assemblage"; Kaufman incorporates not only genealogical materials and technical forms but also the social structural dynamics of families and other more or less institutionalized relations of care.

Ladson Hinton, Yvette Flores, Carol Franz, Isabel Hernandez, and Linda Mittenness write on the treatment of dementia in the "borderlands" of primary care, working in a similar region and managed-care environment within the United States as did Kaufman. But while Kaufman looked at dementia-near-death in the hospital, Hinton and colleagues examine a rather distinct milieu of dementia-in-life, where persons with cognitive and behavioral changes and those who care for them negotiate with primary care practitioners who are often poorly trained in the diagnosis and treatment of dementia and unlikely to seek psychiatric referral, given immense bureaucratic roadblocks.

As Annette Leibing will later note, concerns over the overly cognitive stress of the polythetic definition of the dementias gave rise during the later 1990s to

a (muted) behavioral turn and its accompanying stress on “personhood.” Hinton and colleagues share with many of the authors in this book a commitment to the therapeutic and diagnostic value of this turn. Yet they demonstrate convincingly that what is at stake in the failure of behavior-based diagnosis and the reliance of primary care practitioners on cognitive testing and neurological referrals is not simply an ideological commitment by physicians or families to an exclusively cognitive understanding. On the contrary, both caregivers and clinicians struggle to reach a “good enough” intimacy. Despite this frequent will to mutual engagement, the promise of intimate care repeatedly fails. Hinton and colleagues offer several reasons for this failure, further contextualizing these by structuring their analysis as a comparative study of care groups they identify as either Anglo or Latino.

The dominant reason for failure is structural: the changing organization of clinical time and labor, limited training in geriatrics or dementia care, and a fairly Kafkaesque pattern of psychiatric referral built into long-term medical ambivalence about psychiatry and intensified by consolidating privatized strategies of cost containment. Hinton and colleagues draw on earlier work by Kaufman on the management of stroke to summarize this part of their argument: “[Sharon Kaufman] notes that ‘the structure of social services and health care delivery, as well as their limits, creates the facts, the only knowledge that patients and families have as a basis for decision making and coping with long-term disability.’”

Such available reason, constrained by issues of temporal and fiscal rationalization, avoids ambiguity. Despite the promise of the behavioral turn, Hinton and colleagues point out that it increases ambiguous information for clinicians who are poorly able to manage it. As in Nascher, what is at stake is the failure of the medical binary of the normal and pathological, a failure that within a managerial regime with particularly low tolerance for what is understood as ambiguity demands the persistent separation in everyday practice of the cognitive and the psychiatric. Returning to Kaufman’s assemblage, it may be that ambiguity can only be tolerated under the sign of thanatology. In any event, the juxtaposition of these pieces leaves as an open question the relation of biopolitics and behavior in the current moment.

The focus on “behavior” and, in a later chapter in this book, on “coherence,” suggests a shift of scholarly emphasis away from memory. Yet André Smith’s chapter compellingly demonstrates how complex any dispensation of the cognitive and the behavioral must be. He examines the subjective experience of persons with memory problems who in most cases fail to receive a diagnosis of what they understand as early Alzheimer’s disease or a related brain disorder. Smith, in three of his case studies, suggests that “seeking an evaluation for dementia can be seen as an act of resistance against the stigma of psychiatric labeling.” Resistance here is being used carefully, in sympathy with a

large somatization literature that Hinton and colleagues also cite in noting differences that emerged between their Latino- and Anglo-identified populations. For Smith, “diagnostic categories do not simply describe underlying psychopathologies but also serve to label the moral status of problematic behaviors” in everyday life. In contrast to the sites delineated by Kaufman and by Hinton and colleagues, for these women, dementia’s Kraepelinian form as a purely cognitive and “nonbehavioral” syndrome reduces the ambiguity and stigma of a psychiatric diagnosis. Dementia places the burden of illness in the arena of life itself, beyond responsibility and the threat of a politics—in Agamben’s Aristotelian language, beyond *bios*. For these sufferers, it is this space of life itself, and the hint of a genetic explanation that secures it, that offers a refuge. Memory loss, genes, and bare life line up against the threat of depression as an overwhelming life-in-the-world.

If dementia—whether as the proxy or promise of bare life—comes to stand against the pain or ambiguity of indeterminate relations and values and therefore self-limits its interpretation in the terms of personhood or behavior, the biopolitics of epidemiological reason are a critical site where the stakes in dementia-life are articulated. Janice Graham, in her review of a much larger project, offers through what has been called the “ethnography of the document” a careful engagement with the “culture” of norms and forms whereby epidemiologists can effect a translation apparatus between the distinct languages and practices of different specializations, clinical milieus, and localities and produce dementia in the unambiguous form Kraepelin had attempted to wrest out of Alzheimer’s original data. Graham’s effort is not simply to “deconstruct” the databases she studies, demonstrating the erasures and ellipses beneath the putative commensurability of different data sets, but rather to develop a form of reading them that can both reassert the lost specificities of illness and location and yet capitalize on the power of large data sets. The goal in part is collaborative, part of a moment in which the heterogeneity of the dementias is recognized and, under the sign of pharmacogenomics, new criteria of distinctiveness sought. In an unexpected way, her project exemplifies the “anthropology of incommensurability” that Elizabeth Povinelli (2001) frames as a critical response to late liberalism, and we are confronted with the question of what an illiberal epistemic culture of medicine would look like. In the effort to imagine such a beast, Graham turns to Dumontian anthropology and hints at a different relationship of value to life.

Jesse Ballenger reviews an earlier clinical shift, the rise of Alzheimer’s disease as a diagnostic category, and the clinical and social transformations predicated on this change. Parts of this story have been classically and powerfully engaged by Patrick Fox (1989), Jaber Gubrium (1986), Martha Holstein (1997), and others, but what Ballenger does is to locate the assemblage of contemporary geriatric reason within two closely bound moves: the idealism of a postwar

“gerontologic persuasion” (his reading of the work of Leo Simmons is particularly elegant) and its use of psychoanalysis, and what he calls a biomedical “deconstruction,” meaning in this case an unpacking and distancing, of irreversible “brain disease” on the one hand and reversible disorders, social conditions, and aging *tout court* on the other. Whereas Smith shows the importance for his interlocutors of an Alzheimer’s diagnosis as less stigmatizing than the threat of an affective disorder, Ballenger troubles the ability of a radically biologized dementia to achieve the “gerontologic” dream of a destigmatized old age.

### Genes

What biologization entails, of course, is itself up for grabs. Margaret Lock, Stephanie Lloyd, and Janalyn Prest evaluate a contemporary shift in expert understanding of the genetics of dementia, the correlation of genetic markers with late-onset Alzheimer’s disease, which through the 1980s was still understood as the sporadic, “nongenetic” type of the condition, noting that “genetics is implicated in an as yet poorly understood, complex fashion in late-onset AD, as it is in numerous other common diseases. When making estimates about the susceptibility of individuals to a particular disease on the basis of their genotype and, which is inevitably compounded by the varying “penetrance” of virtually all disease-producing genes, resulting in a wide range of phenotypic effects in individuals, uncertainty is compounded enormously, and the prediction of who exactly is at increased risk is fraught with difficulty.”

Given this uncertainty, Lock, Lloyd, and Prest are interested in the parallel penetrance of what we might term *genetic publicity*. They are troubled by social scientific critiques of scientific and media “geneticization” that presume rather than investigate how variously positioned individuals come to understand the relation of genetics to life. In contrast, they find that “geneticism” characterizes some but by no means all professional and media publicity and that despite this publicity, families and advocacy groups “minimize the contribution of genetics.”

Life in the face of dementia, for both experts and laypersons, is life amid a multiplicity of exigencies. Advances in expert knowledge of genetic susceptibility can constitute one such exigency, but the relevance of such advances, particularly given their failure to date to translate into effective therapy, is contingent at best.

### Subjectivity

Dementia in the early twentieth century is being reconstituted, therefore, through a multiplicity of such exigencies, the various turns described above:



the making of dementia-near-death with the proliferation of life-extension technologies, the behavioral turn, the genetic turn, and what Annette Leibing in her chapter calls the turn to personhood.

The discussion on personhood addresses broader assembled social forms that, after anthropologists Stephen Collier and Andrew Lakoff, we might call regimes of living. For Collier and Lakoff, such a concept addresses a variety of situations that raise questions such as “What is human life becoming?”

By “regime of living” we refer to a tentative and situated configuration of normative, technical, and political elements that are brought into alignment in situations that present ethical problems—that is, situations in which the question of how to live is at stake. Here the word *regime* suggests a “manner, method, or system of rule or government,” including principles of reasoning, valuation, and practice that have a provisional consistency or coherence. To say that such regimes relate to questions of *living* means: first, that they concern reasoning about and acting with respect to an understanding of the good; and second, that they are involved in processes of ethical formation, that is, in the constitution of subjects, both individual and collective. (2005, 23)

What is at stake in this turn to personhood emerges powerfully in the chapters by Athena McLean, Anne Davis Basting, Pia Kontos, Roma Chatterji, and John Traphagan. McLean troubles “clinical applications of reminiscence and developmental understandings of the life course” that read the lack of an apparent “capacity to produce a coherent and authentic life story” as the sign of a loss or failure of selfhood. Working in the northeastern United States in an old-age-care facility with a primarily Jewish resident population, she evaluates patient narratives for a coherence that is presumed missing. Reframing a dominant literature that finds that “considerable loss of coherence occurs, particularly in the ability to create logical time sequence . . . and sticking to the point,” McLean subjects these narratives to formal linguistic criteria for coherence, demonstrating that the story of Mrs. Fine offers “a reasonable narrative structure” and “a socially shared coherence system.” However, as challenges to such formal criteria, gaps and lack of verisimilitude appear. Addressing the latter, McLean makes a strong argument for an analytic shift from “coherence within the text to coherence within the person.” She addresses relational and environmental sources of incoherence, suggesting that the fragmentation of the narrative reflects not only cognitive processes of dementia but also the institutionally mediated fragmentation of a life-world on the ward. Fine’s story is no longer reduced to its status as a departure from the facts and compelling evidence of dementia: given the interweaving of internal (the illness) and external (the institution) sources of incoherence, her story becomes a form of living.



In closing, McLean argues for the necessity not of deconstructive accounts that decenter all meaning but in so doing evade the specific work of text-making such as that accomplished by Mrs. Fine, but of a phenomenology attentive to the production of subjects through language and “coherence work.” Such coherence is not an essentialized quality of a universal subject but a product of specific regimes of labor involving persons within intersubjective milieus.

Anne Davis Basting uses storytelling and theater as experimental techniques in the fashioning of new milieus for coherence work. The *TimeSlips* project created forms of listening and shared retelling in a series of distinct sites in two American cities. Coherence and personhood are neither essentialized absences of Alzheimer’s victims nor presences of heroic survivors-with-Alzheimer’s. They are possibilities within spaces of story-making. Nor does Basting essentialize the redemptive power of narrative: *TimeSlips* is an account of specific techniques, distinct engagements with distinct populations. It is experimental in the serious sense. Like McLean, Basting distinguishes storytelling from reminiscence, questioning the presumption of an earlier and naturalized gerontology that life course review is a necessary and sufficient practice of late life.

*TimeSlips* is not only an experimental form of therapy, both for the person with dementia and for the caregiver; it is also a form of publicity. At stake is the constitution of a public that may identify the loss of memory, continuity, and apparent coherence, and of a familiar voice, with the loss of a possible present, with the end of the person, and with death-in-life. Anthropologist John Borneman (1997) has suggested the reformulation of the anthropological interest in kinship as the study of forms of caring and being cared for. What the pragmatic orientation of *TimeSlips* and its apparent success demonstrates is that forms of care are not merely cultural patterns or individual or collective strategies: *they are critically public and mediated phenomena*. Practices of subjectification involve a theory and practice of mediation.

Pia Kontos approaches the question of presumptively lost coherence from a radically different angle, not by critical practices of listening and of eliciting voice, but by troubling the necessary relation of voice and of language to the constitution of the subject, a turn away from the *presence* of language to the ground of Mauss and Merleau-Ponty, and then from Merleau-Ponty to Bourdieu. Here deconstructive practice is not opposed to a phenomenological understanding: Merleau-Ponty is used to frame a subject in and of the body, bracketing the question of language and the metaphysics of presence. Like McLean, working in an institution with elderly Jews, in this case in Canada, Kontos focuses on the bodily movements rather than the language of residents. Despite the effects of dementing illness, the residents she describes “exhibited selfhood *in the face of severe cognitive impairment*. It is a notion of selfhood that speaks of a complex interrelationship between the primordial and the social characteris-

tics of the body.” Practices of daily life—dressing, praying, dancing, weaving—give coherence and communicability to action. Kontos’s account of an exchange of nonsense syllables between two home residents is powerful in the intercorporeal selfhood it reveals:

Even when speech is incoherent and void of linguistic meaning, in face-to-face interaction there is a smooth and appropriate alternating pattern of vocalizing, as well as gesticulating, back and forth. With the utterance of only “Bah,” “Shah,” “BRRRRRR!” and “Bupalupah,” Abe and Anna were able to communicate without any recourse to intellectual interpretation. There was a fittingness and a meaningful relationship between the rise and fall of their pitch, their pauses, and their postural shifts. . . . What this example illustrates is Merleau-Ponty’s argument that communication dwells in corporeality or, more specifically, in the body’s capability to gesture.

Like Thomas Csordas (1993) and other anthropologists who have used Merleau-Ponty to trouble disciplinary logocentrism, Kontos engages Bourdieu’s revision of this “capability of gesture” as a socially located *habitus*. Her analysis of the class-specific gesture and meaning-making of persons often read as but death-in-life troubles any ethnography of senility rooted only in the phenomenology of the voice.

Roma Chatterji’s chapter is critical in locating these debates over voice, gesture, and the subject not as abstracted ethnographic or experimental argument alone but as forms of engagement with complex and specific genealogies. Regina Pacis, the *verpleeghuis*, or nursing home, in the Netherlands where Chatterji conducted fieldwork, was structured according to explicit phenomenologically based criteria that emerged in relation to the history and economy of the Dutch welfare state and specifically to the wartime and postwar institutional goal of the physical rehabilitation and economic “revalidation” of wounded bodies. Although the meanings of revalidation are reworked (as “reactivation”) given that the *verpleeghuis* residents are not being positioned to reenter the labor market, the old-age home shares with its predecessors a fairly elaborate set of commitments to “phenomenological” techniques of milieu therapy focused on the mindful body in space and time. Thus, despite the division of the institution into somatic and psychogeriatric wards, notes Chatterji, institutional practice and culture are not organized around explicitly cognitive criteria: “*Dementia* as a term, has very little operative significance in the organization of *verpleeghuis* work. Instead it is subsumed within more functional categories that are able to discriminate quantitatively between different kinds of corporeal capability,” notably the ADL, or Activities of Daily Living, scale.

The use of the ADL is of course not limited to such a genealogical frame, and what is critical in Chatterji’s discussion of Regina Pacis is the limit—if one

pays attention to these genealogies of practice—of the adequacy of a putatively Foucauldian critique of such scales as regulative sites of pastoral power. Within the regime of the institution and of its first director, Cornelius Leering, the ADL is mobilized less as a regulative and hierarchized norm of ability and invalidity and more as an index of the coherence of the “public” and the “intimate,” in keeping with Dutch cultural norms of privacy and sociality. For McLean and Basting, coherence is intersubjectively achieved; as for Kontos, coherence is less a matter of language than of the potential for bodily movement in space and time. Leering and the chronotopic structure of the *verpleeghuis* are deeply influenced by Merleau-Ponty and other phenomenologists, and Chatterji draws on Rabinow’s (1989) discussion of French modernity in delineating the assemblage whereby a modernist parceling out of space by function is mapped “onto the phenomenological body of the invalid resident.”

The two wards thus each articulate a different space of intersubjective engagement, a difference Chatterji crystallizes in the story of Mw. Klasen, whose movement troubles the norms of the somatic ward and is successfully transferred. Chatterji tacks between a Foucauldian critique of institutional “dividing practices” and an attentiveness to the technical goals of the institution in producing subjects despite the fragmentation of illness, personal history, and institutional life. “Dividing practices also produce subjectivities. Patients become who they are in the process of interactive reflexivity with others in the ward.” The two halves of the institution offer distinct productions of normalized subjectivity as alternative regimes of life.

While the phenomenological regimes of the *verpleeghuis* may be located within a broader experimental history of European welfare form, Annette Leibing’s chapter examines the temporal specificity of the personhood turn. By the mid-1990s in the large cities of southern Brazil, the new disease category of Alzheimer’s was suddenly “everywhere,” in its wake reconstituting old age as a new kind of life: “something ‘less alive,’ a new kind of being.” Institutions were founded or renamed as Alzheimer’s centers, drawing on the charisma of the category, and within these—despite the formal devaluing of noncognitive, behavioral and “subjective” criteria of evaluation and care—staff experimentation slowly gave rise to norms and forms that seemed to minimize client and caregiver discomfort. What emerged by the end of the decade, according to Leibing, was a shifted focus on “personhood” and an apparent division between “hard” and “soft” forms of dementia expertise: “The center soon had its ‘personhood war’”—it was divided into two kinds of knowledge, with the academic psychologist working in part “in the doctor’s way” (with scales and structured interview) and the “different” (empathetic) doctors forming bridges between the two fractions. This division was given force by claims elsewhere, particularly in Europe, for the internationalism of personhood as a “movement.”

Leibing's discussion goes far beyond the Brazilian case. She locates the rise of the nonperson in the postwar institutional transformation of the global North and the rationalization of psychiatry. She fleshes out the argument for personhood, developing the idea of a biosocial death (related to Kaufman's idea of dementia-near-death) that makes dementia life a kind of devalued bare life and locating pastoral efforts to "rescue" the biosocially dead as a broader feature of turn-of-the-century welfare. Although Leibing shares the commitments of the personhood camp, she recognizes the slippery slope between critical rescue and pastoral regulation and locates the growth of personhood in part in terms of the exigencies of pharmaceutical reason. Whereas the genetic turn has been less productive of pharmaceutical care, the personhood turn promises a proliferation of sites and projects for intervention. Personhood—hitherto the elusive philosopher's stone in discussions of the sociology of dementia—is revealed as yet another life-resisting, death-defying machine.

Like Chatterji, John Traphagan wrestles with the usefulness of a Foucauldian analytic of power, here in reference to state-sponsored efforts in a town's senior center in rural Japan to inculcate new forms of disciplined practice in old age. The center, the Furiiai Puraza, offers classes designed to encourage the "moral ideal" of *ikigai*, which Traphagan translates as practices of self-actualization and which are central to being and remaining a good *rōjin*, an old person. He analyzes the classes and center administration within a broader "strategic field" constituting the good *rōjin*: "At the center of this strategic field of power is senility, which in certain forms represents a basis for differentiation, distinguishing the good *rōjin* from the bad."

Senility marks the failure of a disciplined interdependence. Traphagan discusses both biomedical framings of senility and *boke*, the latter, unlike the former categories, represented as a state over which one has some control. Drawing on Dorinne Kondo's work, he discusses the "pedagogy of self-enactment" that constitutes an ideal self across the life course and that is rooted in interdependency. *Boke* threatens the continued discipline of self-work as one becomes dependent without the apparent possibility of reciprocation.

Traphagan details many other sites where an active and interactive health discipline is encouraged, together constituting the linked practices of *machizukuri*, or town-making, and *hitozukuri*, or person-making. These disciplinary practices are both exquisitely regulative and highly valued by the various subjects they constitute. State officials and planners mobilize them to address the concerns of a growing population of frail and dependent elderly in an aging rural hinterland. Older persons perform "full effort" at their *ikigai* to avoid *boke* and to live an ideal, ethical life; but they also use the performance of effort as "a tactic . . . to manipulate potential positive and negative sanctions."

Traphagan's chapter emphasizes the "isomorphism" of governmental

practices, techniques of self-making, and reflexive understandings of local and national value. Like Chatterji, he engages normalizing practices not only through the optic of power but also as part of a regime of living. What the chapter powerfully demonstrates is how central senility is to regimes of living, which are reorganizing the space of living in rural areas like “Yonegawa,” places we might term zones of senescence: as in the Renaissance England of Reginald Scot, senility becomes a critical site through which persons and relations constituted by shifts in forms of scale and space, labor and population, and care and exchange are rendered both governable and good.

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## PART ONE



# Changes in Clinical Practice





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## Dementia-Near-Death and “Life Itself”

SHARON R. KAUFMAN

This chapter is about the cultural work that dementia does, the sociomedical uses to which it is put in the American hospital at the end of life. I suggest that dementia works there in three ways: as a rationale for facilitating death, as a contested feature of what matters about the patient’s identity, and as a moral-clinical designation of value when a frail life is perceived to hang in the balance. In performing this multiplex work, dementia makes manifest one aspect of the ethics and politics of life itself in the negotiations it elicits about “quality of life,” “loss of personhood” and “diminishing life”; in debates about what constitutes “normal” and “natural” decline toward death; and in cultural ambivalence about whether the end of “meaningful life” is reason enough for death.<sup>1</sup> Dementia has entered the domain of choice; to confront dementia is to be faced with options for maximizing function, minimizing suffering, and organizing care. Decision making is inevitable.

Moreover, dementia, as a mutable category of knowledge and cultural form, obscures the distinction between life and death. In its various stages—early, moderate, advanced, severe, and end-stage—dementia is a condition both of death-in-life and of life-in-death. This ambiguity becomes more profound as the disease progresses, and it lies at the heart of the anguish about what to do. This ambiguity is what makes dementia so compelling for families; so unnerving in the context of the cultural importance of memory, control, and reason; and so unsettling to the existing order of things.

As with other medical sites in which productive technologies are scrutinized by ethnographers, dementia-near-death brings together biomedical and socioeconomic features of contemporary American health-care delivery in novel ways to permit and create a further remapping of the notions of life,

person, and value.<sup>2</sup> Specifically, the normalization of clinical techniques to control the timing of death, the ubiquitous structural imperative of patient and family decision making, quandaries about the relation of the *person* to the body when disease masks or destroys normal consciousness, disputes about the goals of medicine when the end of life is imminent, and the fact that clinical interventions are possible up to the moment of death all converge at this site. That convergence has multiple effects. For example, a new kind of patient population is produced. The ethics of medical and familial responsibility are further complicated.

Canguilhem's prediction that "the science of life no longer resembles a portrait of life" (1994, 317) is a useful starting point for thinking about dementia as a form of cultural production and, more broadly, for adding to an anthropology of "life itself." In their histories of the modern life sciences, Canguilhem and Michel Foucault point out that the concept of *life*, as a specific object of knowledge, to be known through the modern biological sciences, did not exist until the end of the nineteenth century. Foucault writes, "Historians want to write histories of biology in the nineteenth century; but they do not realize that biology did not exist then, and that the pattern of knowledge that has been familiar to us for a hundred and fifty years is not valid for a previous period. And that if biology was unknown, there was a very simple reason for it: that life itself did not exist. All that existed was *living beings*, which were viewed through a grid of knowledge constituted by natural history" (1970, 128; *italics added*).

The idea that life as a process, mechanism, and structure could be studied (and perhaps ultimately understood) owes its emergence to the rise of theories of evolution and owes its expansion to concepts formed through the sciences, first physiology, and more recently molecular biology and genetics (Canguilhem 1994; Franklin 1995). Importantly, by the mid- to late twentieth century, knowledge of the living body and the forms and structures that constitute life, especially DNA or the genetic code, "became intrinsically linked to interventions that transformed those living bodies" (Rose 2001). Life, health, illness categories, and death were objects to be acted on via the instrumentalization techniques that the biological sciences and clinical medicine offered (Franklin 2000; Rabinow 1996, 2000).

Here I explore how cultural meanings about aging, senescence, dementing illness, and the "natural" life span are inscribed in biological materiality and the biomedical techniques that enable us to know what life is. The biological and biomedical, in turn, shape understandings of how the person with dementia is bodily (that is, fundamentally) constituted and provide moral and socio-economic frames for the range of interventions. Uttered today as a gloss for any neurological condition that slowly or rapidly destroys cognition, memory, reflexivity, and expressive capacity, dementia is a modern form of life itself, in the sense that biomedical and related apparatuses are brought to bear on a diag-

nosed condition, transforming "living beings" into victims, patients, and research subjects with a degenerative brain disease and rationalizing a host of management strategies.

### The Changing Relationship of Old Age and Dementia

That both the nature of aging itself and the relationship of old age to dementia have been debated for well more than a century is significant for the contemporary fact that (in the United States at least) dying requires certain kinds of decisions and interventions in order to be considered "good," "natural," or "humane." Whether normal aging is a disease, whether senility in old age is normal, and whether aging per se leads inevitably to death are all questions that persisted long before recent forms of medicocultural negotiation emerged. Although the terms of the debate have shifted since the nineteenth century with the growing sophistication of biological knowledge and with changes in the politics of medical science and the structure of health-care delivery, the debate itself is ongoing (Holstein 1997).

Once a synonym for old age, by the late nineteenth century, the term *senility* referred specifically to the weakness and decrepitude that characterize old age, and it gradually gained pathological connotations (Achenbaum 1978; Cole 1992; Haber 1984). The gradual shift in the perception of senility gave rise to a medicocultural site for debates about the classification of symptoms, behaviors, and old age itself and, especially, whether old age was a normal physiological process or a pathological condition. When, in 1907, Alois Alzheimer described the clinical condition that bears his name, dementia associated with old age was still considered a normal, expected part of age-related decline. The normal aged body, regardless of how healthy or diseased, was characterized by that particular pathological sign (Herskovits 1995; Katz 1996, 44). "If old age was a period of progressive decline, then the signs and symptoms of dementia were expected, if not inevitable, a "normal" correlate of old age. Thus, in what may seem contradictory to modern readers, turn of the [twentieth] century investigators often described 'normal' aging somewhat quixotically as pathological . . . in this way, dementia could be simultaneously 'normal' and 'pathological'" (Holstein 1997, 7).

Physicians practicing at the beginning of the twentieth century found it almost impossible to separate ordinary, normal changes of late life from organic brain disease. In 1909, I. L. Nascher, the New York physician who coined the term *geriatrics*, aimed to separate the concepts of *old age* and *disease* and cut through the debate of the period with the assumption that old age is a normal condition (yet one requiring distinctive medical attention). He sought, following Charcot, to separate "normal senile degeneration" from pathological "softening" of the brain. Yet the separate explanations of *normal* and *pathological*

offered in his foundational text of 1914, *Geriatrics*, are muddled, and he found the task of clinically distinguishing normal degeneration from pathological signs to be impossible (Cohen 1998, 64). Nascher's work, though authoritative in the United States, did not provide definitive clarification about relationships between advanced age, dementia, and decline at the end of life. Debates about pathology and normalcy in old age, especially vis-à-vis mental disease, continued. One theory of aging as a chronic disease was taught in American medical schools at least until the late 1930s (Cole 1992, 207). In the period between World Wars I and II, two opposing views of old age competed for acceptance in American medicine: "One school considered 'senility' a pathological disorder; the other described it as a normal physiological state. In 1941, it remained 'a major problem for science to determine which is correct'" (Gray [1941] cited in Achenbaum 1978, 120).

The move from "senility" to "senile dementia" to "Alzheimer's disease," well documented as the medicalization of senility by social scientists (Fox 1989; Holstein 1997), indicates the gradual decoupling of normal aging from distinct brain pathology. Yet debate remains lively today in clinical medicine and gerontological science about whether Alzheimer's disease is a distinctly pathological state or a quantitative extreme of normal aging (Herskovits 1995). The plaques and tangles that characterize the disease can be seen as well in healthy elderly brains on autopsy and sometimes are not present in the brains of those diagnosed with Alzheimer's. In addition, some of the behavioral symptoms of Alzheimer's (especially those of forgetfulness) can be found in normal, healthy older persons (Drachman 1983; Goodwin 1991; Gubrium 1986). Attempts to distinguish normal aging from discrete medical conditions of the brain plague contemporary researchers and clinicians. Ambiguity about which conditions are normal or pathological is reflected in recent titles from the geriatric and gerontological literatures, such as "Dementia of the Aged: Disease or Atypical Accelerated Aging?" "Geriatric Ideology: The Myth of the Myth of Senility," and "Aging versus Disease: Which Changes Seen with Age Are the Result of Biological Aging?"

The idea of *age-related disease* muddies the waters further and is of interest here because aging and disease, separately or together, can cause death. Arteriosclerosis and the decalcification of bone, for example, are expressions of normal, ordinary human aging "until they progress to a point at which they lead to diseases such as heart attacks, strokes, osteoporosis and renal disorders. How one identifies the point of transition is not clear" (Blumenthal 1993, 1272). Arteriosclerosis can be thought of as disease or as normal aging, depending on the definition of aging (Forbes and Hirdes 1993). Some scientists and clinicians propose that aging and disease be viewed as a continuum rather than as discrete categories, using the example that there may be a continuum of brain lesions from normal aging to Alzheimer's disease just as there is a continuum of arte-

riosclerotic changes from normal to disease entity (Forbes and Hirdes 1993; Von Dras and Blumenthal 1992). For instance: "[F]rom the biopathological perspective, virtually all of the lesions associated with dementia . . . are commonly seen in the non-demented aged as age-dependent lesions. And in both non-demented and demented subjects various combinations of these are also commonly encountered. . . . The aging-disease relationship with respect to dementia has also been regarded as a threshold phenomenon in which dementia occurs when aging changes exceed a particular limit" (Von Dras and Blumenthal 1992, 286).<sup>3</sup>

### **Dementia, Death, and Value: The Ethics of *Life Itself***

While those debates continue, they have been joined in recent years by a new set of concerns about the relationship of dementia to death, to quandaries over life prolongation, and to the widespread desire and bureaucratic need to control the timing of death. These concerns are born of the fact that, first, feeding tubes, antibiotics, and surgery of all kinds can and do extend demented lives for prolonged periods; and, second, memory, consciousness, and the modern task of self-making are considered essential to being fully alive (Cranford and Smith 1987; Foucault 1970, 1974; Giddens 1991; Taylor 1985). Dementia has entered the domain of the ethical because the "fact" of the *person* can be questioned and because, often, death is a matter of a decision. One must choose. The discourse of apocalyptic demography—namely, Alzheimer's is "the disease of the century"—coupled with the widespread fear of losing one's mind, feeds concerns about whether, and when, one should choose death—for oneself or for another. The late-nineteenth- and early-twentieth-century attention to the classification of symptoms as normal or pathological has been supplemented today by ethical, institutional, and economic imperatives about the classification of life-sustaining treatments as appropriate or not. Considerations of the "rightness" of prolonging life or of dying take center stage, as do evaluations of the "right" time to die and the temporal nearness to death of the demented person. These considerations are further troubled by questions about when "dying begins," the moral and clinical relevance of subjectivity to life prolongation, whether the person with dementia is still "alive," and which medical interventions contribute to or relieve "suffering." *Dementia-near-death* problematizes the subject in an unprecedented way.

Inescapable today is the fact that demented life (as all forms of *life itself*) is the object of debate about value; it must be accorded a value. The "new ethics of biomedical subjectivity" (Novas and Rose 2000, 502; Rabinow 1996, 2000) can be characterized by disputes over value, which are made apparent, first, in the ubiquitous discourses of "quality of life," "the right to know," the "right to choose," and "risk assessment" that penetrate so deeply in the affluent sectors

of Western societies and, second, in the life strategies opened up through biomedical techniques (such as assisted reproduction, genetic screening, mood-altering drugs, and plastic surgery). One's biological destiny, and that of one's progeny, is no longer fixed and immutable. Prevention, enhancement, and intervention are possible, even into advanced age. We can choose, and it is our responsibility to choose, because biomedical technique has extended choice to every aspect of existence (Rose 2001, 22), including the timing of death. In the case of dementia-near-death, death in the hospital is facilitated or postponed according to a negotiated calculus about the value of a particular kind of vulnerable life in relation to assumptions about the nearness of that life to death.

### The Clinical Articulation of *Forms of Life*

The disease category *advanced dementia* is a window onto changing knowledge about the organization of *life itself*, and those changes are revealed in the ways clinical medicine grapples with what to do (because it must do something) in the face of death. Two examples highlight the unstable understandings of this form of life:

1. In response to the exponential growth of the use of feeding tubes in persons with advanced dementia, therapeutics took a stand in 1999–2000 and changed course. The *Journal of the American Medical Association* and the *New England Journal of Medicine* published statements reflecting new medical thinking about the treatment of that condition. Contrary to standard U.S. clinical practice of the preceding two or three decades—which had considered tube feeding by percutaneous endoscopic gastrostomy (PEG) as appropriate therapy to prevent aspiration pneumonia, prolong survival, reduce risk of pressure sores or infection, improve function, and provide “comfort”—academic clinicians and geriatric researchers decided that tube feeding did none of those things (Finucane, Christmas, and Travis 1999; Gillick 2000). Evidence had accumulated from a series of clinical studies that food and water given by feeding tube to persons with advanced dementia caused rather than ameliorated suffering and did not contribute to the extension of life, regardless of whether that life was considered “meaningful” by any standard. Thus tube feeding was no longer appropriate and necessary medical care for persons with advanced disease.

The authors of both articles were careful to note the limit of their claim—only in *advanced dementia* was tube feeding no longer medically indicated. Yet in their reflections on the clinical evidence, the writers of both these state-of-the-art articles made sense of advanced dementia in a new way—as a form of life that has lost all potentiality except the move toward death. Its reconfigured characterization, being near death, justified

and rationalized the withholding of nutrition and hydration at the same time as it reorganized value about this kind of life. This general pronouncement, however, did not immediately eradicate or ease dilemmas associated with the goals, on the ground, of caring for any individual patient or one's own family member.

2. In a study to examine treatments and survival of patients with "end-stage dementia" following acute illness, researchers documented the interventions received by 216 hospitalized patients. The rationale for conducting the study was as follows: "An estimated 1.8 million people in the United States are in the final stages of a dementing illness (e.g., Alzheimer disease, vascular dementia) and are unable to recognize family, dependent in activities of daily living, unable to communicate, and experience repeated infections and other complications. Despite the prevalence of advanced dementia, little is known about the prognosis of patients with this condition who develop a superimposed acute illness (e.g., pneumonia)" (Morrison and Siu 2000).

The researchers found that advanced dementia is not viewed as a terminal diagnosis by physicians or families, that patients with end-stage dementia receive "as many burdensome procedures as cognitively intact patients," and that there is an absence of awareness about the poor short-term prognosis for these patients. They suggest that efforts be turned to the provision of palliative or comfort, rather than life-extending, measures.

Both these examples reveal how clinical medicine is working out an understanding of and an approach to this form of life. Moreover, both engage, at the same time as they attempt to end, one aspect of the societal debates about what forms of life are worth sustaining, why, and for how long.

In a different sort of articulation expressed beyond the clinic, *advanced dementia* is juxtaposed with *early dementia*. Both designations, *early* and *advanced* dementia, are noteworthy for the distinctive ways in which they reorganize societal understanding of this disease by incorporating death into their schema. *Early* dementia further specifies this form of life that pushes decline, disease, and death earlier into the life course. On the one hand, the specter of genetic testing opens the possibility of "living with" dementia for years prior to the appearance of any symptoms. On the other hand, contemporary understandings—that the disease progresses via the loss of abilities acquired during infancy and early child development—brings death into life slowly. It is generally acknowledged that the death of the *person* and the *self* will occur in stages that can be differentiated over a protracted period of time. *Life* will diminish via a pattern of developmental regression (Reisberg 1999; Shenk 2001) at the same time that *death* will advance within the person and the person's body.

Dementing illness is widely characterized as a process that slows down



death. The novelist Jonathan Franzen (2001), reflecting on the death of his father from Alzheimer's, notes that the disease is like a prism that refracts death into a spectrum of its parts: death of autonomy, death of memory, death of self-consciousness, death of personality, death of the body. These features of the disease can be considered separately, even when they are observed to occur together, so that the phased death of the demented person is exquisitely described as the disease worsens. With the diagnosis of early dementia, the process of dying takes place over decades and is reflected in such well-worn phrases as *death in life*, *death before death*, and *never ending death*.

When the condition becomes *advanced* and is accompanied by other life-threatening illnesses, consideration of techniques for allowing death vie with those of prolonging life, as the preceding examples from the medical literature show. The medical pronouncements, that tube feeding is no longer humane or efficacious for extending life and that comfort measures should be employed for end-stage disease, are often irrelevant for family members struggling to sustain a valued life. Those pronouncements are sidelined by staff concerned with honoring family demands. Moreover, in the hospital, that new knowledge cannot compete with the initial press to prevent death. Most often death is not named as possible or inevitable until shortly before it occurs. Thus, when death is finally pronounced as an impending truth by medical staff, the "choice" to withdraw or withhold therapies makes dying appear, to families, to be "speeded up."

### Negotiations about Life when Death Is Near

I now turn to ways in which dementia is invoked and ignored in the hospital at the end of life and the ways in which knowledge about the demented person, disease, life itself, and the worth of a particular life come together for negotiation. The hospital practices in which dementia is implicated provide one example of how clinical medicine governs the end of life and how death is elided with ways of knowing life. The following two stories of patients' pathways to death are common, and they reveal the tensions surrounding the protection, extension, manipulation, and demise of that kind of life. Highlighted in these stories are the "choices" confronted by family members, who often feel they are being asked to choose between "life" and "death," as though those notions were equally weighted. Confusion between inexorable decline, possibly hastened by dementia, and disease that may be arrested by medical interventions confounds that choice, and families often refuse to choose anything at all. Staff, by contrast, feel the pressure of the hospital system to move things along to death when they know it is inevitable. Within the rules and norms of the hospital world, families and medical staff each engage the patient's life with different sensibilities about the relevance of dementia, along with other signs of end-stage disease, for calculating an appropriate time for death.

### **Acute Disease, Heroic Intervention, Organized Death: Dorothy Mason**

HOSPITALIZATION, DAY 1: At ICU (intensive care unit) rounds, I follow the team to the bed of Dorothy Mason, and the doctor tells me that she arrived last night from a nursing home with "bad pneumonia, bad lung disease, and Alzheimer's disease. I don't know how she got here," he says, "but her son was with her. He wants everything done." The nurse assigned to her tells me, "If this were my mother, I'd let her go. I don't know why the son is doing this—guilt? need? If she doesn't get better, the doctors will begin to talk to the son about taking her off the mechanical ventilator and letting go, but not until she doesn't start to get better." Another nurse says, "She came from the nursing home extremely malnourished, weighs seventy-five pounds, and looks like she arrived from Auschwitz." All I can see is the head of a very frail old woman who is connected to a breathing machine and to several intravenous lines for fluids and medications. Mrs. Mason is seventy-nine years old. Someone at the nursing home called the paramedics when Mrs. Mason was observed to be in respiratory distress; she was brought by ambulance, with high-flow oxygen, to the hospital emergency room and intubated there.

DAY 2: The lens through which all hospital patients are viewed is colored by the imperative to move them efficiently along one of several treatment pathways—to life-saving treatments, to cure or stabilization, or to death. Several nurses sketch a sociomedical portrait of Mrs. Mason for me. "She's a 'no code,' but still on the vent and getting nutrition and care. We just won't do CPR [cardiopulmonary resuscitation]," I am told. Another nurse says, "She was made a no code at 10:00 P.M. last night. Up to then the son wanted everything done. The doctor talked to the son earlier, then at nine o'clock last night he went to him again, explained the situation again, and asked him, 'Would you really want us to pound on her chest and crack her ribs?' That's when the son reluctantly agreed it was OK to make his mother a no code." Later, the nurse on the evening shift says, "The son made the decision to continue full-out antibiotics for twenty-four hours. If there is no improvement by tomorrow, he'll consider withdrawing care. He has moved a lot, from thinking she was a viable hospital patient to acknowledging that she might die. He's come far."

DAY 3: There is no improvement. Mrs. Mason is not responsive, though her eyes open sometimes and she seems to look around the room, but nurses tell me that she cannot purposefully move her eyes; there is no intent behind the look, no *person* behind the stare. That clinical judgment—that the patient is not fully, really alive—often contradicts the opinion of family members, who tend to see purposefulness in small movements and to think that the conscious person they knew before the crisis is still there, hidden within a sick body.

Mrs. Mason's son wants to continue antibiotics for an additional twenty-four hours to "see what happens" and then consider withdrawing life-sustaining treatments. The patient's nurse for today confides to me: "She should never have been put on a ventilator in the emergency room. She should have had a nasal cannula, and then she would have eventually died, peacefully. . . . She has had Alzheimer's disease for a long time and has been incontinent for a long time. She came in with bilobar pneumonia [pneumonia in both lobes of the lungs]. In the nursing home they weren't treating it, which was wise on their part, but she wasn't supposed to die, because she wasn't made a no code." The nurse goes on to say that it is difficult for Mrs. Mason's son to see anything other than a strong mother who has bounced back before: "She had been sort of moving along, incontinent, demented, getting more frail, with lousy nutrition, but not that sick. This is the first time he's seen her really sick, maybe going to die. So he can't accept it at first."

DAY 4: At the bedside I speak with Mrs. Mason's son for the first time. He is sitting close to his mother's bed and looking at her tenderly, talking to her and holding her hand. She is unresponsive. He tells me, "She had a living will done about eight years ago, and in it she was clear that she didn't want her dying prolonged. Now it's tough in the hospital because she couldn't have predicted this sort of a situation and I don't know if this is prolonging her life." He had been with her in the nursing home when the nurses there called 911. He had come to the hospital with her. The doctors in the emergency room needed to know immediately if they should intubate her because without mechanical ventilation she would have died. With tears in his eyes he reports that he said, "Yes, go ahead," because he wanted her to live, was hopeful she would stabilize, and could not accept being singled out to be responsible for her death at that moment. Although he made that decision quickly, he tells me he agonized over it. "It isn't her time yet," he says and tells me she had been hospitalized a year earlier and had "come back" from other crises. "She is tough." But he would not want her to live indefinitely on a ventilator and neither would she. He only wants her to have the opportunity to get better, to get off the ventilator.

"You're not seeing the really tough decision points," he tells me. "They happened earlier. My toughest decision was moving her from home to assisted living eighteen months ago." She had covered up her Alzheimer's disease well. "She was social and she had a good sense of humor." He knew things were changing, but he did not know how bad things were until about a year ago when he moved her to the nursing home and she was diagnosed with advanced Alzheimer's. Regarding the hospital requirement for a "code status" decision, he volunteers that he made his mother a no code. He says to me, "Some families might think making a no-code decision is participating in killing the patient, but I don't think so." (He does not mention what I was told two days before by

the medical and nursing staff, that he had had to be talked into making that decision.)

DAY 8: The nurse calls me to the bedside, dramatically pulls the sheet off Mrs. Mason, and says, "Look at this." She has been trying to turn Mrs. Mason and is having a great deal of difficulty. Mrs. Mason's limbs are so contracted, her legs so tightly wrapped around one another, that the nurse cannot disentangle them. Mrs. Mason is not responding to the nurse's maneuvers or to our conversation. I am looking at emaciated legs with the skin hanging directly on bones that look brittle, as if they would shatter if they were touched. I have never been this close to such frailty.

DAY 10: Mrs. Mason's son continues to want "aggressive" care, that is, continued mechanical ventilation, nasogastric tube feeding (use of a thin tube inserted through the nose that delivers nutritional liquid to the stomach), and antibiotics for the recalcitrant pneumonia. The medical staff is trying a different antibiotic. I go to Mrs. Mason's bedside with a technician who is going to draw her blood. He speaks to her in a loud but caring voice, close to her face, telling her what he is going to do, and she turns her head to stare at him. I reintroduce myself, and she turns to me and stares. But she does not respond in any other way or even blink.

At the bedside I speak again with Mrs. Mason's son and also with her daughter, who has just arrived from another state. Mrs. Mason is looking at her children, that is, her eyes seem to focus on them, but I cannot be sure. It is impossible for me to tell if she is hearing and then comprehending our conversation, because she is so unresponsive. The nurse comes in to draw her blood. Mrs. Mason's son and daughter both repeat to me that they do not want their mother to be on life support. I am not sure if they realize that their mother is, indeed, on life support.

DAY 12: The intensive-care doctor mentions to me that Mrs. Mason's kidneys and other organs are beginning to fail. Her family doctor discusses her failing condition with her children for some time and urges them "to withdraw ventilator support and let her die." They listen and agree. She dies shortly after the ventilator is withdrawn, with her children, the family doctor, and the intensive-care specialist at her bedside.

### **Slowing Diminishing Life, Debate about Life: Nhu Vinh**

BACKGROUND: Mrs. Nhu Vinh's medical condition was not unusual; nor was the response to it of her daughter, Mrs. Tran. Mrs. Vinh, age eighty-four, had been diagnosed with Parkinson's disease six years before her current hospital-

ization, though in retrospect, Mrs. Tran tells me, her mother had had symptoms long before the diagnosis. Shortly after her diagnosis, she needed round-the-clock care at home, which Mrs. Tran arranged with attendants. But, Mrs. Tran says, her mother still had “quality of life.” She could go out to family functions and enjoy herself. The past two years, however, had become much more difficult as the disease had progressed. Mrs. Tran relates the story of her mother’s decline while we sit together in her mother’s hospital room. She has just washed Mrs. Vinh’s long gray hair and is spreading it out across the pillow as her mother lies sleeping. It is a warm day and Mrs. Tran has turned on a fan to help dry her mother’s hair. Mrs. Vinh is breathing through a nasal cannula. Her hands, visible above the sheets, are extremely contracted.

In the months before her hospitalization, Mrs. Vinh could not walk. It took three or four hours to feed her each meal. The attendants, whose work Mrs. Tran supervised closely, would spoon pureed food into her mother’s mouth and they were extremely careful to watch that she swallowed each mouthful. Mrs. Vinh had become incontinent and demented. But she could still interact with her daughter. Six weeks before I met the patient and her daughter in the hospital, the home attendants, doctors, nurses, and speech therapist who were caring for Mrs. Vinh all agreed without debate that Mrs. Vinh was not getting enough nutrition and needed a feeding tube inserted into her stomach.

Mrs. Vinh had the routine, low-risk, low-tech procedure to insert what is known as a *g-tube*. But since that time, Mrs. Tran tells me, her mother has had nothing but problems, especially recurring reflux and fevers. Mrs. Tran says with pride that in the two years prior to the insertion of the tube, her mother was not hospitalized and nothing had ever gone wrong.

ADMISSION TO DAY 6: After six weeks of problems following the placement of the feeding tube, Mrs. Tran admitted her mother to the hospital. Mrs. Vinh had pneumonia from aspirating her own secretions, and in addition the *g-tube* had accidentally moved (“migrated,” in medical language). Upon admission to the hospital, physicians treated the pneumonia and suggested replacing the *g-tube* with a tube inserted into the jejunum (*j-tube*), the small bowel, in order to avoid the regurgitation and possible aspiration of food into the lungs.

The procedure would require general anesthesia, and Mrs. Tran debated, along with her large extended family, whether the surgery was the right thing to do. They finally decided to go ahead with it. “This was a very, very hard decision, because we knew she was a high-risk surgical patient,” she tells me. Mrs. Tran is adept at quickly translating her way of knowing into language that American health-care providers can easily understand, and she explains that for her family, as Buddhists, and as Asians, the decision was not based on quality-of-life considerations—“My mother hasn’t had any quality of life for two years.” The family simply wanted to prolong Mrs. Vinh’s life. However, they did not want to

do anything that would create pain and suffering. They had decided previously that Mrs. Vinh would not be put on ventilator support if she could no longer breathe on her own, and she would not be subjected to CPR if her heart stopped beating. Other than that, her life should be maintained. Mrs. Tran explains these decisions and adds other things she wants me to know about her. Her father had been a well-regarded Buddhist practitioner. She had come to the United States from Vietnam thirty-five years ago. Her very young grandchildren, she says proudly, speak Vietnamese. She has a disabled cousin whose care she supervised for many years. She herself works in a health profession and has taken a leave to care for her mother. She is spending most of her time, day and night, at her mother's bedside.

DAY 7: The surgery, which took place the day after Mrs. Vinh was admitted to the hospital, was not complicated, but Mrs. Vinh has not been doing well since then. She has not regained her previous physical condition and mental state, as the medical team and family had hoped. The doctors treating her have written in her medical chart, "end-stage care," "dementia and chronic vegetative state," and "continues to deteriorate." The physicians tell Mrs. Tran that her mother's condition is deteriorating, that she will not survive. She was still aspirating, despite the j-tube, so she could not be fed through it, and Mrs. Vinh is now receiving antibiotics, food, and morphine through an intravenous line, a situation that cannot go on indefinitely.

Expressing both her convictions and her ambivalence, Mrs. Tran tells me, "My mother is a fighter. She wants to live. I know this about her very deeply. All of this talk about quality of life is not relevant. She wants to live, even in this condition; that is why she struggles to breathe so much; that is why they gave her the morphine, to make her breathing easier. But I don't know. Maybe they just should give her more morphine till she stops breathing. . . . I want her to live, but I want her to be comfortable." Mrs. Tran's brother is on his way to the hospital from his home in another city. Mrs. Tran says that her mother is waiting to die—waiting for her son to come and see her.

Now, six days after the surgery, the medical team wants to stop giving Mrs. Vinh infection-fighting medications and move her along to her death. They assume she is not conscious and know she is at the end stage of her disease. They see no reason to prolong her dying and perhaps cause her to suffer. They want to create a comfortable death. The hospital social worker tells Mrs. Tran that the staff wants to meet with the family as soon as her brother arrives. Mrs. Tran, quite familiar with predictable (and desired) hospital pathways, asks rhetorically, "Why do they want to have a meeting? We've already made her DNR [(do not resuscitate) order] and no intubation. I am ready to take her home if she can be discharged. I can handle it. I am set up for it with new caregivers. My mother didn't have oxygen at home before, but we'd get it this time, and I'd learn how to

do it. This is not a problem. We've discussed everything already. There is no need for a meeting. Why do they want a meeting? It's because they want to tell me that if they take off the oxygen mask she'll die more quickly. That leaving on the mask is prolonging her life. It's just like the ventilator. If you remove the mask, she'll live maybe a few hours, or a few days or a few weeks, but she'll die sooner. That's why they want to have the meeting." Mrs. Tran is quite aware that the medical team views her as the obstruction to a quicker death.

The Vinh family conference was scheduled to take place as soon as the son arrived. The conference follows the standard format for medical staff communication with families: medicine speaks what it understands to be the truth about the patient and outlines the proper course of events, and the family is expected to understand, to agree, and "to get with the program." The doctor, an immigrant from China, speaks first and begins by reviewing the patient's medical condition. He is thoughtful and describes her condition as best he can.

MD: We removed the g-tube but now your mother is having problems with the j-tube. We're treating her with antibiotics. She was in the ICU for a day or two, intubated. She still has pneumonia. That is not going away. She still has off-and-on fevers. Her breathing is more labored, more fast and shallow, because she doesn't have enough oxygen in her lungs. Basically, I'm sorry to say, she's not doing well, and I want to give you a true picture. This situation is difficult for everyone and for the medical profession as well. I'm afraid she's going to die very soon. She almost died already a couple of times. We have no way to treat her condition. I'm afraid she's going to keep aspirating because of her secretions, even if they suctioned her around the clock. Regarding her nutrition, we are hoping the j-tube will work. But meanwhile we're giving her IV [intravenous] feedings—it is life support. We can do this short term but not long term. To me this is not in her best interest. She's not communicative. She is demented. We can keep her alive a little while, though even with the best management, she can die anytime. There's really no good treatment for her difficulties. My recommendation is that we should keep her comfortable, keep her mouth from getting dry. I recommend that we cut down on the oxygen. She's getting fourteen liters at the moment—that's a lot. And stop the antibiotics and let her go to sleep. Let nature take its course. I'm very sorry. She's lived a full life. She's very near the end of her life at this time. There's no more quality of life. Most people in her condition would have died by now.

MRS. VINH'S SON: Quality of life?

MD: She's not aware of her environment. She doesn't demonstrate anything. She cannot respond in any meaningful way.

MRS. TRAN: Sometimes, in rare moments, when she opens her eyes, when she

hears me talking she turns her eyes toward me. So we can't say that she's totally unconscious. I believe she recognizes my voice.

SON: If you don't stop any treatments how long will she live?

MD: I don't know. Days, hours, months. Her GI [gastrointestinal] tract is not working. She can't absorb nutrients. Antibiotics are not keeping the fever under control.

SON: Is she's suffering? She's not conscious, as you say.

MD: She's not getting pain medications or sedatives.

MRS. TRAN: We are giving her morphine.

SOCIAL WORKER: Are you worried about her comfort level?

SON: I'm basically wanting to know if she is alive. Is she conscious? Is she's suffering?

MD: Well, her body is alive; you're keeping it alive. Her consciousness is minimal. There are gradations of this, of consciousness.

MRS. TRAN: But she's been like this for years.

MD: As far as suffering, I don't think she's in pain, but I can't know for sure. Even if we do everything, I don't know how long she'll live. Most families won't keep someone alive on tube feeding.

SON: What is your recommendation?

MD: Let nature take its course.

SON: What does that mean?

MD: Stop the feeding and antibiotics. Give her a little oxygen for comfort only. Give a little morphine for pain. But let nature take its course. Even with the current treatments, I don't think she'll live more than a few days.

SON: We have some family members missing. We want to meet as a family.

MD: She's in limbo land, between life and death. Regardless of our interventions, she'll die.

SON: It's very important that she has all the comfort.

*(The doctor leaves the room.)*

CASE MANAGER: Absolutely, that's what we want to do.

MRS. TRAN: So we can't talk about discharge?

SOCIAL WORKER: The doctor's job was to give you the medical picture and his recommendations.



MRS. TRAN: Does she have to be hospitalized?

SOCIAL WORKER: That's a hard call. The fever is an issue. Could we set this up at home? You'd have to be trained.

MRS. TRAN: We're talking about a short time until she dies, regardless of what we do; that's what he said. Right?

SOCIAL WORKER: Yes. If you withdraw some of these things we can predict more closely, maybe. But if you keep all the interventions we cannot predict. Whatever you decide we'll accommodate.

MRS. TRAN: Are you in a hurry? Is there pressure? (*Looks to her brother and asks him:*) Can you make a decision now? If we withdraw everything she'll die—correct? She still has living brothers and sisters. Maybe they'll feel that isn't right. That's a big decision.

SOCIAL WORKER: How much time do you need?

SON: Two or three days at most.

MRS. TRAN: One sister is in France. A brother is in New York. You have to realize this is a difficult decision. This is a life-and-death decision. He's saying if we leave everything she'll die slower. If we remove everything she'll die faster. It's still a decision of life and death. I really feel pressure from you.

SOCIAL WORKER: I sense that. But in a few days we need to know.

MRS. TRAN: We want her home.

The conference ends and everyone stands up to leave. Mrs. Tran tells me she is going to leave the hospital for a while. She is not sure what the staff is going to do, but she is going to let her mind rest and not think about this—at least until she comes back in the evening. The social worker says that someone always takes the heat about putting pressure on families, and this time it was her turn, but she did not mind. The nurse case manager goes to see Mrs. Vinh, and it is obvious to her that she has taken a turn for the worse. She thinks the patient will die quite soon.

Two hours later Mrs. Tran leaves me a telephone message. She is crying as she says, "My mother just passed away at 6:20 P.M., and she had the elegance to pass away without her children making any decision."

### **Affirming Life, Allowing Death**

Proactively "shortening" a life is a complicated matter. Where is the line to be drawn between giving permission to stop life-sustaining treatments and aiding the death of another? Families often conflate "not treating" with "causing" death; and that conflation is a source of the anguish that so many associate with hospital death. Most families I encountered strongly resisted authorizing death,

regardless of the specific condition of their relative. They remained hopeful that medical technology and expertise would save life and were reluctant to learn that often it fails to do so. Even though families are told that technological support is only maintaining the bodily functions, not the *life*, of the patient, unless and until they are convinced that it is certain that death will result from a medical condition, the pressure to withdraw supportive therapies can appear to be the same as or akin to outright murder. Much family resistance to staff requests for "decisions" is the result of the connection that families make between killing and withdrawing treatments.

Dorothy Mason, malnourished and with severe pneumonia and advanced dementia, suffered respiratory distress and was rushed to the hospital, where she died after twelve days on a mechanical ventilator in the ICU. Her children thought she could recover from the pneumonia despite her extreme frailty and they advocated for aggressive treatments that the staff considered inappropriate. Her son could not, would not, quickly authorize his mother's death in the emergency department, for that, from his point of view, was what he was being asked to do. Why should he authorize death when emergency medicine saves lives? He hoped for her recovery, ignored her advanced Alzheimer's, did not acknowledge pneumonia as her final illness, and certainly did not "prepare" for her death according to popularized psychosocial scripts. He pressed for continued treatment and struggled deeply with the fact that she would not, could not, be saved if she had a cardiac arrest. Doctors and nurses eventually persuaded him to authorize the DNR order that would prevent his emaciated, demented, and very ill mother from having to undergo a resuscitation attempt. But first he had to ponder for days the relationship of authorizing the DNR order to murder. Only when Mrs. Mason's family physician named death as real, told the family that their mother was clearly dying and would die no matter what, did her son assent to the withdrawal of life-support technologies.

Nhu Vinh, with advanced Parkinson's disease and dementia, was in the last stage of her illness and at the very end of her life when her daughter brought her to the hospital. Knowing her mother was near death, she nonetheless struggled to keep her alive with a feeding tube. To Mrs. Vinh's doctor, the patient was not *alive* in any meaningful sense (she lacked any expressive capability); and that "truth" was indicated by all her bodily signs, including her apparent lack of consciousness. For the doctor, Mrs. Vinh's general condition—very near death—trumped the vagaries of consciousness. For the patient's daughter, Mrs. Vinh was very much alive—she even died *elegantly*. The patient's son wanted to know the operational definitions of *quality of life*, and *let nature take its course* vis-à-vis his mother's condition, since the doctor introduced those concepts. He needed to learn whether her condition could be classified as *life*. Any attribution of suffering would flow from that designation, as would any decision on his part about terminating life. The doctor made the ambiguous point that though the

*life* of the patient is questionable, the family is keeping the patient (or at least her body) *alive*, and that is an *unnatural* (and perhaps pain-causing) thing to do. The patient's son remarked to the assembled group that if the staff was going to place on the family the responsibility for actively terminating his mother's life, then the relatives needed to meet as a family to gather support for such a profound act. The pressure on Mrs. Tran to allow, as quickly as possible, the removal of Mrs. Vinh's life-supporting measures was among the most extreme that I encountered. But the staff felt that they had to respect Mrs. Tran's reluctance, and if Mrs. Vinh had continued to hover at the threshold of death instead of dying shortly after the conference with the family, the health-care team would have helped set up life-sustaining care for her at home.

Physicians sometimes unwittingly offer contradictory directives to families; and a kind of doublespeak, evident in the Vinh family conference, revolves around the mystery of *life*, the difficulty of easily defining life's end point, and the fuzzy characterization of the relationship between the two notions. It emerges in the language that physicians use to explain physiological decline, the absence of beneficial treatments, and the role dementia plays in the nearness to death. It takes the following shape: "Your mother is not actually (or completely) dead, or dead yet, but neither is she alive." Or, "She's not really alive, but we can keep her alive a bit longer." Or, "He has no meaningful life, but we can continue to take care of him." Practically, *life* and *death* merge in this language. *Life* is present, but to the physician, the condition of that life indicates the inevitable transition to death. Families see unresponsive or machine- and tube-dependent patients and have no idea what to make of the gray zone in which their relative hovers. So they prefer not to acknowledge it. They are asked to make decisions, but they have too many doubts about the *life of the person* whom they can see with their own eyes. They cannot follow staff directives without substantial anxiety about what they are being asked to do.

### Conclusion

Both these stories reflect routine responses to old age and disease in the United States and they exemplify common patterns of care and negotiation. In an earlier era neither Dorothy Mason nor Nhu Vinh would have been hospitalized, though specific disease labels might have been attached to their conditions. But today families must imagine *either* impending death caused by some combination of age and disease *or* treatable medical conditions regardless of age and disease. And then they must choose. Staff and family must respond to the life that is being maintained at the threshold of death by enacting what they perceive to be the most respectful and least painful passage to death *or* the best methods for continued maintenance of life. Their negotiated decisions about appropriate intervention and their desire to save life but also to facilitate the

least worst death together discursively operationalize life and reverence for it.

Conceptions of expected physiological processes as the body nears death (for example, that it is normal to stop eating); knowledge of what constitutes the normal progression of dementia toward death; and how evidence for the life of a person is to be judged, and by whom, are all at stake in those negotiations. I have illustrated at another medical site of cultural production that "choice" replaces "nature" when contested life is prolonged by biotechnologies because something can and must be done (Kaufman 2000). But it is a specific kind of moral choice: the potential or suffering or quality of life of this kind of person must be weighed against the finality (and comfort) of death. That choice both results from and affects changing medical categorizations, institutional imperatives to "speed up" or "slow down" death, and deliberation about value. In the ethics and politics of life itself, dementia is one more emergent example of a mutable form.

#### NOTES

1. This interpretation is inspired by the work of Nikolas Rose.
2. Among such other medical sites entailing scrutinized technologies are reproductive technologies, organ transplantation, molecular biology, and genetics.
3. See also Gubrium 1986: "It is not yet possible to clearly differentiate dementing illness from normal aging, and that the attempt to do so is a social construction to create order from the disorderly aspects of living with dementia" (50).

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## The Borderlands of Primary Care

### Physician and Family Perspectives on “Troublesome” Behaviors of People with Dementia

LADSON HINTON, YVETTE FLORES, CAROL FRANZ,  
ISABEL HERNANDEZ, AND LINDA S. MITTENESS

Midway through our interview, Mrs. Jones, whose husband was diagnosed with Alzheimer’s disease two years earlier, began talking about a change in her husband that distressed her—his forgetfulness. My immediate association was to short-term memory loss, a core part of the professional criteria of dementia. She then told us a story about his inability to set the alarm in their house in response to her admonitions to do so. Again, her description appeared to conform to the clinical criteria for dementia, which include functional decline and difficulties with higher-order cognitive tasks that require planning and sequencing (executive functioning). At this point, her story seemed off the central focus of our research: how families understand, manage, and seek help for the behavioral changes of a person who has been diagnosed with dementia. What followed next, however, surprised me. Mrs. Jones described how her husband became frustrated when he was unable to set the alarm, and then proceeded to “vent at her,” which she described as his getting very angry and pounding on the walls of the house. These outbursts occurred often and represented a change from how he had been before he was diagnosed with Alzheimer’s disease. We later learned that despite being very involved in her husband’s medical care, she had yet to mention these violent outbursts to his primary care physician. While the reasons for not telling his physician never became entirely clear, her own nonmedical, psychosocial explanation of his distress, a sympathetic physician who reinforced her interpretation of his behavioral changes, and the realities of a very constrained health-care system all played important roles.

This vignette highlights some of the core issues that will be explored in this chapter, which focuses on the behavioral changes of people with dementia as observed and responded to by families and primary care providers. We use the

term *behavioral changes* to refer to the diverse set of noncognitive symptoms (for example, depression, irritability, psychosis, wandering, agitation, aggression) that fall outside the formal diagnostic criteria for dementia (which emphasize cognitive symptoms and functional decline), yet are common clinical manifestations and are cited by family caregivers as among the most challenging aspects of living with a person who has been diagnosed with dementia (Chappell and Penning 1996; Chenoweth and Spencer 1986). For those interested in the anthropology of senility, primary care settings are important sites for study because that is where most people who suffer from dementia are diagnosed and treated (Small et al. 1997). Yet despite the enormous public-health significance of Alzheimer's disease, "underdiagnosis" and "undertreatment" of dementia is ubiquitous in primary care (Boise et al. 1999; Callahan, Hendriel, and Tierney 1995). This lack of medicalization is striking because it occurs against the backdrop of clinical guidelines highlighting the need for early diagnosis and of considerable optimism among scientists and clinical researchers about the ability of pharmacological and nonpharmacological interventions to delay the progression of cognitive decline and ameliorate behavioral symptoms (Doraiswamy 2003). This disjunction between "expert" knowledge and routine clinical practice raises intriguing questions about how behavioral changes in persons with dementia are valued and responded to in primary care settings, where older adults, their families, and physicians come together. Anthropological perspectives may help us to understand how social and cultural processes influence the occurrence and timing of medicalization of cognitive decline, functional impairment, and behavioral change in older adults who meet criteria for dementia.

This chapter is based on early analysis of interviews conducted with families and primary care physicians who provide care to a person who has received a formal diagnosis of some type of degenerative dementia (such as Alzheimer's disease). To frame our analysis, we use the concept of borderlands. Our use of this concept developed from the observation that clinical encounters in primary care have the potential for intimacy and supportive intervention as well as conflict, misunderstanding, and unnecessary or even dehumanizing medicalization. The concept of borderlands, which was developed in postcolonial feminist discourse, holds together the dual aspects of these settings that are so important to the experience and actions of families and primary care providers. Gloria Anzaldúa describes borderlands as "physically present wherever two or more cultures edge each other, where people of different races occupy the same territory, where under, lower, middle, and upper classes touch, where the space between two individuals shrinks with intimacy" (1987, 19). Her writing, which derives from her own experience growing up as a Latina woman on the Texas-Mexico border, highlights the psychological meaning of living between two cultures. Among other things, this postcolonial situation requires of those who live



in it a tolerance of the ambiguity that results from contact with multiple, sometimes contradictory cultural frames.

The concept of borderlands is relevant to our examination of behavior change among people with dementia and primary care settings in at least three ways. First, behavioral aspects of dementia have occupied a borderland in the history of the professional description and diagnostic criteria of dementia. After years of languishing in the shadows of cognitive symptomatology, there is now a flourishing scientific discourse and debate about dementia behavioral symptoms, their etiology, and their management. Second, in routine primary care settings, “troublesome” behaviors often elude formal medical intervention because of their ambiguous nature. Families and primary care clinicians struggle to clarify, understand, and negotiate care for these changes, highlighting what Sharon Kaufman (1993) has referred to as the boundaries of professional authority. Third, primary care settings can be viewed as contested spaces. They are contested because of the sometimes competing agendas of patients, families, primary care providers, insurance companies, and health systems. Within these borderlands of primary care, families and primary care providers are not passive, but actively resist what they view as oppressive bureaucratic structures or inadequate care.

In this chapter, we will describe two cases that differ substantially in the degree of intimacy and trust that is achieved between family and primary care physician. Despite their differences, each case shows the relevance of borderlands to the experience of families and primary care physicians, with particular attention to how these clinical and interpersonal processes of care are influenced by larger structural forces (health-care bureaucracies, political economy of health care, physician education), which operate somewhat in opposition to “expert” discourse on the diagnosis and management of Alzheimer’s disease and related dementias. Our attention to the structural and cultural contexts of care is influenced by the work of Cohen (1995), who emphasizes the need to examine multiple perspectives, including those of biology, culture, and political economy, in relationship to local contexts and politics of communities and families in order to account for medicalization of senility. The importance of structural constraints in the management of chronic illness in contemporary American health-care settings has been highlighted by others (Good 1998; Kaufman 1993; Kleinman 1998; Mitteness and Barker 1995). These structural constraints, combined with the lack of formal training for primary care providers in the care of persons with dementia and the latter’s skepticism of “expert” knowledge, converge to make the medicalization of noncognitive, behavioral changes less likely. The outcomes are varied, and they are complicated by cultural, gender, and age differences in the clinical encounter. Before discussing the case material, we review historical and contemporary perspectives on dementia behavioral symptoms to highlight their borderland status.



### Nosological Borderlands from Past to Present

In this section we focus on the marginalization of behavioral symptoms in diagnostic criteria for dementia, despite ample data showing that they are common clinical features, and then turn to a description of the reemergence of behavioral symptoms as an area of active scientific interest in dementia research. We will not review the critique of the construction of Alzheimer's disease and other forms of dementia as distinct disease entities (Gubrium 1986; Lyman 1989). Clinical diagnostic criteria for dementia emphasize cognitive symptoms and deemphasize noncognitive, behavioral symptoms. For example, according to the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV), the most widely used diagnostic manual in American psychiatry, dementia is a clinical syndrome characterized by cognitive impairment that represents deterioration from a previous state and is associated with functional decline (American Psychiatric Association 1994). Cognitive impairments are further defined as short-term-memory loss and at least one additional domain of cognitive impairment, such as apraxia, agnosia, aphasia, or loss of executive functioning. There are multiple diagnoses (based on presumed etiologies) that fall under the general rubric of *dementia*, including a cluster of what are commonly referred to as the *degenerative dementias*: Alzheimer's disease, vascular dementia, and frontotemporal dementia. The first two dementia subtypes are much more elaborated in DSM-IV, and behavioral symptoms are not part of the core description of either. Clinicians are, however, encouraged to subtype, specifying predominant behavioral symptoms (that is, with delusions, with depression, or with behavioral disturbance), although this is not essential for diagnosis or billing purposes. While frontotemporal dementia does not have explicit diagnostic criteria in DSM-IV, its clinical description does include an emphasis on changes in personality and behavior (Miller and Gustavson 2000). It is worth noting that one of the core diagnostic criteria for dementia with Lewy bodies, which is not included in DSM-IV but will likely emerge as a diagnostic category in DSM-V, is the presence of visual hallucinations.

The omission of behavioral symptoms from the description of Alzheimer's disease can be traced to the early part of the twentieth century. In a historical review of the social and scientific construction of the Alzheimer's disease category, Cohen (1995), citing Berrios (1990), demonstrates how behavioral symptoms moved to the periphery of the diagnostic criteria for this particular subtype of dementia. Alois Alzheimer's initial description of a patient with Alzheimer's disease in 1906 gave equal weight to both cognitive (memory loss) and behavioral (hallucinations, delusions, depression) symptomatology. Several years later, Emil Kraepelin used this clinical description as the basis for the creation of a disease category bearing Alzheimer's name, distinguishing it from senile dementia, which was first described several decades earlier by Binswanger. As reviewed by Fox (1989), the distinction between senile dementia

and Alzheimer's disease was much debated at the time and over the ensuing years. Fox makes the point that technological developments, particularly the development of the electron microscope, which allowed more detailed study of brain neuropathology, were critical in the elimination of the word *presenile* from the definition of Alzheimer's and paved the way for its description in DSM-III and beyond. However, as highlighted by Cohen (1995) and Berrios (1990), the DSM retained Kraepelin's emphasis on cognitive symptoms in his description of Alzheimer's disease and deemphasized the noncognitive symptomatology that was so carefully documented and emphasized by Alzheimer himself. While DSM-III did include "personality change" as one of the core criteria for dementia, this was subsequently dropped in DSM-IV.

Although behavioral changes are not part of the criteria for Alzheimer's disease and vascular dementia, clinical and social gerontological literature over the past twenty years has continued to highlight their importance. In one of the earliest clinical epidemiological studies, Reisberg and colleagues (1987) found that 58 percent of Alzheimer's patients had significant behavioral symptomatology, with delusions, agitation, day-night disturbance, motor restlessness, and violence among the most common symptoms. Community-based epidemiological studies have also found that mental and behavioral disturbances are much more common in people with dementia compared with their nondemented or mildly cognitively impaired counterparts (Hinton et al., forthcoming, Lyketsos et al. 2000). Early on, studies of families revealed that what was often most disturbing to them was not the extent of cognitive impairment or disability, but the disruptive behavioral symptoms, such as hallucinations, delusions, and agitation (Schulz et al. 1995). Subsequent studies found that these symptoms are associated with elevated caregiver depression and felt burden, increased rates of hospitalization, early institutionalization, excess disability, and higher health-care costs (Beeri et al. 2002; Donaldson, Tarrier, and Burns 1997; Finkel et al. 1998; Norton, Malloy, and Salloway 2001; O'Donnell et al. 1992; Schulz et al. 1995).

Current scientific discourse on behavioral symptomatology contains two alternative sets of theories about etiology. From the perspective of neuropsychiatry and neurology, there is a strong tendency to view these symptoms as brain based, that is, a result of pathological changes in the brain, particularly in neurotransmitter systems such as acetylcholine, dopamine, serotonin, and norepinephrine. In an example of this approach, Jeffrey Cummings has recently published an article speculating that acetylcholine deficiency, which has long been considered a factor in the development of cognitive deficits, is also implicated in the development of neuropsychiatric symptoms (Cummings and Back 1998). This medical approach to behavioral symptoms leads to an emphasis on pharmacological substances as a treatment. In contrast, perspectives on the etiology of behavioral disturbances from a social work and nursing perspective

give greater emphasis to environmental and psychological factors. Cohen-Mansfield (2001), in a recent summary of research, highlights three alternative formulations: (1) behavioral problems as signs of underlying unmet needs or, essentially as idioms of distress; (2) stress/vulnerability causing behavioral problems as a result of a process in which dementia lowers the threshold at which environmental stimuli influence behavior (for example, overstimulation); and (3) learning/behavioral models. This formulation of behavioral problems underpins a set of nonpharmacological approaches to treatment.

To the critical eye, much remains ambiguous about behavioral symptoms. While symptoms such as hallucinations are abnormal, where one draws the line between normal and pathological levels of other neuropsychiatric symptoms, such as depression or aggression, remains unclear. Reflecting this, existing instruments that measure behavioral symptomatology (Cummings 1997; Reisberg et al. 1987) are continuous and do not clearly demarcate “normal” from “abnormal,” leaving uncertainty about where this boundary lies. When symptoms are present, clinicians must rely heavily on the statements of family caregivers, whose reports are filtered through the lens of their own emotional states, biases, and agendas, making older adults with dementia more vulnerable to the medicalization of behavior in response to caregiver distress. Finally, pharmacological and nonpharmacological interventions for behavioral problems, while clearly helpful in some clinical situations, have modest effects overall (Bourgeois, Schulz, and Burgios 1996; Trinh et al. 2003). Nonpharmacological interventions remain underused, perhaps reflecting a bias in research toward a neuropsychiatric (brain-based) view of symptomatology.

### **The Larger Project**

The case studies that follow are drawn from a larger, ongoing study whose overall goal is to better understand patterns of help-seeking and barriers related to behavior changes in people who have received a formal diagnosis of some type of degenerative dementia. Interest in the role of sociocultural factors, specifically gender and ethnicity, led to a comparative focus on Latinos and Anglos. Thus, our study focuses primarily on the social responses to behavior changes after the point of diagnosis through in-depth qualitative interviews with both families (spouses or adult children) and primary care providers (PCP). Families were selected from two sources: a memory-loss clinic at a major university hospital and an ongoing epidemiological study of older Latinos. Interviews are conducted first with family members and then, with the family's permission, PCPs. Family interviews focus on the caregiver's experience of caregiving; the challenges they face in day-to-day care, including any behavioral difficulties; their patterns of help-seeking (both formal and informal); and their experience of care in primary care settings. The interviews with PCPs focus on their experi-

ences in the diagnosis and management of dementia and on their care of the specific person with dementia through whom they were identified.

### The Contexts of Primary Care

As documented by Fitzhugh Mullan (2002) in *Big Doctoring in America*, the field of primary care has undergone dramatic changes in recent years, largely as a result of managed care. Many physicians have given up solo practices to become members of larger groups in an increasingly competitive health-care marketplace. Our data were gathered in a major metropolitan area in Northern California, where a higher percentage of elderly opt for managed-care plans, which restrict choice but often offer enhanced coverage for medications. Most of the clinicians we have interviewed thus far are internists or family practice physicians who work in outpatient clinic settings with typical patient loads averaging twenty-five hundred patients. The percentage of elderly patients on individual physician panels varied widely, from a low of 10 percent to more than 50 percent. Few physicians received specialty training in geriatrics, with most learning “on the job.”

There is great variation across health systems and primary care clinics in the support systems provided for clinicians in their management of patients with dementia and their families. Since few of the PCPs have particular expertise in dementia or psychiatry, the availability and accessibility of referrals to specialists, particularly neurologists and psychiatrists or other mental health professionals, is a major concern. Although neurologists are generally perceived to be available, providers consistently complain about linkages with mental health, and psychiatry in particular. In one system, there is significant integration of physical and mental health care, with a behavioral mental health specialist available on site to assist clinicians. At the other sites, mental health remains more of a “theoretical” than a real resource and is marginalized in these stories except as the object of considerable complaint.

As a result of this, patterns of specialty referral for dementia are heavily tilted toward neurology, with the burden of recognition and treatment for psychiatric problems falling on the PCP. There are also emerging differences between PCPs in urban and rural areas, where access to resources such as specialists; translators; and social and medical programs for the elderly with dementia and their families, such as day care, visiting nurses, and support groups, is much sparser. The lack of access to specialists, combined with problems in finding additional time to deal with both the physical and psychological health of these elderly patients, difficulties in billing for behavioral problems, and limited and expensive pharmaceutical arsenals for treating dementia patients, plus the reams of paperwork and forms required to allow the family to access support, places a heavy burden on the PCP.

The overall approach to managing behavioral problems that we are finding is what one PCP refers to as “reactive care” in which the family is relied upon to seek out help for these “problems.” The primary care office can be viewed as the borderland to which patients, caregivers, and physicians bring their respective cultures—personal, social, and structural—to bear on providing care for the elderly with dementia. Within clinical encounters, families and primary care clinicians often share intimacy and caring at the same time that they struggle to clarify, understand, and negotiate care for the ambiguous nature of behavioral changes, highlighting the borders of professional authority and personal responsibility.

### **The Jones Family and Dr. Henry**

Surveys find that Americans are quite critical of physicians generally, but they tend to hold their own personal physician in much higher regard. Satisfaction and a degree of closeness would seem to characterize the relationship of a number of family caregivers and PCPs we interviewed, including the Joneses and Dr. Henry. Mr. and Mrs. Jones, both retired professionals, are healthy looking, energetic adults in their mid-seventies and have lived in their current home, which is located in the suburb of a major metropolitan area, for nearly as long as they have been married, fifty years. Although they are still active as a couple in many volunteer organizations, in travel, and in social events, Mr. Jones has become more dependent on his wife for initiating and maintaining these activities. More recently, Mrs. Jones took over the finances of the family. With no local family members to help care for Mr. Jones, Mrs. Jones pays caregivers to help out so that she can maintain some semblance of the autonomous active lifestyle to which she was accustomed.

When Mrs. Jones first noticed her husband’s memory loss two years ago, she was distressed by the cavalier attitude of her husband’s PCP in making the diagnosis and felt that the physician was not thorough enough in his assessment. A self-described “go-getter” who is heavily involved in her husband’s care, she sought a second opinion through a memory-loss clinic and had her husband switch doctors to Dr. Henry, in that order. She is quite complimentary when speaking about Dr. Henry, her husband’s current PCP, who accurately diagnosed her husband’s heart condition one year ago, enabling him to get a pacemaker that may well have saved his life. At the same time, she expects relatively little from him with regard to dementia care, in part because she views the neurologist as being “first” (in order of involvement with her husband’s dementia care) and as more of an expert.

MRS. JONES: Dr. Henry seems to want to get on top of all the little minor things before we hit a big problem. He’s got too many patients. I can never keep

him there long enough. But he's the one that if he doesn't know, he'll find out before we come back the next time. He doesn't know about medications. See this Aricept and Exelon and all that. He didn't know much about that—nothing in fact—but he does now.

INTERVIEWER: Dr. Henry didn't know anything about those at all?

MRS. JONES: No. I mean he's a GP [general practitioner].

On the surface, Mr. Jones suffers from what would be characterized clinically as "mild" dementia; he appears quite normal—is extroverted and jovial—and is able to interact in a socially appropriate ways with others. In addition to the dementia, he suffers from heart disease, diabetes, and hearing loss. Despite his apparent cheerfulness, Mr. Jones can become quite irritable and—in the past six months—more physically aggressive. These episodes tend to be triggered by Mrs. Jones's attempts to get him to do things around the house, such as setting the house alarm, or taking his own medications.

MRS. JONES: Like his pills, he said, "I don't know where you keep them." "Take your pills now." I have a card there that tells him exactly what to do in the morning. Turn it over, exactly what to do at night. "Where are they, where are my pills?" "Same place they were yesterday: in the basket on the table." He would get so mad at me when he can't remember how to do his blood count.

INTERVIEWER: And he gets frustrated?

MRS. JONES: Terribly, I really don't think that I should help him step by step because the more I help him, the more he expects me to help him. . . . Right now the big thing that we got going, we have an alarm system in the house and I make him set it every night. It's four digits, which is our secret code, and then two other things that he has to push. I make him undo it in the morning when he gets up. If he doesn't, then he sets off the thing and it's awfully loud. I told the neurologist that's what I was doing, and he says "Fine, that's great," so I feel that the more I make him think, the better off he's going to be. Maybe I'm wrong.

INTERVIEWER: How do you deal with that when he, you know, gets frustrated or angry? How do you . . . ?

MRS. JONES: I don't hit the wall like he does sometimes. Going down the hallway there, *pow!* I don't do that. I just say, "Now think, think."

INTERVIEWER: How often does that happen?

MRS. JONES: (*Crying*) Every day now . . . 'cause he takes pills twice a day.

Although initially Mrs. Jones seemed to downplay the extent and intensity of her husband's irritability, it is apparent here that these episodes are both

frequent and quite upsetting to her. As she put it, “He vents at me.” She understands his frustration and anger as a psychological response to his problems with memory and functioning and his growing dependence on his wife. Reflecting on his difficulties, she says, “Well, I know what causes it. It’s that he doesn’t want to give up his man-in-charge and he has had to.”

Mr. Jones is under the care of both a neurologist and his PCP, yet Mrs. Jones says that she has not discussed the seriousness of these episodes of agitation with either of them. His neurologist sees him infrequently and the visits are brief. Asked why she does not talk to Dr. Henry about it, she drew the distinction between “physical” and “mental” health issues and emphasized that he is the expert in the former, rather than the latter.

INTERVIEWER: And would there be any reluctance to mention the moods, or the irritability, or the swearing to Dr. Henry?

MRS. JONES: Oh no, I could do it, but I don’t know what good it would do. I don’t think he would appreciate me saying anything because his interest in [Mr. Jones] is in the physical part of him, not in the mental part of him.

Although Mrs. Jones clearly has high regard for Dr. Henry, she does not feel that he is “knowledgeable about the disease,” and her husband has enough physical health problems. This attitude was somewhat surprising, as our initial sense of Mrs. Jones was that of a very agentive (that is, assertive and aggressive) caregiver. It is as if she does not want to jeopardize the satisfactory medical care she receives for her husband by being too demanding of the PCP regarding dementia or emotional care.

In important respects, Dr. Henry, a young family-practice physician, agrees with Mrs. Jones’s assessment. Dr. Henry does note that the primary behavioral problems are “essentially surrounding fatigue types of issues and lack of wanting to do very many things, sort of being semiwithdrawn . . . the wife also noted a few instances of a short temper, agitation types of things.” However, he has not seen the Joneses in more than six months—the period during which Mrs. Jones said the venting became worse. He admits he does not really know how severe the “agitation” is, in part because Mr. Jones and his wife seem to perceive these incidents differently:

DR. HENRY: You know, when I was talking to them about this . . . and having him sit there and go, “Ah, I don’t see that,” and having her say, “Yes, I saw it,” and this and that. I take the road that life-experience-wise they’re a lot more experienced than I am. But I always tell all my patients it doesn’t matter the age difference between us, I’m going to be open with you. . . . He [Mr. Jones] totally downplays it. He doesn’t really see it as a problem and I don’t know if it actually is a problem or if it’s just normal spouse conversation. Yeah, I



didn't think that it was something that was concerning enough for me to intervene.

As a participant in this borderland, Dr. Henry has alternatives that are limited not only by structural constraints but also by the limits of what he observes or is told. In this relatively brief two-year relationship, the differences in age, experience, training, and agendas as well as the structural constraints of the medical system both benefit and interfere with adequate treatment of Mr. Jones.

Dr. Henry describes his role as a PCP as that of being an "anchor" for his patients and a conduit for the opinions and recommendations of specialists, which he can interpret for families:

DR. HENRY: I think that my primary role is an anchor, OK? And that is having good communication with the family members or caregiver for that particular patient and then making sure that they're associated with a neurologist. Also having close follow-up—which I haven't had with him yet—close follow-up with him, keeping an eye out for any changes, also as a person that the family can feel comfortable coming and saying, you know, I went and saw this doctor, they prescribed me this type of medication, I have this question regarding this medication. I have a little bit more time on my hands and little bit more follow-up capacity to be able to let me pull up a couple of articles on this particular treatment regimen and I can review that with you sort of like an educator as well.

However, in his practice, this integrated model does not work well when mental health specialists are needed, though it is unclear that this is an option he has ever considered for the Joneses. Access to specialty mental health is particularly difficult because for many patients, including Mr. Jones, benefits have been "carved out" to a group of mental health providers separate from the providers of the rest of his health care. He described at length how cumbersome and difficult it is to refer patients for mental health treatment as a result of the presence of mental health carve-outs. As a result of the long delays in getting patients referred, he often finds that he is left to manage the mental health problems at least for a while: the phenomenon he describes, mental health carve-outs, have become much more common over the past ten years with the spread of managed care. They were introduced in response to mental health parity legislation largely because major health maintenance organizations (HMOs) were concerned that they would not be able to contain the mental health costs. Mental health benefit is carved out to another bureaucratic entity, which is subcapitated to care for the mental health care at a certain level of benefit, for the specified populations. In the context of mental health carve-out, Dr. Henry often finds that when patients do receive mental health treatment,



the communication from the providers of mental health care back to the PCPs is inadequate; care becomes fractured. The relative lack of access to mental health specialty care has changed Dr. Henry's strategies for managing mental health issues so that he relies much more heavily on neurologists and himself, even for problems that he considers to be psychiatric.

### **Discussion of the Jones Family and Dr. Henry**

What is most striking in this case is the failure to "medicalize" Mr. Jones's behavioral symptoms. Dementia is a chronic illness, and there is often considerable "uncertainty" about the cause of "changes." Are they essentially expressions of interpersonal distress in response to his wife's efforts to keep him mentally active, a psychological reaction to his growing dependence on his wife, or signs of underlying brain disease? Mrs. Jones settles on an explanation that attributes Mr. Jones's irritability and aggression to marital discord triggered by the difficulties in adjusting to his increased dependence on his wife and to her prodding that he does more. From Mr. Jones's perspective, these outbursts are understandable responses to a tragic loss of ability to function as he once had; his increasing reliance on his wife; and role reversal, which threatens his sense of self and manhood. Even with us, Mrs. Jones seemed to downplay the significance of his "venting" episodes and has yet to speak with physicians about the worsening venting and wall banging. Interestingly enough, even though Mrs. Jones says that she has not spoken with Dr. Henry in detail, Dr. Henry apparently has observed some of these spousal dynamics in his office visits. While hedging his bets somewhat, he basically views their difficulties as "normal spouse conversation" and thus outside his domain. For Mrs. Jones, what is clearly at stake in the issue of whether her husband's irritability is caused by psychosocial stress or his Alzheimer's are issues of loss, personhood, and identity that go very much to the core of their marriage. The alternative of medicalization of the irritability, though potentially providing relief from the strain of coping with these problems, is to let the disease enter further into their personal lives. In addition, she does not view Dr. Henry as a resource for these types of problems—only for physical health issues. Dr. Henry, by contrast, appears to be doing his best to mediate the problem away, considering each person's opinion in an egalitarian fashion and attempting to do his best to negotiate a solution, much as if he were providing marital counseling. While Dr. Henry values Mr. Jones's perspective, there is a tacit assumption that Mr. Jones's "voice" needs to be balanced with that of his wife, reflecting his diminished autonomy personally and his ability to make medical decisions for himself. While Mrs. Jones has sought expert help both for Mr. Jones's physical health problems and for his dementia diagnosis, that same energy has yet to be used in regard to the behavioral problems.

The multitude of constraints revealed in our interview with Dr. Henry suggests a somewhat different yet complementary reading. For patients who have been diagnosed with dementia, the reality is that PCPs and systems of care are often poorly equipped to provide the type of care that is described by experts. In the case of Mr. Jones, Dr. Henry sees him once every four to six months, mainly for management of Mr. Jones's physical health problems. Mrs. Jones and Dr. Henry mutually allow care of his dementia to be performed by a neurologist, who allots fifteen to twenty minutes for office visits every six months or so. Although mental health specialty care is a theoretical possibility, it is not even under consideration yet by either the family or the physician. In any case, it is for all practical purposes out of reach, because of maddening layers of bureaucracy, which severely limit access and disrupt continuity. Mrs. Jones and Dr. Henry agree that the latter has little expertise in managing the "mental health" aspects of care; they also persist in viewing Mr. Jones's emotional problems as constituting a marital style as opposed to a concomitant of dementia. These constraints may tacitly operate to direct efforts at help seeking away from the formal health care system and toward other sources, such as Mrs. Jones's network of female friends. Thus, in this case, the medical office becomes a borderland where personal, marital, medical, and psychiatric issues collide, yet remain unresolved, if not unrecognized. Finally, we are left to wonder if Dr. Henry's resistance to medicalize is shaped by his own reluctance to engage "mental health issues" in his practice, to keep a lid on this Pandora's box.

### **The Garcia Family and Dr. Paul**

The systemic constraints and challenges that physicians face in the delivery of services to patients who have been diagnosed with dementia is furthered nuanced by linguistic and cultural differences between physician, family, and patient. The intimacy needed to forge a treatment alliance of family members, patient, and physician is difficult to achieve when the physician misunderstands or lacks the cultural knowledge to contextualize the patient's idioms of distress.

Mr. Garcia and his wife live in a small modest house located in an alley between two streets. Both were born in Michoacan, Mexico, and moved to the United States more than fifty years ago. They have been married for fifty years and are both in their seventies. Mr. Garcia is a retired farmworker and is monolingual Spanish speaking. They have four children; two live in the Sacramento area. While Mr. Garcia lives with his wife and cares for her day to day, their oldest son, José, manages his mother's health care, in a pattern that is quite common among immigrant Mexican families. At this point in time she is basically nonverbal, yet is still able to perform some basic care. A social worker comes to the home once every few months to evaluate her condition, and the

family has hired a caregiver to help out for a few hours a day, to provide additional support for Mr. Garcia.

For the past four years Mrs. Garcia has experienced multiple health problems. In addition to suffering from her ongoing diabetes, high blood pressure, heart condition, recent stroke, and memory loss, in 1999 she was hospitalized for six months because of sepsis—at one point falling in to a coma. The resulting weight loss, decrease in appetite, and continued extreme pain, as well as her increased distress, depression, and anxiety, spurred José to become aggressively involved in his mother's health care. He changed health systems in late 1999, leaving the mother's long-term physician for a new PCP and also searching for better solutions to his mother's depression, anxiety, and hallucinations.

The central theme of the interview with the Garcias, told primarily from José's perspective, is the struggle to obtain an accurate diagnosis and treatment for his mother's behavioral symptoms. Their story is an interesting one, because it begins with her development of feelings of depression, anxiety, and memory problems while she was also suffering from a number of other health problems. Later, the mother started having visions of her deceased mother and father. When the son brought these symptoms to the attention of her PCP, the latter diagnosed her with depression and prescribed an antidepressant. José was not satisfied with the diagnosis, because his mother's visions signaled to him that her troubles could not be explained just as depression or nerves: "The most alarming sign was when she said she saw her father or mother. I was sure this was not part of her depression."

José discussed these symptoms with her PCPs and complained over and over again that her symptoms could not possibly be attributed to irritable bowel syndrome or depression alone, yet the PCP continued to maintain that all these things were part of the depression and part of the aging process itself.

MRS. GARCIA'S SON: She was in the care of a doctor, but the doctor would always say that it was due in part to her age, and in part to a problem—ah, she was very depressed and had a lot of problems with anxiety. And the doctor attributed those mental problems to that. I would tell the doctor that it wasn't OK, that her behavior was not OK, her behavior was not in accordance with a depressed person, with a person with anxiety.

After about a year, Mrs. Garcia's new PCP left the clinic and she came under the care of her current PCP, Dr. Paul, who also spoke some Spanish. When José approached the new doctor, however, he felt that he received a similar response to his concerns about this mother's behavioral symptoms.

MRS. GARCIA'S SON: Well, this doctor left and we got another one. Then when we got the other doctor we spoke to him about the same problem. And this doctor was almost—I don't know why they have the same mentality—he

said something similar to what the other doctor had said, but . . . I would always tell him that it wasn't logical, their explanations.

He also requested that his mother be seen by a psychiatrist, but felt that his doctor stonewalled and was very defensive because his authority had been challenged. About the same time that Mrs. Garcia switched health systems, José set out to research the Internet for answers. He had learned about Alzheimer's disease on the television show 20/20 and felt that his mother exhibited many symptoms of that condition; he then went online to research information, finally finding the Web site of a memory-loss clinic. He arranged for his mother to be evaluated there, and she was diagnosed with Alzheimer's disease. This provided him with an explanation that made sense. Armed with a diagnosis of Alzheimer's and recommendations from the memory-loss clinic, which included treatment of the hallucinations, José was finally able to get his PCP to prescribe an antipsychotic medication for his mother's hallucinations. While her depression, anxiety, and hallucinations have stabilized, José feels quite bitter about his experiences in the health-care system and continues to search for an alternative site of health care for his mother.

Although the Garcias' journey to finding care for Mrs. Garcia has been riddled with difficulties, her son, wanting answers, fought his way through a nonsupportive system to find them. He has been relentless in finding a doctor or clinic that would give him "logical answers" to his concerns. He challenged doctors' diagnoses to the point of arguing with them. He explained that living in this country means fighting for answers, for the things that you need. His father, by contrast, has a more accepting, passive approach to medical care. This includes a much more deferential stance toward doctors, through the belief that they must know what they are doing. It is clear that neither approach has yielded optimal care for Mrs. Garcia's complicated comorbid medical and behavioral problems.

This case shows us how the approach to health care of an educated bilingual adult child differs from that of a monolingual immigrant farmworker. This is not to say that all migrant monolingual farmworkers would take this passive approach, yet we have had similar cases in which adult children are the ones taking the lead in their parents' health care. They are more aggressive about getting answers to their questions. They do not have the cultural value that a doctor must know what he or she is talking about and is not questioned. Furthermore, knowledge of English, the ability to converse directly with physicians, and the capacity to seek answers by using technology facilitated José's search for a solution to his mother's illness. Mr. Garcia, however, was hesitant to challenge the medical status quo. In fact, he was guarded about the interview itself, expressed hesitancy in challenging the doctor, and was uncomfortable with his son's assertiveness. In Mrs. Garcia's case, without her son's intervention, she

would still be undiagnosed, suffering from hallucinations, depression, and anxiety and not receiving the appropriate treatment. Since her diagnosis, she has been given medication for Alzheimer's disease and for the hallucinations, which ceased shortly after she began taking the medicine.

This case reflects some common patterns of caregiving among Latinos. While the spouse was involved in the day-to-day care of his wife, it was the adult child who negotiated the health-care system. In other families we have interviewed who have several adult children, most if not all are involved in supporting the ill parent by taking him or her to the doctor, searching for information and treatment, and supporting the spouse by taking on these tasks. Moreover, we have noted significant differences in how immigrant compared with U.S.-born children negotiate the barriers to health care. Mexican-immigrant adult children appear to feel less comfortable challenging, confronting, or even questioning physicians. It must be noted that most of the caregivers we have interviewed primarily migrated from rural Mexico, have less education, and may have had less access to health care while in Mexico. Therefore, as a result of these demographic characteristics, they may appear to have less agency. The pattern of deferring to authority may be exacerbated postmigration, as they are not able to negotiate the health-care system without adequate English-language skills.

Dr. Paul is a young family-practice physician who presented himself as a caring, but naive and overwhelmed, physician, unprepared for the challenges of dementia care. Even before we were through the consent process, he began talking about the terrible impact of mental health carve-outs on clinical care. This was a major theme throughout the interview, as he described the enormous difficulties involved in referring patients for mental health evaluation—something that often places him in the position of having to manage patients. He says that his patients' mental health services are constantly being carved out to new sets of providers. This has several effects. For patients who are on cognitive enhancers, for example, a new insurance company may require a lengthy prior-authorization process before the patient is allowed to get the medication. This results in a period of time when they do not take the medication, because their prescription from the old insurance has run out but they are not yet approved by the new insurance company. Some of these patients go "downhill" when they are taken off the medication. This is such a problem that Dr. Paul is inclined to prescribe cognitive enhancers less readily. He says that his patients' insurance is changing "all the time." Another problem is that in the current system, he has to wait for a long time before he can arrange for his patients to see specialists, particularly mental health specialists. While he often finds himself forced to see them, he then faces the hurdle of billing for the services, as the insurance company will often not allow him to charge under psychiatric diagnostic codes.

He described Mrs. Garcia's case in some detail, particularly the family dynamics. Clearly, this was a challenging and frustrating case, one that caused the

clinic to take the extreme position of limiting office visits, because of the high frequency of these visits, which included the family's often showing up unannounced. Dr. Paul felt that their pattern of help-seeking was driven by Mrs. Garcia's son, who, he believed, had unrealistic expectations about the extent to which his mother would recover. Interestingly, the issue of dementia was rarely discussed in the background of that conversation, with more emphasis being placed on family dynamics. There was relatively little discussion from him of the dementia diagnosis. However, he also tells us that the focus of the family was less on dementia symptoms and more on her physical ailments—in particular her abdominal pain. He readily admits that he does not have either the time or the training to manage many medical issues in his practice, including dementia and mental health issues:

DR. PAUL: I'm not the best, I'm not the best qualified. And I don't have enough time, and that's tough, it really, you know, it is very hard to know, I cannot believe how much other medicine that I do, that I really don't want to do, and it's not that I don't want to do this, but there are some aspects I really don't want to do, and I'm like, oh, wow, want to see a specialist, next appointment, six months, well I guess we're working together for a while here until we get this taken care of or worked through.

As the interview moves to a description of the patient, it is interesting that dementia is so much in the background of this case. This may have some important consequences for care. For example, Dr. Paul describes his exasperation at the inconsistencies in his patient's presentation—when she is in the room alone and when she is in the room with her son. However, he suggests that this may be a result of her loss of verbal abilities as well as cultural differences between himself and the family. The difficulties of communication with the family, since the patient is not a reliable source of information, may make it much more difficult to identify and treat behavioral symptoms, particularly when the family is labeled as a “problem” family:

DR. PAUL: This is the tough part, because I think he went overboard and then it was very hard to then figure out where the compromise was, because you'd really rather have somebody say, “Something's different,” as opposed to the same thing over, and over, and over again. Something's different then, then, oh, now I got to pay attention. Maybe now there's something wrong that we can try to address, and that was hard.

INTERVIEWER: In this family did you feel that the family dynamics contributed to good or better care for her, that the son was as involved as he was, or did you think that the family dynamics, did the son and the father agree basically? Did they have the same agenda?

DR. PAUL: I don't think they had the same agenda. The son's agenda was to get

her back [to] how she was. She's not the same, get her back, and the husband's agenda was not that. He just wanted her to feel comfortable. He didn't want her to be in pain for sure, but I think he understood when there was nothing wrong, he was like, OK, there's nothing really wrong. OK, he was much more accepting, right from the get-go.

At the same time as Dr. Paul had some insight and appreciation for the plight of the Garcia's, he seemed particularly limited—both in his professional training and in the health-system bureaucracy in providing care for them.

### **Discussion of the Garcias and Dr. Paul**

This case exemplifies the inherent difficulties of delivering medical services to the elderly with dementia while needing to negotiate managed care, carve-outs, and the challenges of a cross-cultural medical encounter. Dr. Paul experienced the family and the case as a difficult one. Despite his feeling that he was culturally aware, and that his Spanish benefited the interactions that he had with the family, Dr. Paul appeared unaware that somatization of behavioral and psychiatric symptoms is common among Latinos and may well have explained Mrs. Garcia's presentation. He also appeared not to be aware of the highly interdependent nature of many Mexican-immigrant families or the role of adult children as linguistic and cultural interpreters or brokers for the parents and, instead, problematized José's effort to help. What we were unable to ascertain was whether the conflicts arose from the extreme differences in agendas—José's to bring his mother back to her original health, alleviate her pain, and treat her depression and hallucinations; Dr. Paul's to care for this frail elderly patient with multiple health problems at the same time as he conformed to the bureaucratic demands of his clinic and colleagues.

Dr. Paul's self-admitted lack of training and experience in assessing and treating people with dementia and his limited cultural awareness appeared to create a frustrating and unsatisfactory relationship for both him and the Garcias. Once the family was labeled *problematic*, and their contact with the clinic was significantly constrained, the medical encounter became a contested borderland for both, one where the doctor and clinic staff were viewed as excessively controlling, if not denying, care to Mrs. Garcia. The family felt no connection to the doctor and the doctor appeared to feel burdened by the family's demands, precluding the development of the intimacy, respect, and cooperation that Latinos value in their interactions with doctors.

### **Conclusion**

The extent to which these borderlands of primary care are constrained by economic and bureaucratic structures needs to be highlighted. Lack of adequate



training in geriatrics and mental health for PCPs, large patient panels and relatively short office visits, very limited access to specialists for anything other than consultation, and lack of continuity in formal services are just some of the structural barriers that limit the options available to families and physicians in managing the sometimes “troublesome” behaviors of people with dementia. When resources are very limited, the expectations of both patients/families and PCPs may be realistically lowered with respect to the nature and type of care for behavioral symptoms. The situation described here for behavioral change in dementia is similar to what Sharon Kaufman described in her study of people rehabilitating from stroke. She notes that “the structure of social services and health care delivery, as well as their limits, creates the facts, the only knowledge that patients and families have as a basis for decision making and coping with long-term disability” (1988, 339). These constraints make nearly impossible, for many families, the careful biopsychosocial assessment that would lead to careful consideration of behavioral symptoms of environmental, interpersonal, and biological causes of behavioral change; prioritization of early nonpharmacological interventions, and the use of medications only as a last resort. Instead, the constraints of primary care in many cases dictate that there will be, at best, careful use of pharmaceutical agents to ameliorate symptoms that are presented by families, often at the point of “crisis.” Ultimately, this reflects the larger problem of a health-care system that has long excelled at handling acute illness, but that fails, often miserably, in the management of illness that is chronic.

These forces powerfully shape the experiences of PCPs and families, who, however, are far from passive. In these cases we can see the extent to which behavioral changes remain a borderland in the diagnosis and treatment of dementia by going unrecognized, misunderstood, or undiscussed in the primary care office. Within these borderlands, the influence of ethnic/cultural and gender differences and the power inherent in the role of the physician, caregiver, and health system can be acknowledged, recognized, and renegotiated to create sites for collaborative partnership in healing and support, as in the case of the Joneses, or a failure to treat adequately, as in the case of the Garcias. In some instances families and physicians can be seen actively resisting systemic pressures, trying their best, sometimes heroically forging humane and decent care for older adults who have been diagnosed with dementia and their families. Otherwise, these borderlands, as is especially apparent in the case of the Garcias, can be characterized by deep interstices within which the human connection that fosters healing can be lost. We suggest that these borderlands need not be sites of respite from marginalization (Alarcon 1998; Anzaldúa 1987), but also as active terrain where physicians, patients, and patients’ families can form partnerships that contest the influence of bureaucracy and unnecessary medicalization. We argue for a closer analysis of systems issues and of the impact of these on providers, families, and patients.



## NOTE

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## Negotiating the Moral Status of Trouble

### The Experiences of Forgetful Individuals Diagnosed with No Dementia

ANDRÉ P. SMITH

There is evidence to suggest that individuals who complain of memory problems but have no objective deficits constitute between 12 and 30 percent of the patient population that is seen in memory clinics (Almeida et al. 1993; Berrios, Marková, and Giralá 2000). There are conflicting views about the clinical significance of such complaints. Berrios, Marková, and Giralá (2000) remark that because these patients do not fit into any accepted definition of memory disorder, attitudes toward “persistent memory complainers with negative neurological, neuropsychological and neuropsychiatric assessments tend to be harsher, particularly in memory clinics whose objective is to collect patients for dementia drug trials” (384). Yet most recently, there has been a growing clinical interest in this population because of the possibility that very mild symptoms of cognitive impairment could, in some cases, progress to overt dementia at a later stage (Petersen et al. 1999).

Although much research is now being directed at developing more sensitive psychometric instruments to detect these potentially milder symptoms of dementia, little is known about the subjective experiences of individuals whose complaints of cognitive impairment do not fall within quantifiable parameters. To address this gap in knowledge, this study provides an in-depth account of the histories of four women ranging in age from forty-four to fifty-seven years who underwent full clinical evaluation for complaints of mild and sporadic memory lapses but did not meet criteria for a dementia disorder. While these women reported impairment that fell outside the realm of psychometric verification, they nevertheless experienced profound subjective distress that was not necessarily identified during clinical evaluation. This account situates these women’s

memory problems in relation to the struggles and challenges that characterized their lives and how these issues were dealt with during clinical assessment.

### Literature Review

There is a complex and overlapping nomenclature to describe persons with cognitive impairment that diagnostically extends beyond the normal range relative to same-age peers but fails to meet criteria for dementia with regards to the severity of deficits. Kral (1962) initially proposed the term *benign senescent forgetfulness* in reference to a slowly progressing age-related mild memory decline, which he distinguished from *malignant senescent forgetfulness*, a more rapidly progressing decline consistent with dementia. Several terms have since been introduced, including *mild dysfunction* (Johansson and Zarit 1997), *age-associated memory impairment* (Crook et al. 1986), *late-life forgetfulness* (Blackford and La Rue 1989), *predementia* (Reifler 1997), *mild cognitive impairment* (Zaudig 1992), *very mild dementia* (Stroeble et al. 1995), and *cognitive impairment, not dementia* (Graham et al. 1997). The fourth edition of the *Diagnostic and Statistical Manual for Mental Disorders* (DSM-IV [American Psychiatric Association (APA) 1994]) features research criteria for mild neurocognitive disorder (MND). MND refers to objective impairment verified by cognitive assessment and associated with an identifiable neurological, medical, or substance abuse condition and that interferes with social, occupational areas of functioning. DSM-IV also features a diagnostic category for age-related cognitive impairment attributable to the aging process but that is within normal range given the person's age. This condition can apply to individuals who, for example, experience difficulties remembering names or appointments or solving complex problems despite the absence of a mental disorder or neurological condition.

The preceding categories likely capture a heterogeneous group of conditions with varying severity, etiology, and course given that the continuum between what is normal and what is pathological for dementia is not well understood. Research on mild cognitive impairment has been spurred by longitudinal evidence suggesting that such impairment can progress to overt dementia in 10–15 percent of cases (Petersen et al. 1999). There is also a more urgent need to identify dementia-related mild impairment accurately with the recent advent of drug therapies that can slow the progression of cognitive decline, particularly when prescribed early on in the disease.

Several nondementia factors have also been associated with mild cognitive impairment, including fatigue, depressive symptoms, sensory impairments, and other physical disabilities, as well as social, cultural, and educational issues (Tuokko, Frerichs, and Kristjansson 2001). Among those factors, the relationship between depression and cognitive functioning has been best documented (Kahn et al. 1975; La Rue, Swan, and Carmelli 1995). In particular, depressive

symptoms have been associated with self-reported problems with basic cognitive processes, including memory and concentration (Bola et al., 1991; McGlone et al. 1990; O'Connor et al., 1990; Basset and Folstein 1993; Watts and Sharrock 1985). In a meta-analysis of studies on depression and memory impairment, Burt and Zembar (1995) found a significant association between depressed mood and memory impairment.

Finally, there are several concepts that seek to account for the presence of subjective memory complaints in the absence of any diagnostic findings on neuropsychological, neurological, and neuropsychiatric testing. For example, Berrios, Marková, and Giralá (2000) propose the concept of *mnestic hypochondria* (MnH), which is adapted from the DSM-IV (APA 1994) diagnosis of *hypochondriasis*. MnH occurs when patients misinterpret normal fluctuations in memory function and develop unwarranted preoccupations about a disease causing cognitive impairment. Berrios, Marková, and Giralá identified fears of growing older, a self-reported history of an undiagnosed heart attack, and the death of a parent as precipitants for this condition. Similarly, Hanninen and colleagues (1994) reported subjective memory complaints to be positively associated with tendencies toward somatic complaining, increased feelings of anxiety about physical well-being, and more negative feelings of one's own competence.

Another concept accounting for subjective concerns about memory functioning is that of *anticipatory dementia*, which was proposed by Cutler and Hodgson (1996) to explain fears of developing Alzheimer's disease (AD) in individuals experiencing normal age-associated memory changes. In their initial study, the authors had hypothesized a greater propensity among adult children with a living AD parent to interpret normal fluctuations in memory performance attributable to normal aging as indicative of the onset of AD, particularly if they believed the disease to be inheritable. They recruited fifty men and women between the ages of forty and sixty years, twenty-five of whom were adult children of a living parent with AD, and twenty-five who were a matched group with no family history of dementia. Using composite measures of memory appraisals, the authors reported significant bivariate and multivariate relationships between self-assessments of memory functioning and concerns about developing AD. Contrary to expectations, these findings held true both for adult children with an AD parent and for adult children in families where AD was not present. Concerns about developing AD were greater for females, for the unmarried, for younger persons, and for those who believed that AD is inheritable. Cutler and Hodgson speculated that the increased visibility of AD and the success of private foundations and public agencies in educating the public about the disease and its symptoms were possible factors contributing to anticipatory dementia. Subsequently, Hodgson, Cutler, and Livingston (1999) conducted a qualitative analysis of the responses of adult children with AD parents,

contrasting them to those of adult children with non-AD parents. The authors hypothesized that adult children of AD parents developed a greater self-awareness of even minor fluctuations in their own cognitive functioning as a result of having being intimately attuned to their parents' cognitive loss as caregivers.

Despite several concepts to account for mild cognitive impairment, whether it be objectively verified or otherwise, there remains little information about how individuals actually experience such impairment, particularly in relation to the ways they make decisions about seeking clinical help. While existing studies offer possible explanations for why such individuals interpret their symptoms as those of dementia, little is known about their life circumstances and what specifically triggers concerns about cognitive impairment. In this study I address this gap in knowledge by discussing the lived experience of memory problems in four women ranging in age from forty-four to sixty-five years. The intent is to situate these women's interpretations of impairment in the context of their everyday lives and how their concerns were dealt with during clinical evaluation.

### **Background Information and Methods**

The pseudonyms of Claudia, Vivian, Sonia, and Marilyn are used in the discussion of these women's experiences. Claudia is a forty-four-year-old single mother of one teenage daughter and works as an elementary school teacher. Vivian is a forty-seven-year-old married woman with two children from a previous marriage who is employed as a cashier in a large department store. Sonia is a fifty-year-old mother of two teenage children who is on sick leave from her job as a hospital nurse. Marilyn is a sixty-five-year-old married woman with two children who volunteers her time as a coordinator in an evangelical mission. Claudia and Marilyn described their symptoms as being the early signs of Alzheimer's disease (AD), whereas Vivian and Sonia believed they were suffering from an "organic brain disorder," which they described as being similar to AD.

These women were selected from a larger qualitative investigation conducted by the author on the diagnostic experiences of fourteen patients and twenty-four family members at a Canadian memory clinic, henceforth referred to as the Clinic (Smith and Beattie 2001). The author is a sociologist who is not affiliated with the Clinic. Of that group of patients, three had probable AD; five, possible AD; and six were diagnosed as having no dementia. This no-dementia group included the four women mentioned here as well as two other patients who are not discussed because neither complained of memory problems and both were evaluated as part of a study on genetic risk and AD. All four women took part in an extensive multidisciplinary evaluation at the Clinic according to established protocol and underwent radiological and laboratory investigations as indicated. They were assessed by a geriatric medicine specialist, a neurologist,

a psychiatrist, and a geneticist. Paramedical assessments were also conducted by a psychologist, a social worker, and a speech-language pathologist.

I collected data according to consent by observing the women's respective clinical evaluations and family conferences at which they were informed about their diagnoses and by conducting two semistructured home interviews with each woman and her spouse. In one case, a daughter was also interviewed. The first set of interviews took place following the clinical evaluation and the second set after disclosure of the diagnosis at the family conference. The elapsed time between the evaluation and disclosure was eleven weeks on average. All interviews were transcribed verbatim, reviewed, and coded for salient comments from participants. By means of inductive reasoning, the topics were gradually grouped into more refined themes.

### **Situating Memory Problems in Everyday Life**

In this section I report on the participants' experiences of memory problems within the context of events in their personal lives and at work. Claudia complained of memory lapses that started about one year prior to her assessment at the Clinic. At that time, she was living through a series of stressful events at work and in her personal life. She divorced her first husband because she could no longer cope with his erratic behavior and multiple hospitalizations for bipolar illness. She gained sole custody of her daughter, remarried, and relocated to a new city to accommodate her second husband's employment situation. This meant that she had to relinquish her position as school librarian, which she had held for ten years and very much enjoyed. She also left colleagues who had been part of her support network during her dealings with her first husband. She found work again as an elementary school teacher, but did not adapt well to her new job because of her lack of experience in the classroom. Shortly afterward, she separated from her second husband because of his alcoholism and abusive behavior. Around that time, her daughter, whom she described as the "teenager from hell," attempted suicide and was placed under the care of a psychiatrist. Claudia said she felt overwhelmed and fearful that she would fail as both schoolteacher and parent. She consulted her family physician, who prescribed an antidepressant.

During that time, Claudia had several memory lapses that triggered fears about having the early symptoms of AD, a disease that had taken her mother earlier. For instance, she recalled how one day at school, she forgot about sending one of her pupils to the principal's office and was reminded of his whereabouts by the other pupils when she started to look for him in a panicked state. On several occasions, she also forgot the names of colleagues at school functions and once misplaced important class preparation material. In another incident, Claudia canceled her credit cards, which she believed lost, only to



remember later that she had put them away in a safe deposit box to prevent overspending. As the following comment indicates, Claudia also experienced word-recall problems: "I said to my daughter one time, "Oh, get the milk out of the, uh, uh," and I'm looking at her, "the cold thing, the cold white box, the, uh, fridge." And I'm going, "Oh, God." At the time of the interview, Claudia was concerned that she would be dismissed from her job as schoolteacher on the grounds that her memory lapses endangered the safety of her pupils in the classroom.

In Vivian's case, she began experiencing memory lapses about eighteen months prior to her assessment at the Clinic. At the time, she had divorced and obtained shared custody of her two teenage sons. She later remarried and found employment as a display manager in a large department store. She went on stress leave because she could no longer cope with the constant critiques of other employees about her store displays. Her family physician diagnosed her with depression and put her on an antidepressant. While on stress leave, she became increasingly forgetful to the point of doing things she described as "so stupid" she did not even want to disclose them to her husband. Her memory problems eventually subsided and she returned to work as a cashier with the same employer but at a different store. However, her memory problems soon returned, interfering with her ability to operate her cash register. She would frequently forget specific key sequences needed to operate the register and had to look them up in an instruction manual, which was embarrassing when there were long lines of customers. Vivian said those memory lapses made her feel "stupid" and "incompetent." She was convinced she would soon lose her job.

Vivian did not believe that her diagnosis of depression explained why she had recurring memory problems. Instead, she came to believe that she suffered from an undiagnosed "organic brain disease" similar to AD. During the interview, her husband dismissed his wife's concern and attributed her inability to operate the cash register to a lack of understanding of the "logic" behind its key sequences. Vivian retorted that there was no logic to those sequences and that she just had to memorize them, something she was unable to do because of her brain disorder.

The other two participants, Sonia and Marilyn, reported similar memory problems. Sonia was working as a nurse at a local general hospital when she began forgetting to do particular care procedures for her patients. She eventually went on extended sick leave and received treatment for depression from a psychiatrist. She stayed at home, managing a hobby farm she co-owned with her husband. She continued to experience memory problems and requested a referral to the Clinic because of concerns about having an AD-like brain disease. As for Marilyn, she sought a referral to the Clinic because of concerns about having the early symptoms of AD. She reported forgetting the names of friends and colleagues, which she felt interfered with her ability to adequately carry out her



responsibilities as event coordinator for an evangelical mission. She was not receiving treatment for depression at the time of the study but reported having been on antidepressants for several years following the death of her son.

### **Referral and Clinical Evaluation**

Claudia, Vivian, and Marilyn were referred to the Clinic by their respective family physicians; Sonia was referred by her psychiatrist. All felt that their doctors had not taken their memory complaints seriously. For example, Claudia consulted four physicians before finding one willing to refer her to the Clinic. Sonia said her psychiatrist initially told her that an assessment at the Clinic would be futile but eventually agreed to a referral if only to reassure her about her memory function. Vivian obtained a referral from her family physician after repeatedly arguing with him that her depression did not cause her forgetfulness. She said he eventually agreed to refer her, stating that her memory problems were beyond his “expertise.” Marilyn was referred more readily by her family physician, although he did mention that her concerns were exaggerated.

These women also reported that their husbands, family members, and friends had dismissed their concerns about memory function. For example, Vivian did not tell her husband about her referral to the Clinic because she feared he would think it was “silly.” Her husband found out about the referral when the Clinic’s coordinator contacted him at work to set up an appointment time for his wife. Vivian had assumed the Clinic would contact her directly, not realizing that the Clinic coordinator instead preferred to make arrangements with relatives, rather than patients, who were often too impaired to organize their own appointments. Although initially dumbfounded by his wife’s decision, he eventually supported her in the hope that the assessment would alleviate her fears about having a brain disorder. Likewise, Claudia did not want to tell her immediate family about the referral because she feared they would dismiss her concerns as unwarranted. However, she disclosed it to several of her friends, none of whom felt she had serious memory problems. Claudia equated their behavior to her own denial of her mother’s early symptoms of AD. Finally, for Sonia and Marilyn, their respective husbands were more supportive of their decisions to be assessed at the Clinic, but neither believed that his wife suffered from dementia.

Each patient underwent a multidisciplinary assessment that included radiological and laboratory investigations. All were evaluated by NINCDS-ADRDA<sup>1</sup> criteria for AD and by DSM-III-R criteria for dementia (APA 1987). Not only did all patients perform well within the normal range on all tests; their ability to consistently report instances of memory lapses on separate occasions naturalistically reaffirmed the intact nature of their memory function. In one instance, Claudia cited as evidence of her failing memory the need to purchase an alarm

watch to remind her about meetings, yet readily admitted being able to remember which meetings she needed to attend whenever the alarm went off.

At first glance, it would be easy to dismiss these cases as those of “worried well” individuals. Yet the Clinic coordinator commented that it was not uncommon for family physicians to refer younger patients to the Clinic because of their psychological problems:

The word is out that we are not just for Alzheimer’s disease, that we do the related disorders. And there are people out in the community that know that’s what we’re looking at. A lot of the referring physicians, if the patients are young, rather than trying to deal with the psychosocial issues and family matters and things like that, they’ll send them out and see what we can do. Some are still working. They’ve got subjective complaints. They can walk in and say, “Look it, I don’t think I’m functioning at my previous level.” So they’re just maybe a little freaked that they forgot so-and-so’s birthday on Friday. But a lot of those are turning out that they don’t meet criteria. I’m not saying that they don’t have problems, but they don’t meet the formal DSM-IV criteria for dementia. Just being unable to think of a word is considered to be a symptom associated with so many normal conditions. You can’t tell what somebody’s got. It goes with depression, it goes with anxiety, it goes with attention disorders, it goes with distraction, it goes with memory problems, it goes with language problems, it just goes with everything. It is nondiagnostic.

Findings from an internal Clinic report confirm the coordinator’s observations. Patients not meeting criteria for dementia account for 25 percent of all referrals, and out of that number, only 13 percent are later diagnosed with a dementia disorder upon reassessment. These findings, along with studies by Almeida et al. (1993) and Berrios, Markovà, and Giralà (2000), suggest that significant clinical resources are being devoted in memory clinics to the evaluation of individuals with subjective complaints of cognitive impairment that cannot be verified by objective testing.

### Negotiating the Moral Status of Trouble

In accounting for why these women interpreted their memory problems as symptomatic of dementia, I offer in this section an explanation that is based on the notion that diagnostic categories do not simply describe underlying psychopathologies but also serve to label the moral status of problematic behaviors. More specifically, the argument is that these women considered the alternative diagnosis of dementia as a way to resist the stigma they perceived to be attached to the diagnosis of depression. Goffman (1963) defined stigma as an “attribute that is deeply discrediting” and that reduces the bearer “from a whole and usual

person to a tainted, discounted one" (3). The discrediting nature of depression has been well documented in the literature on mental illness. Depression is one of several serious mental illnesses that continue to elicit generally unfavorable attitudes from members of the public (Bhugra 1989). Having one's name associated with depression can be detrimental to one's career and future. For example, Glozier (1998) found that personnel directors in a sample of two hundred U.K. companies were much less likely to hire an applicant described in a vignette as having depression over someone with diabetes. A famous example of discrimination is the case of former U.S. senator Thomas Francis Eagleton, who was dropped as running mate by presidential candidate George McGovern shortly after the 1972 Democratic Party convention when it was revealed that Eagleton had been hospitalized for depression.

Particularly relevant here is the distinction between felt and enacted stigma (Scrambler and Hopkins 1986; Jacoby 1994). Whereas *enacted stigma* refers to concrete instances of rejection or discrimination toward the person with a stigmatized condition, *felt stigma* reflects that person's expectations of how others will react to the condition. There is evidence to suggest that being diagnosed with depression can produce intense experiences of felt stigma. For example, Angermeyer and colleagues (2004) found that patients diagnosed with schizophrenia and major depression had equal expectations about negative reaction at work and in the domain of interpersonal interaction, although patients with schizophrenia reported far more frequent actual incidents of stigma. The intensity of the felt stigma appears to be related in part to concerns that depressed individuals have about how others will interpret the legitimacy of their condition (Schreiber and Hartrick 2002). Others in the depressed person's social environment may seek to determine whether the depression is legitimate on the basis of whether life circumstances justify the severity of its symptoms. If those circumstances are judged as lacking the necessary severity, then the depressed person may be perceived as deficient, weak, or incompetent in handling the ordinary pressures of work and life.

As Gray (2002) remarks, the concept of felt stigma has two advantages. First, this concept acknowledges the precariousness of maintaining a normal identity once a stigmatized label is applied; and it underlines the importance of accounting for the ways a person manages the social presentation of his or her stigmatized condition in light of anticipated rejection. A common management strategy is to conceal the diagnosis and minimize one's involvement in social situations where disclosure could occur. However, the experiences of these women suggest another strategy whereby an alternate and less stigmatized label is considered to explain problematic behaviors in a less discreditable manner. To better understand this process, it is crucial not to dichotomize between dementia and depression on the basis of their respective psychopathological features. Undoubtedly, being diagnosed with dementia is a much less desirable

option given the condition's irreversible and ultimately fatal pathology. By contrast, depression is an eminently treatable and thus comparatively hopeful illness. However, these women were less concerned about the prognostic implications of being diagnosed with dementia and instead focused on the perceived positive societal reaction associated with this label. In that sense, the anticipation of being diagnosed with dementia can be understood as a heuristic device that conveys a lack of control (and thus responsibility) over discreditable behaviors and thus reduces the possibility of one's being interpreted by others as being morally disreputable. This is possible because the label of dementia shifts the cause of personal problems away from the morally charged realm of psychiatry onto the more neutral ground of neurobiology. A dementia diagnosis points the finger at a pathology that is outside one's control, thus diffusing moral responsibility for discredited behaviors in everyday life.

Biologization as a stigma-management strategy has been documented in women with major depression who explained their condition almost exclusively in neurobiological terms (Schreiber and Hartrick 2002). This responsibility-absolving feature of a biological explanation has also been documented by Weinberg (1997) in patients receiving treatment for substance abuse and mental illness. Those patients often described their psychiatric conditions as non-human agents that controlled their daily lives. They learned to justify rule-breaking behaviors as "lapses" during which they had been momentarily overtaken by their disorders despite efforts to resist. Herman (1993) has also documented similar strategies among some deinstitutionalized psychiatric patients who developed "beyond-my-control" interpretations of their condition as a way to diffuse the stigma associated with severe mental illnesses. Lock (1990) has also documented the use of culture-specific labels to destigmatized psychiatric distress in a group of first-generation Greek women immigrants in Montreal, Canada. These women had unusually high rates of depression, anxiety, and psychosomatic distress that were locally labeled as *nevra* (nerves), an umbrella condition described in terms of feelings of bursting out, breaking out, and boiling over. Lock found that women suffering from *nevra* also had life histories characterized by social isolation, marital discord, and poverty and often worked in the city's notorious garment industry, where they confronted racism and sexism on a daily basis. Lock argues that while the symptoms of *nevra* suggest a psychosomatic reaction or an anxiety disorder under DSM nosology, the condition should actually be viewed as a culturally specific outlet for the social isolation and work exploitation experienced by these women. In that sense, *nevra* allows for a more socially acceptable way of labeling the distress these women experienced in everyday life.

Thus, one can argue that the women described here attempted to secure a more socially accepted label for the distress they experienced while struggling with alienating work situations and traumatic life events. This was particularly

evident for Claudia, Sonia and Vivian, who clearly expressed in their interviews that they regarded the diagnosis of depression as inadequate for explaining the problems they were experiencing. For example, Vivian was convinced that her inability to operate her cash register resulted from a condition she described as an “organic brain disorder along the lines of a stroke, a lack of circulation to the brain causing some atrophy and subsequent memory loss.” Sonia attributed the errors she made while working as a nurse to a mild form of a brain pathology similar to AD but less severe. In the following comment, Claudia explains how her diagnosis of depression stirred fears of ending up like her first husband, who had bipolar illness.

You have to understand that my daughter’s dad is a manic-depressive. He was in the mental ward thirteen times in the last two years we were married. In 1985, my husband screamed out, “I’m the Antichrist,” and threw himself in front of a bus. And I have been in the hospital’s waiting room when the police had been called because he had started to take his clothes off. I’ve seen people in the mental ward. I don’t want to end up like that. So, when you say things to me like I might be mentally ill, well, that’s pretty strong words, you know, because I have seen mentally ill people. I took Prozac, Zanax, and everything. They did absolutely nothing, and I only went on them on the doctor’s recommendation. They were just trying to see if they could ease the tension, the anxiety, or whatever. Reading the report, it sounds like, you know, “We tried this mentally ill lady on Prozac, and we tried this mentally ill lady on Zanax . . . ”

Like Sonia and Vivian, Claudia viewed her having a mild form of dementia as a more likely explanation for her memory problems. She also more readily disclosed this prospect to others, whereas she never mentioned her depression. This behavior suggests that, like the other women, she anticipated the dementia label to elicit a more favorable response. There is some evidence that supports the validity of this expectation. For example, Werner and Davidson (2004) conducted face-to-face interviews with 150 Jewish Israeli adults to ascertain their emotional responses to a vignette depicting a person with the symptoms of AD. This person elicited more positive than negative feelings, including compassion, concern, and sympathy. Using a similar methodology with female undergraduate students, Wadley and Haley (2001) found that a vignette depicting a person exhibiting inappropriate behavior in a social situation produced more sympathy, less blame, and a greater willingness to help when a label of AD was provided as compared to no label or a label of major depression, because unlike depression, AD is seen as a brain pathology outside of the person’s control. These findings highlight how people are less likely to attribute moral blame to problematic behaviors when a biological label is applied.

The significance of the dementia diagnosis in diffusing stigma and moral

blame for these women is further underlined by how they reacted when told they did not have dementia. For instance, Vivian reacted angrily and felt the Clinic had not taken her condition seriously. In the days following disclosure, Vivian began to entertain an alternate explanation for her memory lapses, thinking that perhaps they were caused by a head injury she had sustained while playing baseball as a child. She cited a “lazy eye” as evidence for the presence of undiagnosed brain damage. Sonia was also disappointed but more accepting of the lack of clinical findings, in part because of the manner in which disclosure was managed. While Vivian was notified of her assessment results over the phone, Sonia was seen by the Clinic’s neuropsychologist, who suggested that the absence of findings could have been an artifact of the instruments’ lack of sensitivity in detecting mild cognitive symptoms such as those caused by higher levels of stress. This approach validated Sonia’s experience of impairment while providing her with a nonpsychiatric explanation for her symptoms.

The neuropsychologist used a similar approach with Claudia, who initially resisted the suggestion that stress could cause her to be forgetful. She eventually agreed to consider the explanation once it was emphasized that anyone having to cope with stressful events like the ones she experienced in the past year would have had similar memory deficits. She worked on reducing her stress level to improve her memory performance. Reflecting on her involvement with the Clinic, Claudia said, “I have one of those personalities that likes reassurance. I guess what I’m looking for is a pat on the back. The Clinic was saying, you know, ‘You’re OK.’ But I had a couple of bouts of forgetting, which has put me back on the alert. Maybe these will never go away. Maybe those are normal aging memory losses that every single forty-five-year-old has. But I guess I react a little more emotionally than normal.”

While the neuropsychologist’s interventions did not address the alienating circumstances that contributed to these women’s distress, they nevertheless normalized their experiences as legitimate reactions to difficult life events. One wonders if these women would have decided to seek a referral to the Clinic had a similar approach been used by their respective family physicians.

One caveat is that diagnostic labels tend to obscure the relationship between memory problems and alienating work or life circumstances. For example, in Vivian’s case, while she had difficulties in operating her cash register, she had also started her job during the busy holiday season without adequate training. In Sonia’s case, she started making mistakes at work at a time when her workload increased as a result of health-care cutbacks and a shortage of nursing staff. As for Claudia, she took on a new position as schoolteacher, despite having minimal experience in the classroom. Those work circumstances undoubtedly compounded the stressful life events these women endured, including divorce, abuse, and single parenthood.

### Perception of Genetic Risk

The perception of being at risk for having inherited AD is another factor that accounted for why some of the participants interpreted their memory problems as indicative of dementia. In particular, Marilyn expressed the fear that her memory lapses were symptoms similar to those that had afflicted her mother, who had been diagnosed several years earlier with “organic brain syndrome,” an older diagnostic designation for dementia. Similarly, Claudia was concerned about having inherited AD from her mother. In the following comment, Claudia compares her impairment to her mother’s early symptoms: “When my memory started to fail in the last two or three years, I did panic a lot. I have the history of AD from my mother. Some of the signs are so indicative of what Mom used to do. That’s why they freaked me out. It wasn’t just the memory losses; it was the way some of the memory losses were similar to my mother’s.”

Claudia positioned herself as the latest victim in a long matriarchal line of AD sufferers. She surmised that her grandmother, although never diagnosed with dementia, had committed suicide because she was experiencing the early symptoms of AD and did not want to face the prospect of losing her mind. Claudia believed she was a carrier for “the AD gene” and wanted to be tested to confirm her suspicion:

At my age and with what’s going on, I would want to be tested. I’d rather know now because let’s say I got it, then I would downsize. I would make provisions for Sandra and then I’d live life to the fullest. Not that I don’t live life to the fullest now, but at least my goals would be a bit more time oriented, which is important, you know, if I am aiming to retire at age sixty-five. I’ll be forty-five in October. If I have the gene, then I might aim to retire in ten years. What I would have to do is to downsize so that I put money in a pension so I’ll be taken care of or somehow transfer all my stuff to Sandra and then be poor and a ward of the court. You know, let’s face it, that’s the name of the game, you know, if I got that ill.

Claudia said she would also have her daughter tested but under the false pretense of getting a “routine blood test” so as not to worry her needlessly. While this comment shows a lack of knowledge about informed-consent procedures, it nevertheless reflects a genuine concern about genetic risk. Claudia’s daughter was bluntly dismissive of her mother’s concerns, saying she behaved like someone with AD to get sympathy from others.

An assessment performed by the Clinic’s geneticist revealed that neither Claudia nor Marilyn had positive family histories for the inherited forms of AD. Yet, their concern about being at risk may have been amplified by increasingly salient reports of AD being a genetic disorder, although genetic mutations account for only 1–2 percent of all cases of the disease (Post, Whitehouse, and Zinn 1998).



## Conclusion

In this study I have explored how social context mediated the experiences and help-seeking behavior of individuals complaining of mild and sporadic memory problems. In their paper on anticipatory dementia, Cutler and Hodgson (1996) suggest a need to further examine the relationship between depression and unwarranted concerns about having dementia. The cases discussed here suggest that this relationship is complex and multifactorial. One factor predisposing some individuals to interpret mild fluctuations in memory performance as symptomatic of dementia is the perception of being at risk for having inherited AD from a parent. It also has been suggested that the stigma attached to a diagnosis of depression could predispose some individuals to seek an alternate explanation as a way to diffuse the moral blame sometimes associated with that psychiatric label. A diagnosis of dementia represents a morally neutral alternative that situates memory lapses within the realm of neurobiology, thus exonerating afflicted individuals from responsibility for whatever troublesome behaviors may have been caused by the "impairment." Thus, seeking an evaluation for dementia can be seen as an act of resistance against psychiatric labeling. To borrow from Lock (1990), dementia "comes free of moralistic rhetoric" (250). However, while the diagnosis of dementia allows individuals to negotiate the moral status of their circumstances and diffuse the stigma attached to psychiatric labels, it may also serve to obscure the contribution of alienating social conditions to personal distress.

## NOTES

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# Diagnosing Dementia

## Epidemiological and Clinical Data as Cultural Text

JANICE E. GRAHAM

What meanings are hidden in the plaques and tangles of an atrophying brain, in the artifacts of diagnostic clinical history, in the bioinformatic matrices of an epidemiological database? Or in the lived experiences of a still-active mind trying to express a voice, to perform an action, but unable to find the means to do so? How do seemingly disparate bits and pieces of pathology, clinical history, social relationships, and specialist training come together? How do these fractured components form interpretable constellations that help us better understand the science; the sufferers; the relationships between dementia, data, and the diagnostic process?

In this chapter, I explore the concepts used by clinicians in the practice of differentially diagnosing dementia. Based upon standard clinical texts, and from the many “cases” seen in the past and discussed among colleagues, a medical diagnosis is an interpretation that a clinician constructs by piecing together *symptoms* provided from the narrative of a suffering person during a clinical interview and *signs* from that person’s physical examination and tests. The frequency of occurrence of these symptoms and signs form characteristic patterns that match those of other, similar cases or stand out as somewhat different. The patterns direct the physician along one or another diagnostic path. Researchers collect these diagnostic symptoms and signs with other information and inscribe them in clinical, epidemiological, and health-service databases. These facts inform and direct health-care practice, policy, and planning. Over time, the data also serve to transform the standardized diagnostic criteria.

What is often unrecognized is that the culturally conditioned practices of the people and institutions that construct the data are also, often unknowingly, incorporated into the body of these databases. The instruments that dictate

facts, the assemblages of local and expert knowledge used to guide choice, and the decisions that are arrived at and appear in these electronic repositories as separate yet interrelated elements allow a researcher to explore similarities and redundancies, as well as incoherences and incommensurabilities. This chapter shows the extent to which physicians see through the lenses of their clinical specialties in the execution of standardized criteria, how dementia is actualized in diagnostic practice and then written into data, and how these data may disclose more than the raw information instantiated within.

The methodology described here includes a comparative analysis of the established medical criteria with data from nearly three thousand extensive clinical assessments of elderly people that were collected as part of a national-population representative epidemiological survey of dementia. The bilingual Canadian Study of Health and Aging ([CSHA] 1994, 2000; Graham et al. 1996a; Tuokko 2003) involved interviewing 10,263 Canadians age sixty-five and over, from British Columbia to Newfoundland. Most lived in the community; 12 percent resided in institutional care facilities. All participants received the Modified Mini Mental State (3MS) screening test for cognitive impairment (Teng and Chui 1987). From the community, all those who tested positive for cognitive impairment and a sample of those testing negative were followed up with a more extensive neuropsychological assessment, clinical examination, and medical history ( $n = 1,608$ ). All residents of care facilities received the clinical examination (1,255). Relatives of all study participants provided personal and family history using section H of the Cambridge Mental Disorders Examination (CAMDEX) (Roth et al. 1988).

I worked as the clinical database manager for the CSHA between 1991 and 1993. My initial job was to determine the reliability and validity of the clinical data from the eighteen study centers. Later, during doctoral and postdoctoral studies in anthropology, neuroepidemiology, and geriatric medicine, I explored the differential diagnoses of cognitive impairment and dementia in light of standardized criteria. Although the majority of dementia diagnoses were subtyped as Alzheimer's disease, I began to examine other possible paths toward subtype differentiation within the dementia syndrome.<sup>1</sup>

IN THIS CHAPTER I detail a comparative approach to understanding dementia from three separate but connected sources of information:

1. The established clinical diagnostic criteria for dementia as derived from the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) (APA 1987, 1994), the tenth revision of the *International Classification of Diseases* (ICD) (World Health Organization [WHO] 1989, 1993) for vascular and other dementias, and the NINCDS-ADRDA<sup>2</sup> criteria for probable and possible Alzheimer's disease (McKhann et al. 1984). Later developments introduced

new criteria, for example, for dementia of the Lewy body type (McKeith et al. 1992), that had not originally been targeted during the CSHA survey. I call this information the *written standardized text*.

2. An epidemiological database electronically compiled from raw data, cataloging symptoms and signs collected as part of a national epidemiological study by clinicians from several specialties (*database text*).
3. The often unknown information embedded in the database text that can show, as in the examples presented here, important relationships between signs and symptoms, and also how specialists, who represent local expert cultures within medicine, differentially operationalize standardized criteria for dementia (*belief-practice text*).

### Databases as Cultural Text

I wish to make the claim that a database can be understood as a text in the way that Hanks (1989) defines *text* as a “sociocultural product and process . . . [that] can be taken (heuristically) to designate any configuration of signs that is coherently interpretable by some community of users.” The text is located in the “social matrix within which the discourse is produced and understood” (95–96). My position is that the database holds unique information, but importantly, as a text of the culture that produces it, it remains “subordinate to culture” (Bibeau and Corin 1994). It contains facts or ideas that are not easily disaggregated from the values and beliefs of those constructing the data.

There is considerable potential for databases to be more productively engaged as organic structures for interpreting beyond what Latour and Woolgar (1986) call “brute facts.” By reconfiguring the sets of elements within a database, we can explore classifications, similarities, differences, and relations that the observers who initially collected the information and created the database may not have recognized. While new tools in informatics allow for easier navigation of archived data that await innovative findings through secondary analyses, it becomes ever more important to remain cautious of these secondary analyses, or data prospecting, since, as Dumont has told us, referring to very different materials, “all documents [do not] have the same value” (1986, 191). In secondary analyses of existing databases, especially those that are maintained over long periods with several timepoints of data entry, the ethnographer can track and uncover how the meanings that are assigned to objects shift over time, what Appadurai (1986) has called “the social life of things.” In a chapter that pays particular respect to the works of Mauss, Dumont emphasizes the ethnographer’s task “to dig beneath the best native information” to the “underlying facts, which are almost unconscious because they exist only in collective tradition. But these are the real facts, the *things* [cf. Durkheim!] that we shall try to reach through the documents” (1986, 191). Anthropological methods are

adaptable to interpreting electronic fieldwork sites (databases), where “almost unconscious” facts can be found in what I call here the physician’s “belief-practice text.”

Social and historical drivers, the political nature of data, are locked in and can also be constructed from these seemingly static repositories. The variables initially observed, collected, and correlated can be countered by an almost infinite array of factors that are not included. While epidemiologists struggle to assure users of the controlled nature of the databases they design, that is a very limited and essentialist representation of what is, in actuality, a stochastic world in ever changing activity. While prediction is the central pillar of science (Casti 1990), and is approached using deduction in physics and astronomy, for example, the capability to explain lessens progressively as we move into biology, economics, and other social sciences and into the humanities. However, some level of prediction is possible, even if only in a statistical sense as a probability statement with degrees of confidence. And while some interpretations may be better than others (Eco 1990), it is important that the criteria used to make such determinations transparent for scrutiny.

If a strength of the morally and practically “obliged” ethnographer (Lambek 1991, 49, in theory; Maranda 1994, 435, in practice) is in orchestrating multiple voices and meanings, why not extend our study sites and fieldwork to databases, where much activity is being deposited? Yet we must endeavor to create a space in these electronic mines for sociohistorical context, without which there would be no limit to the ambiguity of the symbols (the signs and symptoms) that compose meanings, which tell so much more about the cultures, situations, and individuals relating within. “Context implies that all meaning is a matter of degree, probability, multiplicity, and, from the individual’s point of view, indeterminacy” (Friedrich 1986, 19). The exercise here is to consider the textuality of databases and diagnoses. It allows *poetics*, the diversity of voices, styles, practices, and politics, to play in harmony with *science*, which articulates methods to determine degrees of probability of these various interpretations.

An anthropologist’s critical attention to how power resides in and transforms arrangements between individuals and groups can show how dominant ideological and social patterns are intimately related to hegemonic ideologies and practices. Empirical, systematic research methods allow us to attend to the sources, agencies, and relationships that are used to construct facts in science.

We can deconstruct the truth claims of science by showing the radical historical specificity, and so contestability, of the very layer of the onion of scientific constructions. Anthropologists underline how scientific activity is not always about uncovering “nature.” It is a fierce fight to construct reality. Ethnographers slay positivistic facts and accepted ideals that create an aura of facticity (fact seeking, fact finding) in a sea of interpretations. Making biopolitics clearer, and acknowledging the ethical-political choices involved in what are

reported as neutral positions of fact in these proliferating databases (Agamben 1998; Keenan 1997), remains a work in the anthropology of science and biotechnology (Bibeau, Graham, Fleising, forthcoming).

The database is not the antithesis of hermeneutics. The ambiguities present in the actual lives of people and the institutional bodies that surround them are recorded and incorporated into databases; they are fuzzy and muddled, despite their predefined categories. Coded facts do *assault* the hermeneutical position, but they also *compel* attempts to interpret and understand. People can enter databases after the fact and create (compute) new variables from the old, build new models, algorithms, and criteria that were not conceived at the time the data were written. We can dissect the old, and write new stories. Multiple interpretations can be read. Databases are imperfect objects created by experts targeting the other. Nevertheless, they offer a landscape of ethnographic riches.

### **Dementia: Making Sense of the Diagnostic Categories**

At the 1996 *Lancet* conference to address “the challenge of the dementias,” Raymond Tallis, an eminent British geriatrician, strongly suggested that it was time to “reboot the disk” in the nosology of dementia, to let us start anew with different models of criteria.<sup>3</sup> While I agree, this clinical directive does, however, require some caution, for it is the structure rather than the content of our nosological “disks” that requires rethinking. It is the very content, in all its disarray, that might allow us to reinvent more dynamic “categories” that may prove to have buried within them useful connections, with the capacity to address the personal interrelationships and management of, and perhaps therapeutic approaches to, those suffering from senility and their caregivers and families. Existing data are rich resources that reveal the direction the models might take. In this chapter I make the case for an anthropologically inductive interpretive approach, which nevertheless makes use of sophisticated mathematical modeling to build upon the strength of interpretations. This approach contrasts with the deductive techniques more commonly used in epidemiology and in medicine.

The growth of interest in cognitive impairment has generated new approaches to dementia with an increased appreciation of the central importance of heterogeneity in its subdiagnosis (Graham et al. 1997, 1999). The syndromic diagnosis (that is, the definition of dementia) was revised both in DSM-IV (APA 1994), and in ICD-10 (WHO 1993). Dementia, using these criteria, is clinically identified as a progressive degenerative disorder characterized by “a decline from a previously higher level of functioning” and by multiple cognitive deficits that “must be sufficiently severe to cause impairment in occupational or social functioning” (APA 1994, 134). An appreciation of previously unrecognized causes of cognitive impairment, such as frontotemporal dementia (Lund and



Manchester 1994) and dementia of the Lewy body type (McKeith et al. 1992), has coincided with substantial changes in the way in which more established causes of dementia are being redefined. Significant emerging developments in understanding vascular causes of cognitive impairment have been driven by the ability to target identifiable risk factors, which have so far eluded researchers of Alzheimer's disease (Roman et al. 1993; Chui et al. 1992; Rockwood et al. 1994, 2000; Hachinski 1992, 1994; Mitnitski et al. 1997; Nyehhuis and Gorelick 1998; Graham et al. 1999; Jellinger and Mitter-Ferstl 2003; Erkinjuntti et al. 2004). As a result of improved understandings of the existence of these definable subgroups, Alzheimer's disease—which had the full support of a remarkable lobbying platform by the National Institute of Neurological and Communications Disorders and Stroke (NINCDS) committee within the United States National Institutes of Health (NIH) (McKhann et al. 1984; Fox 1989; Adelman 1995)—has encountered a challenge to its former preeminent diagnostic status (Erkinjuntti et al. 1994; Blennow, Wallin, and Gottfries 1994; Emery and Oxman 1994; Bowler and Hachinski 2003). The development of treatments and the role of the pharmaceutical industry in restructuring this understanding provided a market opportunity during the 1990s. But that is another story (Graham 2001, 2003).<sup>4</sup>

Despite a few voices that could be heard promoting “the ubiquity of brain/mind interactions” and warning that “problems in living necessarily influence brain state and structure” (Eisenberg 1986, 503), the predominant mindscape of the medical community has been focused on a pathological/anatomical explanation for degenerating cognition and behavior. Although causes of the various subtypes of dementia cannot be determined in the absence of readily available biological markers, an assessment of the personal and medical history of the clinical symptoms and signs is required in order to diagnostically differentiate the subtypes. The overlap of configurations of symptoms and signs, compounded by multiple comorbidities (Graham et al. 1996b, 1999; Mitnitski et al. 1997; Jellinger and Mitter-Ferstl 2003), represent key challenges to the etiological diagnosis of dementia.

In clinical practice the presence of one sign may not necessarily sound an alarm. Rather, the emergence of certain *combinations of symptoms and signs* characterizes a disorder. Clinicians meet this challenge by recognizing patterns of symptoms and signs. Our group showed, however, that diagnoses are not always distinguishable when based simply upon the presence or absence of these signs and symptoms; rather, it is conditional relationships among the symptoms and signs that form probabilities for a particular diagnosis and for more than one diagnosis within an individual. By establishing that diagnostic probabilities can be ascertained from identifying the co-occurrences of symptoms and signs, this approach illustrated what is foundational to clinical reasoning: symptoms and signs do not occur independently, but are conditional on each other.

While with the CSHA, I had established that the clinicians' diagnoses met



the standardized criteria for dementia. This was done by developing a series of algorithms that initially mimicked the standardized text for dementia as set out in the DSM and ICD texts (Graham et al. 1996a).<sup>5</sup> I later examined how signs and symptoms, which were recorded in the data, interrelated with one another (Graham et al. 1996b, 1996c). Importantly, these analyses revealed redundancies in diagnostic activity—more than one constellation of signs and symptoms can constitute a single diagnosis. The evidence that a single diagnosis can actually be derived from very different patterns of signs and symptoms brings us closer to the meanings of the anomalies and inconsistencies and atypical presentations that are characterized in the elderly.

Additionally, the semiological catalogs, the bundles of meaningful symptoms and signs that define a diagnosis of dementia, can be quite specific for a given clinician or specialty, while varying among clinical specialties. While “harmonization” of standards remains the mission of many international private and public agencies (presumably to reduce redundancies and the costly repetition of drug trials in each regulating country), this standardization will be at the cost of multiple variant diagnostic interpretations, each plausible and potentially revealing of unknown but important relationships that are worthy of further study. By calling for more, rather than reduced, opportunities for variability in clinical representations, I challenge a clinical epidemiological tradition of standardization and of analyzing or “reading” a database as if it were a telephone book. Instead, not wanting to limit potential diagnostic interpretations, I suggest that Umberto Eco’s (1990) “encyclopedia” approach can be adapted to reading database texts. This is an unusual inductive approach to reading epidemiological databases, but it paves the way for novel possibilities for understanding dementia, as well as other heterogeneous disorders.

Dementia subsumes an already formed mind, adding to but also taking away from it. How these bits and pieces form relationships and mark the type of dementia is the subject herein. The effects of how different clinicians hearken, or call attention (Haraway 1997, 210), to the existence of particular signs or symptoms in creating the diagnosis is of importance, and so, too, is the evidence for co-occurrence and *relationships* among the elements used to classify the subtypes for dementia (for example, Alzheimer’s diseases, dementia of the Lewy body type, vascular cognitive impairments, and frontotemporal dementias). As Dumont suggested in looking at social castes, order results from a consideration of value and, necessarily, context. Considering value and Leibniz’s struggle to embrace difference in the whole (1986, 252), I looked to the data for the configurations formed by idea-values or value-ideas of clinicians about dementia (the belief-practice text). Illustrating an empirical fit with Leibniz’s concept of the “whole,” the interrelating signs and symptoms form (hierarchical) structures that underline the type and severity of the dementia.

The statistical strength (probabilistic value and context) among them varies, marking a particular subtype or severity.

By looking for associations between the constellations of symptoms and signs in the differential diagnoses and severities found in our sample population (in the database text), my colleagues and I found that certain symptoms and signs were conditional upon one another in forming a particular diagnosis. With more than four hundred variables in the CSHA clinical data, we did not intend to analyze all possible relationships. Instead, fifty-six variables were selected on the basis of their suspected clinical relevance. Nineteen of these symptoms and signs showed statistically significant probabilities (frequencies) and variance across fifteen diagnostic categories, including no cognitive impairment, cognitive impairment but no dementia; mild, moderate, and severe forms of Alzheimer's disease and vascular dementia; four subtypes of possible Alzheimer's disease; Parkinson's dementia; unspecified other dementias; and unclassified.<sup>6</sup>

A synergy index was calculated from the number of significant connections (synergies) divided by the square root of the diagnostic sample size. The pattern of associations (the "coordination" of the items) varied according to the specific diagnosis. For example, as a given sign is present, the probability that another sign is present systematically increases ("synergism") or decreases ("antagonism"). Importantly, these relationships between the signs and symptoms fall apart, decreasing significantly as dementia progresses (Graham et al. 1996b). Dementia progression and specific etiologies have characteristic patterns of decline and destruction from the strong synergy that exists between symptoms and signs for those with no cognitive impairment. Those with no cognitive impairment had many coordinations (that is, strong synergy). This synergy decreased in those with severe dementia, and there were intermediate pictures for mild and moderate forms. There was significant reduction (more than ten times) in the values of our synergy index in the severe Alzheimer's disease group compared with results for the no-cognitive-impairment group. Synergy reached a maximum value in the no-cognitive-impairment group (55.6), declining to 5.8 in those with severe Alzheimer's, 3.3 in those with severe vascular dementia, and 3.0 in those with Parkinson's dementia. There is a strong relationship between activities of daily living (basic personal tasks of everyday life) and instrumental activities of daily living (those found in independent living, for example, the ability to do one's own shopping). This synergy score dropped from 7.42 for those with no cognitive impairment to 2.64 for those with cognitive impairment not dementia (CIND), and from 1.84 to 1.17 to 0.99 among those with mild, moderate, and severe Alzheimer's disease. Particular diagnoses give rise to discernible patterns of synergy and antagonism; the coordination of items in Alzheimer's disease is distinct from the coordination of items in

vascular dementia, for example. The different configurations of signs and symptoms, buried in the CSHA database, reflect etiology and stage for frailty and cognitive aging (Mitnitski et al. 1997; Graham et al. 1999).

WHEN DIAGNOSTIC CATEGORIES can be disaggregated into the elements used to construct them, and the relations between these items are revealed, then culture and nature can be seen to comfortably coexist in relationships neither wholly natural nor cultural; nosology has what Latour (1993) might refer to as a “symmetrical” anthropological landscape, one that weaves both culture and biology. Each trope of clinical decision making is precipitated on some configuration of signs and symptoms that reveal themselves as distinct constellations. I suggest that any constellation of events has probabilistic dimensions, with different degrees of overlapping clusters of interconnected elements. The nosologies currently in use rely on hard categories; they cut up a degenerative process into segments that mask, rather than mirror, a plurality of different socioneurodegenerative processes (Lyman 1989; Davies 2004). Built-in redundancies mean that many different routes can be followed. As Tallis reminds us, these are people encountering a process in which “life becomes an impenetrable solitude of a series of disconnected moments” (personal communication), witnessed by involuntary egoism with the failure to engage in the organized interest of others. The demented person is conscious, yet his or her purposive actions give an enigmatic cast to a context no longer shared with others. Without memory, the sufferer does not experience shared continuity through time (Tallis 1996). And the current medical approach to determining hard diagnostic categories indeed also reflects this discontinuity. Having seen where the database text reveals relationships that are not articulated in the standardized criteria, let us turn now to what is buried in the belief-practices of medical mindscapes and clinical cultures that are diagnosing dementia.

### Medical Mindscapes

I have suggested here that one can read the CSHA database as narrated stories by some seventy-six physicians representing five clinical specialties. These hidden and unintended stories provide us with an extraordinary view of the cultural activity of the diagnostic practices of clinicians. Shepherd, in examining the role played by British nosologists in psychiatric classification, noted that after considerable international work on the schizophrenias by the WHO’s ICD, “it quickly became apparent that the major source of variation among experienced clinicians was the difference between their nosological schemata, all of which were subject to influence by the various schools of psychiatry” (1994, 3). But “culture is a perspective on reality, rather than a collection of categories marking differences among individuals” (Corin 1994, 101). The fervent activity

directed at international standardization in case ascertainment and assessment of severity is an attempt to gain what Shepherd refers to as a “common language, a psychiatric Esperanto, [that] constitutes no more than a necessary prerequisite for a rationally-based nosology” (3).

The exercise of standardizing empirical evidence is intriguing, but it may well result in the reduction or loss of important details that provide us with the key to unlocking a terrain that presently remains illusive. While the idea of comorbid dementias, of an Alzheimerized Parkinson’s or vascular dementia, existed (Emery and Oxman 1994), only more recently has evidence begun to corroborate the theory (Graham et al. 1996b, Mitnitski et al. 1997; Jellinger and Mitter-Ferstl 2003). Importantly, those standardizations use the probabilities or synergy coordinations between signs and symptoms that represented these emerging classifications (Graham et al. 1996b; Mitnitski et al. 1997; Graham et al. 1999).

In areas of medical diagnostics that are undergoing shifts in classification, such as that encountered among the evolving dementia etiologies, important information (which might be called empirical evidence but certainly is not necessarily limited to that epistemological terrain) is frequently overlooked, reduced to an incomprehensible construct, or lost entirely. Attention to this lost, or (adopting a genomic analogy) *junk* data (the butterfly effect in systems, where sensitivity to initial conditions result in a hurricane oceans away [Gleik 1987]), might have led to innovative breakthroughs in understanding the particular syndrome and its many different manifestations in individual sufferers. For instance, those suffering dementia of the Lewy body type could be easily identifiable as “different from Alzheimer’s disease” using the probabilistic method. They could be prevented from being prematurely hurried along a degenerative path when misdiagnosed with Alzheimer’s disease and subsequently prescribed the neuroleptic medications harmful to those suffering Lewy body dementia that are commonly used in Alzheimer’s sufferers.

Almeido-Filho and colleagues argue convincingly for inclusion of a cultural reading of nosology:

[V]ariations in disease categories and criteria through history and across cultures and societies make clear the lack of “objectivity” of diagnostic categories. Phenomena associated with mental health, disease and care must be conceived as historical, context-sensitive, fragmented, conflictive, dependent, and uncertain processes, therefore more efficiently modelled as open systems. In a particular social and cultural setting, the professional conception of such specific model-objects shall be the result of the application of a methodological practice equally context-sensitive, interactive and pluralistic (n.d., 10).

The symptoms and signs used by each clinician are based on the physician’s

training, reading, and clinical experience. This is information existing in the mindscape of all clinicians and is based on the material they have read and all the patients they have examined. It includes a whole range of attitudes that can be included in what epidemiologists call *biases* (Sackett 1979), which “sneak in” to the pursuit of objectivity (Huston 1995; Klein et al. 1995). As noted by Corin, “The diagnosis only exists and has value in relation to the specific semiological system of the clinician” (Almeido-Filho et al. n.d., 9).

Empirical data do not always form the basis of nosology in psychiatry, and “consequently, the definition of discrete disorders remains an artifact of sometimes arbitrary criteria that leave the classification of milder and intermediate forms of distress ambiguous” (Kirmayer 1989, 327). As is done in much of the anthropological study of medicine, Kirmayer focuses particularly on the meaning of the symptoms to the patient, on how “culture influences symptoms from their inception.” As a result of this focus, there is a valuable body of information on the profound cultural meanings of symptoms. Cultural variations in the manifestations of these symptoms are being addressed by the “new cross-cultural psychiatry” and influence much of medical anthropology and psychiatry (Good and Good 1981; Kleinman 1987, 1988; Kirmayer 1989; Littlewood 1990), making room for alternative approaches to the exploration of eternally evolving concepts of clinical practice (for example, Eisenberg 1986, 1995). The universality of disease categories continues to be questioned as epistemological considerations generate, in extreme instances, “a view of psychiatry as a cultural product of Western societies in the same way as are the diatonic scale and Coca-Cola. These products can be exported all over the world and may be appreciated by the local populace, but are no more valid than indigenous music or vegetables” (Leff 1990, 305).

Even Kraepelin, a century ago, took a “far from dogmatic” position on the relationship between symptoms and disease etiology. He “accepted the existence of both psychological and biological factors and recognized that their nature and role were in many cases hypothetical or unknown” (Pichot 1994, 237). It was Kraepelin’s essentialist ideal, which is described here by Pichot: “If we had at our disposal all the scientific facts, we could define the categories either by symptomatic, pathogenic, or etiological criteria, but the three resulting nosologies would be identical, a perfect correspondence between the three levels being postulated. Accordingly, if we do not yet have a sufficient knowledge of the mechanisms and the causes, the study of the symptoms, of their conditions of apparition, their nature, and their evolution will result in a ‘natural’ nosology” (236–237).

My work, presented in this chapter, focuses on the collection of symptoms and signs that are reported by physicians in the act of diagnosing dementia. While the examination of a patient is interpreted by clinicians as empirical evidence for their diagnostic opinion, it is also shaped by the conceptual tropes of

their discipline. For the purpose of exploring how they place different weights, different interpretations of importance, on particular items or particular intertextual configurations of their observations of symptoms, signs, and behaviors in a person, I accepted their observations as facts in the world. I could thereby explore the potential to uncover the direction in which cultures of clinical specialties influence diagnostic practice. Whether this will provide a “greater understanding of the whole” by embracing difference will remain elusive until there is a shift from the existing categorical thinking to a dimensional approach that examines probabilities within the symptoms and signs.

Some earlier epidemiological surveys have used operational criteria for dementia that neglect the essential “social functioning” dimension in the definition of dementia (for example, Pfeffer, Afifi, and Chance 1987; Evans et al. 1989). Responding to these studies, colleagues and I found that neuropsychologists and physicians had different but complementary approaches to diagnosing dementia. Diagnostic agreements were greater when the patient had higher education, while depression and lower 3MS scores in dementia sufferers decreased diagnostic consistency between the neuropsychologists and physicians (McKnight, Graham, and Rockwood 1999). Neuropsychologists relied on performance ratings on the neuropsychological tests and less on functional activities (Larrea et al. 2000). There are differing approaches by clinical specialties to criterion selectivity. A continental divide that had existed between more socially engaged old-age psychiatry in the United Kingdom and a more psychoneurological approach in the United States had closed by the turn of the previous century as the hard facts of neurological signs have gained diagnostic supremacy over that of the social affect and general well-being of the person. The neurological brain attracted the medical attention of clinical specialists, while the psychosocial contextualized mind of people with dementia now goes largely ignored (Eastwood 1990, 1995; Eisenberg 1986).

### **Local Cultures of Medical Specialization**

Physicians use the inventory of tests that they learn in medical school as prisms through which they look at their patients. Even though they ostensibly examine patients using the same standardized criteria, they rely most strongly on the signs that they have skills in detecting and in the instruments that most efficiently and effectively assist them in achieving a diagnosis. While the voices of clinical medicine may appear united, I suggest that different paths that are taken toward achieving this goal are oriented around the ecology of the particular specialty or school. Even when it is manacled to the operational criteria and standardized protocol, we can see in evidence that the clinical world of dementia too is organized around different cultural percepts and worldviews.

Seventy-six physicians representing five areas of medical specialty—family

TABLE 4.1  
**Characteristics of All People Receiving Clinical Assessment  
 (n = 2,914) by Clinical Specialty**

	<i>Family practitioner</i>	<i>General internist</i>	<i>Geria- trician</i>	<i>Neuro- logist</i>	<i>Psychia- trist</i>	<i>All</i>
3MS score	66.3	66.2	62.3 <sup>a, b, d</sup>	65.7	57.1 <sup>a, b, c, d</sup>	64.0
Age	81.6	82.2	82.5 <sup>a, e</sup>	81.8	80.9	82.0
Education	8.2 <sup>b, c, d</sup>	9.1	9.0	8.8	8.2 <sup>b, c</sup>	8.6
Percentage living in institution	40.1	36.1	45.3 <sup>a, b</sup>	43.9	52.8 <sup>a, b, c</sup>	43.1

Figures represent significant differences, when adjusted for multiple comparisons, with <sup>a</sup>family practitioners; <sup>b</sup>general internists; <sup>c</sup>geriatricians; <sup>d</sup>neurologists; <sup>e</sup>psychiatrists

medicine (n = 36), general internal medicine (n = 6), geriatric medicine (n = 21), neurology (n = 8), and psychiatry (n = 5)—performed the clinical assessments in the CSHA. There was very good diagnostic consistency among the physicians from across the country and extremely high concordance (98 percent) of their diagnoses with DSM-III-R criteria for dementia and NINCDS-ADRDA (92 percent) (Graham et al. 1996a). A kappa measure for interrater reliability measured 0.81, for a near-perfect agreement. As the diagnosis was made more specific, however, from a comparison of dementia/not dementia, to dementia/CIND/no impairment, to dementia subtyping, the consistency declined. Additionally, there were some differences in the patient populations seen by some clinical specialties. For example, 53 percent of the CSHA participants who were examined by psychiatrists were living in institutional care facilities, whereas the majority (60 percent) of people seen by family physicians lived in the community. In a U.S. study, Rybicki, Johnson, and Gorell (1995) found that primary care physicians were more likely to refer Parkinson's cases to a neurologist if the patient was younger, was male, had a private insurance plan, used health care more often than the norm, and used hospital-based clinics for their primary care. This selective referral bias remains an important deterrent to hospital-based case-control studies. The randomized representative sample of elderly Canadians selected for the CSHA was meant to counter this form of systematic bias. Despite this study design, however, CSHA psychiatrists saw proportionately more institutionalized elderly than did the other physicians (although residence could be controlled in subsequent analyses). In general, their patients



had a lower 3MS score and lower education level than the people examined by the other study physicians (Table 4.1).

Considerable variation in specialist differential-diagnostic opinion became apparent. Neurologists diagnosed proportionately almost twice as many people with probable Alzheimer's disease than did psychiatrists, who, in turn, diagnosed two and a half times the proportion of vascular dementias compared with the neurologists, and about 1.5 times more frequently made "other specific dementia" diagnoses (which include Parkinson's dementia, alcohol-related conditions, postinjury to the head, tumors, normal pressure hydrocephalus, frontal lobe disorder, Pick's disease). General internists and psychiatrists made proportionately fewer probable Alzheimer's disease diagnoses than the others, with internists identifying more people with possible Alzheimer's disease (which includes four distinct subcategories of atypical presentation, vascular components, Parkinsonism, and comorbidity) and psychiatrists finding vascular dementia at roughly three times the rate that neurologists made the same diagnosis in the community population and twice the rate in the institutionalized elderly.

General internists and neurologists diagnosed vascular dementia the least among the clinical specialties. The general internists were also least likely to place a person into an unclassifiable dementia category. Psychiatrists, by contrast, placed 15 percent of community-living elderly into this category, in comparison to an average rate of 7 percent for all physicians.

If we look to particular characteristics of the diagnostic patterns by the various clinical specialties for all people represented in the CSHA, including those with no cognitive impairment and those with cognitive impairment but not meeting dementia criteria (that is, CIND), we see some interesting differences. Even when controlling for residence, psychiatrists found significantly fewer people to be cognitively normal. Corroborating the findings of Wind and colleagues (1995), but different from what was found among German general practitioners who tended to overestimate impairment (Cooper, Bickel, Schäufele 1992), CSHA family practitioners and internists were less likely to make a dementia syndrome diagnosis than were the other specialists.

The people diagnosed as cognitively normal seemed to have relatively similar characteristics across examining specialists, although those seen by geriatricians and neurologists had higher cognitive scores, and there was a slightly greater proportion of institutionalized elderly seen by family practitioners than by geriatricians (Table 4.2). Among the people diagnosed with CIND (Graham et al. 1997), there were few differences associated with clinical specialty, although those examined by psychiatrists were younger than the people seen by geriatricians, and those seen by internists had higher education on average and a smaller proportion were institutionalized (Table 4.3). However, when we look at the people diagnosed with dementia (Table 4.4), those seen by the neurologists



TABLE 4.2  
**Characteristics of People Diagnosed as Cognitively Normal  
 (n = 921) by Clinical Specialty**

	<i>Family practitioner</i>	<i>General internist</i>	<i>Geria- trician</i>	<i>Neuro- logist</i>	<i>Psychi- atrist</i>	<i>All</i>
3MS score	82.8	82.8	86.2 <sup>a, b</sup>	87.2 <sup>a, b</sup>	85.6	84.6
Age	79.8	80.7	80.0	80.3	80.6	80.1
Education	8.6	9.7	9.7	10.2	8.9	9.2
Percentage living in institution	21.8 <sup>c</sup>	17.0	13.1	22.0	15.4	17.9

Figures represent significant differences, when adjusted for multiple comparisons, with <sup>a</sup>family practitioners; <sup>b</sup>general internists; <sup>c</sup>geriatricians; <sup>d</sup>neurologists; <sup>e</sup>psychiatrists

had a higher 3MS score than those examined by other specialists. The people seen by CSHA psychiatrists tended to be slightly younger; those examined by the geriatricians had, on average, a lower 3MS score for cognitive functioning along with a higher level of education.

Finally, Table 4.5 provides the probabilities of twenty-one symptoms and

TABLE 4.3  
**Characteristics of People Diagnosed as Cognitively Impaired but Not  
 Dementia (CIND) (n = 861) by Clinical Specialty**

	<i>Family practitioner</i>	<i>General internist</i>	<i>Geria- trician</i>	<i>Neuro- logist</i>	<i>Psychi- atrist</i>	<i>All</i>
3MS score	70.5	69.6	72.1	71.0	71.5	71.1
Age	81.3	81.3	81.8	80.5	79.4 <sup>c</sup>	81.3
Education	7.9	9.1 <sup>a, d</sup>	8.2	7.7	8.1	8.1
Percentage living in institution	42.0	30.4 <sup>c</sup>	44.7	39.1	45.5	41.8

Figures represent significant differences, when adjusted for multiple comparisons, with <sup>a</sup>family practitioners; <sup>b</sup>general internists; <sup>c</sup>geriatricians; <sup>d</sup>neurologists; <sup>e</sup>psychiatrists

TABLE 4.4  
**Characteristics of People Diagnosed with Dementia  
 (n = 1,132) by Clinical Specialty**

	<i>Family practitioner</i>	<i>General internist</i>	<i>Geria- trician</i>	<i>Neuro- logist</i>	<i>Psychi- atrist</i>	<i>All</i>
3MS score	41.4	44.3	36.9 <sup>a, b, d</sup>	46.3 <sup>e</sup>	36.9	40.0
Age	83.9	84.5	84.7	83.8	82.0 <sup>a, b, c, d</sup>	84.1
Education	8.0	8.4	9.0 <sup>a, e</sup>	8.6	8.0	8.5
Percentage living in institution	58.7 <sup>c, e</sup>	61.0	68.9	61.4	70.3	64.5

Figures represent significant differences, when adjusted for multiple comparisons, with <sup>a</sup>family practitioners; <sup>b</sup>general internists; <sup>c</sup>geriatricians; <sup>d</sup>neurologists; <sup>e</sup>psychiatrists

signs assessed for everyone diagnosed with dementia by the specialty of those diagnosing. An additional four demographic items—the 3MS score, age, years of education, and percentage of this study population living in an institution—are also provided. Probabilities that were significantly different from those of the other clinical specialist groupings are identified. Even controlling for multiple comparison, only three items show no variation between the clinical specialties. These are impaired abstract thinking and impaired judgment, both of which remain consistently high in all people suffering from dementia, and paranoid behavior.

## Conclusions

Addressing the cultural dimensions of the experience of Alzheimer's disease and of other dementias for the sufferer and caregivers was not the goal of this chapter (see, instead, e.g. Henderson 1990; Gubrium 1986; Cohen 1995; Herskovits 1995; as well as other chapters in this volume). Estes and Binney (1991) have described in detail many of the arguments against the biomedicalization of aging that have privileged the clinical over political and ontological constructs. It is precisely these clinical constructs that I have targeted in my novel approach to dementia, for these constructs are the tropes by means of which physicians make diagnoses. I have shown, however, that these clinical constructs are not separate from cultural practices and beliefs by focusing on what clinicians use to assemble a diagnosis of dementia and its subtypes.

TABLE 4.5  
**Probability of Symptoms for All Diagnoses of Dementia by Clinical  
 Specialty (Number of Diagnoses)**

<i>SYMPTOM</i>	<i>Family Practitioner (n = 322)</i>	<i>Internist (n = 100)</i>	<i>Geriatrician (n = 454)</i>	<i>Neurologist (n = 145)</i>	<i>Psychiatrist (n = 111)</i>	<i>TOTAL (n = 1132)</i>
Facial bradykinesia	.132	.055	.141 <sup>b</sup>	.211 <sup>a, b</sup>	.243 <sup>a, b, c</sup>	.149
Limb bradykinesia	.190	.074 <sup>a, d, e</sup>	.145	.285 <sup>a, c</sup>	.206	.176
Limb tone	.341	.187 <sup>a, c, d, e</sup>	.467 <sup>a, d</sup>	.344	.374	.383
Agnosia	.444 <sup>b, d, e</sup>	.179	.471 <sup>b, d, e</sup>	.321	.250	.406
Memory impairment	.917	1.00 <sup>a, c, d</sup>	.921	.864 <sup>c, e</sup>	.949	.923
Impaired focal signs	.329	.200 <sup>a, c, e</sup>	.373	.252 <sup>c, e</sup>	.436	.336
History of stroke	.245	.282	.308	.172 <sup>c, e</sup>	.317	.272
Arterial hypertension	.351	.229 <sup>c</sup>	.383	.294	.296	.340
Impaired abstract thinking	.893	.862	.929	.882	.913	.905
Impaired judgment	.808	.785	.835	.784	.807	.814
Diminished activities of daily living	.554	.586	.662 <sup>a, d</sup>	.472	.682 <sup>a, d</sup>	.602
Emotional incontinence	.086	.109	.210 <sup>a, b, d</sup>	.049	.208 <sup>a, b, d</sup>	.146
Somatic complaints	.072	.224 <sup>a, c, d</sup>	.068	.128	.196 <sup>a, c</sup>	.104
Depression (MD exam)	.096 <sup>e</sup>	.139	.072 <sup>d, e</sup>	.167	.233	.113
Depression (CAMDEX)	.419	.541 <sup>a, c, d</sup>	.378	.317	.548 <sup>a, c, d</sup>	.413
Episodes of agitation	.190	.207	.330 <sup>a, b, d</sup>	.119	.371 <sup>a, b, d</sup>	.260
Personality changes	.753	.788	.755	.634 <sup>a, b, c, e</sup>	.835	.750
Difficulties with everyday activities	.793	.788	.860 <sup>a, d</sup>	.731	.809	.813
Paranoid	.231	.278	.231	.201	.278	.236
Cerebrovascular problems	.436	.404	.429	.273 <sup>a, b, d, e</sup>	.608 <sup>a, b, c</sup>	.427
Mobility difficulties	.663	.719	.708	.515 <sup>a, b, c, e</sup>	.722	.674
3MS score	41.4	44.3	36.9 <sup>a, b, d</sup>	46.3	36.9 <sup>d</sup>	40.0
Age (years)	83.9	84.5	84.7	83.8	82.0 <sup>a, b, c, d</sup>	84.1
Education (years)	8.0	8.4	9.0 <sup>a, e</sup>	8.6	8.0	8.5
Percentage living in institution	58.7 <sup>c, e</sup>	61.0	68.9	61.4	70.3	64.5

Figures represent significant differences, when adjusted for multiple comparisons, with <sup>a</sup>family practitioners; <sup>b</sup>general internists; <sup>c</sup>geriatricians; <sup>d</sup>neurologists; <sup>e</sup>psychiatrists

In this chapter I present various diagnostic approaches to dementia and its subtyping by physicians, carried out in clinical practice, collected, and then inscribed in a database text. Historically, anthropology has kept distant from broken bones and “organic” disease in examining health, illness, and sickness. In taking on a syndrome that can be explored as disease, illness, and sickness (Young 1982), I advance here a methodology that employs an anthropology of diagnostic process, examining the physician’s own data for hidden relationships that usually go without saying. In the process, I reveal potentially useful “bundles of criteria” specific to the refined skills and training of subcultures within clinical medicine.

Exploring the manner in which senile dementia is classified by expert research clinicians places emphasis on how they “distinguish-choose-posit-assemble-count-speak” (Castoriadis 1987) through the data they report. The choices they make often reveal the underlying premises with which they engage in diagnostic practice. The assemblage of signs, symptoms, and behaviors collected, cataloged, and interpreted by clinicians in diagnosing dementia, and the clinical diagnostic decision-making process in general are represented in a database text. I have elucidated this text using what Eco refers to as an encyclopaedia perspective. The database, I suggest, represents a “systematic assemblage of the key configurations which connect elements in a given culture,” which, like an encyclopaedia, “can be seen as providing the major codes and key categories that prevail in a culture, including the preferential schemas that determine the architecture of that culture, and the semantic web that links cultural elements together” (Bibeau and Corin 1994, 10).

I have shown that we can empirically draw the intertextual relational properties of the individual items that make up the constituent units of diagnostic practice. Symptoms and signs gain meaning via their interactions, through their synergies and antagonisms. Furthermore, they can be used as building blocks in the construction of the social imaginary of medical mindscapes. They hold within their relationships to one another hierarchical orderings that represent particular distinctive expressions of etiology and neurodegeneration. My methodology develops a preliminary and exploratory heuristic instrument (an algorithm with synergies) that produces a differential diagnosis for dementia based upon clinical decision-making probabilities and groupings of clinical factors. The methodology has been used to develop more refined definitions through access to bodies of information that are concealed in databases. New and evolving categories of dementia can be probabilistically estimated on the basis of already existing data. It can thereby be used to demonstrate the conceptual shifts and overlaps at the level of diagnostic discursive practice (Foucault 1972, 60) and the construction of illness as an object of diagnostic activity (Good 1994, 66).

Particular tropes direct clinical specialists in their choice of configurations

of symptoms and signs. Psychiatrists look more carefully at the affective qualities of their patients, on depression, somatic complaints, agitation, emotions. The context of social functioning is of some importance for psychiatrists. Neurologists examine the neurological signs, activities, and functioning, while affective and personality characteristics seem less important for them. Geriatricians focus on functional and global concerns; their patients' competence in activities of daily living, that is, their ability to perform everyday tasks, is clearly significant, but so too (and no doubt related to the individual's capacity to function) are configurations of neurological components. These additional elements in the geriatrician's toolkit likely reflect geriatric medicine in Canada, where it is a subspecialty in which the practitioner focuses on geriatrics after having already specialized in internal medicine. General internists appear to represent a more diverse group, placing less focus on the "aging" individual and more on the mechanistic systemic signs and symptoms; family practitioners consider the management and care of the patient and the patient's family and seem to be less concerned with a specific etiological diagnosis and more interested in the ongoing ability of the aging individual to continue to function in his or her everyday life.

Rather than follow international harmonization attempts to funnel the perspectives of these different practical approaches into one reduced set of criteria that can be universally applied to all, in this chapter I make a case that, instead, we might be better served by embracing differences in diagnostic practice. Although a standardized toolkit has practical utility in addressing common concerns and public-health policy, much might be gained by allowing many different approaches. The loss of information when a standardized approach is forged should be avoided, for it leads to items that go unrecorded, which cannot then be reflected upon, and which are removed from the landscape of possibilities. These lost bits and pieces might have had the potential to later answer the questions that further our inquiry and knowledge.

I have described how clinicians and the medical-scientific community interpret dementia through belief-practices that are not often consciously known. I believe that the approach I have taken as a means to understand this represents a similar decision-making model that the physicians themselves use. I have, however, found no other such attempts to examine the probabilistic relationships of the meaningful units of diagnostic activity. Clinicians' own texts, comparing their standardized diagnostic criteria to their practices as recorded in their databases, were used to unravel the constellation of elements (signs, symptoms) of diagnostic meaning. This approach includes a multiplicity of voices of clinicians diagnosing dementia, their interpretations of the particular tests, and technologies used distinctively by them to identify symptoms and signs that represent meaningful aspects of some disease process.

Through a recognition of databases, dementia, and diagnostic processes as

technoscientific objects, the tension between structure and agency, that is, the relationships between the databases, as well as the databases themselves, have been examined. I relied on the epidemiological database created by these same scientists and clinicians for disclosure and understanding. This serves both to facilitate their important quest to diagnose more accurately and efficiently, while providing us with the information on the discourse they engage in to go about this task. The relationships between the signs and symptoms, what I called synergism and antagonism, were described and used ontologically to construct other diagnostic narratives. Multiple comorbidities and severities were thereby illustrated.

My approach addresses the issues of standardization, reliability, and validity that are inherent in epidemiological, clinical, and anthropological interpretations; and in the process of advancing the clinical-medical-scientific inquiry into the syndrome of dementia and its differential diagnosis, I elucidate elements and aspects of clinical culture in diagnostic practice. Evidence of several paths to diagnosis were provided, incorporating many different configurations of symptoms and signs in diverse semiological catalogs. If this argument is sound, then perhaps we should consider a reexamination of the importance of emphasizing the standardization of diagnoses and explore instead the wealth of information contained in the plurality of clinical approaches that are currently hidden under the guise of standardization.

#### NOTES

1. The CSHA clinical exam had been designed in consultation with several international studies, including a World Health Organization (WHO) study on dementia (Amaducci and Baldereschi 1991), and with the Consortium to Establish a Registry for Alzheimer's Disease (CERAD) project in the United States (Heyman 1990), whose work continues and has been widely influential in international studies (e.g., Prince et al. 2003). During the 1990s, I consulted extensively with an international group of expert dementia diagnosticians, which included a team of Canadian neurologists, geriatricians, psychiatrists, neuropsychologists, and epidemiologists from across Canada (Graham et al. 1996a). I also met with investigators in the Eurodem (European Community Concerted Action Epidemiology and Prevention of Dementia) and the U.K. Medical Research Council (MRC) Multicentre Study of Cognitive Function and Ageing (Cooper and Bickel 1984; Copeland et al. 1987).
2. National Institute of Neurological and Communicative Diseases and Stroke/Alzheimer's Disease and Related Disorders Association.
3. Ironically, the banquet menu at this meeting of the invited leading international dementia experts, held during the height of the variant Creutzfeldt-Jacob (mad cow) epidemic in the United Kingdom, included a robust serving of haggis.
4. Identification of a population experiencing some form of mild cognitive impairment that did not meet the dementia criteria (CIND) in my *Lancet* article in 1997 expanded the Canadian prevalence rates from 8 percent of the population over sixty-five years old with some form of dementia to 25 percent of this same population having some form of cognitive impairment. Despite my emphasis that CIND was a heuristic

category, identified for research purposes only, its market potential for the fast-emerging therapeutic products was not lost on the pharmaceutical industry, or on medical researchers who were funded for clinical trials. I had developed qualitative and ethnographic methods for an approach to assess dementia progression and treatment responses from the perspectives of the sufferers and their caregivers (Joffres, Graham, and Rockwood 2000; Rockwood et al. 2002). Attention to individual problem areas provides a detailed inventory of events that allow for a more meaningful interpretation than that provided by the usual psychometric characteristics, as well as important references for counseling patients with what was being clinically referred to in research circles at the time and increasingly marketed as the “new entity of pharmacologically treated dementia.” Patient expectations are marketed by pharmaceutical companies (Graham 2001). My most recent work has turned to an exploration of the moral basis of profit and drug regulation (Graham 2001, 2003). A primary drive behind diagnostics is therapeutics, which has multiple stakeholders, including corporate interests. The life history of a pharmaceutical involves a relationship between finance, research, and marketing.

5. For example, a diagnosis of dementia demands that a series of criteria be met, including memory loss, a decline from a previous higher level of functioning, and cognitive loss that affects social functioning. All these items had to be met in the clinical diagnoses to establish consistency with the diagnostic criteria.
6. The following symptoms and signs used are for the synergy index (from Graham et al. 1996b). *Clinical history*: arterial hypertension, episodes of agitation, stroke, memory, mood (for example, anxiety, sadness); *CAMDEX (informant interview)*: clouding/delirium; and *neurological examination*: facial bradykinesia, limb bradykinesia, limb tone, neck tone, muscle bulk, strength, posture, limb coordination, gait pattern, resting tremor, action tremor, voice, focal signs.

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## The Biomedical Deconstruction of Senility and the Persistent Stigmatization of Old Age in the United States

JESSE F. BALLENGER

Last scene of all, that ends this strange eventful history, is second childishness and mere oblivion, sans teeth, sans eyes, sans taste, sans everything.

—Shakespeare, *As You Like It*

This oft-quoted characterization of the seventh and final stage of a person's life has usually been taken as a commonplace of old age: this period has always been stigmatized. In particular, the mental losses associated with age, "second childishness and mere oblivion," have been among the most deeply stigmatized conditions. In its frightening totality—effacing the memories and abilities that are widely seen as the very essence of personhood—senile dementia seems to taint the entire experience of aging. In its relentless inevitability, deeply associated with aging and the mere passage of time, it makes a mockery of the achievement of longevity.

But if senility has always been stigmatized, it has not always been stigmatized in the same way. In this chapter, I will discuss some of the complexities of the stigmatization of senility in the United States since World War II. In doing so, I intend to challenge the view that the causes of stigma are ignorance and mystification and that the remedy, therefore, is scientific progress and education. Stigma is the product not simply of ignorance but of deeply felt anxieties about the coherence and stability of the self. To be sure, scientific progress and education remain important for a variety of reasons, but they will not address the sorts of anxieties that produce stigma.

After World War II a diverse array of professionals in the emerging field of

gerontology sought to remove the stigma surrounding senility and old age through scientific understanding and education. By the late 1970s, they sought to destigmatize aging by recasting senility as Alzheimer's disease, a problem in the brain, not of the mental or moral fortitude of the person suffering from it. Since then, researchers can claim much in terms of scientific progress and public education concerning Alzheimer's. Yet I will argue that Alzheimer's remains at least as stigmatizing as "senility" was before it, and that this stigma continues to overshadow the entire experience of aging.

### Representing Senility in the Modern United States

Since the late nineteenth century, representations of senility have been part of a broader narrative on the fate of old age in modern society—about whether the aging body and mind could possibly keep up with the frenetic pace of change in an industrial and postindustrial age. The image of the senile, especially of the senile man, has been one of the most prevalent stereotypes for managing anxiety about the coherence, stability, and moral agency of the self under the conflicting demands of liberal capitalism.

There is perhaps no better example of the stereotype of the senile than that found in the writing of George Miller Beard, the New York neurologist who, in the 1870s and 1880s, popularized the diagnosis of neurasthenia, an ailment that many historians have seen as emblematic of late-nineteenth-century American anxiety about the pace of modern industrial society. Historians of aging have seen him as one of the principle architects of the scientific legitimization of the denigration of old age (Achenbaum 1978, 46–47; Graebner 1980, 30; Cole 1992, 161–190).

In Beard's *Legal Responsibility in Old Age*, first published in 1874, we can see the modern stereotype of the senile in its most characteristic and vitriolic forms. Beard asserted that the brain and the mental and moral faculties that depended on it were subject to deterioration and in fact normally would decline more rapidly than the rest of the body. "Men die as trees die," he argued, "slowly, and frequently at the top first. As the moral and reasoning faculties are the highest, most complex and most delicate development of human nature, they are the first to show signs of cerebral disease; when they begin to decay in advanced life we are generally safe in predicting that, if neglected, other faculties will sooner or later be impaired. When conscience is gone the constitution may soon follow (Beard 1979, 11).

For Beard, senile mental deterioration could only be regarded as a calamity, signifying the start of the gradual, vegetative process of death—the slow, top-down withering away of a life. The dissolution of the intellectual and moral faculties was not a simple process, however. "Very few men decline in all the moral faculties," Beard observed. "One becomes peevish, another avaricious, another

misanthropic, another mean and tyrannical, another exacting and querulous, another sensual, another cold and cruelly conservative, another vain and ambitious, and others simply lose their moral enthusiasm, or their moral courage, or their capacity of resisting temptation and enduring disappointment" (11). Beard thus represented the senile in a number of characteristic guises—as miser, tyrant, fool, and dirty old man.

Whatever the particular form, Beard represented the senile as hopelessly out of step with the times. Failing to fulfill the complex intellectual and moral tasks required of individuals in modern society, the senile were ultimately an obstruction to progress. Beard thought that the biologist Louis Agassiz, who died shortly before *Legal Responsibilities* was published, was a perfect example. "The intemperate manner of his opposition to the theory of evolution," Beard argued, "by which he was so rapidly winning favor among the thoughtless and ignorant, and so rapidly losing favor among the conscientious and scholarly, may find its partial, if not complete explanation in the exhausted condition of his brain" (11n).

In pointing to Agassiz's unwarranted influence on the "thoughtless and ignorant," Beard represented the senile as dangerous. Society could no longer afford to indulge a reflexive reverence for the aged. Most people, Beard feared, revered the aged blindly and disproportionately and were credulously persuaded by the opinions of the aged on the merits of past accomplishments or, what was worse, on the merits of age alone (19–20). In the case of Agassiz, the "conscientious and scholarly" would revere Agassiz for "*the original work that he did before his fortieth year*" (emphasis in the original). But they would not be influenced by his late opinions, which were clearly the product of the mental deterioration of aging, a sign of what was "well known" to Agassiz's friends—that he actually "began to die" long before his death in 1873 (11n). Beard's representations of the senile as dangerous extended also to practical affairs of public and private life, where the senile were perhaps even more disruptive. "Corruption in political and business life, and breaches of trust, are very common among the old, as every morning newspaper bears witness," Beard asserted; and "offenses that depend on the sexual passion are not infrequent among the aged; for it is a fact of interest that in the decline of life we sometimes return to the vices of youth" (30).

Overall, the impressive variety of moral and intellectual failures used by physicians such as Beard to illustrate male senility can be read as a catalog of nineteenth-century middle-class anxieties about a masculine self imperiled by progress. The dominant gender ideology in the Victorian era figured men as aggressively competitive and bold. The moral failings and calamities that Beard ascribed to senile men threatened to undo a man at every stage of his life in this highly individualistic and competitive society. Projecting these failings onto a figure—the aged man—visibly marked as decadent and diseased helped restore

a sense of moral stability. Whatever particular guise that figure might take, he was always and above all the very picture of the ruined man. But if the doddering old man, afflicted with cerebral degeneration of one sort or another, might unravel under the conflicting pressures of the modern world, the young man, in his intellectual and moral prime, would surely flourish.

The stereotypical representation of the senile man as presented by Beard remained dominant in medical and popular texts through the 1940s. It can be clearly seen, for example, in William Osler's (1979) infamous joke that men, having forfeited their productivity and creativity as they aged, ought to be euthanized at the age of sixty-five. Ignatz Leo Nascher, in *Geriatrics*, published in 1914, devoted a chapter in the textbook to "sexual perversion," examples of which were always figured male. These, he argued, were not indications of "depravity or inverted sexuality," as they were in the young. Rather, the condition was simply a reflection of the "weakened mentality [and] diminished control over the emotions" that afflicted old men (Nascher 1979, 504–506). Many gerontologists have argued that it has persisted as a salient representation of aging down to today (Shenk and Achenbaum 1994; Nelson 2002).

### The Gerontologic Persuasion in the Postwar United States

Following World War II, the popular and professional literatures on aging were reshaped by the creation of gerontology as a field of research and practice by a diverse array of biomedical and social scientists, policy makers, activists, and entrepreneurs interested in tapping the "gray market." These various groups, allied only loosely and at times in conflict with one another on various matters of policy or analysis, nonetheless shared an optimistic attitude toward aging and a commitment to improving the lives of the elderly—what I term the gerontologic persuasion (Calhoun 1978; see also Achenbaum 1995; Katz 1996).

To those imbued with the gerontologic persuasion, negative attitudes toward the elderly no longer seemed tenable. Consigning the fastest-growing segment of the population to "corner rocking chairs, to lifeless rooming houses, and even to mental hospitals" was increasingly seen as a major threat to the future prosperity of the nation (Tibbitts and Sheldon 1952, 2). The gerontologic persuasion of the post–World War II United States set out quite literally to reverse the negative assumptions about old age that had dominated discourse about old age since the late nineteenth century. Where the old, and particularly old men, had been seen as unable to adjust to modern society because they were decrepit and senile, gerontologists and other advocates for the elderly began to argue that the elderly were in fact made decrepit and senile primarily because modern society no longer made a place for them. The relentless adoption of new technological and bureaucratic means of production, it was argued, deprived



older men of their traditional place in society as essential repositories of valuable wisdom and experience. The problems of aging were thus seen as an unintended—and unnecessary—effect of modernization.

This idea was formalized by Yale anthropologist Leo W. Simmons, in his widely influential 1945 book, *The Role of the Aged in Primitive Society*. Synthesizing and statistically analyzing ethnographic literature on seventy-one preindustrial cultures from around the world, Simmons argued that different types of cultures produced different attitudes toward and roles for the aged. Although ostensibly concerned in this work only with “primitive” cultures, his implicit comparison of the exotic opportunities for fulfillment open to the elderly in these cultures with the dead end of modern old age constituted a powerful critique of the treatment of the aged in modern society. In a later article, Simmons made the comparison explicit. “In anthropological perspective,” he wrote, “it is literally true that societies achieved a very good old age for a few long before there could be any substantial age at all for the many. But modern civilization has reversed the process and the problems” (1952, 43). He went on to argue that while senility was a virtually universal phenomena, it was an ascribed status whose timing was culturally contingent. Senility was not an objectively measurable state of physical weakness, mental infirmity, or both, but an ascribed status of uselessness and burden, a status that “may be attained under various degrees of physical and mental debility in different societies.” Although all societies evidently made some distinction between old age and senility, the senile phase of old age “has had little significance for the simple societies which were never able to sustain more than a few really old people anyway, and those under conditions in which the very helpless could not long survive.” This was not true for modern society, where this “helpless and hopeless period of life [was taking] on paramount importance” because economic and medical progress was successfully removing the physical barriers to old age. “While modern civilization has greatly progressed in the promise of longer life for larger proportions of the population,” Simmons argued, “it has disrupted many of the time-tested adaptations of the aged, and perhaps even regressed in its solution of the problem of successful aging.”

Yet Simmons remained optimistic. The ultimate lesson for modern society was that “the basic qualities of successful aging rest . . . upon the capacity of individuals to fit well into the social framework of their own times, to win their rights to prolonged participation and recognition, and to know when they are through.” In short, society had only to cease dwelling on the problems of old age and focus instead on its opportunities; society could not solve the problems of old age for the elderly, but could allow the elderly to create meaningful roles for themselves. “It is possible that these potentialities wait to be rediscovered, developed, and refitted into our own times,” Simmons concluded. “This may, indeed, be an old frontier that calls for new pioneering” (44, 50–51).

This account of the problems of aging as the pathological by-products of modern society was explicitly or implicitly present in most discourses on aging through the 1960s. For example, sociologists and educators writing about retirement argued that the challenges it posed to the elderly and society were unprecedented; the need to cease remunerative labor at the arbitrary age of sixty-five was a product of the vagaries of industrial society's labor market, and society was challenged to find new meanings for old age that had traditionally been supplied by work (for example, see Donahue and Tibbitts 1950; Kaplan 1953; Friedman and Havighurst 1954; Havighurst 1960). Similarly, problems associated with the family and social network of the elderly were typically attributed to modernization; the report of the first White House Conference on Aging, held in 1961, suggested that issues within family life and friendships were the result of the rural-urban population shift and of improvements in transportation and communication that increased mobility and undermined traditional patterns of caring for the elderly within families and neighborhoods (U.S. Department of Health, Education, and Welfare 1961, 223–224). But the idea that modern society created the problems of aging was perhaps most prominent in psychiatric discourse, where it was employed as an explanation for mental deterioration in old age. For example, in David Rothschild's account of the social origins of senile dementia, he argued that "in our present social set-up, with its loosening of family ties, unsettled living conditions and fast economic pace, there are many hazards for individuals who are growing old" (1947, 125).

Other psychiatrists took this approach further, arguing that brain pathology itself was a symptom of social pathology. Maurice Linden and Douglas Courtney argued that "senility as an isolable state is largely a cultural artifact and . . . senile organic deterioration may be consequent on attitudinal alterations" (1953, 912). The authors acknowledged, however, that this hypothesis was difficult to prove. David C. Wilson, writing in 1955, was less circumspect, arguing that the link between social pathology and brain deterioration was simply a matter of waiting for "laboratory proof" to support what was adequately demonstrated by clinical experience—that the "pathology of senility is found not only in the tissues of the body but also in the concepts of the individual and in the attitude of society." Wilson cited the usual hallmarks of pathological social relations in old age: the breakup of the family, mandatory retirement, and isolation. "Factors that narrow the individual's life also influence the occurrence of senility," he asserted. "Lonesomeness, lack of responsibility, and a feeling of not being wanted all increase the restricted view of life which in turn leads to restricted blood flow" (905). The pathology of modern society, it seemed, could be discerned within the constricted blood vessels of the aging brain.

Whatever the merits of this model of the social production of "senility" as an account of the pathogenesis of dementia, those who embraced it were generally

successful in winning a series of significant policy changes that helped to transform the experience of aging in America after the 1960s. The material circumstances of old age were markedly improved, with people over age sixty-five moving from the poorest age group to one of the best off; significant legal protections had been won against age discrimination in the labor market, negative stereotypes were challenged, and the elderly themselves organized for political action on their own behalf in large and influential advocacy groups such as the American Association of Retired Persons (AARP) (Calhoun 1978; Laslett 1991; Haber and Gratton 1994).

### **The Biomedical Deconstruction of Senility**

With these developments, the expansive concept of senility that had been the basis of psychodynamic psychiatry and gerontology in the 1940s and 1950s was no longer seen in the gerontologic movement as an effective way to approach the problem of aging. To a more aggressive and politicized group of gerontologists and aging advocates in the 1970s, *ageism* had become a keyword in their efforts. The term was coined by Robert Butler in 1968 to describe the “process of systematic stereotyping of and discrimination against people because they are old, just as racism and sexism accomplish this with skin color and gender” (1975, 12). One of the worst aspects of ageism was the belief that the process of aging entailed inevitable physical and mental decline. Virtually all the physical and mental deterioration commonly attributed to old age was more properly understood, Butler and other gerontologists argued, as the product of disease processes that were distinct from aging. The term *senility* was thus particularly obnoxious, in Butler’s view, and ought to be abolished. It was not a medical diagnosis at all, but a “wastebasket term” applied to any person over sixty with a problem. Worse, it rationalized the neglect of those problems by assuming that they were inevitable and irreversible. “‘Senility’ is a popularized layman’s term used by doctors and the public alike to categorize the behavior of the old,” Butler argued. “Some of what is called senile is the result of brain damage. But anxiety and depression are also frequently lumped within the same category of senility, even though they are treatable and often reversible.” Because both doctors and the public found it so “convenient to dismiss all these manifestations by lumping them together under an improper and inaccurate diagnostic label, the elderly often did not receive the benefits of decent diagnosis and treatment” (9–10). Butler did not discount the reality of irreversible brain damage, as had an earlier generation of psychiatrists. Rather, he argued that the ageist refusal to systematically distinguish the various physical and mental disease processes from one another and from the process of aging itself exacerbated the tragedy of mental illness in old age.

From his position as first director of the National Institute on Aging (NIA),

established in 1974, Butler focused on making funding for research into Alzheimer's disease a priority. In so doing, he played a key role in breaking down the broad concept of senility that was aggressively pursued in biomedicine in the late 1970s and the 1980s. In part, deconstructing senility involved developing effective diagnostic procedures to systematically distinguish between irreversible dementias produced by conditions such as Alzheimer's disease, and reversible dementias caused by treatable conditions (National Institute on Aging Consensus Task Force 1980). More important, it entailed recasting irreversible progressive dementia in old age as a number of disease entities distinct from aging—the most prominent being Alzheimer's disease. This was accomplished by clinical neurologists, neuropathologists, and biochemists who entered the field in the late 1960s and 1970s. In the view of this new generation of researchers, Alzheimer's disease was clearly to be regarded as a brain disease, and research returned to the conundrums involving the correlation between pathology and dementia, and the distinctions that could be made at a pathological and clinical level between disease and aging and between presenile and senile dementia. Far stronger correlations between pathology and dementia were made by the British group of Blessed, Tomlinson, and Roth. American researchers led by Robert Terry and Robert Katzman dropped the distinction between Alzheimer's disease and senile dementia, arguing that at both the clinical and the pathological level, they were identical. More important, this new generation of researchers argued that this entity was not part of aging, but was a disease whose mechanisms could be unraveled through basic research leading eventually to effective treatments and ultimately prevention—hence their insistence on the term *Alzheimer's disease* rather than the more general *senile dementia* or *senility* (Katzman and Bick 2000). There was nothing especially new in these arguments; they had all been made, albeit more tentatively, decades earlier.<sup>1</sup> Nor did research of this period end debate around these issues.<sup>2</sup> But in the context of the 1980s, these claims did allow researchers, aging advocates, and policy makers like Butler to make a convincing case that public resources should be allocated for research into Alzheimer's disease. This case was very persuasive in the federal arena, with the result that by the end of the 1980s, the NIA budget for Alzheimer's disease research had increased by more than 800 percent (Fox 1989).

### The Persistence of Stigma

But if this biomedical deconstruction of senility has been a clear success in winning public support for research into Alzheimer's disease, it has been at best ambiguous in lessening the stigma of old age. Alzheimer's disease advocates often claimed that the new conceptualization of the disease, based on advances in neuroscience, and the ambitious public awareness campaigns that had

accompanied it had lessened the stigma of late-life dementia. But there is much evidence to suggest that stigma has in fact been heightened.

Educational material aimed at the general public and Alzheimer's victims and their families in particular frequently contained assurances that there was nothing stigmatizing about Alzheimer's. "There is no reason to be ashamed or embarrassed because a family member has a dementing illness," the authors of *The 36-Hour Day*, the most popular guidebook for families of Alzheimer's victims, assured readers. "Many brilliant and famous people have suffered from dementing illnesses. Although dementias associated with the final stage of syphilis were common in the past, this is very rare today." Similarly, they thought that if the public understood that the unsettling behavior of the demented was a symptom of a *disease*, stigma would be lessened. "It is important for those around him to remember that many of the person's behaviors are beyond his control: for example, he may not be able to keep his anger in check or to stop pacing the floor. The changes that occur are not the result of an unpleasant personality grown old; they are the result of damage to the brain and are usually beyond the control of the patient" (Mace and Rabins 1981, 7–9).

But such formulations fundamentally misconstrue the nature of stigma. Stigma is more than the degree to which the suffering of victims can be attributed to something being "wrong with them," or to which they "brought the suffering on themselves." Stigma is the amount of anxiety surrounding the boundary between the normal and the pathological. Put another way, stigma is directly related to the social stakes of a particular set of behaviors or symptoms that are judged to deviate from some notion of normal. (These behaviors and symptoms may or may not be brought together under the rubric of a disease category.) The behaviors and symptoms commonly brought together in the category of *having a cold* are not deeply stigmatized, even though those who cough, sniffle, and sneeze clearly have something "wrong" with them, and are often "blamed" for their failure to rest properly, take vitamin C, suck zinc lozenges, or drink echinacea tea. There is simply too little at stake in whether one does or does not have a cold for it to be highly stigmatized.

In the United States at least, the stakes involved in behaviors and symptoms variously called senility or Alzheimer's disease became enormous in the twentieth century, calling into question the very personhood of those who exhibit them. Alzheimer's attacks the cognitive skills necessary to maintain both an inner sense of selfhood and, perhaps more important, to present a stable and coherent self to others. "This illness strikes at the very core of our being, depriving the individual of the qualities that endeared them to all around them," writes one physician in the foreword to a caregiver's account of the disease. "There is little physical pain, disfigurement, or mutilation. . . . Instead, the disease insidiously robs the victims of their unique thought processes, their insights, their judgment, their ability to learn new information. Without these

capabilities, the adult human regresses to an earlier, dependent life" (Ellis 1991, vii). As a result of these losses, dementing persons have been deeply stigmatized—not for having the disease per se, but for their resulting inability to carry off their role as respectable middle-class individuals.<sup>3</sup> Nor could attributing these failures to changes in the brain that are beyond the control of the victim lessen the stigma, for loss of self-control, awareness, and personal responsibility are themselves perhaps the most horrifying things imaginable to middle-class Americans. Consider the promotional copy on the back cover of a sensational "supermarket" paperback on Alzheimer's disease titled *The Living Death*: "They steal. They shoplift. They're violent. They 'expose' themselves in public. They're verbally abusive. They lie. And they don't know any better. Meet some of the 4 million Americans who have Alzheimer's disease in the pages of *The Living Death*" (Lushin 1990). The Alzheimer's disease victim, it seemed, was guilty of the most loathsome violations of propriety. In his or her total loss of self-control, the sufferer, as portrayed in the stereotype, was the epitome of the failed individual, just as the figure of the senile man had been in the nineteenth century.

Representations of the Alzheimer's disease victim were a means of maintaining the distinction between decent, middle-class citizens and the sort of failures invoked on the back of this paperback. Thus, if the exemplary Alzheimer's disease victim was, before the disease struck, a solid, respected, middle-class citizen—as represented by Alzheimer's advocates—he or she became someone or something quite different as the disease progressed. The stereotypical Alzheimer's sufferer was in fact at the outer limit of stigmatization—often represented as a stranger, a ghost, a shadow, a nonperson. This distinction between the stable, respectable self before the disease and the confused, discredited self that was lost to the disease was at the core of representations of the Alzheimer's victim, which were frequently instantiated by the Alzheimer's Disease and Related Disorders Association (ADRD). For example, in 1984, the association began using a graphic that consisted of a series of close-up photos of an attractive, intelligent-looking woman in her mid-fifties. Each photo was identical, except that, moving from left to right, they faded from sharp black and white to gray, with the last image virtually blank—suggesting visually the gradual effacement of the self. In its newsletter, in a brief caption explaining the graphic, the association noted that "the image of the [Alzheimer's] victim 'getting further away' is reflected throughout ADRD's posters, magazines and newspaper advertisements, as well as in the theme song, 'It's a Long Goodbye'" (ADRD 1985).

The persistence of stigma clinging to Alzheimer's and aging was perhaps most perfectly articulated in *Beyond the Thin Line*, a little-known novel by Robert Gard, published in 1992. Gard had written some forty books before this novel, most of them dealing with life, history, and culture in Wisconsin. According to the report on the book's dust jacket, at age eighty-two Gard was an excellent

example of what gerontologists describe as successful aging. “Never even thinking of retiring,” he maintained “a heavy schedule of writing, teaching and lecturing.” Gard characterized the book as “a fictional synthesis of one of the great human dramas and tragedies of our time—Alzheimer’s disease,” one based on his experience of watching a longtime friend become demented (Gard 1992, ix–x). In a long passage describing the subtle early indications of dementia in his friend, Gard vividly describes his own fears of dissolution. Observing the residents of a nursing home to which his friend has been confined, Gard senses that they have all “passed some invisible line. They can never come back and their families know this and perhaps have witnessed it happening over years, but they could not prevent, nor could they identify exactly when their loved one crossed the line of no return” (21). But where was this line? How and when did one cross over it? “The line is a mystery. Little by little it becomes knowable to friends and family, but hardly ever to the stricken persons. Often they are unaware of the presence of such a line. My friend Harry didn’t know, but his friends became slowly aware, very slowly, and in some disbelief. They didn’t understand” (22). Gard describes a number of incidents that occurred during Harry’s descent into dementia, a recounting that culminates with his discovery that Harry was on a locked ward of the Veteran’s Hospital, where he had been admitted for diagnosis because he was apt to wander away and become lost. “I could only feel shocked, and conferring with other close friends of Harry I learned that it was all true. Little by little Harry had been slipping toward the line” (23).

For Gard, finding this line was crucial, for it defined the boundary between the normal and the pathological, between a coherent, stable self and the incoherent, chaotic dependency of dementia. Yet the line was almost impossible to detect, except when it had been irrevocably crossed. It could only be discerned through the closest scrutiny of the behavior not only of others but of oneself as well.

I found myself beginning to watch for the line in several older friends and even in myself. I began taking careful heed of where I put things, of noting what my daily habits were and if I ever varied from them unknowingly. Sometimes I thought I could discern small lapses—at home I would head for another room to get a certain object and entirely forget what it was I went to fetch. I learned that these small signs were almost universal in older people, however, and that the larger lapses, the confusion, the wandering away were more serious. Of these I was not guilty, and I noted that in my public addresses, of which I gave a fair number, my train of thought was never broken or inextricably lost. I could talk for two hours without notes and never lose track of where I was. I was told that this was encouraging, and that I was certainly not yet approaching the line. But the line



became an antagonist. In my imagination it grew almost into a living thing, a reality, and I fancied I saw it often drawn for this person or that. When one considers the line it becomes easy to think in negative terms, and to become fanciful about many aspects of life. Often I heard friends say, "The thing I dread most is becoming senile," and I wondered whether they too were aware of the line. (21–23)

Although Gard felt reassured that he was not "guilty"—that he was not approaching the line beyond which his status as a responsible, respectable person would be open to serious question—that reassurance could never be more than provisional and temporary. Despite being a prolific author, despite maintaining a fully active and productive life into his eighties, Gard continued to carefully scrutinize his behavior and that of those around him, trying desperately to detect the line of no return. Why was this so important to Gard? Even if its signs were detected early, nothing could be done to prevent Alzheimer's disease. In paying such careful attention to the signs of approaching dementia in himself and others, Gard was trying to reassure himself that his selfhood was secure and stable.

Despite the best intentions of professionals in medicine and gerontology to destigmatize old age by recasting *senility* as *Alzheimer's disease*, the latter a more clinically precise term and a disease entity that is slowly yielding its secrets to the explorations of biomedical science, their discourse has merely reinforced the boundary line that separates the senile from the rest of us. That line emerged, at least in its modern form, in representations of the senile that appeared toward the end of the nineteenth century. But it is a line that palpably remains with us, structuring knowledge, policy, and the experience of every aging individual—a line that has been drawn and redrawn in the hope that somehow it need never be crossed.

#### NOTES

1. The distinction between Alzheimer's disease and senile dementia had been problematic from the moment it had been made. By the 1940s, as research pointing to the clinical and pathological similarities of the two conditions piled up, researchers were hard pressed to maintain the distinction, though for a long time the logic of age categories remained compelling. This can be seen in a 1941 article by William McMenemy and Eugene Pollack, in which they argued that the distinction between senile and Alzheimer's *presenile* dementia should be made not on the basis of pathology, but on whether "the mental illness commenced at an age when the patient still retained normal vitality, the decline in which is usually evident somewhere between the ages of 60 and 70" (683). A decade earlier, William Malamud and Konstantin Lowenburg (1929) had argued that their own findings and the preponderance of evidence in the literature suggested that Alzheimer's disease was not limited to the presenium, but that nonetheless the distinction should be maintained on pragmatic grounds. Since little was actually known about senility, saying that Alzheimer's disease was a form of



senile dementia would not add anything to the understanding of Alzheimer's but would blur the meaning of senility by linking it to conditions occurring in earlier ages. In 1936, Rothschild and Jacob Kasanin argued that practical considerations dictated the opposite: because the pathological pictures were so similar, advances in understanding Alzheimer's would have the practical benefit of shedding light on the larger problem of senile dementia. "It is evident," they concluded, "that in a broad discussion of Alzheimer's disease one must include also the problems of senility in its normal and pathologic aspects" (293). The distinction between Alzheimer's disease and senile dementia persisted in official nosology until the mid- 1970s, but in 1940 it had little meaning. Most researchers of this period acknowledged that Alzheimer's disease and senile dementia were for all practical purposes the same entity, but found no compelling reason to abandon the traditional distinction.

2. British psychologist Tom Kitwood has claimed that the best contemporary correlations leave as much as an 80 percent variance between pathology and the degree of dementia. Kitwood is one of the few contemporary researchers working with a psychodynamic model of senile dementia, one that is very similar to Rothschild's. See Kitwood (1987, 1989, 1997).
3. Of course, this is not to suggest that people who, in one way or another, are outside the broad notion of "middle class" do not suffer from Alzheimer's disease. Indeed, one would expect—political representations notwithstanding—that factors such as poverty would compound the suffering of Alzheimer's disease. But this broad notion of *middle class* dominated the Alzheimer's disease movement (as it dominated most other areas of American culture). The experiences of other people have not been represented in the Alzheimer's disease policy discourse, and it would require another sort of study to bring that experience to light.

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## PART TWO



# The Role of Genomics in Alzheimer's Research



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## Genetic Susceptibility and Alzheimer's Disease

### The Penetrance and Uptake of Genetic Knowledge

MARGARET LOCK, STEPHANIE LLOYD, AND JANALYN PREST

I think it's safe to say we will have individualized, preventive medical care based on our own predicted risk of disease as assessed by looking at our DNA. By then each of us will have had our genomes sequenced because it will cost less than \$100 to do that. And this information will be part of our medical record. Because we will still get sick, we'll still need drugs, but these will be tailored to our individual needs. They'll be based on a new breed of designer drugs with very high efficacy and very low toxicity, many of them predicted by computer models.

—Francis Collins, Director of the National Human  
Genome Research Institute, *Time*

Comments and claims, such as the preceding by Francis Collins, as well as reports about newly located genes, appear with increasing frequency in the media these days. The sociologist Alan Peterson argues that such stories are deemed newsworthy “precisely because they offer people the promise of being able to re-make themselves anew—to ‘play God’—so that they can better deal with, if not overcome, the reality of disease, disability and death” (2001, 267). Because of the possibility that such stories may bring about changes in individual behaviors, Peterson insists that it is important to investigate how “gene stories” selectively present “facts, themes, and claims, and thereby help limit what can be known about health, disease, and embodiment” (267). Adding a sense of urgency to such an investigation is the claim commonly made by clinical

geneticists and many other medical specialists today, that all diseases must be recognized as having a genetic basis (Lock, forthcoming).

While social scientists such as Peterson have contributed to an understanding of the way in which media coverage of knowledge claims in science are biased, albeit often inadvertently, additional factors are clearly at work in connection with knowledge uptake (Conrad 1999, 2001; Peterson 2001). Authors often assume that a relatively simple trickle-down process takes place as knowledge is passed from one domain to another, for example, on the one hand, from basic scientists to health-care professionals and then to patients and, on the other hand, from basic scientists to the media and then to the public at large. Embedded in this assumption lies another: that a uniform body of scientific knowledge exists and experts are in effect united in their understanding about what types of action should be taken on the basis of this knowledge. Peterson is critical of such a position, as are we, and goes on to note that research shows that laypeople have a more sophisticated and critical view of genetics than is generally acknowledged by medical experts (2001, 1256; see also Kerr, Cunningham-Burley, and Amos 1998). However, observing that the public holds a critical or skeptical view of genetic research tells us little about the way in which genetic science is understood or used by this same public.

The expansion in knowledge about molecular genetics that has occurred during the past two decades, particularly since 2001, when the “completed” map of the human genome was heralded, have indeed led to Manichaeian prophecies about the implications of this new knowledge. Genetic advancements are thought to have unlimited promise for medical developments that will benefit all humans, but at the same time, fears have run rampant about the unleashing of unprecedented eugenic powers and the potential engineering of social inequality at the molecular level. Often scapegoated, the media is but one culprit in the authorship and perpetuation of these parallel discourses: the scientific community, politicians, advocacy groups, ethicists, and social scientists have contributed to both. In this chapter we set out to counter both some of the more hyperbolic of these claims that genetics is revolutionizing medicine and the way health and illness are understood by both professionals and the public.

Much of what has been written to date by social scientists about the new genetics has focused on life-threatening conditions in which the involved gene or genes follow a Mendelian pattern of transmission, and therefore inheritance patterns and calculations of risk (but rarely severity) can be made with great accuracy.<sup>1</sup> However, as yet, rather little has been written by social scientists about complex, multifactorial diseases such as Alzheimer’s disease (AD). Being alerted to susceptibility, particularly for a disease such as AD that is largely restricted to the elderly, does not confer the same order of knowledge as that of being told that one carries a mutation for a disease that is lethal much earlier in life and that may already have been transmitted to one’s children. Before gener-

alizations are made about what effect genetic “truths” are likely to have on individuals, the scientific “facts” and material effects of specific diseases must be taken into account. Social scientists can be as guilty of reductionism as are certain geneticists when theorizing about abstracted futures, if such theorizing is not grounded in the materiality of the body, or if it conflates the lived experiences associated with various diverse illnesses.

To counter this type of reductionism, we focus here on a particular disease, late-onset AD, which provides an interesting example precisely because of the way in which genetic knowledge has recently been implicated in etiological theories about this condition. Unlike other diseases that exhibit a Mendelian pattern of inheritance, including *early*-onset AD, genetics is implicated in an as yet poorly understood, complex fashion in *late*-onset AD, as it is in numerous other common diseases.<sup>2</sup> When making estimates about the susceptibility of individuals to a particular disease on the basis of their genotype,<sup>3</sup> which is inevitably compounded by the varying “penetrance” of virtually all disease-producing genes, resulting in a wide range of phenotypic effects in individuals,<sup>4</sup> uncertainty is compounded enormously, and the prediction of who exactly is at increased risk is fraught with difficulty. Under these circumstances, conveying genetic information to people who are affected by a specific disorder or to those who are “carriers” of a gene for the disorder, and to their family members, becomes problematic. In this chapter we consider the state of current genetic knowledge surrounding late-onset AD, specifically, the way in which key parts of it are packaged and disseminated in clinical settings, by the media, and for the public at large. Emphasis is given to the types of information to which people in each of these domains have access, the information they communicate to others, and the information they use personally. We have found that in the course of translation of information across groups, there is an uneven penetrance of ever changing genetic knowledge into both popular and professional discourse about AD causation.

### Enlightened Geneticization?

In 1992 Abby Lippman coined the term *geneticization* to capture what she perceives as an ever growing tendency to distinguish people one from another on the basis of genetics. She argues that geneticization is both “a way of thinking and a way of doing, with genetic technologies applied to diagnose, treat, and categorize conditions previously identified in other ways” (1998, 64). Lippman is concerned above all with a possible reinforcement of racism, inequalities, and discrimination of various kinds that already exist in abundance, as a result of a renewed conflation of social realities and biological difference grounded in genetics. She suggests that we may well be witnessing an incipient neoeugenics, as do many other contemporary writers (see, for example, Kitcher 1997).



Adam Hedgecoe, a social scientist, understands the use of genetic knowledge and technologies as just the latest in a long line of attempts to advance our understanding of the body at the molecular level and is less inclined than he believes Lippman to be to see geneticization as “an opportunistic tactic employed by doctors to gain power over patients” (2001, 877).<sup>5</sup> Hedgecoe argues for recognition of a concept of “enlightened geneticization,” by which he means that even though the contribution of environmental and other factors are today widely accepted in scientific discourse about disease causation, genetic explanations are nevertheless prioritized and subtly divert attention away from nongenetic factors (see also Spallone 1998). Hedgecoe (2001) has shown how this discourse of enlightened geneticism is reproduced in psychiatric medical literature. He agrees with Lippman that genetic determinism, although more subtle than was formerly the case, is at work, but he points out that geneticization, as does medicalization more generally (Lock and Kaufert 1993; Lock, forthcoming), has some positive attributes. For example, it is abundantly clear that once a disease is medically recognized, particularly when behavioral changes are involved, then social stigma and allocation of individual and family responsibility for the occurrence of such conditions are reduced (McGuffin, Riley, and Plomin 2001). What is more, many families appear to take comfort in being told that a disabling condition is the result of faulty genetics and therefore, by implication, has nothing to do with moral shortcomings (Turney and Turner 2000). It remains to be established if this finding applies to AD, as it does to psychiatric illness. Preliminary inquiries indicate that in many circles, stigma is no longer associated with AD, now regarded as the result of unavoidable neurobiological changes and, moreover, that a good number of people believe that these conditions are part of the unavoidable process of aging. However, stigma clearly remains attached to mental illness, even in contemporary psychiatric practice (Marc Miresco, personal communication), so that the “urge” to geneticize may be greater in psychiatric circles and among the families of psychiatric patients.

The arguments of Lippman and Hedgecoe are insightful, but in the case of AD, and no doubt other multifactorial conditions, even when a susceptibility gene is incontrovertibly associated with a disease, it does not follow that geneticization, even in an “enlightened” form, will become the dominant mode of conceptualizing the condition at all sites where it is investigated, treated, or managed. Although an enlightened geneticism is apparent in certain types of professional discourse in connection with AD, dissent and disagreements, and above all differences in emphasis, are evident among various groups of specialists—basic scientists, neurologists, clinical geneticists, clinical psychologists, psychiatrists, and others (Lock, forthcoming). Nor is a focus on genetics steadfastly embraced by the media, which usually acknowledges that, almost without exception, multiple risk factors are at play. Advocacy-group literature mini-

mizes the contribution of genetics, as do the majority of patients and their families as they face the massive burden of dealing with a disease as devastating as is AD. Our research shows that what is common when involved patients and families discuss the possible causes of AD is that, in addition to behavioral, social, and environmental factors, references to hereditary tendencies are made at times. However, other than among geneticists, highlighting the contribution of specific genes is left at the margins of most discussions.

At a broad level of generalization, the concept of geneticization alerts us to the persistence of a particularly insidious form of reductionism that may well be exacerbated by the current widespread fascination with emerging knowledge in molecular and population biology. As technologies of molecularization and knowledge in connection with the new genetics change, so too will the social meanings associated with specific conditions, and it will be of great interest to track such changes. In the idiom used by researchers engaged in mapping out the sociology of science and technology, late-onset AD is a boundary marker that serves as an “interface” between multiple social worlds that draw upon and emphasize different sources and types of information and interventions (Fujimura and Clarke 1992).

### **Living with the New Genetics: Biosociality and Genetic Citizenship**

Social scientists have introduced several new concepts in order to convey the responses of the public and, more specifically, of individuals and families who are directly affected by the new technologies of genetic testing and screening. Rayna Rapp and colleagues have posited the concept of “genetic citizenship” as one response to new information yielded from genomics research. Their research has documented how certain families and networks of families increasingly coalesce around lethal and highly disabling single-gene diseases that afflict their children. Such groups provide mutual social support and lobby the United States Congress for improved research funding (similar activities happen in many other countries). These activists are painfully aware that only rarely will drug companies invest in research for the kinds of diseases that affect their families. Because of their relative rarity, there is no profit to be had in researching the “orphan diseases,” and lobbying for public funding is deemed essential. This is genetic citizenship in action, and it involves not only mobilization of affected people but also new ways of envisioning the future (Rapp 2003).

Two decades ago, Edward Yoxen (1982) suggested that our newfound abilities to detect “pre-symptomatically ill” individuals would ensure that virtually all of us would shortly be subject to increased medical surveillance. More recently, Carlos Novas and Nikolas Rose have raised important questions about what it means to be designated as “genetically at risk” (2000). On the basis of their perusal of Huntington’s disease Web site exchanges, Novas and Rose argue

that genetic testing does not generate a sense of fatalism, as many have predicted, but rather brings about "genetic responsibility," a bonding that is grounded in a molecular optic and that transforms relationships between expert and patient and within and between affected individuals, families, and communities.<sup>6</sup> However, it has also been shown that among those families in which Huntington's disease is prevalent, the majority of individuals choose not to undergo genetic testing.

In his 1996 essay "Artificiality and Enlightenment: From Sociobiology to Biosociality," Paul Rabinow cites the geneticist Neil Holtzman, who envisions a time when early detection of genetic susceptibility and predispositions will become routine. Rabinow chooses to underline only one of the many issues that he believes arise from this prediction. First, he notes "the likely formation of new group and individual identities and practices arising out of these new truths." He then points out that such groups already exist, formed on the basis of the firsthand experience of diseases such as neurofibromatosis, groups whose members meet to share their experiences, educate their children about the condition and its genetic transmission, finance changes in the home environment to facilitate home care, lobby for funding for further research in connection with the particular disease associated with their family, and so on. "This is what I mean by biosociality," writes Rabinow. In rhetorical mode he adds: "I am not discussing some hypothetical gene for aggression or altruism. Rather it is not hard to imagine groups formed around chromosome 17, locus 16,256, site 654,376 allele variant, with a guanine substitution." Rabinow is quick to add that these newer groupings will not overtake older categories and, contrary to the claims of certain population geneticists, may even enhance the spread of racism because of a heightened sensitivity to biological difference (1996, 91).

Ironically, Holtzman has since gone on to forcibly argue against claims that genetics will revolutionize the way in which disease and illness are understood. "Statements like these clothe medicine in a genetic mantle. The result of efforts to identify genes that have a role in common disease suggests a different picture: the genetic mantle may prove to be like the emperor's new clothes" (Holtzman and Marteau 2000, 141). He argues that, ultimately, with the exception of Mendelian disorders, the mapping and sequencing of the human genome will have little impact on the understanding, treatment, or prevention of disease, in large part because of the incomplete penetrance of genotypes for common diseases.

Of course, in contrast to the "orphan" diseases, no genetic citizenship is required in order to place heart disease, cancer, or AD in the spotlight; governments and the pharmaceutical industry are both deeply invested in trying to reduce the financial and social burden associated with these conditions.<sup>7</sup> The existence of support groups for such diseases precedes the consolidation of molecular genetics by many years, and in the case of late-onset AD, their ac-

tivities continue largely unchallenged and unchanged by the new genetic knowledge.

For the remainder of this chapter, we will focus on AD, providing a brief review of current medical understanding about the role of genetics in AD causation, followed by an overview of how this knowledge is usually interpreted among experts. The opinions of several clinicians concerning the state of genetic knowledge of AD will be presented. The position taken by AD societies and the media with respect to current theories about the genetics of AD will be discussed. Ethnographic data based on interviews in progress with relatives of people who have been diagnosed with AD will then be presented. These findings show that even though AD is molecularized by basic scientists and many clinicians conceptualize the disease very differently from the way they did so a few years ago, thus far almost nothing has changed in actual clinical practice as a result of insights gained from genetics. This is also the case for the literature produced by advocacy groups and for families, as they confront the daily reality of caring for someone with AD. Any thought of being genetically at risk, or of shouldering a genetic “responsibility” is generally outweighed by numerous other exigencies for the majority of people whom we interviewed.

### **Disease of the Century**

It is estimated by many experts that AD—a “living death” as some describe it—will strike between a quarter and a half of us by the time we are in our eighties. The range of these estimates demonstrates the fallibility of epidemiological data, but hyperbole is useful for maintaining funding. Even if the lower rate is a better prediction, very many of us are implicated as future patients, caregivers, or both, suggesting a remarkable challenge for social imaginaries of the future.

AD is ranked as the fourth-biggest killer in the United States, and the massive sum of \$100 billion a year is currently spent on the care of 4 million AD patients in the United States.<sup>8</sup> It is assumed that these costs will double as the baby boomers grow older, and by 2030 the number of cases will have tripled unless a “cure” is found. It has been reported that AD costs U.S. businesses more than \$33 million in “lost productivity and absenteeism” and that these costs will soar as the baby boomers take time off to care for their elderly relatives (“Alzheimer’s Disease” 1998). Clearly, no lobbying is needed to encourage a search for a cure for this disease—very well funded research is under way to pin down the genes implicated in AD.

### **Genetics and the Clinician**

#### ***An Abundance of Genes***

Until recently, late-onset AD had been described as sporadic, because familial inheritance patterns did not appear to be at issue.<sup>9</sup> However, ten years ago, an

event radically disrupted this perception: one particular allelic variation of the gene known as apolipoproteinE (ApoE) located on chromosome 19 was shown by linkage studies carried out in the laboratory of Alan Roses to be associated with late-onset AD (Strittmatter et al. 1993). This finding has since been verified in more than one hundred laboratories and has been described as the best demonstrated of all scientific findings in recent years. ApoE, already implicated in heart disease before its association with Alzheimer's was noted, is a polymorphic protein with three alleles, 2, 3, and 4, that appear to be universally but unequally (clinally) distributed around the world. It is the ApoE  $\epsilon 4$  variation that places individuals at increased risk not only for contracting AD, but also for an earlier age of onset of the disease by as much as seven to nine years. Despite consensus on these findings, it is at the same time agreed that the allele *determines* nothing with respect to the incidence of AD. All that can be inferred is that the ApoE  $\epsilon 4$  genotype confers a greater degree of *susceptibility* but that it is neither necessary nor sufficient to cause the disease. It is assumed that combinations of gene-gene and gene-protein interactions as well as interactions with environmental variables must also be implicated in the onset of AD, and a great deal of time and energy is currently being invested in establishing what contribution these other variables make to the disease occurrence and its age of onset (Tilley, Morgan, and Kalsheker 1998).

In 2001 a newly located susceptibility locus was reported in *Science* on chromosome 10 (Myers et al. 2000). Other sites are currently under investigation to locate yet more genes that may contribute in some way to AD incidence. These sites are located on chromosomes 9, 12, 13, 15, and 19. In carrying out these investigations, researchers are attempting to do much more than pinpoint what is happening at the molecular level once AD has become established; they are attempting to demonstrate how risk of AD is increased by the presence of specific alleles, which are activated under as yet poorly understood conditions at various points along biological pathways that are essential to normal brain functioning. The excitement around these investigations is palpable, and the molecularization of professional understanding of AD is undeniable.

John Hardy, the chief of the genetics laboratory of the United States National Institute of Aging, stated during a presentation at the 2002 biannual AD conference held in Stockholm that "genetics underpins our understanding of this disease AD," adding that "findings from genetics are the baseline for research into AD."<sup>10</sup> But Hardy's presentation, and others like it that focused on genetics, while they received a great deal of attention at Stockholm, caused only a limited stir. The reason is that, including the ApoE  $\epsilon 4$  discovery ten years earlier, no findings that derive from knowledge about the genetics of AD have as yet resulted in clear advances of any kind in the prevention or treatment of the disease.<sup>11</sup> Similarly, there is limited predictive value of knowing one's ApoE status because of the difficulty of converting this knowledge into useful informa-

tion for clinicians and individuals attempting to relate individual status to future risk of developing the disease.

### ***Estimating Risk: Epidemiological Shuffling of “Knowledge in Flux”***

Research in connection with late-onset AD is amply demonstrating that genes are unequalled shape-shifters, the products of both evolutionary and recent human history and, at times, of toxic environments or of serendipitous mutations as a result of faulty replication.

Population genetics must be relied upon in attempts to establish what characteristics place certain populations at an increased risk for AD. The problem with assessing individual risk from these types of studies is no different from the difficulties inherent in the application of large-scale epidemiological information to any specific case; epidemiology is not “about” individual cases, but “about” populations and probabilities. In addition to this basic problem, there are several other sources of potential misunderstanding.

Since 1993, a large number of population studies have been published on the ApoE gene and its relationship to AD in which the focus has been on so-called Caucasians (Growdon 1998; Korovaitseva et al. 2001; Roses 1998; Saunders 2000; Silverman et al. 2003). Inconsistencies about the effects of the ApoE gene within this literature have the potential to cause confusion. For example, estimates of the number of individuals with AD who carry the  $\epsilon 4$  allele range from 30 to 90 percent (Liddell, Lovestone, and Owen 2001; Ritchie and DuPuy 1999) and many studies do not specify whether these numbers refer to those who are hetero- or homozygous, further confounding the matter.<sup>12</sup> In addition, researchers report that between 23 and 68 percent of AD patients do not have the ApoE  $\epsilon 4$  allele, serving to highlight the complex and elusive nature of the association between susceptibility genes and the pathology of AD (Farlow 1997).

In addition to retrospective studies of individuals who already have AD, many studies attempt to estimate the number of people with ApoE  $\epsilon 4$  alleles who will eventually develop AD. There is considerable variation between the estimates presented in these prospective studies. Depending on the study consulted, the number of individuals who are heterozygous for the ApoE  $\epsilon 4$  allele and who are expected to develop AD range from 7.6 to 47 percent. The range for homozygous individuals is between 21.4 to 91 percent (Holmes 2002; Farlow 1997). For a healthy person to be given a 91 percent chance of getting AD in the future no doubt creates a significantly different anxiety level from that of a 21 percent chance.

In contrast, there is better agreement that individuals with ApoE  $\epsilon 4$  alleles have an increased *relative* risk of developing AD. The literature suggests that a person with one  $\epsilon 4$  allele has three times the chance, and a person with two  $\epsilon 4$  alleles has between eight and thirty times the chance of developing AD compared with someone with no  $\epsilon 4$  alleles (Holmes 2002; Swartz, Black, and St.

George-Hyslop 1999). However, the baseline on which this probability is estimated is rarely provided, and without this information, relative-risk estimates are highly misleading, although they still have the power to create anxiety.

Other studies report that individuals with first-degree relatives suffering from AD have between a 10 and 50 percent chance of developing AD by the time they are ninety (St. George-Hyslop 2000). In this case, the broadness of the risk estimate seems to be so wide as to be of little value for individuals, particularly given that the majority will have died of some other cause before age ninety.

For those individuals with two ApoE  $\epsilon 3$  alleles (about 60 percent of the population in Europe and North America), risk for AD is estimated as “average,” and it is calculated that about a quarter will develop AD once over the age of eighty. Relatively few people carry ApoE  $\epsilon 2$ , although it is proportionally more frequent among several populations other than “Caucasians.” Those who inherit two copies of this gene are thought to be at very low risk of contracting AD, and this allele appears to be protective, in contrast to the ApoE  $\epsilon 4$  allele.

One of the principle causes of confusion about genetic risk for AD is inherent to the research design. Holmes (2002) and Ritchie and Dupuy (1999) suggest that in many studies, present numbers do not represent the population at large, because they are based on clinical samples.

The emphasis on ApoE  $\epsilon 4$  in research literature obscures the fact that many other factors have been associated with late-onset AD (including other candidate genes, head trauma, environment, diet, and lifestyle). Further, ApoE  $\epsilon 4$  has been shown to work in unexpected ways in certain populations. For instance, among Pygmies, and other populations whose subsistence economy was relatively recently predominantly that of hunting and gathering, ApoE  $\epsilon 4$  apparently protects against AD. This finding holds when controlled for age (Corbo and Scacchi 1999). Low rates of AD have been reported for parts of Nigeria, and the presence of an ApoE  $\epsilon 4$  allele does not appear to be implicated when it does occur. However, ApoE  $\epsilon 4$  is significantly associated with AD among African Americans, although less so than in populations of “whites” (Farrer 2000). It is argued that other risk-reducing factors (in Africa) *and* risk-enhancing factors (in North America) must therefore be implicated, including no doubt diet and environment and other genes and their protein products, but researchers also acknowledge limitations to the research methodologies used thus far. Clearly the specific role of ApoE  $\epsilon 4$  in AD is far from perfectly understood.

The bottom line is that individual risk assessments for late-onset AD that make use of genetics are at present so vague as to be deemed by the majority of clinicians and researchers to be of little or no use in clinical care (Farlow 1997; Liddell, Lovestone, and Owen 2001; McConnell et al. 1998; St. George-Hyslop 2000; Tilley, Morgan, and Kalsheker 1998). Although it is acknowledged that this situation may change in the future, currently, official guidelines put out by professional and health-policy-making institutions and organizations, and by



advocacy groups in the United States, Canada, and the United Kingdom, state that genetic testing for ApoE status should not be carried out routinely. This is justified especially because there is no known prevention or treatment for AD that is more than minimally effective.

### *Clinicians' Practice and Knowledge in Flux*

AD is frequently used in departments of genetics today as a model for teaching genetic complexity and for illustrating gene-environment interaction. The general consensus among medical professionals about the contribution that an ApoE  $\epsilon 4$  allele makes to increased risk for late-onset AD has brought about a fundamental shift in thinking that is not as yet reflected in the media or in advocacy literature (see below). As noted earlier, what was until very recently understood as a sporadic disease—as happenstance—is now considered by the majority of medical experts to be genetically transmitted, if at an uncertain rate. The assumption is that a great deal more remains to be learned about the genetics of AD and that when these advances are made, we may then be in a position to make some major breakthroughs with respect to medications, perhaps in the form of pharmacogenetics (Hedgecoe n.d.). However, this shift in theoretical perspective does not as yet in any way affect patient management. The following are excerpts selected from interviews with twenty-eight clinicians who practice in Canada, the United Kingdom, and the United States, carried out between 2000 and 2002.

One of the interviewed clinicians described his position:

It's very hard now to talk about sporadic—nongenetic—Alzheimer's. Sporadic would be rare—and even then genes are involved—the result of a sudden isolated mutation but not passed on in families. Until recently we thought that no genes were involved in this disease, that it was just aging—but now we know there are: genes are involved with aging and with the pathologies associated with aging. But genes are not causative—it's just that genes increase the risk, or accelerate a process that is already under way. This process would not get expressed as pathology unless genes like ApoE  $\epsilon 4$  are present, so that the “normal” changes of aging are transformed, resulting, for example, in an excess of plaques.

An eminent molecular geneticist who is also a clinician stated:

Genes *for* Alzheimer's are not *for* anything at all, they simply contribute to one's risk for getting late-onset Alzheimer's. We're talking about common polymorphisms, not mutations, and there's going to be at least four to six of them involved with Alzheimer's—maybe more. They could have arisen simply by chance, or it could be a bit like cystic fibrosis or sickle cell.<sup>13</sup> In



the case of Alzheimer's, the gene protects you from something (we don't know what, of course) during most of your life, but you pay the price later on because of the long-term negative effects it has on the body.

A third clinician, although he does not dispute the importance of genetics, sounds a cautionary note:

All we can do is make a judgment of likely cause. Genetics are one influence among many leading to dementia. I'm very skeptical about the whole genetic frenzy—there's so much hype and no money left over for improved nursing homes and home care. We simply don't have a coherent story for why dementia happens—we have fashions in theories about it, that's all. The more genes they find, the more reasonable and sensible the story will become because of course genes, or their products, are involved with just about everything that happens to the body.

A geriatric epidemiologist openly challenges the idea of AD as a disease.

As far as I'm concerned, genes are just other variables. They are markers, inherited markers, that have to be put into the pot for analysis along with other variables to see how they look. The great mistake with AD is to assume that because there is one end point there is one cause and one treatment. I don't think AD is a disease. I think we should be talking about the brain and about dementia because now we know that virtually all dementias are mixed.

One clinician only, a psychogeriatrician, when focusing on incidence, chose to emphasize the effects of lifestyle in clear preference to genes:

You can have Alzheimer's without predisposing genes—the genetics are overblown. Alzheimer's is clearly linked to lifestyle. It all depends on where you work professionally as to what you think about cause, prevention, and best treatment. I think that lifestyle changes are crucial—there is evidence that exercise lowers incidence, and diet is crucial because cholesterol is involved in plaque production. People with diabetes are vulnerable.

In none of the clinicians' accounts is a naked language of genetic determinism made use of in discussion of late-onset AD. Although all involved researchers and clinicians recognize the contribution of the ApoE  $\epsilon 4$  allele, this knowledge has no effect on the clinical care they offer. Given these conditions of uncertainty, a consensus does not exist among health care professionals dealing with late-onset AD about the utility of current genetic knowledge in connection with this condition and not one believes that genetic testing for ApoE  $\epsilon 4$  should be used routinely in the clinic.<sup>14</sup>

## The Transfer and Translation of Knowledge in Flux

In this section we focus on how information about risk factors, assumed mechanisms of the disease process, theories of causation, and therapeutic options are portrayed in various forums in order to understand what types of information reach AD sufferers and their families and caregivers.

A common assumption held on the part of health care professionals interviewed in this study is that most, though not all, media reports create unwarranted hype about the possibility of curing life-threatening diseases once the involved genes are located. This claim has also been made by social scientists who have argued that there has been an increase in genetic determinism and reductionism by the general public, whose ideas have been largely shaped by media representations (Nelkin and Lindee 1995). However, a number of social scientists critical of Nelkin and Lindee's statements have pointed out the anecdotal nature of many of their claims and emphasized the need for thoroughly grounded empirical studies on this issue. In fact, contextualized studies by such critics demonstrate that genetic determinism is perhaps not as strong as has been suggested and that recent discourse about genetics in the media is more nuanced than was previously assumed (see, for example, Miller 1995; Condit 1999; Condit, Ofulue, and Sheedy 1998; Hedgecoe n.d.). Our research tends to support this latter perspective.

The sensationalism of the claims made at times in media headlines *cannot* be denied, but in order to judge media reports, careful reading of their content is required. For example, the manner in which genetic knowledge is presented varies in complexity and in the weight granted to it as compared to other variables implicated in disease causation. Moreover, the popular media is not the only source of information about genetic knowledge directed at the public. Systematic empirical examination of multiple sources of knowledge about genetics is needed for full evaluation of the way in which scientific knowledge is translated and transmitted to the public. To this end, we begin our study by examining discourse about genetic risk and AD that has appeared over the past decade within three bodies of literature: popular media (newspapers and magazines), educational materials produced by pharmaceutical companies that is distributed through clinics and by general practitioners, and the literature produced and distributed by advocacy and support groups.<sup>15</sup>

### **Media**

It has been shown that as scientific data are translated for use in the media, a process of simplification and homogenization frequently takes place (Conrad 1999) and that "user-friendly" vocabularies are made use of. Conrad (2001) has further analyzed the manner in which media coverage of genetic discoveries tends to fall into a "frame" of genetic optimism, in no small part because of the

style of journalistic writing and editorial concerns. Good news is always in short supply, and coverage of genetic discoveries and their associated promise, no matter how remote, are easily deemed newsworthy and make it past the editorial cutting-room floor. By contrast, stories that tell of retractions or discredited scientific studies stand little chance of making it to print, except in specialty science magazines.

To a certain extent, Conrad's observation that media coverage of genetic knowledge tends to optimistically herald the promise of new discoveries and to oversimplify, or even misrepresent, the studies on which their stories are based, holds true for some of the media coverage of the science of AD. However, while "AD-gene stories" may gloss the scientific knowledge surrounding AD and make bold headlines, they do *not* necessarily fall into the trap of presenting simple stories of genetic determinism or pipe-dream cures, as described by Nelkin and Lindee (1995). In fact, rather than focusing on genetics, the majority of news coverage of AD concerns itself with caregiving responsibilities, celebrity victims, and studies that explore "nongenetic" theories of causation. Genetics is but one small part of the picture of AD that has been portrayed over the past decade. While the media may be guilty of promoting genetic optimism in certain headlines and in a limited number of stories, especially older ones, it is not at all evident that this is reflective of media coverage of the disease in general.

One reason that the genetics of AD may no longer have a central place in newspapers and magazines is that the media tends to have peaks of interest in studies presenting novel findings at the time of their initial "discovery." As Conrad (2001) predicts, there is a saturation point at which time something is just no longer news, and unless a new research angle is presented regarding a disease, its coverage in the media will dwindle. Within the media coverage, the promise of genetics has been displaced by the most recent findings from scientific studies that do not relate directly to genetics. Recent media stories have focused upon possible prevention of AD through cognitive and dietary strategies, experimental vaccines, and the promise of early detection through monitoring of homocysteine blood levels or by means of brain scans.

When the genetics of AD are mentioned today in newspaper articles, such reports are more often than not cautious and nonspecific: "It is unclear what causes AD, though it is likely a combination of genetic predisposition and environmental factors" (Picard 2002). Others clearly state that while researchers have identified genetic links to a number of diseases—of which AD is listed as but one—the inheritance of a genetic mutation does not guarantee that a disease will develop, only that there is an increased susceptibility as additional genes and environmental factors also appear to be implicated (Andrews 2002).

In recent media coverage, the ApoE  $\epsilon$ 4 gene is usually mentioned in connec-

tion with findings from other studies. For example, the *New York Times* reports that the protective effects of Vitamin E are not observed in those “with a gene variation apolipoprotein  $\epsilon 4$ , which has been *linked* to Alzheimer’s” (Kolata 2002; emphasis added). The involvement of genetics, regarding the same finding about Vitamin E, is reported in another newspaper as “the ApoE  $\epsilon 4$  gene, which indicates an *inherited risk* of developing Alzheimer’s” (Immen 2002; emphasis added). Other articles report on studies showing that high-fat diets increase sevenfold the risk for those who are genetically predisposed to develop AD (“Les graisses” 2000). It appears that in newspaper coverage the linkage of ApoE  $\epsilon 4$  to AD is understood as a given, but its role is portrayed in subtly different ways and in association with other variables.

The most problematic element observed in media coverage of AD and genetics was figures and estimates of incidence and risk that were uncontextualized. For example: “Those who carry a certain genetic characteristic have 16 times the risk of developing Alzheimer’s disease” (“La génétique” 2001). Or, as claimed in *Time*: there is a 91 percent chance that someone with two copies of an “Alzheimer’s-related gene will develop Alzheimer’s” (“Numbers” 2000). This failure to contextualize figures and the misrepresentation of estimates of risk are not confined to media coverage, as the source of figures quoted in the media are most often taken directly from involved scientists, or from spokespersons for or media releases supplied by advocacy groups such as the Alzheimer’s Society and the Alzheimer’s Organization.

Therefore, while these stories tend to reflect a certain simplification of details, as predicted by Conrad (2001), upon careful reading, the media cannot be accused of creating unwarranted hype about an imminent discovery of “cures” for or ultimate causes of AD.

### Pharmaceutical Educational Materials

Educational material about AD produced by pharmaceutical companies is heavily relied upon by physicians and nurses when explaining AD to newly diagnosed patients and their families, but these information sources adroitly sidestep theorizing about causation: “In some cases, Alzheimer’s disease may run in the family. In other cases, no other family members are affected . . . researchers generally believe that the cause may be a combination of several factors. They are working very hard to find out more about the causes of Alzheimer’s disease” (Pfizer Canada 2001, 2). While theories of causation in general, and more particularly of genetics and heredity, are given scant attention in the pharmaceutical educational materials, when they *do* appear, they are usually glossed over as “family history,” and there is a failure to clearly distinguish between early- and late-onset Alzheimer’s disease.

The few allusions to genetics that appear in pharmaceutical-company educational handouts are usually drawn from other sources, such as the Canadian Alzheimer's Society's *Alzheimer's Disease and Heredity Fact Sheet* (2002). Pharmaceutical handouts also direct patients and caregivers to "educational" Web sites that are more detailed in their discussion of causality and risk. Here ApoE  $\epsilon 4$  makes a brief appearance: "Recent medical research suggests that people who carry a specific gene variant—apolipoprotein (ApoE), ApoE  $\epsilon 4$ —may be at increased risk of AD after age 60. Research is being undertaken to further explore this possibility."

### Advocacy Organizations

In addition to drawing on the material distributed by pharmaceutical companies, physicians routinely refer patients to local support and advocacy groups such as the Canadian Alzheimer's Society or the American Alzheimer's Association. These organizations offer a broader range of information than can be found in the general media or through the pharmaceutical-industry-sponsored Web sites, in large part because such organizations have mandates to both support and make available "state of the art" research and to convey this information in a manner that is accessible to patients and caregivers, as well as to the research and clinical communities.

Despite their mandates to pass along the newest information, the Alzheimer's Society statements with regard ApoE  $\epsilon 4$  are cautious and qualified: "[S]cientists now believe, *in some cases*, the pattern of inheritance of the ApoE  $\epsilon 4$  allele can be used to estimate subsequent risk, and age of onset." The Alzheimer's Society specifies that while ApoE  $\epsilon 4$  has been linked to various forms of the disease, it is clear that the allele does not *cause* the disease but rather is a potential risk factor. Risk estimates provided by the Alzheimer's Society are also vague: "[T]hose with 2 copies of ApoE  $\epsilon 4$  will have a *higher* risk of developing the disease in their early sixties, while those with 1 copy of the allele will *more probably* develop AD after the age of seventy" (emphases added). No concrete figures are provided. Given that relatives of AD patients are not routinely tested for their ApoE genotype, it would be interesting to know if such vague statements aroused an interest in genetic testing among relatives of AD patients. An unspecified "higher risk" may be cause for concern, as might be the prospect of "more probably" developing AD, even if only in one's eighth decade of life. But such statements could equally have the opposite effect.

The Alzheimer's Association's Web site offers general estimates of average worldwide lifetime risk for developing any type of Alzheimer's (5 percent by age sixty-five, 10–15 percent by seventy-five, and 20–40 percent by eighty-five; having one parent or a sibling doubles risk to 10 percent by sixty-five, 20–35 per-

cent by seventy-five, and 40–80 percent by eighty-five). The authors state that risk increases with the number of affected relatives, and having more than one affected sibling results in the greatest increase in risk. “This is explained through shared genes, whose influence may be large or small—deterministic genes, in the case of FAD (familial AD). In the case of sporadic AD ‘susceptibility’ or ‘risk’ genes—they raise the likelihood of a particular outcome but do not ensure it” (Alzheimer’s Association 2002).

The association cautions, “Analyses of the exact amount that ApoE  $\epsilon 4$  raises risk are inconsistent, and the precise mechanism by which the ApoE genotype affects risk is not yet completely understood” (Alzheimer’s Association 2002). What the society fails to point out is that the general-risk figures provided by lifetime estimated risk are not well defined in the scientific literature. For example, included in lifetime estimated risks of succumbing to AD are not only those diagnosed with late-onset AD, but also those with early-onset AD. Further, as with the materials produced by pharmaceutical companies, these pamphlets at times conflate early- and late-onset forms of AD: “For a few families, there is a definite connection between family history and AD. While for others, a family history of Alzheimer’s Disease puts them at a greater risk than someone with no family history” (*idem.*). Such a statement does not clearly differentiate between the two forms of AD, which have very different meanings and outcomes for afflicted individuals and their family members.<sup>16</sup>

MUCH OF THE information and commentary that makes its way into pharmaceutical educational materials and media coverage is based upon the information provided by organizations such as the Alzheimer’s Association and the Alzheimer’s Society. The groups are often quoted in media accounts to bolster and confirm the importance of new scientific studies and findings concerning AD. These sources of knowledge are also primary channels for information about the nature and causes of AD. We suggest that the import of these sources is probably as significant as that of the clinician in providing information about AD to patients, family members, and the public at large.

Participation in an eight-week support group for families of patients with AD confirmed the impression gained from the advocacy literature: the care of patients is given top priority for discussion in these organizations, and the presumed causes of AD, including the possible contribution of genetics, is granted only a minimal amount of attention, if more than is available through other sources. Our interviews with family members of AD sufferers make it clear that a very discriminating reading of what is presented in the media and as the latest “breaking news” is common; readers critically assess the importance of “discoveries” and most often recall only those articles that are directly related to their preexisting interests.

### **Disparate Uptake of Knowledge in Flux among Families of Alzheimer's Patients**

We began our study of the circulating information on AD causation and genetics with the assumption that this knowledge flowed from basic science and epidemiology through the clinical setting then through pharmaceutical, advocacy, and media representations, finally “trickling down” to the public at large. However, what was discovered was characterized less by “flow” than by disjuncture, translation, and a disparate uptake of this fluctuating knowledge. Interviews carried out in Montreal with the children of AD patients indicate that the children’s concerns and beliefs about AD are no more a simple reflection of the information available in the media than they are a result of current epidemiological or clinical knowledge.<sup>17</sup>

While many were quick to state that they kept abreast of media coverage of AD, it was unusual for respondents to recall in any detail the stories that they had read or watched on television. Furthermore, their statements did not indicate that they necessarily remembered or put their faith in information given to them in clinical settings. Pharmaceutical and advocacy information pamphlets were more likely to be sources of information on daily coping and care than on AD causation. For the most part, respondents’ concerns were focused on the day-to-day management of their parents. Learning to cope with a sick and dying family member was much more pressing for them than was thinking about one’s own risk of developing AD.

These findings contradict the writings of those social scientists who have indicated, in relation to “genetic” disorders, that people tend to worry about genetic risk, that this risk will be central to their life choices, and that knowledge about genetic risk will play a role in increasing self-surveillance. Clearly, the specific pathologies and prognostic effects of the disease under consideration limits what generalizations can be made. In what follows, we present several of the most common themes that have appeared in interviews in connection with attitudes about AD and beliefs about its cause(s).

#### **Clinical Encounters**

Many respondents indicated that their parents’ clinicians did not add substantially to their knowledge about the causes of AD, for the simple reason that doctors rarely took time to discuss potential causes of the disease. Instead, most of the discussion tended to center around diagnosis, therapy, and the immediacy of caregiving. Respondents said that they spent time with the doctor inquiring about the stage of their parent’s disease, prognosis, and daily care.

Replies to the question “What did the doctor tell you about AD?” usually took the following form: “That it is progressive, that it would simply continue and there will be a point in time that my mother will need another type of



care . . . that it is not reversible; there are some medications that might help stabilize it to some degree, but that none of these are. . . there is no cure. So it is a progressive, degenerative disease” (Ari Rosen, age fifty-three, salesperson).

While sitting in on doctor-patient appointments, we observed that the monitoring of patients’ complicated drug regimens, often including multiple medications to slow disease progression, in addition to others prescribed for concurrent conditions, often consumed virtually all the available time, making it difficult to engage in in-depth discussions about disease causation or other matters.

However, in most cases respondents reported that their parents’ clinicians had at some point suggested several potential causes of AD, none of which was granted much more weight than the others. Clinicians reported that they were particularly uncomfortable discussing potential genetic causes of AD, since so little was known about their influence on risk assessments and because this information might result in unfounded concerns among patients. Answers such as the following were commonly given to the question “Did your doctor tell you anything about cause or prevention?”

I don’t inquire very far into the doctor’s knowledge base. They don’t know, they don’t know exactly, the doctors, do they? I don’t think so. They research and research, but they don’t know where it comes from” (Françoise Boisvert, age fifty-eight, hairdresser).

I can’t say that we were overwhelmed by medical evidence. It’s not like we get the feeling anybody really knows. With there being so many questions out there, as to what is AD. It’s a catch-all term for many illnesses. What is it? Unless you can even grasp why it happens, I guess to an extent, then you aren’t doing really more than just giving it a name.” (Hélène Talbot, age thirty-six, lawyer)

### **Diseases Run in Families**

Although most respondents were not aware of any specific genetic risk factor involved in the development of AD (ApoE was not once introduced spontaneously by respondents into the discussion), those who did speak of a genetic component to AD usually thought of it in one of two ways. They either stated that they probably had a fifty-fifty chance of developing AD (as a result of inheriting the gene from their affected parent) or that this parental gene makes an unknown contribution (the increased risk is uncertain and possibly quite small). The vast majority of respondents usually presented their understanding of intergenerational transmission of AD in terms of familial tendencies; in other words, anything one’s parents “had” had a chance of being passed along. For instance, it was commonly explained that one could inherit from one’s parent



personality, eye color, or a tendency toward a particular sickness, but when respondents were asked to describe their understanding of hereditary transmission, they resorted to statements such as “Certain traits are in the family”:

I have always said to myself that it's hereditary. Because there is so much of it in the family, it makes me think that it's hereditary. (Françoise Boisvert, age fifty-eight, hairdresser)

What I understand about this disease is that . . . I think . . . that it is inevitable. It transmits from parents . . . that is what I think. . . . My fears are important. My mother often said to me, “Look at me, I am seventy-seven and I am in good shape, you can hold on to that.” And that's right, except that I have a 50 percent chance of getting the disease because my father suffered from the disease. So I have worries about the fact that I could potentially have the disease. This worry doesn't prevent me from functioning or anything, I just think about it. It is just something that could happen because my father had it and because other members of the family had this disease . . .

I wouldn't say that inheritance of AD was automatic, but the percentage is larger. But I wouldn't say that it was automatic. It is sure that if you look at the percentages, if there is someone close to you, like a mother or father, you have more chances of having it, but I wouldn't say 100 percent. The chances are probably just higher. (Nicole Boucher, age fifty-two, office worker)

It's possibly not transmissible but probably I have more chances to have it than my neighbor who doesn't have it in his family, yes. I try not to think about it though. This topic isn't on my mind each day. (Jean-Pierre Côté, age thirty-nine, lawyer)

Some respondents reasoned that if they shared other traits (especially personality) with their affected parent, then it was more likely that they would have inherited the AD trait from that same parent:<sup>18</sup> “My mother worries more about my brother than about me. She thinks his personality is more likely to be similar to hers than mine. My brother and I have talked a bit about that” (Celine Goulet, age sixty-two, college professor). Or they suggested that they had had enough bad luck in the form of other diseases that they presumed were inherited from their parents to ensure that it was unlikely that they would also inherit AD: “My father died of a sudden heart attack, and that would be my choice. And there's Crohn's in my father's family and I somehow think: OK, if I picked up *that* gene, how likely is it that I have the AD gene, too. Can I have them both? I hope not” (Celine Goulet, age sixty-two, college professor).

Several respondents had an understanding of the genetics of AD that mir-

rors that of the geneticists who were interviewed: “Do I think that there is a genetic component . . . yes! I think everything has something genetically related, but I think there could be a propensity towards whatever it may be, could be asthma, heart disease, AD, cancer, and I think there’s others factors that may make it surface or not” (Celine Goulet, age sixty-two, college professor).

Many respondents suggested that they made an effort not to research or think about AD, its causes, or their chances of getting the disease. Their explanation for this response was that because no cure existed, they were not interested in estimating their risk for AD, since they would not be able to do anything with the information: “Dr. Jefferson once said to me, ‘There is a test.’ I said, ‘Do you have a cure?’ He said, ‘No.’ I said, ‘Then why should I take the test? Because if I took the test I could go straight, if the results were not to my liking, I would go straight to the Jacques Cartier Bridge and jump!’ I know that my greatest fear is I don’t ever want to put my husband or my children through that. But I don’t see the point of knowing” (Esther Blumberg, age fifty-eight, homemaker).

Others stated that they had concerns about other diseases that might either threaten their future health or with which they or a family member were already struggling that were of more immediate import in their lives: “We have other medical histories that I have to deal with in my family, my father as I said had colon cancer, my mother had lymphoma, my mother’s late brother had lymphoma, so there is clearly some other risk profile in the family that I’m more concerned about than I am about the AD actually” (Ari Rosen, age fifty-three, salesperson).

### A Good and Active Life

The importance of “good living” is a common theme that comes out in many of the interviews. Virtually all respondents suggested that they tried to live a healthy life by reducing stress, by exercising, and by eating well. Some, responding at times to medical recommendations, took vitamins, and others used or considered use of hormone replacement therapy (though most were aware of the recent stopping of clinical trials in connection with this treatment). The detrimental effects of stress were acknowledged and the importance of an active lifestyle, social and cognitive, was frequently mentioned as likely to be protective factors against AD. But people were well aware that good living was unlikely to stave off AD forever: “Well, prevention . . . I mean, I’ve gone to lectures and everything on Alzheimer’s and they say, you know, keep your brain working, keep your brain active, try and do things. But you know, my mum worked her whole life, she played bridge, she played mah-jongg, you know, she did everything. Her mind was working all the time, so you know, how do you figure that one out? There is no answer, you know? She was very active her whole life” (Ethel Goldman, age fifty-six, homemaker).

### **Aluminum . . . and Other Theories of Causation**

When asked directly what they believed may have caused their parents' AD, respondents were likely to postulate causes that did not originate from clinical encounters; and in most cases, these theories had not been "run by" their clinicians. These speculative theories apparently arose from efforts to reconcile many pieces of information on risk factors that respondents had accumulated from various sources. Head injuries, aluminum, stress, depression, diet, alcohol consumption, and lack of exercise and cognitive stimulation were liberally evoked as causative. On the whole, respondents held to complex explanations about who gets AD, and why, which they kept separate from unfocused ideas about the hereditary aspect of the disease. In other words, many people intuitively held theories of multiple causation and implicitly recognized a complexity, over which they may have some limited control.<sup>19</sup> Secondarily, inherited traits, over which there can be no control, may also make a contribution. No doubt for this reason, their significance was not given a great deal of prominence:

You know, my mother never exercised. She never dieted. She never had to diet, thank goodness. She ate everything, and she always prided herself on eating fatty foods and ice cream and fried things, and she never had to lose weight. And my mother's brother, who was also brought up in the same household, same thing, he never did anything to watch his weight or watch his diet, and they never exercised. So now I'm thinking, maybe that was one of the reasons, who knows? (Ethel Goldman, age fifty-six, homemaker)

My mum got divorced about twenty-five years ago . . . and then her world kind of crumbled, and at that time too her job she was doing—she had only worked in the workforce a couple years, but her job was eliminated, the company moved and so she babysat for me full time. But she became more and more reclusive in terms of less social activities, less outings, and I think really, lack of stimulation, lack of outside interests, beyond the family not a lot of friends, so possibly lack of stimulation and social activity. (Nancy Robertson, age forty-two, nurse)

My mother had an accident. We have a country place up north, and she was cutting wood one day—this is all before I even brought her to the doctor—and she got hit by an ax. She hit the wood and the wood hit right here [on the head]. She became blue, black, her eyes, everything. So I always thought that this . . . maybe this was the cause of it. (Rosa Bellini, age fifty-four, factory worker, retired)

I think of environmental factors, OK. I think of the pollutants in the air and I am very neurotic about things like that in general. So I would just

write that [AD] off as another example of living in a highly industrialized city, where there's a lot of pollutants. My mother didn't live near high-tension wires, but close to the highway for most of her life, so I . . . I mean that's also what my focus is, and I don't know about her early childhood, what may or may not have been a factor, on her own personal level. Until she remarried it was high stress. I don't know if that contributes or not, for me it's guessing, really. (Celine Goulet, age sixty-two, college professor)

### Hearsay or Heresy

The sources that contributed to these “lay” theories of causation were difficult to pin down. When pressed for detail, respondents claimed to have read something somewhere or seen something on TV, to have been just guessing, or to have often made extrapolations from other illnesses and widespread discourse about health and disease prevention. It was rare that respondents would be able to specifically recall whether the source of information had been the media, an advocacy organization such as the Alzheimer's Society, their doctor, or communication with others with some intimate experience of AD. And yet these diverse, vaguely recalled pieces of information seemed to have had as much or greater influence than the actual clinical encounter in shaping respondents' perceptions of AD and the role that they believed genetics might play in the development of the disease.

While only a few respondents could identify the sources of their theories of disease causation or of particular knowledge about AD, circulating speculations about risk factors and possible protective strategies had clearly penetrated the minds of family members. Although none mentioned folic acid or the reported benefits of Vitamin E, many had heard that staying “cognitively active” might help, as might regular ingestion of anti-inflammatories, and many are familiar with the debated benefits of hormone replacement therapy in women. There is little doubt that hearsay was at work. Does this selective uptake and use of knowledge about AD, with its subjugation of genetics factors, amount to heresy against current scientific knowledge?

### Knowledge in Flux

Interview responses clearly indicate that first-degree relatives of patients diagnosed with AD were generally not very interested in learning about the causes of the disease. They were unlikely to push their clinicians for detailed information about the science of AD. Nor were they searching for ultimate causes and exhibited a more than healthy skepticism of the scientific and genetic discoveries they stumbled across. They were well aware that the discoveries announced in the media did not always prove to be accurate and that promised advances

were slow to materialize. Most respondents said that they were not interested in learning about their risk of developing AD until there was something they could do about it, something more than maintaining a healthy lifestyle. They trusted that the clinician following their parent, with whom they had regular contact, would keep them abreast of what they needed to know.

It might seem surprising that so few relatives of AD patients were interested in understanding the cause, or causes, of the disease or in estimates of their own risk. But perhaps this is *not* so surprising in light of the fact that all those people interviewed in Montreal were in the throes of caring for a sick parent. These people suggested that the possibility of their developing AD was far away and not nearly as immediate as were their concerns about the illnesses with which they were currently dealing—be it their own Crohn's disease, their spouse's cancer or heart disease, or their parent's AD. While stating that they saw their risk of developing AD as something far off in the future, most also intimated that they did not *want* to think in terms of future risk. This might be a situation in which pragmatic disregard has a place, since circumspection does not lead to circumvention.

These interviews have helped to identify some of the factors implicated in the uptake, or lack thereof, of genetic knowledge. There is no simple "trickle-down effect" at work here. Instead, we observe an extreme form of incomplete penetrance of the current genetic knowledge surrounding AD. Despite the fact that genetic researchers have uncovered one gene that is indisputably associated with an increased risk for AD, respondents, when they spoke about heredity, did so in a simplified fashion with no reference to ApoE. They recalled having read about genes in newspapers, hearing about them in public lectures, and being told certain things by their physician. However, the knowledge was recalled in general terms (quite possibly as it was given to them) and was positioned alongside other speculative theories. Interestingly, respondents more often introduced aluminum exposure as a possible risk factor than they did genetics, and if they read about aluminum, they likely read about ApoE  $\epsilon 4$ , since these two items hit the general media at roughly the same time, ten years ago. This suggests a selectivity in uptake and use of knowledge that has not been emphasized in previous social science studies of the public understanding of science. It is possible that the apparent immediacy of poisoning by toxic metals, along with the fact that one can relatively easily choose to avoid this purported source of AD risk, creates more concern than does the possibility of risk estimates based on genotypes, which one can do nothing directly to modify.

Even though media headlines have announced a genetic component to AD, the content of the articles tends to stress the complex interaction of genes, the environment, and yet-to-be-determined cofactors. However, the majority of current popular media coverage of AD is concerned with the shortage of home

care for sufferers, or with the latest studies concerning anti-inflammatories or folic acid. Genetics is but one small part of the picture portrayed in the popular media, and these articles are often less striking to afflicted families than other articles, of which there are many, that emphasize the lived reality of the disease.

Clinicians are located at a major point of disjuncture in the transfer of knowledge concerning genetics and AD. Certain clinicians, such as those in specialty memory clinics, are conversant with cutting-edge genetic science and are active researchers, but they do *not* transmit this information to their patients, because in their opinion it has no effect on clinical care or recommendation about family care of patients.<sup>20</sup>

The goals and purposes of the clinical encounters at which family members are present need to be held in mind: the interview respondents were not patients suffering from AD and did not necessarily perceive themselves as potential patients even in the future; rather, they were caregivers. It seemed to be the general opinion of our informants that to engage in speculation about susceptibility and possible risk for themselves would be inappropriate in the clinical setting, where their parents' needs took precedence.<sup>21</sup>

## Conclusion

As a result of developments in molecular genetics, most health-care professionals now think that genetics is implicated in all disease processes, including those of complex diseases, such as AD, but they also recognize that multiple genes, proteins, and the environment are inevitably implicated. Our data show that there is a disjuncture in the uptake of this knowledge, at least in connection with AD, by patients, families, and the public. Advocacy groups, authors of pharmaceutical literature, and clinicians themselves do not emphasize the implications of genetic findings to patients, families, and the public; on the contrary, they often withhold their professional position with respect to these findings, or else make clear their ambivalence about the clinical usefulness of genetic information. In the popular media, the "discovery" of new genes associated with AD are reported, but these are far outnumbered by those articles about the benefits of vitamins and lifestyle that may help to prevent the occurrence of this disease. Further, at least as often as prevention, caregiving is the subject of these reports. Similarly, support groups for AD will, for the foreseeable future, continue to focus on patient care rather than highlighting the numerous genes and proteins that have been targeted as contributing to the disease, whose predictive value is little or none.

Reasons for deemphasizing new genetic research within a clinical setting appear to be twofold. First, to date, the complex mechanisms whereby genetics

has an impact on AD disease causation are by no means understood. The effects of ApoE, which is the closest thing to a genetic “smoking gun” scientists have found, are anything but obvious. Knowledge of an individual’s ApoE status does not affect diagnosis, prognosis, or treatment and therefore does not make a difference in a clinician’s ability to care for that individual. Second, aside from withholding information about genetics and AD because of the limited predictive value of ApoE status, a further reason for the deemphasis of genetic knowledge is that caregivers in the clinical setting are most concerned and worried about the details of caregiving and what the future has in store for their parent. Concerns and speculation about their own future risk is actively avoided.

Professional and popular understandings of the role of genetics in illness vary from disease to disease, and so too do the form and degree of geneticization, genetic citizenship, genetic responsibility, and biosociality. In order to predict the effects that genetic knowledge may have, it is necessary first to understand and contextualize the state of professional and popular knowledge surrounding a particular disorder. Most important, what is relevant for Mendelian diseases cannot be extended to complex diseases in which susceptibility, rather than causative genes, are implicated. Further, it is necessary to recognize that different diseases will have very different effects on individuals, families, and communities. Some of the reasons for this include the varying age of onset, the form that the disease takes, and its particular pathological effects, along with differing perceptions among individuals about the disease. For instance, some respondents in this study indicated that their fears of developing AD were less than their fears of developing other disorders, because they assumed that AD would strike only very late in life. Nonetheless, others had grave fears of putting their children through the difficulty of dealing with a parent with AD in the future. Without detailed knowledge of these factors, it is not possible to understand what form geneticization or genetic responsibility may take.

Not only scientists, but also social scientists, risk participating in hyperbole about the new genetics when they focus attention on geneticization at the expense of considering the impact of the lived experience of disease on patients and families. Our research demonstrates that the transfer and uptake of knowledge and its penetrance into lay understanding of disease causation is in part dependent on its pragmatic value for the listener and its consistency with individuals’ broader beliefs about health and illness. Rarely did respondents suggest that their understanding of AD was significantly different from their understanding about other late-onset diseases; they posited that heredity and lifestyle were probably both implicated in AD, cancer, and heart disease. Beyond the understanding of some respondents that the disease might “run in the family,” genetics played a small part in perceptions about AD, taking a backseat to the pragmatics of living with, and caring for, an afflicted family member.



## NOTES

1. As the mapping of genes becomes increasingly sophisticated, it has become clear that risk estimates are very often lower than was previously believed to be the case, in some instances, considerably lower. What was formerly assumed to be certain is no longer the case (Almquist et al. 1997).
2. As a result of genetic research, AD is now conventionally divided into early- and late-onset forms. Early onset, "familial" AD, is associated thus far with approximately 170 extended families worldwide accounting for perhaps 2 percent of all cases of AD. Genetic markers for this form of the disease have been found on chromosomes 1, 14, and 21, one variation of which is inevitably present in vulnerable families. These genes are autosomal dominant mutations and are understood by most specialists as genetic "determinants," although twin studies have shown that age of onset for identical twins can differ by as much as ten years, strongly suggesting that the environment also plays a role (Tilley, Morgan, and Kalsheker 1998). Onset of the early forms of the disease is almost without exception between the ages of thirty-five and sixty, with another form starting a little later in life and occasionally not making an appearance until age seventy. In all cases of early onset, the condition progresses rapidly to florid dementia and death.
3. Many genes are polymorphic and have a number of variations that are widespread in the human population. Those allelic variations that have been associated with an increased risk of developing a disorder are known as *susceptibility genes*. Such gene variants are neither necessary nor sufficient to cause specific diseases, however, as, compared with the population at large, an individual who carries one and especially two copies of such alleles is believed to have an increased risk of protracting the relevant disease. Even so, people with two copies of a susceptibility gene may not get the disease, indicating that other, as-yet-unidentified factors are involved.
4. *Penetrance* (a term coined by Vogt [1926]) refers to the frequency with which a gene manifests itself in the phenotype of carriers. Phenotypic expression is a function of both genotype and environmental factors. Penetrance is reduced or incomplete when carriers fail to demonstrate the associated phenotype.
5. A shift toward a molecular approach in biology began in the 1930s (Kay 1993). This shift was associated with a search for what constitutes "life," and was made possible by the development of several new technologies. For two decades, molecular biology focused on protein structure and function. After 1953, when the significance of the discovery of DNA was recognized, the emphasis switched dramatically to genes, culminating in the Human Genome Project. In recent years proteomics has again become a major focus in molecular biology and is the subdiscipline that currently holds out the most hope for the development of new, individualized medications and for elucidating numerous complex biological pathways, including those associated with AD.
6. This Internet research is open to critique in that it represents only those people who have been motivated to turn to the Web sites. Others, even when they have "genetics" in the family, avoid such sites. There is no evidence that they exhibit a "genetic responsibility" or that they believe that it is necessary. It is also worth noting that only between 10 and 15 percent of people in Huntington families take up offers for testing.
7. Concepts of *genetic citizenship*, *genetic risk*, and *genetic responsibility* are likely to be useful when researching early-onset AD, which has a Mendelian inheritance pattern.
8. Epidemiological figures for other countries, such as Canada, are often derived from



estimates of the figures in the United States. With Canada having one-tenth the population, Canadian estimates are commonly assumed to be one-tenth of those in the United States. What is lost in mathematical gerrymandering are potential differences in disease incidences that might result from different social and economic circumstances such as very different medical and social service systems.

9. When a disease has a very late onset, as does AD, it is difficult to reconstruct family genealogies effectively to document disease transmission, with the result that disease occurrence *appears* sporadic.
10. At this same conference, an epidemiologist clarified the way in which genes are believed to be implicated from before birth in connection with what will happen to one in old age. Genes influence the building of "cognitive capacity," this epidemiologist argued, starting in the intrauterine environment and playing a large role throughout infancy and childhood and into early adult life. During interviews, AD experts frequently claimed that people with high IQs and with extensive education are at considerably less risk for AD than are others. The epidemiologist's presentation made it clear that what is assumed in such statements is that genetic predisposition influences the laying down of the neurological networks required for brain functioning. Certain biologically predisposed individuals will end up as adults with fewer synapses and, as a result, are likely to have lower IQs and therefore will complete less schooling. It is assumed that the plaques, tangles, and cell death associated with AD will do proportionally more damage in a short space of time to such people.
11. A recent *New York Times* article reported debate among specialists with regard to the limited efficacy of existing drugs, stating that it may be decades before real progress is made (Grady 2004).
12. The term *heterozygous* refers to the case in which a person carries only one ApoE  $\epsilon 4$  allele (along with an ApoE  $\epsilon 2$  or 3, for example). Someone who is homozygous for ApoE  $\epsilon 4$  has two of these alleles.
13. In the examples, the involved gene has been shown to protect against a specific disease, but if individuals are homozygous for the gene then they will develop cystic fibrosis or sickle cell disease.
14. In the two clinics located in teaching hospitals with which we are most familiar, patients and their families are routinely asked to provide blood for the various research projects that are under way. Several of these projects involve testing for genes and proteins believed to be associated with AD in the hope of finding clues that could lead to the development of an effective medication. If the family agrees to participate in one or more of these studies, blood is drawn and the sample is then anonymized before it is sent for analysis. The results of such testing are not made available to patients, families, or clinicians, and therefore participation has no effect on clinical encounters. Should an effective medication be developed, only then would samples be rematched with specific patients.
15. This analysis is based upon database searches (Canada Newdisc and Factiva [Dow Jones Index]) covering the above-mentioned time period, which cover major Canadian newspapers in French and English, such as the *Montreal Gazette*, *La Presse*, *Le Devoir*, *Le Soleil*, the *Globe and Mail*, the *National Post*, and the *Toronto Star*, in addition to popular magazines such as *Canadian Living*, *Chatelaine*, and *Macleans* and CBC news coverage. The *Washington Post*, the *New York Times*, *Report on Business*, *Time*, and *Scientific American* were also examined. (It was not within the scope of this analysis to examine British and European media sources, but a comparison of the manner in which media representation of AD and genetics might differ from the North American con-

text might prove an interesting cross-cultural comparison). Because of the multinational makeup of the Canadian population, it is to be expected that many Canadians will be exposed to foreign media sources. However, as the intent of this analysis is to explore the media coverage that our “typical” respondent would have most likely been “exposed” to, we have limited ourselves to these representative sources.

16. Familial Autosomal Dominant AD (FAD) is identified as rare (5–10 percent of all cases), and “Sporadic AD” is described in the pamphlet as the common form, accounting for 90–95 percent of all cases. It is noted, “The role of heredity in Sporadic AD is unclear and continues to be the subject of intense research” (Alzheimer’s Society 2002).
17. This study was based on interviews of 40 first-degree relatives whose parent was suffering, or had suffered, from late-onset AD. The sample includes English- and French-speaking Montrealers and represents three different clinical sites. Recent immigrants were excluded. No detectable differences between responses of men and women or between people of different ethnic backgrounds were observed. All names that appear are pseudonyms, to ensure anonymity.
18. Richards (1996) suggests that Mendelian genetic explanations may contradict lay understandings of inheritance grounded in kinship concepts. He finds that disorders that “run in the family” are often linked to other associated groups of characteristics, which one may or may not inherit from the affected parent. This anti-Mendelian phenomenon, which Richards calls *blended inheritance*, is taken up in another paper by the authors that looks at the manner in which adult children of Alzheimer’s disease sufferers grapple with the complexity of risk estimates for AD based on ApoE status (Prest, Lloyd and Lock, in progress, “When It ‘Runs in the Family’: The Interplay of Heredity, Inheritance, and Genetics in Understanding Risk for Late Onset AD). In spite of the fact that these respondents have undergone education and genetic-counseling sessions, in addition to being followed for one year and completing numerous qualitative scales that have reviewed the genetic information about ApoE and for AD, we found continued references to blended inheritance and extremely simplified and abstracted genetic explanations. These findings echo the data reported here, but are of great interest in light of the unique nature of the sample population. This paper in progress more fully engages the social science literature on lay understandings of genetics and explores the significance of the lack of penetrance of genetic knowledge surrounding susceptibility and risk for developing AD.
19. For a rich account of how family members grapple with theories of causation, see Annette Leibing’s research on AD in Brazil (2002), in which she depicts “the struggle for meaning situated at the interface of biomedical explanations and intuitive insights.”
20. One future objective of this ongoing study is to characterize the exchange of knowledge concerning AD that takes place between general practitioners (or nonspecialist clinicians) and patients and their caregivers. Such interactions are likely to constitute a majority of the clinical encounters concerning memory loss. Although the theory is speculative, we anticipate that even less genetic knowledge is transferred in these encounters, in light of findings from our research conducted in the specialist clinics.
21. It is possible that the family members raise their concerns about their risk for getting AD with their own general practitioners or family doctors. This part of a research project is yet to be carried out.

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## PART THREE

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# The Organization of Voice, Self, or Personhood



## Coherence without Facticity in Dementia

### The Case of Mrs. Fine

ATHENA HELEN McLEAN

The narrative turn in the study of aging has brought forth a variety of nonpositivist, nonrealist approaches to examining an elder's life story within the terms of the story itself, independent of its truth content. Beginning with the early 1980s, anthropology witnessed a flood of studies concerning the life history approach (cf. Bertaux 1981; Crapanzano 1980; Shostak 1981). By 1988, however, the influence of illness in the construction of one's life history received little attention (Kaufman 1988, 217). Since then, bolstered by interpretive approaches to narrative in anthropology (e.g., Rabinow and Sullivan 1987), as well as theory and methods from literary criticism (Bakhtin 1981), philosophy (Ricoeur 1981, 1984), and cognate disciplines (Polkinghorne 1988, 1996; Cohler 1993; Bruner 1991; White 1980, 1987), social scientists have increasingly examined the place of narrative production in the construction of meaning for persons confronting illness (Kaufman 1988; Mattingly 1998), disruption (Becker 1997; Lovell 1997), or the frailties of aging (Gubrium 1993; Kaufman 1986; Rubinstein 1988, 1990; Rubinstein, Kilbride, and Nagy 1992; Holstein and Cole 1996).

Whereas many clinical applications of reminiscence and developmental understandings of the life course have been informed by positivist notions that view language as direct reflections of a fixed coherent self, recent autobiographical works in gerontology (Gubrium 2000, 2001; Gubrium et al. 1994; Birren et al. 1996; Coleman 1999; Kenyon 2001) or at large (Climo and Cattell 2002) have been shaped by more critical approaches.<sup>1</sup> Studies problematizing the notion of a coherent fixed self (Ewing 1990; Gubrium and Holstein 1995) have been informed by a postmodern appreciation of the dialogic production (Bakhtin 1981) of multiple ever changing selves produced in diverse contexts.



The self-consciousness demanded by self-critics of ethnography (Clifford and Marcus 1986; Marcus and Fischer 1986) has stimulated the emergence of native voices (first-person accounts of indigenous, subaltern, or other), while soundly delivering the postmodern message that the researcher is not revealing “truth,” only her own particular reading of the field as text. The influence of analyses of text-based (not natural-language-based) discourses from disciplines such as literary studies has further directed studies of narrative away from realist concerns with how well they reflect “actual experience” or the narrator’s inner life, or with how accurately the narrator’s recollections portray actual events, objectively validated by external evidence. Increasingly, narratives are being examined as texts that cohere within themselves, independent of any external validity of their truth value.

Most analyses of life stories in gerontology, however, have concerned elders who are not cognitively impaired,<sup>2</sup> perhaps because this group has been seen as more capable of reflecting upon the past in constructing their own stories. For these elders, life narratives have been appreciated for providing coherence, resolution, or direction to the condition of their current lives independent of the authenticity of the content of their narratives. When elders are cognitively impaired, however, questions arise about their capacity to produce a coherent and authentic life story, even though authenticity is not ordinarily a concern. Perhaps the powerful influence of the biomedical model, with its realist emphasis on objective evidence, has inhibited efforts to collect life narratives from cognitively impaired elders, in spite of the contention of nonpositivist narrative studies that the need for external validation is unnecessary or irrelevant (cf. Denzin 1989; Bruner 1991; Polkinghorne 1996). Even more likely, the attention that biomedicine has drawn to decaying brains and loss of reason in the senile elderly has led researchers to discount these elders’ capacities to produce meaningful discourse and has dissuaded them from exploring their life histories.

Thus, with few exceptions (Hamilton 1994; Sabat 1991, 1999; Crisp 1995), there has been limited attention to investigating life stories of persons with dementia. This chapter will contribute to knowledge in this area through the discussion of the life story of one elderly woman with dementia. After describing the study, the narrative, and the context of its production, I will examine the extent and nature of coherence in her story, using formal textual and nontextual criteria. Through these criteria I will consider the relevance of facticity (or “truth”) to coherence in performance, text, and personal integration. I will also examine the meaning of the narrative in light of the existential and material conditions of its production. The chapter will conclude with a brief discussion about the limitations of postmodernist approaches to the study of narratives of elders with dementia and consider both the gains and possible risks of externally validating the stories of these elders.

## Research Considerations

### *The Setting*

The study took place over a nine-month period from September 1993 to July 1994. The site was a locked forty-bed special care unit of a five-hundred-bed private nursing home complex in the northeastern part of the United States. Although mainly Jewish, the residents varied in socioeconomic background and country of birth. The affiliation and close proximity of the nursing home to a well-regarded hospital was a major source of attraction for many families. The special care unit was one of two identically designed units that together housed the most severely cognitively and behaviorally impaired elders in the nursing home.

The unit, Morgan II, was intermittently noisy because of the degree of disinhibition and disturbance of its residents. Disturbed behaviors included frequent repetitiveness, verbal aggressiveness, physical combativeness, and undressing in public. Despite the extreme behaviors of its occupants, this unit had an excellent reputation in the community. However, elders rarely entered the unit directly from the community. Rather, they were transferred there from other units in the nursing home, because of deterioration in their condition or escalation of disturbed behaviors.

The residents were overwhelmingly female, at a rate of 85 percent, about 10 percent higher than the national average for nursing homes. They ranged in age from 68 to 98 (with both extremes being males). The median age of all residents was 88.5. Fourteen residents were in their 90s, twenty-one in their 80s, and four in their 70s; a single male was in his 60s.

### *Methodology of the Larger Study*

The purpose of the project was to study qualitatively the communicative interactions of residents with dementia who manifested seriously disturbed behaviors. The goal was to examine the specific contexts in which the disturbed behaviors occurred, evolved, and resolved or escalated in order to determine whether they may have represented failed efforts at communicating rather than, or in addition to, organic deterioration.

I spent approximately nine months on the unit. My methodology was ethnographic and included participant observation; detailed recording of observations; and informal and semistructured interviews with the members of the staff (everyone from housekeepers to physicians), family members, visitors, and wherever possible, the residents themselves. I conducted observations on a daily basis. Although the majority of these observations were conducted during the day shift (7:00 A.M. to 3:00 P.M.) and during several hours of the evening shift (3:00 P.M. to 11:00 P.M.), there were also many days when I stayed throughout the second shift and part of the night shift (11:00 P.M. to 7:00 A.M.). There were also

occasions when I spent twenty-four consecutive hours on the unit in order to observe residents whose disturbances had no predictable pattern, or who would be disruptive after 11:00 P.M. The twenty-four-hour stays gave me a fuller flavor of the flow of life on the unit, offering me a closer look at the way the residents experienced it every day of their lives.

Before selecting the unit for study, I first spent time visiting it and speaking with the head nurse and support staff to ensure that the residents would be appropriate for my purposes. On the day that I formally began my research, the assistant director of nursing introduced me to the unit staff, affirming the administration's interest in cooperating with the study. Shortly after arriving on the unit, I described my research focus to the staff and to residents' families (persons designated as responsible parties and others whom I might eventually interview). I explained to them how I would be probing into areas that they might think were irrelevant but that this was necessary for gaining a fuller picture of the context in which disturbances occurred. I also explained that I might appear "nosy" at times, but reminded everyone that the areas into which I inquired were necessary for my study. As the study progressed, the staff and family members were generally cooperative, but a few of the nursing assistants were not very forthcoming, because, despite my efforts to convince them otherwise, they continued to suspect that I was a spy for the administration.

Whenever possible, I wrote my field notes immediately following a conversation or observation to ensure the fullest retention of details. If much activity had caught my attention but I was unable to document my observation at that time, I wrote a brief outline that identified the points that I needed to develop. After leaving the unit, I elaborated on the outline.

I kept my field notes in two separate files. A general file documented my detailed observations about life on the unit. This included observations about interactions between the many persons who lived, worked, or appeared there; caregiving routines; work organization; and of course, disruptive behaviors. I also kept a file for each of six residents I chose for more intensive, focused study. These residents typically manifested the most disruptive behaviors, some by fighting with the staff or other residents, others by making great demands on staff time. In addition to the ethnographic research, I studied the current and past medical records of Morgan II residents in order to gain some understanding of how their condition, including their disturbed behaviors, had changed over time.

Before selecting six residents for intensive study, I spent one month making general observations and inquiries of the unit staff. I spoke with the head nurse of the unit, a registered nurse, and the care managers, generally licensed practical nurses, from every shift. In addition, I spoke with nursing assistants, who have the most direct contact with residents, to obtain their assessments about the most disruptive, behaviorally disturbed residents. A resident might be quiet

on two shifts but terribly disruptive at 3:00 A.M., so I made a point to talk with staff, especially nursing assistants from every shift. I jotted down lists of their candidates, asking for reasons for their selection. I then compared names on the lists to see who most frequently appeared, with the plan to choose those who were identified most often as being “disruptive.”

### **Focusing on Mrs. Fine**

#### ***Selecting Mrs. Fine for Intensive Study***

Among the main contenders for intensive study was Mrs. Fine, an eighty-five-year-old woman who had been admitted to the home almost three years earlier. Mrs. Fine was identified as being agitated and aggressive with other residents to whom she felt superior. During mealtimes she would compare her food with that of other residents and complain. She would frequently hit other residents or throw food or beverages at them. Targets were residents whose behaviors were visibly disturbed or to whom for some reason she took a dislike. Her behavior had been getting more aggressive in recent weeks, so she appeared on most of the “most disturbed residents” lists I had collected. Mrs. Fine was also known for getting very upset in her single room, where she commonly stayed alone. She would often scream that someone had been going through her belongings and that something valuable was missing. She was also known to suffer from delusions and to hallucinate at times, insisting that a man had entered her room. She would occasionally be up at night, yelling intermittently between naps. Most recently, she had begun to disrobe and occasionally to display exhibitionist behavior.

In addition, Mrs. Fine had a severe expressive aphasia, a language disturbance resulting from focal lesions (Thompson 1987, 146), with word-finding difficulties that left her tearful and frustrated when they interfered with her efforts to speak. The range and extent of her disturbances and the general agreement from the staff about them had convinced me to include her in my study.

#### ***Mrs. Fine’s Medical History***

Mrs. Fine presented with a somewhat unusual medical history, inconsistent diagnoses, and a history of frequent moves within the facility. About a year prior to her admission to the nursing home, she had become confused, suffered a stroke, and fell and broke her hip. Subsequently she experienced periods of depression and delirium, both involving confusion and hallucinations. These led to two brief psychiatric hospitalizations in the year before her admission to the nursing home.

Mrs. Fine was admitted to the nursing home with a diagnosis of major depression, multi-infarct dementia associated with her stroke, and periodic delirium (paranoia, delusions, and hallucinations). She also had arthritis and a

history of falls. While continent at the time, she performed very poorly on a cognitive exam, unable to identify her location, age, or married name. She also indicated that her husband had died one year ago, when he had actually died twenty years ago.

During her stay at the home, her dementia received various diagnoses ranging from Alzheimer's disease to multi-infarct dementia to mixed dementia. In fact, her clinical picture was very irregular and did not follow a pattern of progressive decline. Despite her very poor performance upon admission on one cognitive test (the Blessed), she performed much better on the Mini Mental State Exam (MMSE) three years later (scoring 21 out of 30).<sup>3</sup> Reports of her history of continence also varied enormously, with clear improvement over the most recent year.

Since her admission, Mrs. Fine had moved to four different units, including two admissions to Morgan II. The moves were generally a result of her aggressiveness toward better-functioning residents on the other units. A fall just a year after admission left her wheelchair bound, incontinent, and angry. Since her last return to Morgan II, she had received physical therapy, was able to walk again with a walker, and regained continence. Her heightened independence had improved her mood considerably.

About a week prior to my coming to the unit, Mrs. Fine had just returned from a brief hospital stay following left-side weakness and an inability to speak. Tests indicated that she had not suffered another stroke, but more likely, a transient ischemic attack. Additional neurological assessments showed that she had mild cortical atrophy, no new infarcts beyond the earlier one on her occipital lobe (side not indicated). There was also a mild flattening of tissue (the nasolabial fold) on her right hemisphere. The neurological exam showed signs of dementing disease, most likely Alzheimer's, that was believed to have affected her both short- and long-term memory. Since returning from the hospital, her aphasia also seemed somewhat more marked.

### ***This Unplanned Substudy***

I had been on the unit for about three weeks when Mrs. Fine approached the nurse's station, where I was sitting. She was very upset, so the nurse gently asked her to calm down and went to her room to see what was upsetting her. A few minutes later the nurse exited her room, after assuring Mrs. Fine that her photographs were still there—a periodic worry of hers.

Mrs. Fine then turned to me and beckoned me to join her in her room. This caught me completely off guard. I had not really conversed with Mrs. Fine before, except casually while moving about during the course of my observations on the unit. Perhaps she had sensed my interest in her; if so, this showed an awareness I had not come to expect from someone suffering from dementia.

Since I had never made demands on her, she may also have perceived me simply as nonthreatening company.

As I entered her room (the only single room on the unit), I commented on the many pictures she had displayed on her bulletin board and on how lovely her room appeared. "I did it myself," she proudly proclaimed. This was the beginning of a two-hour-long visit. Mrs. Fine started showing me her pictures, but as she tried to describe each one, her aphasia interfered with her ability to express herself. In frustration at her inability to finish a sentence or locate the right word, she would pull back her head and groan dramatically. I resisted choosing words for her, so as not to rush her or impede her thought processes. However, if she were struggling exceptionally, I might ask, "Do you mean X?" She could then simply answer yes the majority of the time, or no, and try once again. In this way we slowly proceeded through the dialogue. After Mrs. Fine proudly pointed out pictures of her daughters and grandchildren, her eye caught one lovely young woman, and she began to sob. "That's my Gilda, and how I loved her! And she died!" Gradually it came out that Gilda was her daughter, who at eighteen had died as a result of physician negligence. While the details escaped me, Mrs. Fine's expression of suffering the loss of a child was clearly communicated, and her words and emotions moved me to tears.<sup>4</sup>

My own tears apparently touched her and she calmed down, smiled slightly, and continued showing me her pictures. When she came to a picture of her husband, she started to moan and shake her head. At first, I suspected that this was because he was deceased, but her tone of voice and gestures suggested that there was something more to her reaction. After we sat down, I admired the large framed picture on her nightstand of Mrs. Fine in a formal pose and fancy dress. The photograph prompted her to share the following story.

### ***Mrs. Fine's Story***

Many years ago, at a party she attended with her daughter, a man approached her daughter, asking if he could snap a photograph of Mrs. Fine. Although reluctant at first, after some pressure from the man, Mrs. Fine finally agreed. Later she agreed also to have a picture taken with the man's brother.

At that point in her story, Mrs. Fine opened the drawer of her nightstand and pulled out a picture showing her wearing the same dress, this time with the man in her story. Someone had jotted his name on the back of the picture, possibly as a reminder, suggesting perhaps that he was not familiar to her. They were standing side by side formally and holding hands. Mrs. Fine looked at me and said, "I never saw that man again."

After the party, Mrs. Fine took the photographs to be developed at her local pharmacy. Her husband, who had returned early from a business trip, before going home stopped at the pharmacy to pick up some medicine for her. The

pharmacist looked at him in a puzzled way, wanting to know if he was her husband, because he had seen her (referring to the photograph) with another man.

After hearing this, Mr. Fine grew suspicious, and upon returning home and seeing the picture, he became incensed, convinced that his wife had become involved with that man. He then went to visit Mrs. Fine's sister and her husband, Mr. Fine's business partner, to see if they knew anything. Her brother-in-law confirmed that she was seeing another man.

"What a lie!" Mrs. Fine complained to me, again getting upset, holding her hands to her temples and shaking her head.

To punish her, her husband withdrew all their money from the bank and gave it to her sister and brother-in-law. He then signed over his business as well. She was left penniless and with a furious spouse.

I asked Mrs. Fine if she and her husband had separated because of this event. She said they had not, but that he refused to talk to her, believing the others over her. Even her daughter could not convince him of her innocence.

I asked if her husband had left any estate for her children. She said he had not, but that they were nevertheless financially secure. However, she reiterated, "But I have nothing, just this" (referring to her room), while her sister bought a very big house with the money. She added that this same sister took all her jewelry after she entered the nursing home, claiming that Mrs. Fine would no longer need it.

Within two months Mrs. Fine's husband was dead. She believed, in retrospect, that he knew the end was coming, which is why he hurried to transfer their money and business to her sister, as punishment. "But," she insisted dramatically, turning to me, "it was not the money that upset me; it was his going to his grave, still not believing me, when never once was I unfaithful to him!"

Once again, she became upset, shaking her head and then tossing it back in despair, while sighing in agony. I expressed my empathy and stated how very difficult this must have been for her. "Exactly!" she agreed.

A couple of months after Mrs. Fine's husband died, her daughter went to another party, where she expected to see the man in the picture. He never appeared. A few days later, the man who took her picture showed up at Mrs. Fine's door to inform her that his brother had died. He then explained how his brother, who had been terminally ill, had been admiring Mrs. Fine, which is why he had wanted to take his picture with her.

It was these events that had left her alone and penniless.

Mrs. Fine appeared relaxed after completing her tragic tale. Then she smiled and wished me greater happiness in my life than the horrors she had been meted. She asked that I not share this story with anyone on the staff for fear it might get back to her sister and cause a family upheaval; however, she did grant me permission to talk with her daughters.



### Methodological Issues

Although I typically audiorecord and transcribe interviews that I conduct with family members, I did not expect to be gathering any formal life histories with residents of Morgan II, given the severity of their impairment. So I was unprepared to tape-record Mrs. Fine's story. Even if I had had my tape recorder with me, I suspect, Mrs. Fine would have been reluctant to let me turn it on, given her intermittent paranoia. Also, I would not have wanted to risk having a device interfere with her narration. In addition, as those of a cultural anthropologist, my transcriptions would have been used for analyzing the general content of the story, rather than for linguistic microanalysis, so I did not fear that the analysis would suffer by relying on my reconstruction of her story.

Soon after I left Mrs. Fine's room, I attempted to reconstruct and record our conversation and the detailed elements of her story as fully and accurately as possible, preserving quotes and her emotional expression as I remembered them.

### Checking the "Facts"

On three subsequent occasions, Mrs. Fine repeated parts of this story, changing some of the details each time. The plot remained the same—her having been photographed with this man and her husband's disbelieving her story. What differed were the identities of the relatives who had lied to her husband and who had personally benefited at her expense. On these occasions, Mrs. Fine substituted her daughter Ethel and her son-in-law for her sister and brother-in-law. Thus, there was some arbitrariness in the elements she had selected for her story. Because of these discrepancies and my curiosity about the veracity of her story, I decided to investigate some of its "facts."

I discovered that the staff were inclined to discount her statements as fantasy even when they were not. One nurse said that Mrs. Fine had never lost a daughter and warned me not to believe her stories. However, the head nurse, who also distrusted many of her stories, and Kathy, another of Mrs. Fine's daughters, confirmed that a third daughter had indeed died as a young adult.

In talking with Kathy, I learned that Mrs. Fine had started telling some version of this story several months earlier. I also confirmed that Mrs. Fine's husband had died twenty years before her admission to the nursing home. About ten years after his death, Mrs. Fine met Mr. Haller, the man in the picture, at a party, and they developed a serious relationship that lasted until his own death eight years later, about two years before she entered the nursing home. The two men had not overlapped in time. Kathy felt that Mr. Haller had offered her mother companionship and had "doted on her."

Kathy indicated that her father had never rejected her mother; he had



adored her throughout their life together, giving her whatever she wanted. Like Mr. Haller, he was a generous, loving man: “My mother had the distinction of being loved by two men in her life.”

She related that her mother was always saving money and was quite prudish. Kathy’s husband, during a later, impromptu telephone interview, stated up front that he did not like his mother-in-law and commented that she used to “boss around” her “spineless” husband, showing “little respect for him.” He added that Mrs. Fine was obsessed with money and was suspicious that others—even family members—were stealing from her. He also proffered the statement that Mrs. Fine’s sister, who supposedly had benefited from Mrs. Fine’s losses, was living “on welfare.” Both Kathy and her husband had independently alluded to Kathy’s sister’s having taken some of Mrs. Fine’s wealth—an apparently bitter issue within the family—but neither would elaborate.

### Coherence and Dementia

I was struck by the apparent strength of coherence in this story as well as the unmistakable tragic content of its plot, in spite of distortions in the timing and identity of the characters. After describing some of the distortions, I will review the literature about coherence in dementia and then examine the coherence in this story.

#### *Distortion in Mrs. Fine’s Story*

There were several concrete elements in Mrs. Fine’s story that were inconsistent with the facts reported by her daughter. These included Mrs. Fine’s identification of the man in the picture as a stranger, the compression of time between her husband’s death and that of the man in the picture, and her allegation that her husband had left her penniless. It would be much too easy to consider the distortion as entirely the product of her dementia, which no doubt did contribute to it. However, to disregard Mrs. Fine’s story because of her diagnosis would be to ignore both the importance of her effort in constructing it and its potential meaning for her.

Embracing as authoritative fact the comments of Mrs. Fine’s family is equally problematic. Her daughter reported, for example, that Mrs. Fine’s husband had adored her. Suggesting otherwise, however, Mrs. Fine’s son-in-law claimed that Mrs. Fine had shown no respect for her husband. And Mrs. Fine reported that her husband died believing that she had been unfaithful. Perhaps the “truth” lies within each of these statements and somewhere in between. Each family member spoke from a particular perspective, a unique history of relationship with Mrs. Fine and her husband, and a selective memory of experience.

Still, the concrete information her daughter provided, to the extent it was

accurate, was useful for revealing how Mrs. Fine had significantly reordered sequential events in her life story as well as altered the identity of a principal character and the history of her relationship with him. The family's factual data (dates, temporal sequence of events, and the identity of characters) can serve as a source against which to compare elements selected by Mrs. Fine in constructing her narrative. Although other comments from her family could also be used to interpret aspects of her story, they should not be regarded as the "valid" external indicator of historical "truth." Rather, they should be considered as additional narrative fragments, at various times confronting, informing, reinforcing, or conjoining with fragments of her own memory.

### *Coherence and the Language of Dementia*

The literature on language production in dementia suggests that considerable loss of coherence occurs, particularly in the ability to create logical time sequence (temporal coherence) (Ellis 1996, 483–486) and sticking to the point (thematic coherence) (Davis et al. 1997; Ellis 1996, 488–490; Thompson 1987, 148–149; Cherney and Cantor 1992, 124). Much of this literature asserts that with dementia, and in Alzheimer's disease (AD) in particular (Hamilton 1994, 27), speech is typically fluent, but irrelevant, circuitous, and empty of meaning (Thompson 1987, 147). People with this diagnosis typically are reported to have trouble selecting appropriate details, distinguishing fact from fiction, and determining logical sequential order. Still, their language manifests grammatically correct sentence structure and does not appear unusual except when considered in the context of the larger discourse (Ellis 1996, 474; Crisp 1959, 134). Thus communication, and coherence in particular, appear to be a particular problem for elders with AD (Ellis 1996, 477).

The literature on coherence in AD suggests that in more advanced AD, speech difficulties extend to grammatical errors and are characterized by increasing difficulty in ordering events (problems with temporal coherence), by difficulties in determining logical sequential order (Ska and Guenard 1993, 10–11), and by the inadequate usage of referents (that is, corruption of thematic coherence) (Ellis 1996, 483–490).

More recently, however, researchers have been arguing that the discouraging assessment of speech in those affected by dementia may be indicative of the conditions under which that speech was produced (Davis, O'Neil-Pirozzi, and Coon 1997; Crisp 1995, 134) or of cultural characteristics not taken into account by objective assessments (Bower 1997, 1999). Dismal assessment of the language productions of demented elders may also result from the artificial experimental conditions under which language was produced (Hamilton 1994, 19; Bower 1999, 10; Crisp 1995, 134) as well as from the power differential this creates between subject and researcher (Sabat 1999, 116). Like other researchers of narrative practice (e.g., Gubrium and Holstein 1998), sociolinguists Hamilton (1994, 27)

and Sabat (1999, 117) argue for the importance of contextual and dialogic factors in interpreting their narrative production.

Hamilton (1994, 30) addressed the value of maintaining a personal, sensitive, engaged approach to working with demented elders, and Sabat (1999) underlined the importance of giving them adequate time to find words and to organize thoughts. His unobtrusive “indirect repair” allowed him to periodically confirm his understanding with a simple “do you mean X?” while allowing the elder to take charge of her dialogue. Institutionalized elders in Scotland shared surprisingly coherent poetry with John Killick (1999), after he worked to gain their trust and let them direct the communication. Killick highlighted the importance of empathy, silence, and even self-effacement in promoting dialogue, thus enabling elders to produce language that was more coherent than that suggested by the literature.

### ***Textual Coherence in Mrs. Fine’s Story***

Unlike her diagnoses, which seemed to vary as much as her symptoms, Mrs. Fine’s narrative seemed to have coherence far in excess of what one might expect from someone with dementia, particularly of the AD type. Perhaps her apparent coherence was enabled by the minimalist position I assumed as the lesser actor in our dialogue, quietly helping her complete her words, without imposing my own thoughts. In fact, she led the entire narrative event, from her invitation to me through to the completion of her story.

Despite the apparent coherence of her story, I decided to examine its formal coherence by turning to coherence criteria defined by linguist Charlotte Linde (1993). Like Hamilton and Sabat, Linde locates coherence not in “a disembodied text,” but in the “cooperative achievement” of the discourse participants (Linde 1993, 18). Linde argues that the life story coheres if it (1) has a reasonable narrative structure, (2) follows coherence principles, and (3) provides a socially shared coherence system.

### **A Reasonable Narrative Structure . . .**

Life stories have reasonable narrative structures if they begin with an *orientation* (for example, the party Mrs. Fine described), continue with a *sequence of events* (such as the events following the party), offer an *evaluation* (her husband’s misjudgment and the injustice she suffered), and end with a *coda* (her bidding me a better fate). Several writers have referred to this principle as manifesting “emplotment” (Mattingly 1998; Bruner 1991). Mrs. Fine’s story clearly satisfied this criterion.

### **. . . Follows Coherence Principles**

To satisfy coherence principles, a life story must also *present a rich account, articulate a clear sequence of events, and show plausible causality*. It was here where

Mrs. Fine's story was a bit shakier. Certainly she presented a rich, even moving account, which was especially impressive given the severity of her speech difficulties. Moreover, although some of the events were out of order, her reconstructed sequence was logical. Whether the series of events she presented could have led to her husband's actions would have depended both on her husband and on the history of her relationship with him. The evaluations by her daughter and son-in-law of the relationship between Mrs. Fine and her husband clashed somewhat and only served to confuse matters. It is certainly *possible* that a jealous, angry husband could be provoked to act in this way and that his actions could have led to her poverty. Because he died soon afterward, there was little time for him to reassess and possibly reverse his actions. Her "consequential" living in a small room of a nursing home was evidence to her of her great material losses. Yet anyone who knew the great cost of nursing homes, and especially of private rooms, would realize that she did not ultimately arrive here out of poverty.

**. . . And Provides a Socially Shared Coherence System**

Mrs. Fine's story is readily recognizable as a tragedy (Bruner 1991, 11–12). As the listener, I appreciated the implications of her unfortunate *losses* (her husband, her property, his trust) and the social *injustices* she suffered (his misguided disbelief in her; the gains of her dishonest brother-in-law; her institutionalized existence). What began as an innocent, kind gesture (agreeing to have her picture taken) turned into the source of an indisputably tragic outcome. Not only does her story capture tragic human plights; it is also "worth telling"—two strong features of socially coherent narrative (Bruner 1991). She offered a classic canonical script—an unjustly assumed breach of marital fidelity, resulting in a violation of another canon: marital trust.

By Linde's (1993) criteria, Mrs. Fine's story had considerable coherence in spite of the questions it raised about her husband's responses. Her narrative structure, the sequence of events, and the tragic plot all contributed to a coherent story line that carried a persistent emotional truth.

It was not coherence, but the plausibility of some of the events, that seemed questionable. I did not understand, for instance, why Mrs. Fine, rather than the man who shot the photograph, was responsible for having them developed. The photographs that I saw were in fact large in size and apparently professionally processed, not developed at a local pharmacy. In addition, it seemed odd that the pharmacist to whom she took the pictures to be developed would have looked at them and, even more odd, taken the liberty to ask Mr. Fine if he was her husband, although it is hard to know how her local pharmacy actually conducted business, from the perspective of Mrs. Fine, as a shopper there, accumulating experiences that formed the basis of the memories, from which she drew fragments. It seemed surprising too that the man who took her picture

came to her house to tell her of his brother's death, even though she claimed not to have known him. Still, there may have been little details—*background knowledge* (Bruner 1991, 10)—that she had not shared with me that might have provided a context to clarify her construction (cf. Gullette 1997, 204). Although a greater understanding of these details might have improved the plausibility of these events, it would not have affected the degree of coherence in Mrs. Fine's story.

### **Beyond Textual Coherence: "Truth," the Self, and Meaning**

Even though Mrs. Fine's story was coherent, it departed from historical reality (Kohli 1981, 64). Aside from some ambiguous or questionable details in her content, her reordering of events and misrepresenting as a stranger the man with whom she had experienced an eight-year relationship call into question the external validity of her story. In this section, therefore, I will consider the relevance of facticity—or externally verifiable "historical truth" (71)—to coherence in life stories. However, I will look beyond Linde's textual coherence principles to other ways in which an elder's life narrative may achieve coherence. Last, I will examine the relationship of life stories to issues about the self and meaning for elders.

### **Coherence and the Question of Facticity/"Truth"**

#### ***Subjective "Truth" versus Performative Coherence***

In contrast to most analysts of life stories, Peter Coleman argues that a life story must have "truth value" (1999, 134)—but of a subjective "truth" as understood by the narrator, not of one determined by an objective observer (137). In contrast, Denzin locates the importance of coherence in autobiographical narration entirely beyond the truth value of the narrative: "The point is not whether biographical coherence is an illusion or reality. Rather, *what must be established is how individuals give coherence to their lives when they write or talk self autobiographies*" (1989, 62, cited in Gubrium and Holstein 1998, 165; emphasis added). In other words, coherence is produced in the process of creating or performing the life story (cf. Mattingly 1998, 43).

#### ***Narrative Truth: From Coherence within the Text to Coherence within the Person***

Similarly, Bruner argues that life narratives can only reach "verisimilitude," not empirical verification (1991, 4). Linde agrees but focuses mainly on coherence within the boundaries of the text (1993, 220; cf. Mattingly 1998, 34). She later adds that the value of a narrative is in its ability to help organize a speaker's understandings of her "past life, current situation and imagined future" (1993,

220). This demands a coherent, constantly revised life story that expresses “who we are and how we got that way” (3). Coherence systems provide language for creating that new self, *even if that self or the story is a fictitious one* (189; Polkinghorne 1996, 90–1). Linde has shifted from coherence within the text to coherence within the person.

For Bruner too, the point is not the constitution of the text, but on “how it operates as an instrument of mind” in constructing reality (1991, 5–6). “Rather than referring to ‘reality,’ or ‘historical truth,’ the life story actually constructs its own ‘narrative truth’” (13; Polkinghorne 1996, 89; cf. Mattingly 1998, 40–2) that has particular meaning for the narrator (Polkinghorne 1996, 78). Crisp too, describes narratives as the “externalized demonstration of internal mental processes,” (1995, 138) without reference to their historical accuracy. For others, it is within this narrative that identities are constructed (cf. Jamieson and Victor 1997, 170; cf. Coupland and Coupland 1995, 94).

***“Coherence Work” as Self-Constituting and Integrating:  
The Forming of Emotional Truth in the Self***

For Moody, also, the “coherence work” of late-life reminiscence may involve creating a fictional or metaphoric version of the self (1993, xxxiv). Ewing (1990) explains how people create new selves (or self-representations) as they proceed through life and engage in new experiences with different people. The need for coherence becomes apparent only when we encounter a disruption or new life experience that cannot fit into our existing life narrative (Linde 1993, 17); the life story must then change to accommodate that event. The readjusted life story helps to preserve or reproduce the sense of continuity of one’s self (Kaufman 1988, 219).

Fragmentation occurs when a person’s available self-representations (or selves) in a new setting or in new interactions with others no longer correspond to the person’s prior experiences (cf. Randall 1996, 237–238). Whenever this leads to the loss of a sense of wholeness or integration, or when the person is challenged by a new situation, the person creates a more adequate self through a new synthesis and integration in her life story (Ewing 1990, 262).

In narrative productions, self-constitution occurs because of the ability of the narrator to separate herself from the self she is creating (Ewing 1990, 262; Linde 1993, 105, 122). Although distinct selves are created in response to the demands of new life contexts, an illusory experience of wholeness, coherence, or “unity of feeling” is achieved because each self-representation organizes fragments of experiences as if they were constant and timeless (Ewing 1990, 262; Mattingly 1998, 107). Coherence is a symbolic process that depends more on that unity of feeling—an affective state—than on logical rules of text or even on actual past experience (Fernandez 1986, 161; cited in Ewing 1990, 268). It forms its own constant emotional truth.

For Mrs. Fine, suffering both from dementia and the dissatisfaction of her life circumstances, two sources of fragmentation tore at her sense of wholeness. First, her dementia challenged her sense of cognitive integration. Second, her sense of self-integration was challenged by her depersonalizing living conditions in an institutional setting that neither valued nor reinforced her personal history and biography. Finding her current residence in the nursing home beyond her control and comprehension, she attempted a “symbolic reworking” (Lovell 1997, 361), “restorying” (Randall 1996), or “mythological rearranging” (Hankins 1981, 203) of her everyday experience.

Rather than unraveling, Mrs. Fine constructed a narrative that provided an anchor from which she could affirm her identity in the midst of potential chaos and threats to it (cf. Kohli 1981, 71). She wove her story out of “meaning traces” (Polkinghorne 1996, 88) or fragments drawn from her dwindling memory of real and imagined experiences and other texts available to her (cf. Crisp 1995, 137). The powerful self-reinforcement and integrative functions of the narrative were far more significant to Mrs. Fine than was the departure of its content from historical reality.

### The Meaning of Life Stories

Most life narratives are concerned with negative events, suggesting that trouble—frustration, confusion, and misunderstanding—drives people to communicate their life stories (Ochs and Capps 2001, 145–146; cf. Tarman 1988, 185–186). A life story helps make sense of troubling life experience (cf. Mattingly 1998, 25) by reconciling outcomes with expectations (Ochs and Capps 2001, 134). It also creates a sense of order out of potential meaninglessness (Tarman 1988, 185–186). For Mrs. Fine, living in a small room on the locked dementia unit was difficult to comprehend. Her life story helped her reconcile her existential condition with her expectations for something greater by explaining how she ended up there. Although it did not enable her to resolve her situation, it did help her to achieve psychological closure (Ochs and Capps 2001; Polkinghorne 1996, 89).

#### *Meaning in Mrs. Fine’s Story*

According to Ricoeur (1984, cited in Mattingly 1998, 38), the meaning of a story is organized around its ending. The narrator’s “existentially meaningful” plot (Lovell 1997, 355) allows events to unfold toward that ending by organizing reconstituted events and memory fragments—actual, fictional, and borrowed—in a way that enables the narrator to make sense out of her current situation.

Mrs. Fine’s narrative ended with her unhappy living situation. In creating a meaningful story, Mrs. Fine reworked some of the characters and their relation



to her. She transformed Mr. Haller from a companion of many years into a stranger. She re-created her husband from an allegedly “adoring” (Kathy’s view), perhaps “spineless,” spouse whom she dominated (her son’s-in-law view) to a rigid, rejecting, dominating figure, unwilling to listen to his own family. Was she trying to create a husband whose qualities she might have preferred? Perhaps. Was she working out guilt for having supposedly “bossed around her husband”? Possibly. More likely, she reworked her memory fragments, however distorted, about her husband’s behaviors in a way that made sense of the story’s ending: the plot *required* that he reject her, to help explain her current plight. How else might she have come to live in her tiny nursing home room?

By providing a plot directly related to her current situation (her story’s ending), Mrs. Fine’s narrative protected “against the chilling possibility” that her life and current status were “random, accidental, unmotivated” (Linde 1993, 6; Tarman 1988), in short, meaningless. Her plot helped her make sense out of events, regardless of whether they were true (Mattingly 1998, 37). Her photographs provided the trigger for creating meaningfully plotted events—“a strategy of survival” (Crisp 1995, 138; Mattingly 1998, 107)—which is why mislocating them was so upsetting to her. Her compelling “need” to tell her story (cf. Mattingly 1998, 45) was also understandable: it reaffirmed both order in the universe and her place within it.

Mrs. Fine’s narrative also imparted a moral perspective to her life (Mattingly 1998, 29). It served to destigmatize her plight and to exculpate her (cf. Lovell 1997) from blame and responsibility for having arrived there. Through narrative, she was able to transfer the moral responsibility for her current situation from herself to others—the solicitous photographer, her dishonest brother-in-law, her disbelieving husband. Perhaps this is why she seemed so calm, controlled, and even relieved after she finished telling me her story (cf. Crisp 1995, 38).

Mrs. Fine’s narrative was a canonical tale (cf. Bruner 1991, 12) with a twist. That fateful party, the inquisitive pharmacist, the lying brother-in-law all contributed to her current plight. Hers was not the typical story of a cuckolded husband, but of a wrongly accused wife; not of truth prevailing in the end, but of dishonesty gaining victory (her brother-in-law benefiting from her losses). It is a story of undeserved injustice (her living in a single nursing home room with very little) and undeserved gain (her sister ending up with a huge house). There is no resolution here, only an explanation for enduring angst—a sustained emotional truth. She is both victim and heroine, admired by a stranger but rejected by her husband, accused yet innocent; in short, she is the central character of a powerful, yet tragic, plot.

Such a central role can be powerfully sustaining, providing the “lifebuoy of



an identity that is drowning” (Gerbeaud 1987, 138, cited in Crisp 1995, 138). The dialogic process in which she took charge of her production, while gaining affirmation from me, the listener, further reinforced her sense of self-worth.

Mrs. Fine’s tale is also metaphorical. The invalidation, injustice, and particular losses she suffered in her story can be matched in real life by the invalidation she experiences in response to her dementia; the injustice of living in an undesirable situation; and the loss of her freedom, autonomy, and frequent contact with loved ones.

### Discussion and Conclusion

Narrative analyses tend to emphasize the interpretive value or narrative meaning of a story for its narrator rather than the correspondence of the narrated events to an objective reality (Polkinghorne 1996; Mattingly 1998, 39–42; Randall 1996). When a person tells her life story, no matter how fictitious the account, her narrative does not reflect the past, but rather “*becomes* the past” (Randall 1996, 230; emphasis added). Thus an authentic life story is not one that corresponds to an objective indicator of the “truth,” but rather one that is “made” the narrator’s own” (Kenyon 1996, 28–9).

It is not accidental, then, that narrative analyses of persons undergoing aging, illness, or major disruptions in their lives have drawn primarily from interpretive phenomenological approaches (Rabinow and Sullivan 1987), rather than structural or extreme postmodernist ones. The former approaches focus, not on coherence in the text, but on coherence for the subject. They examine the ways in which people construct their identities and inner worlds in order to make sense of their experiences and to preserve a sense of continuity (Mattingly 1998, 107) or restore a sense of order in their lives. These are the most pressing concerns for those threatened with its dissolution, however illusory these may be (Ewing 1990).

Phenomenology embraces the very concepts—subjectivity, inner experience, unity, “truth,” and continuity—that structuralism and postmodernism reject (cf. Mattingly 1998, 140–143). Postmodernism favors partializing concepts—discontinuity, fracture, and contingency—that emphasize the ephemeral quality and arbitrariness of the story. However, even though the content of a narrative may appear arbitrary, the material and existential conditions that gave rise to it are subjectively experienced as very real by the author. This is why Mattingly astutely distinguishes narrative analyses that concern written and oral texts from those that concern lived experience and inner meanings (44).

A danger in focusing strictly on story (or text) is that every story is not equally validated by other cultural scripts. For example, for those with dementia in a medicalized setting, the disease model of dementia serves to invalidate affected persons’ subjective feelings, thoughts, experiences, and emotions as dis-

torted (empirically “untrue”) artifacts of disease and sees their stories as irrational ramblings (Crisp 1995). Extreme postmodernism, despite its celebration of difference, unwittingly reinforces biomedicine’s invalidation of the demented elder by rejecting the validity of the “truth” of her subjective experience. Thus, biomedicine, with its insistence only on empirically validated truth, and postmodernism, with its rejection of all “truths,” both effectively invalidate the subjective experience of elders with dementia.

In discussing the many narratives produced by her cognitively impaired mother, Jane Crisp (1995) recognized a coherence and sense in them that were not apparent to an outsider. Given her perspective about her mother’s history of fears, preferences, and position in her marital relation, Crisp was able to see how her mother’s stories revealed these aspects of her past or served to reverse previous injustices. Crisp introduced external information, not to validate facts or events from her mother’s stories, but to elucidate their possible relevance in light of her present situation.

Because of the compromised rationality of persons with dementia, there is considerable skepticism about taking seriously what they say. However, even when what they say does depart from verifiable facts, elders who tell stories may present a coherent picture, as we saw with Mrs. Fine. It is not the actual historical facts, but their *construction* of a new story that provides meaning to the narrators and gives us clues to their lived experience.

We must ask whether anything can be gained by our turning to external sources of information to understand the stories of persons with dementia. I would argue that we are treading on potentially dangerous territory by risking the elevation of some voices—and narrative truths—over others on realist grounds. To the extent that additional information can reveal sense in a story that would otherwise be disregarded as irrelevant, it should be embraced. External information that offers factual information about dates, events, and characters and clues about their reworkings may also advance our understanding of the story’s meaning for the elder. However, when these sources are used to disconfirm (or even affirm) an elder’s story on the basis of its lack (or presence) of correspondence to external indicators of “truth,” it risks disempowering and invalidating that elder.

I frankly am unsure of how much I gained by talking with Mrs. Fine’s daughter and son-in-law. At the time of Mrs. Fine’s narration, I was too caught up in her story and her struggle in communicating it to worry about any correspondence of its elements to empirical facts. However, gaining confirmation about the death of her daughter *did* make the rest of what she said more convincing to me. But it did so not because it gave me license to believe the rest of her narrative. Rather, it made me aware of the lasting effect of significant events in her life, whether she suffered from dementia or not. Even though several elements of her subsequent story were not historically verifiable, that was beside the

point. Her narration made a convincing case of the significance of its narrative truth in the context of her unhappy living situation and the power of her own agency in reconstructing sense in her existentially and materially constrained life.

#### NOTES

1. See also the special collection in the *Journal of Aging Studies* 12, no. 2 (1998).
2. Exceptions to this include Sabat (1991, 1999) and Hamilton (1994, 1999). These researchers, however, examined narratives produced by elders, but not necessarily their life stories. More relevant here is the work of Crisp (1995), who examined the stories of her mother, who suffered from dementia.
3. Although the two tests measured somewhat different cognitive elements, the Blessed, for example, examining information, memory, and concentration; and the Mini Mental State Exam (MMSE), memory orientation, concentration, language, and constructional ability (Sano and Weber 2003, 27–28), the difference in Mrs. Fine's performance went beyond differences in the tests. It reflected differences in disposition toward being tested as well as actual differences in her in cognitive status during times of testing.
4. This recalls the way in which Sharon Kaufman found the tragic stories of her informant's lives "almost too much . . . to bear" (1988, 222).

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## Creative Storytelling and Self-Expression among People with Dementia

ANNE DAVIS BASTING

When memory fades and one's grasp on the factual building blocks of one's life loosens, what remains? Is a person still capable of growth and creative expression even when dementia strikes? To answer these questions, I relay the story of the *TimeSlips* Project, a research and public-arts storytelling project aimed at nurturing creative expression among people with Alzheimer's disease and related dementia (ADRD) and at sharing the stories that emerged in *TimeSlips* workshops with the public at large to increase awareness of the creative potential of people with ADRD. I will (1) outline the storytelling method and my study of it; (2) analyze the content of the stories; (3) discuss interviews with staff, family caregivers, and student participants; and (4) describe the *TimeSlips*'s outreach program's effectiveness in changing public perception of people with ADRD.

### The Storytelling Method

The *TimeSlips* storytelling method evolved out of a year of experimenting with a variety of exercises in creative dramatics. After espousing the virtues of theatrical performance for older adults in my research on senior theater troupes across the United States, I wanted to see if "playing a new role" could benefit people with ADRD as much as I found it did for the well elderly. People with dementia clearly have few meaningful social roles available to them. With holes where memories of their children and spouses used to be, people with ADRD often lose even the most basic roles available to us all—that of partner or parent. In creating the *TimeSlips* method, I set about to establish a social role for people with ADRD, that of storyteller, that would in turn provide access to meaningful self-

expression. After running a storytelling circle for three months in a long-term-care facility, I set up a research study of the storytelling method to test its effectiveness in four adult day centers, two in Milwaukee, Wisconsin, and two in New York City. The storytelling method has evolved in the years since the research study began in 1998. What I describe here is the structure of the storytelling circles in those four initial adult day center test sites.

The *TimeSlips* storytelling method followed a clear, ritualized structure. At least once a week, a group of people with symptoms consistent with middle-stage Alzheimer's disease gathered in a circle of chairs.<sup>1</sup> With the program assistant, Nichole Griffiths, I trained undergraduate students from a wide range of disciplines (predominantly in the humanities and arts) to facilitate the storytelling. Students and staff worked together to encourage the storytellers to respond to a picture the students brought in each week. Throughout this chapter, I refer to students and staff as *facilitators* and the people with ADRD as *storytellers*. The storytelling circles began with a "welcome," in which the facilitators introduced the activity and greeted the storytellers. Facilitators then read back a story from the previous week to prove to the storytellers that they were indeed capable of creative expression. Next, facilitators handed out an image to each member of the storytelling circle and asked open-ended questions (avoiding "yes" or "no" questions) of the group. One facilitator wrote down all the responses on a sketchpad large enough for all the storytellers to see. All responses, including any nonsensical answers, were validated and woven into the fabric of the story. Facilitators reread the story when they noticed the storytellers' attention starting to drift. A single story often lasted up to one hour, but most ran around thirty minutes on average. In the final step in the ritual, facilitators thanked all the storytellers in turn for their input as a way to acknowledge the significant risk and energy demanded by a full hour of creative storytelling.

Facilitators used a wide variety of images, but all shared one characteristic—they appeared staged or fantastical in some way. We avoided images of celebrities or family photographs because we found that storytellers became too fixated on the "real" story behind the image to freely launch into the realm of the imagination. The images guided facilitators in their choice of questions, which were carefully worded to give the storytellers ownership over the story. Instead of, "What is this character's name?" for example, a facilitator would ask, "What would you like to call him?" Questions focused on the sensory ("What sounds do you imagine in the background?") and on the world outside the picture as well ("Does he have a family?").

The free-form storytelling process demanded that facilitators leave behind preconceived notions of what constitutes a "story." If several storytellers responded with names for a single character, that character had several names. Events often took place in several places at once. Multiple plot turns created a



meandering story line that read more as a chronicle of the storytelling process than as a traditional, linear story with a clear beginning, middle, and end and a focus on conflict and resolution. Because facilitators reassured the storytellers that they could say anything they wanted, since they were making up a new story, the facilitators often received answers that did not make sense to them. These were of two kinds. First, some were clearly meant to challenge the facilitators' promise that they would accept any answer. We referred to these as *challenge* answers. In one exchange, for example, a facilitator asked for a name for a character and promised she would accept any answer. A storyteller looked up at her slyly and said, "Oh, yeah? A-B-C-D-E-F-G." The facilitator wrote down the response and the name "A-B-C-D-E-F-G" became part of the story. The second type of nonsensical answer emerged from the domain of the disease. Several storytellers in each group had great difficulty with language. As the storytelling workshops proceeded and they grew to trust the process, these storytellers would often respond by adding fragmented words or sounds. Facilitators repeated these answers back to them and wrote them down as well as they could capture them.

This free-form style of storytelling runs counter to theories of narrative healing that are now gaining recognition in all corners of health professions. From the outside, the *TimeSlips* method appears to be a "chaos narrative," in the words of Arthur Frank. Such nonlinear narratives are not thought to lead to healing, but stall the patient in the limbo of unresolved and undirected emotions. I argue that Frank's definition is text based—and not focused on process. The *TimeSlips* storytelling may look "chaotic" in terms of text, but the process has a linear narrative underneath it. People with dementia, silenced by confusion and the social pressure to say the right thing, learn to experiment with language and form social bonds with staff and participants in the process. As long as that narrative is clear to all participants (staff *and* people with Alzheimer's), I believe, the nonlinear form of the stories—or any other creative activity—can be part of a healing process. And in fact, we found that facilitators' attempts to make the narratives of the story linear shut down the process entirely.

### **The Outreach Program**

The second goal of the *TimeSlips* Project was to share with the public the stories that emerged in the storytelling circles in order to increase awareness of the creative capacity of people with ADRD. We did this in several ways. First, the facilitators and *TimeSlips* staff created books of the stories told at each center and presented them to the storytellers in celebrations held at each facility. Second, in both Milwaukee and New York, a team of artists associated with the project produced a play (with professional actors) and an art exhibit inspired by

the stories told in each city. Each performance of the play was followed by a postshow discussion in which audience members could share their reactions to the stories and ask questions about the disease. Third, we created a Web site that included stories from all four test sites as well as detailed information about the history and aims of the project.

### **The Research Model**

We received approval from the Institutional Research Board (IRB) at the University of Wisconsin–Milwaukee and secured consent forms from all participating staff, students, and family caregivers as well as assent forms from all participants with ADRD. My assistant and I interviewed staff, students, and primary family caregivers at the outset of the project, in the middle of the storytelling sessions, and again at the end of the project. We held the interviews in person or over the phone, depending on the interviewee's preference. The interviews were "open structured," loosely following our aim to assess interviewees' reactions to and observations of the storytelling sessions without leaning on a pre-fabricated set of questions. The responses that I share here retain the anonymity of the subjects. Gender or other details of the respondent may be changed to protect their identity. In this chapter, I refer to the adult day center test sites as A and B (both in Milwaukee), and C and D (in New York).

To test the outreach model, we received approval from the Hunter College IRB, in New York. The main aim of this study was to test whether the art exhibit, play production, or both, generated a change in audience members' perception of the creative potential of people with ADRD. To address this, *TimeSlips* staff created an evaluation form and inserted it in each play program. A separate evaluation was also available at the art exhibit. All responses were anonymous. Although we held a play and art exhibit in Milwaukee, all responses were anecdotal. This research, therefore, focuses on the New York play and art exhibit.

### **Analysis of the Stories**

All told, the storytelling workshops in all four sites yielded more than one hundred stories. Some stories were only partially complete, as facilitators tried to squeeze in one more tale before the hour was over. Of the completed stories, I analyzed seventeen from Center A and twenty-one from Center B. From the New York workshops, I analyzed sixteen from Center C and 10 from Center D. I discerned the stories' main themes and noted their unique qualities, such as the prevalence of humor or nonsensical answers. Although the stories reflected the unique personality and diversity of each storytelling group, several themes emerged in all four groups. I will focus on individual groups first, and then turn to themes that appeared in all four. I will mainly refer to portions of stories. Full

stories and additional information are available on the project's Web site (<http://www.timeslips.org>).

### Center A

Storytelling workshops in Center A featured a fairly consistent group of up to twelve enthusiastic participants who regularly added songs and even dances to their stories. Of the seventeen stories I analyzed, humor appeared in all; and eight featured main characters that were happy, confident, and likable. These characters commonly encountered social obstacles, including the negative opinions of people around them. The characters most typically overcame these obstacles by remaining true to themselves.

The most common theme that appeared was the desire for freedom—to make decisions, to be uninhibited, and to make choices. In “All the Way to Seattle,” a woman pilot flies “because it makes her feel free, and because her family doesn’t pay her enough attention.” In another story, “Italians from Ireland Getting Their Independence,” the main characters are fighting for their “[Mil]Waukean independence and they are doing what’s right.” The story’s final line, “They got it right where they want it,” asserts the characters’ power and freedom. In the story “Look at Those Legs,” a woman rides to church on an ostrich only to be ridiculed by her fellow congregants. She overcomes this ridicule “because she is very sophisticated” and leads the church in the song “Amazing Grace.”

References to religion and spirituality were also common in this group. In “I’m Glad You’re Dead, You Dog, You,” the two main characters are wrestling over a picture of the Virgin Mary “because she symbolizes all that they desire.” In “She’s down There under the Puppy,” an elephant named Grandfather is not allowed to enter a church because he might break down the walls. He takes solace in his friendship with a little girl who is not afraid of his size, and together they sit outside the church and listen to the choir sing “Abide with Me.”

Another common theme that emerged in the stories of group A was the desire for human relationships, both platonic and intimate. Two main characters in one story, two nuns, were in love, but couldn’t remember with whom. Sexual innuendo was common. In “Tiny Bubbles,” the main character lives underwater and is thinking about a woman he left on the shore. “He’s thinking a whole lot about that woman,” said a storyteller. In “It Goes Toot Toot,” John Hibby and Bill Hobby and their wives “all fool around together.” Explicit sexual references were not uncommon and could make some storytellers uncomfortable. Rather than edit the story, however, which would run counter to our promise to the storytellers that we would include all their responses, we simply encouraged more responses.

Several stories from group A dealt with difficult relationships. Some re-

flected disagreements between children and their parents. In one story, for example, the children sharply disapprove of their parent's wrestling. Some stories joked about traditional gender relationships; men would commonly take on women's duties, as in "Italians from Ireland," where eight women were fighting for independence while their husbands were washing dishes.

The group at Center A was warm and supportive, comfortable with responding to the facilitators' questions with nonsensical answers. For example, in "Everybody Is Eating Corn," a story of a raucous dinner party at a restaurant, one of the main characters is "allegering all over the horn." Nearly every story at Center A featured a fragmented or nonsensical answer. But taken in the context of the storytelling circle, such answers had clear emotional resonance. When repeating nonsensical answers in the retelling process of the storytelling, facilitators aimed to capture the emotion intent behind the sound or words. "Allegering all over the horn" was, in context, a clear reference to a joyful celebration at the dinner party.

### Center B

At Center B in Milwaukee, we worked with a group of storytellers who were much more mixed in their abilities than those in the group at Center A. Of the six storytellers at Center B, one storyteller had practically no verbal language at all. Because communication was more difficult for this group of storytellers, the pace of storytelling was slower here. Several unique characteristics emerged in the stories created by this group, possibly because of the smaller size and slower pace, but certainly because of the strong personalities of several storytellers. Of the seventeen stories in Center A, none included the names of storytellers. In Center B, however, almost half of the twenty-one stories I analyzed included the name of a storyteller or student facilitator as characters. When asked to name a character, some of the group's less verbal storytellers would point to a fellow group member instead of naming the person directly. Drawing fellow storytellers into the tale was sometimes used as a gesture of intimacy and, at other times, a gesture of friendly mocking. Either way, it always drew the group into a deeper engagement with the process. Facilitators called out and emphasized the storyteller's/character's name repeatedly with each retelling, acknowledging the storyteller's presence, creativity, and new role (as character).

Nearly all the stories at Center B contained "challenge" answers and answers that sharply redirected what might be the assumed journey of the tale. Their stories were less concerned with the direction of the plot and much more focused on wordplay. "He's a Tuba Player," for example, begins with "He's Tony the trumpet player from Tampa, trying to get a tune." Tony's wife, whose name is "Music," is "rumored to be dead." In "Thanksgiving Celebration," their story based on an image of a boisterous dinner party, storytellers named one couple

"Pardon Me, I Burped" and "Charles, Who Is No Prince." "When the check comes" for the dinner party, "they'll sober up!" said one storyteller.

Although the members of this group commonly used their own names as the names of characters, they also tended to separate themselves from the story lines and in turn from fellow storytellers. For example, in a story about a pancake-cooking club, one storyteller said, "I wouldn't join that club." In "Waltzing Ladders," when one storyteller said, "Everyone is married and has children so they don't have parties anymore," another countered with, "Then I'm never going to get married!" When one storyteller added church music to a story, another countered with, "No, that's too holy."

In spite of their penchant for sharp wit, participants in Center B also created some remarkably poignant images in their stories that seem to mirror their own feelings and fantasies. Tony the trumpet player, for example "should be forty-two, but he's ninety-nine. He's happy, even though he's alone." In "We Want to See Castro," a little girl goes to Cuba with an elephant. "She's gone far away," said one storyteller, "because kids do that." In response to an image of a man hiding his head in his coat, storytellers named the main character "Headless Joe Wonder" and said that "he lives in a room of despair. He takes it as it comes. You think you can't do anything without a head, but headless Joe Wonder can."

### Centers C and D

The storytelling groups at both New York Centers C and D fluctuated dramatically in size from week to week. Center C had an average of ten storytellers; they ranged considerably in verbal skills, with the majority able to put together two or three words. At Center C, the names of storytellers found their way into the tales, as they had at Center B. But at Center C, storytellers sometimes competed with one another to add their *own* name to the stories. In one story about a male painter and his female model, for example, two women storytellers added their own names to the name of the female model. We included both and hyphenated the character's name. Similarly, in "Mama Bear Does the Cha-Cha," Mama Bear is named after one of the storytellers. The story grew poignant as the storytellers decided that Papa Bear was far away having affairs, but that Mama Bear didn't just sit at home and mope. "Mama Bear and the two cubs are at home, doing the cha-cha." The namesake storyteller, confined to a wheelchair, would lead the group in a dance with her arms with each retelling.

There were few "challenge" answers at Center C, and these stories generally featured likable characters and were peppered with humor. The raucous dinner-party image was imagined to be "John Gotti's birthday party," at which the characters were "eating diet food, because they are all fat!" In a story based on an image of an older couple arm wrestling, storytellers said, "They are falling in love for the first time." Like those of group A, members of this group were

patient with non sequiturs that emerged out of illness, and they acknowledged the contribution of the storyteller who added them with each retelling. For example, one storyteller could not or would not answer with more than “I don’t know.” Facilitators asked if they could add this to the story, and the characters, a group of women accordion players, became the I Don’t Know band. In another example, when asked if there was music in a story about a man with a pigeon sitting on his head, one storyteller enthusiastically made up a song whose only word was *beep*. To great approval from the crowd, she energetically sang it with each retelling of the story.

Center D’s group was very small, although it never dipped below four participants. The group was more physically and emotionally fragile than the others and more linguistically challenged. One member could only add sounds, interspersed with occasional shards of words. Another storyteller had a remarkable gift for poetic images, but struggled to stay awake and to tolerate multiple stimuli. Her struggle was evident in her input to the stories; she often tried to either focus or silence the group. “Every person has a story,” she said, “there’s not a human being that doesn’t have a story. But making it mish-mosh is bad. It’s like a bomb.” In other stories, however, her input encouraged the group to create powerful images. In a story based on an image of a man sitting in an enormous pile of books, they said “He is accepting responsibility to organize this into something. He is orchestrating an orchestra in his mind.” In a tale about a can-can dancer who works with an ostrich, they named her “Holding On, because she’s really just holding on.” The story ended with Holding On contemplating her career. “She never had children, and she thinks she might have missed something. But she has a complex sense of happiness.”

As in other small storytelling groups, non sequiturs were much more common at Center D than in larger groups, in which the increased amount of input meant storytellers could edit themselves. In a story based on the image of the older couple wrestling, one storyteller looked perplexed and said, “All I know is Winnie the Pooh.” Woven into the story, her response became a favorite phrase among the storytellers. As in other groups, the storytellers used the process to play with one another and with the staff. Their humor was vivid. In “An Exquisite Woman,” a woman pilot flies to Russia, where she eats “chicken Kiev in a box.” In “A Horse Is a Horse of Course,” a handsome cowboy is “any age we want him to be . . . probably twenty-eight. And he’s attracted to beautiful women like us!”

### Comparing and Contrasting Centers

Clear differences and similarities emerged in the four storytelling groups. Led by the strong personalities of group members and by the size and nature of the group dynamics, groups at Centers A and C yielded harmonious and playful stories, while Center B participants challenged the process at every step, and

Center D's stories were powerful, dreamlike images pierced by sharp wit. As I mentioned earlier, common themes emerged in all four groups, including the desire for freedom, confidence, and intimate relationships. These desires were also evident in the group dynamics, where storytellers teased one another (and facilitators) by placing one another in the stories, by suddenly changing the direction of the story, or by adding deliberately humorous or provocative remarks. In all four groups, storytellers engaged in the process as a way to express themselves, whether they were attempting to contradict the flow of the story or encourage its progress—whether they were challenging facilitators or sharing a poetic image. In all four groups, storytelling provided storytellers with a valued social role and rare access to meaning-making for people whose language has broken down. Laughter and singing were a prominent part of all four storytelling groups as well, so much so that staff who were not directly involved with the storytelling tended to gather at the edge of the room to listen to the sessions. Clearly, the storytellers retained the capacity to entertain others and themselves with laughter, humor, and joy.

### **Interviews: Volunteers, Staff, Families**

The storytelling process and the stories that evolve from it show that people with ADRD do have creative potential and can play a valuable social role. The stories themselves can tell us only so much about the effectiveness of the workshops; however, interviews with staff, family caregivers, and students can help us discern whether providing people with ADRD with access to a meaningful social role can shift the attitudes of people who care for them.

In Milwaukee, three students participated in the full eighteen weeks of workshops, and five of them facilitated storytelling for nine weeks. In New York, five students facilitated the nine weeks of sessions. All student facilitators were interviewed in their first week in the program and again at the end. During the project, they kept weekly journals of their feelings about the workshops. Interviews with students were open structured and focused on their perceptions of aging, dementia, and people with dementia.

Students in Milwaukee and New York City revealed an initial fear or substantial hesitation about working with people with dementia. Several articulated it as worry that they might hurt the storytellers, physically or psychologically. One student who was studying art therapy had considerable knowledge about dementia from gerontology courses but worried about her lack of practical experience working with such a population. Only one student had worked with people with dementia before and was fairly confident in her abilities. She, however, was fearful of revealing her own disability (dyslexia) in the group. The student volunteers had a high incidence of disability themselves. Of the thirteen students, three had dyslexia and another student was



deaf. I can only speculate that they were especially drawn to a project that encouraged the growth of people with cognitive disabilities. But I can freely conclude that throughout the storytelling process, all four remarked that they gained confidence in their own writing and creative abilities.

After revealing their initial fear of working with people with dementia, the students were surprised at how much they enjoyed the sessions, as shown in their journals and in final interviews. They described the laughter and emotional connection that they had enjoyed with the storytellers as “giving meaning to their day” and making them feel as though they were “useful” and were “important” in the storytellers’ eyes. After several weeks of storytelling, students commonly remarked that the storytellers did not seem to be afflicted with what they imagined to be symptoms of Alzheimer’s disease. In their final interviews, three students shared their concerns that some of the storytellers were misdiagnosed.

Three students wrote about how it made them feel hurt when the storytellers did not remember their names from week to week. If certain storytellers did seem to remember the students, they felt particularly accepted. But two of these students also wrote that despite their not being remembered, they felt a good deal of satisfaction knowing that the storytellers trusted and accepted them. Two students described their growing understanding that the product, the story itself, was not the focus of the project. One student noted: “I think that at the beginning I was looking for the product. I was looking for the good story to come out at the end. And it was so hard! We just had to pull and push and it was like nothing was happening. And then it kind of hit me that we were not really there to get this good story. We were there to be with these people and, you know, maybe appreciate them for being individuals. You know it’s to *our* advantage that we are there sharing with them their ideas and wisdom and creativity.”

The students became very attached to both the process and the storytellers. By the end of the storytelling workshops, they were all able to separate their fears of the disease from their dissipating fears of the people who suffered from it. After the initial, cautious few weeks, the body language, vocal tone, and energy level of the students grew as they interacted easily with the storytellers.

Interviews that I conducted with staff at the four day centers revealed their surprise at the storytellers’ creative abilities. Open-structure interviews at the beginning and end of the process showed that staff experienced a growing appreciation of the process and observed positive behavioral changes in clients. The Center B staff were not directly involved in the storytelling process but remarked in interviews that they regularly read the stories and noticed improvements in the center’s clients: “We have a few people who are in the project who are very, very quiet, and I’m very happy to see them coming forward. The first couple of sessions . . . they were very quiet and you really had to pull everything



out of them and now I've noticed that as each class has been happening, they are more and more open; they'll talk openly and they're more comfortable. They are so happy after you leave, and honestly, we can really get a lot out of them for the rest of the day."

Staff at Center C were also not involved at the outset of the storytelling workshops. At first they were grateful for our giving them an hour in which to invest their attention elsewhere. After the third storytelling session, however, staff were increasingly lured by the laughter and singing in our circle. In the final few sessions, staff had joined the circle, asking questions and laughing and singing with us. Interviews with the two key staff members at Center C suggest two things: staff were surprised by the quality of the stories; and staff gained insights into clients that they had not previously imagined were possible to obtain. One staff member put it this way: "What they say, I mean, some of these stories . . . I gave them to [the director of the day center] and she said, 'Gee, these guys are smart! And funny!' And the family members, Ida's daughter, she read it. And she said, 'That story is funny!' She loved it. And I said, 'See? That's what we're doing here on Thursdays!'"

Staff at Centers A and D were fully involved in the storytelling from the beginning. They joined us in the storytelling circles on the first day and continue the storytelling to this day—a considerable commitment considering that the average turnover rate of staff in this field is near 100 percent. Center A went beyond what we had hoped. The *TimeSlips* Project presented each center with books of all the stories, inexpensively duplicated and spiral bound. The staff at Center A took the initiative to put together (and pay for) three-ring binders and plastic page protectors for high-quality duplications of each image and its corresponding story. They invited the families of storytellers to attend a party at which the staff presented the beautiful books to all the storytellers, each receiving a copy, and thanked them for their contributions. The event was quite moving, as storytellers reviewed their efforts with their families. One storyteller took my arm and said, "You know what's so great about this? It ain't cheap!" I knew just what he meant. The books that the staff had created were works of art, honoring and giving value to the storytellers' creativity. The director of Center A, who was actively involved with the storytelling sessions, offered these remarks: "Being an active participant in this *TimeSlips* Project, I have seen the joy that the process has brought to the participants, the comfort that it has brought to families, the satisfaction and empowerment that it has brought to staff involved. I am also impressed by the insight and awareness that it has brought to the students, as they grow in their understanding of aging, disease, and [the] development of humanness."

THERE WERE RADICAL differences between the interviews with family caregivers that occurred in Milwaukee and those that took place in New York. All but two

storytellers in Milwaukee lived with family members. The two lived in long-term-care programs and attended day centers for added social interaction. In New York, the few storytellers who lived with their families commonly also had at least part-time, paid attendants to care for them. Perhaps because of differences in the structure of care, or because of the gaps in communication with the day centers, only two of the family caregivers we interviewed in New York were aware of the stories. Consequently, they had little information to offer about changes in observed behavior.

Milwaukee families had a much greater awareness of the storytelling process and its impact on the storytellers themselves. Of the fifteen family caregivers we interviewed in Milwaukee, the majority had read the stories either in the single sheets we sent home each week or in the books of stories that we presented to storytellers at the end of the project.<sup>2</sup> Three family caregivers said that they regularly read the book with their loved one with ADRD. Two said they duplicated the books and sent them to other members of the family as a way for them to understand and connect with the storyteller. One told us that the storyteller had become possessive of the book and hid it from her, calling it “his work.” Four family caregivers told us that they believed that the storytelling made a clear difference in their loved one’s behavior. These changes included initiating more conversation, exhibiting less confusion, and expressing an increased sense of enjoyment in life. Within couples, caregivers face tremendous challenges caring for someone with ADRD, not the least of which is the adjustment to the change in roles the couples play. I find the fact that family caregivers could find meaning and affirmation in the stories and the storytelling process in the face of these challenges a testament to the power of creative self-expression.

### **Educational Outreach: Changing Public Perception**

In Milwaukee and New York, the *TimeSlips* Project sponsored art exhibits and staged professional play productions inspired by the stories and characters that had been created in the storytelling workshops. Our aim was to improve audience members’ perceptions about the creative potential of people with ADRD. In Milwaukee, we collected anecdotal responses to the exhibit and play, but in New York we created a more official analysis of the educational outreach model. Analysis of the New York data suggests that it is indeed possible to positively affect public perception of people with dementia.

The New York *TimeSlips* play was produced in an intimate (ninety-nine-seat) downtown (off-off-Broadway) theater known for innovative performances. We selected theater as a genre because the physical presence of the actor on stage can create a sense of empathy with another human being in a way that film cannot, and because people with dementia exist in a fragile world that, like

live performance, disappears after the moment has passed. Our hope was to capitalize on the intimacy of the space, the power of the present moment, and the potential to engender a sense of empathy for people with dementia.

The play is set in an adult day center, where a small group of people gather in a creative-storytelling circle. Weaving communal stories, they free themselves from their private struggles with Alzheimer's to create a wondrous world inhabited by fantastical characters that take on a life of their own. A can-can dancer conceals the long legs of an ostrich beneath her skirts; a singing cowboy serenades his devoted horse; a determined swimmer battles the Hudson to break a world record; and a bookworm struggles to liberate himself from a mountain of books. Through the storytelling process, these fragmented personalities band together to help one another complete their journeys even as memory fails their authors.

In New York, we inserted an evaluation form in each printed program and allowed time after the show and before a postshow discussion for audience members to complete the forms. We received 539 responses over the course of twenty performances throughout the three weeks of the production. We asked a series of general questions to ascertain audience members' ages, occupations, and experience with dementia. We also asked a series of questions directly about the play, including a request for a description of its theme.<sup>3</sup> The most common response (34 percent) was "self-expression," or "expression of an inner life." Next, we asked people if *before* viewing the play they had thought that people with dementia could express themselves creatively, with a measure of 1 being "not at all," and 10 being "quite well." The average response was 6.3, or in the area we described on the form as "somewhat." In the following question, we asked if *after* viewing the play they thought that people with dementia could express themselves creatively. The average response was 8.2.

We analyzed the before-and-after responses according to differences in age, experience, occupation, and date of the performance. Age did have an impact on people's responses, but it was a relatively weak one. We found that younger audience members were slightly more optimistic in recognizing the creative potential of people with dementia. Each age group went up approximately two points from before to after, but younger audience members began from a slightly higher place than that of older members.

Those with experience with dementia (personal or professional) were more positive in their views of the potential of people with dementia to express themselves creatively. Those without experience changed their attitudes more than did those with experience. Both groups increased from their before attitude to their after. Those who worked in health care began with a more positive attitude in comparison with those who did not. Both groups increased two points from before to after, but those in health care began and ended higher than those who

were not. The differences, however, were weak, and the play had a significant impact on every group.

The art exhibit in New York City featured six two-dimensional silhouettes of characters from the stories that had emerged in the New York storytelling workshops. The figures ranged from eight to twelve feet in height and included a pair of waltzing ladders, a woman riding an ostrich, a swimmer, and an elephant. The story itself was handwritten on the figure, so viewers could read it in its entirety. The exhibit was held at the Elsa Mott Ives Gallery at Fifty-third Street and Lexington Avenue, where the figures appeared in the enormous second-floor windows, which overlook a busy intersection. Evaluation cards were displayed prominently in the exhibit, but in spite of high attendance, only seventeen viewers completed cards and dropped them in the evaluation box. The results were similar to what we found in the play. Seven people had personal or professional experience with ADRD, eight did not, and two did not answer this question. All seventeen respondents showed a positive change in their perception of the creative ability of people with ADRD. But the small number makes it difficult to generalize the results or to compare them with the results of the play evaluation cards.

## Conclusion

Creative storytelling supplies a social role, one *with value*, that allows for the integration of past and present, and that acknowledges the *strengths and potential* of the present lives of people with Alzheimer's disease and related dementia. It offers storytellers an avenue for self-expression that frees them from the demands of memory and rational language, which they can no longer master. Creative storytelling can reorient the expectations of professional caregivers so that they are able to recognize new and untapped strengths of their clients, including the capacity for humor, creative imagination, and social skills. It offers staff an enjoyable activity that can also help them develop *their* creative potential. It offers student volunteers an opportunity to separate their fear of Alzheimer's disease and aging from the people with whom they associate these features and can be a first step toward encouraging young people to consider working or volunteering with the elderly. Where broken communication skills fracture relationships with family caregivers and their extended families, creative storytelling can provide a way for individuals to forge new relationships through poetic and openly symbolic expression.

Perhaps because most people assume that people with Alzheimer's disease have no meaningful present, caregivers tend to encourage them to remember the past and underestimate their remaining strengths. While I believe that reminiscence work can be very effective and fulfilling for people wrestling with

the early stages of ADRD, it can lead to frustration and even shame among people in the middle stages, people whose ability to have access to and control language and memory can be severely impaired. For us as caregivers, shifting *our* focus from memory to creativity can open up channels of communication with people with ADRD and offer both client and caregiver the potential for growth. Sharing the creative products of people with dementia in a respectful way can be very effective in raising public awareness about the creative capacity of people who suffer from the condition. This two-pronged approach, both changing the mindset and actions of caregivers and assuaging the public fear of people who suffer from ADRD, is a step toward the cultural change for which gerontologists so urgently call.

#### NOTES

This chapter is based on Ann Basting, "Exploring the Creative Potential of People with Dementia: Dare to Imagine," in *Mental Wellness in Aging: Strengths-Based Approaches*, ed. J. L. Ronch and J. A. Goldfield (Baltimore: Health Professions Press, 2003).

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1. Because some clients at the adult day facilities were not diagnosed with Alzheimer's, staff selected clients whose symptoms were consistent with that diagnoses. All participants experienced memory loss and confusion to such an extent that they could no longer function on their own. Some had very little language left at all. We did not rely on the Mini Mental State Exam (MMSE), as we found that even those who could not take the exam could participate in the storytelling process.
2. Interviews with family caregivers were open-structure telephone interviews, held in the first three weeks of the project and again at the end of the storytelling sessions. We also produced a series of arts events inspired by the creative stories, and we interviewed families again after they had attended the arts events.
3. The average age of audience members was forty-two. Fifty-eight percent had experience with dementia, either personal or professional, and 37 percent of audience members came from an arts background, while 21 percent came from health-care fields.

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## Embodied Selfhood

### An Ethnographic Exploration of Alzheimer's Disease

PIA C. KONTOS

Alzheimer's disease is regarded as the most bewildering and frightening condition facing the aging population in the twenty-first century (Schroeder et al. 1990) and represents a much feared stigmatizing label that carries with it the force of a sentence of social death (Robertson 1991). As Herskovitz notes, senility is characterized as "monstrosity" by the lay media with "clichéd metaphors and representations in which Alzheimer's is characteristically drawn in colourfully dramatic terms that paint vividly disturbing images" (1995, 152–153). Alzheimer's is described as a living death, a never ending funeral, and a private hell of devastation.

The source of the fear is found in much of the Alzheimer's literature in which individuals with dementia are said to experience a steady erosion of selfhood as a consequence of the cognitive deficiencies that lie at the core of the illness (Cohen and Eisdorfer 1986; Mills and Walker 1994). As Fontana and Smith state, with advancing Alzheimer's, what is actually happening is that the self is becoming "increasingly devoid of content" (1989, 36). It is, they say, "unbecoming a self." Others echo these sentiments by describing Alzheimer's as a disease that "eradicates the essence of the person" (Dalziel 1994, 1407), as a process of "drifting towards the threshold of unbeing" (Kitwood and Bredin 1992, 285). Thus, while Alzheimer's is usually described and analyzed in terms of the cognitive dysfunction it produces, there is, as well, a presumed existential outcome: the loss of self with the concomitant erosion of individual agency (Davis 2004; Herskovitz 1995; Ronch 1996).

This presumed loss of selfhood is itself a product of the Western assumption that status as a full human being is completely dependent upon cognition and memory, both of which become impaired with advancing Alzheimer's:

"Alzheimer's disease represents the loss of all those qualities by which we have come to define our humanness" (Robertson 1991, 143). This representation of personhood is itself the legacy of Western philosophy's tendency to split mind from body and to position the former as superior to the latter. In contrast to the Cartesian mind/body dualism, in which human meaning and selfhood are attributed to the mind, I propose to integrate Maurice Merleau-Ponty's (1962) radical philosophical reconceptualization of perception and Pierre Bourdieu's (1977, 1990) sociological exploration of the logic of practice, yielding a theoretical framework that captures the existential immediacy of the body as well as its interrelationship with culture and history (Kontos 2003).

The central aim of this chapter is to explore how this proposed theoretical framework that advocates the irreducibly embodied nature of agency brings a new and critical dimension to the challenge of the presumed loss of personhood in Alzheimer's and, more broadly, to the Western representation of personhood that hinges on cognition and memory. To do so, I will analyze, from the perspective of embodiment that I advocate here, findings drawn from an ethnographic study of an Alzheimer's support unit of a Canadian home for the aged.

### The Setting

Chai Village is an Orthodox Jewish facility that provides long-term care for 472 residents; the majority suffer from Alzheimer's dementia and a small minority have vascular dementia.<sup>1</sup> Approximately eighty residents reside on each floor, the majority of whom are women (82 percent), with the average age of all residents being eighty-eight years.

The present study was conducted on one of the floors that provide support for residents suffering from Alzheimer's dementia. Of the seventy-nine residents on the floor, thirteen participated in the study, three men and ten women, all of whom are Jewish and of Eastern European descent and whose cognitive impairment ranges from moderate to severe (39 percent were severely cognitively impaired).<sup>2</sup> Because of cognitive impairment, informed consent to participate was provided by proxy. Participant observation took place over the course of eight months, approximately eight hours a day, three days a week, during scheduled program activities and mealtimes and when participants engaged in unscheduled activities such as walking or sitting in the hallways.

The focus of my analysis will be a series of occurrences I observed at Chai Village that are presented here in the form of vignettes in order to fully contextualize the events described. Also, where appropriate, I will draw upon other instances from my ethnographic data as well as characteristics of individual participants in this study in order to highlight pertinent points of my analysis.

## Appearance

There is among most female residents the desire to retain a sense of feminine beauty. There is a constant concern with self-presentation such as when Anna insists on putting on lipstick before going to social programs or when Frances places her hand on her chest, preventing her blouse from touching her food as she leans over her plate.<sup>3</sup> The following scene vividly captures Molly's attention to social grace and neatness. It is her frailty and inability to feed herself that makes Molly's attention to appearance all the more significant.

### *String of Pearls*

Molly's wheelchair seemed enormous in contrast with her thin, wizened body. Her legs had severely atrophied, giving the impression of two-dimensional forms. Were she able to stand, she would be no more than five feet tall. Her face was heavily wrinkled but the skin was soft, resembling that of a peach. Her hair was uniformly white, accentuating her China blue eyes. The backs of her hands were the most vivid testament to the near century she had lived. The skin was thin, revealing a network of bones and purple veins. Her hands shook as if powered by an invisible gentle motor.

Despite her withered appearance, there was an indescribable elegance to Molly. I noticed this in watching her as she was brought to the dining room. Once her wheelchair was positioned at the table, a bib was fastened around her neck. Molly then carefully unfolded her napkin and placed it on her lap. Even though the use of the bib made the need for a napkin redundant, she nonetheless insisted on observing this table etiquette.

As a health care aide was feeding her, cereal dribbled from Molly's mouth and coursed down her chin. When the aide tried to give her another spoonful, Molly wrinkled her forehead and gently pushed the woman's hand away. Molly then lifted her bib to her mouth to wipe away the cereal. It was only after her chin was clean that she accepted another spoonful. One might expect indifference from a woman who had lost the ability to feed herself, yet Molly's insistence on adhering to the social graces and her attention to neatness suggested a strong and continuing presence in the world.

She closed her eyes slowly and opened them again, releasing a deep sigh. She then looked around the table as if for the first time noticing that there were others seated with her. She patiently waited to make eye contact with each person to acknowledge his or her presence. Then reaching her wavering hand to the back of her neck, she struggled to pull something from underneath her bib. Extending her arm appeared to cause her pain and discomfort, yet she persisted. She eventually revealed a string of pearls that she was wearing and that had been covered by her bib. She allowed the pearls to pass through her long,



slender, perfectly manicured fingers, placing the necklace ever so delicately atop her bib. With this simple gesture, Molly emerged from her world of decrepitude, incontinence, dementia, and helplessness.

### **Creativity and Self-Expression**

There is a rich diversity of social activities at Chai Village. Among the regular weekly events is the creative arts program, a popular activity among the residents that offers ceramics, silk-scarf painting, drawing, knitting, crocheting, needlepoint, and beading. The following vignette describes Ethel's ability to sew in the absence of any cognitive awareness of her ability to do so.

#### ***Knowing Hands***

Sitting next to Edna, I admired the pink sweater she was wearing. She looked radiant. As I complimented her on the sweater, she looked down at it, perhaps to remind herself of what she was wearing, and announced, "I make all my sweaters." When she looked up at me she exuded a great sense of pride as she smiled and lifted her chest in confidence. Ethel, who was sitting across from us, was listening to our conversation. Eager to include her, I asked if she still did needlepoint. Ethel had numerous colorful canvases decorating the walls of her room, all created by her own hand. Leaning forward in her chair, she asked in a high-pitched voice, "What? I did that before?" Her frown and downcast eyes signaled her confusion. Edna looked at Ethel in utter disbelief and said, "You don't remember if you worked with your hands?" She wildly gestured as though she were weaving. Sinking back into her chair, Ethel shook her head and with a hint of melancholy said, "I don't remember." She then fell into an embarrassed silence and lowered her head.

Several days later I accompanied Ethel to the creative arts program, as she was on a list of residents who participated in this activity. Mrs. Anderson (the coordinator of the program) greeted Ethel with familiarity, confirming that Ethel had in fact participated there before. She showed Ethel to the table and brought her a canvas that had already been stitched with several rows of yarn. Attached to the top of the canvas was a piece of masking tape with Ethel's name written on it. Ethel looked at Mrs. Anderson with concern and said, "I don't know how." In a kind, understanding voice, Mrs. Anderson reassured Ethel by saying, "You don't have to know, but we like you to try." In great distress, holding her hands out with her palms facing upward, Ethel replied, "I cannot." As if it were part of their routine exchange, Mrs. Anderson began stitching a row, to demonstrate how it was done. Ethel watched as though she were observing something foreign. Before reaching the end of the row, Mrs. Anderson encouraged Ethel to take the needle and continue. Then, as if the needle placed be-

tween her fingers had triggered a forgotten ability, Ethel began to stitch. Mrs. Anderson seemed pleased and moved on to assist another resident.

I stood and watched Ethel with amazement. Holding the canvas in one hand, she passed the needle through with the other and in two swift movements the stitch was completed and she began the sequence once again. The rhythm with which she was weaving demonstrated a proficiency that was in striking contrast to her previous proclaimed inability. She very quickly completed the row and, without hesitation, took a fresh piece of yarn in her hand, licked one end, and, pinching it between her thumb and index finger, attempted to thread the needle. The yarn splintered and she was unable to push it through. She licked it once again, and pinching the end several times, she succeeded in passing it through the eye of the needle. She looked up at once, and as our eyes met, she raised the threaded needle in triumph.

### Ritual and Ceremony

As noted earlier, all the residents of Chai Village are Jewish, and Jewishness is a vital, integral part of their daily life. There are two rabbis on staff at the facility, daily synagogue services are offered on site, a centerwide kosher food policy is in place, and there are Sabbath and other holiday observances. The following scenes capture the enactment of different ancient, well-known ritual gestures related to the holidays of Simchat Torah and Hanukkah. Each ritual involves certain symbols that pertain to the Jewish home and family, as well as customs that are physically enacted, and are thus profoundly corporeal experiences.

#### *Prayer*

Simchat Torah is one of the most widely celebrated rituals in the Jewish faith. It is the day of celebration for the gift of Torah, the five books of Moses, whose wisdom enables the Jewish people to know how to live close to God. The Torah scrolls are the holiest of objects and are carefully stored in a curtained altar. Each scroll is handwritten in Hebrew on parchment and then rolled onto two poles that are topped with silver handles. Every Saturday, the appropriate scroll, as determined by the Hebrew calendar, is brought out during the service and unrolled so that a portion of it can be read aloud. The reading of the Torah is seamless; once completely read, it is immediately reread. The rituals of Simchat Torah revolve around a continuous cycle of Torah readings.

On Simchat Torah the synagogue at Chai Village rang out powerfully in hymn. The service leader circled the *bimah* (the central platform from which the Torah is read) while holding the Torah and reciting a short prayer responsively with the congregation. Following Orthodox custom, women prayed in a gallery to the side of the main body of the synagogue, where the men prayed. All had

covered their heads in one way or another—the women with hats, scarves, and even a small swatch of fabric; the men with *yarmulkes* (skullcaps) that were made of paper, cloth, or beads. The men also covered their shoulders with a *tallis* (fringed blue-and-white prayer shawls). My attention was drawn to the center of the synagogue, where the men prayed with intensity and passion. Among the participants stood Jacob.

Jacob would often chastise residents who, because of their dementia, would create disruption. Ironically, his own advanced demented state had limited his verbal expression to the use of single words. Jacob would frequently call other residents names in Yiddish such as *meshugener* (crazy person), *am-ha-aretz* (ignorant individuals who are noisy and continually creating disturbances), *kvetch* (a person who always complains), and *fressers* (people who eat like animals). Although these words would be shouted in single utterances, all are powerful summary interpretations of his perception of the behavior of the targeted individuals. When he was not using single words, Jacob's speech was incoherent, which enraged him. So intense were his outbreaks of rage under those circumstances that staff would have to escort him out of the room.

Jacob moved his lips with the chants of the leader of the service. I watched as he swayed deeply, stepping forward and back, bowing and striking his chest with clenched fists, as is commonly done in Jewish prayer. He was energetic and forceful. Suddenly there was a disturbance in the women's gallery that silenced the congregation. A woman in a wheelchair had mistakenly taken the place of a woman who had just returned from the washroom. The leader of the service paused, and all the congregants shifted uneasily in their seats as the woman shouted that she wanted her place back. Jacob turned to face the woman in the wheelchair—her body twisted and crimped from the effects of a stroke—and in a string of incoherent speech, he yelled at her, shaking his index finger. He was visibly agitated; his body shook with anger. A porter quickly moved to resolve the conflict in the women's gallery and a health-care aide approached Jacob to escort him out of the synagogue. His uncontrollable rage left little choice. However, just as the aide approached Jacob, the leader resumed the service, belting out a prayer. Jacob's response was immediate. His rage was instantly quashed. He fell into a reverent silence, closed his eyes, and resumed his fervent bodily movement of prayer.

Jacob was once again focused on the service. The leader held a Torah scroll and circled the interior of the synagogue, followed by honored members of the congregation, who also held the scrolls. It is customary for synagogue members to reach out and touch the passing scrolls, raising their fingertips to their lips in a kiss, displaying respect for the Torah. Jacob joined in the celebration with this gesture of respect for the sacredness of the Torah. After the procession of Torah bearers circled the synagogue, the leader broke out in joyous song and all the

congregation joined in singing and dancing. In the center of the synagogue the men formed a circle and danced around those who held a Torah scroll. The women formed a circle of their own in their separate gallery and similarly lost themselves in ecstatic fervor. Jacob hesitated for a moment, looking around the room smiling shyly, as if embarrassed about expressing enthusiastic joy in public. But he had little more than slight hesitation in regard to the Torah, twisting his shoulders and hips and snapping his fingers in the air. Despite his initial hesitation, he knew from previous experience that it was appropriate, that his movements and gestures suited the occasion.

It is Orthodox custom for the men to be honored with an *aliyah* (the act of being called up to the *bimah*), in order to say the blessing following the reading of the Torah on Simchat Torah. When the dancing quieted, each male congregant was called up to the *bimah* to say the *broche* (blessing). When Jacob was called forward, he moved firmly and with upright posture to the platform. Without any prompting, he leaned his body over the Torah and recited the prayer with absolute coherence and precise pronunciation. The visiting wife of another resident was seated next to me and, clearly familiar with Jacob's dementia, said, "You can forget everything but you never forget the *broche* over the Torah." Jacob was unable to put a sentence together, but standing before the Torah he was in full command.

### The Way Through

Hanukkah, an eight-day Jewish holiday, is celebrated in remembrance of the rededication of the Temple of Jerusalem after its defilement by Antiochus of Syria. This holiday is marked by the lighting of the menorah, a candelabra containing nine separate candles. The lighting of the menorah commemorates the miracle of Hanukkah, namely, that following the destruction of the Temple of Jerusalem, the cruse of oil that was found in the ruins of the temple and thought to contain only enough oil to burn for one day, in fact burned for eight. On each day of Hanukkah, after sundown, the middle candle is used to light another candle, representing the day of the holiday that has passed. This continues until the eighth day, when all candles on the menorah are lit.

The eighth day of Hanukkah is considered to have special significance as the culmination of the holiday, the day when the menorah burns most brightly. It was on this day that a concert and party were arranged for the residents of Chai Village. The planned festivities attracted more residents than the number that the social programs normally brought in. That the day was set apart was clear from the residents' appearance: the women held purses that were perfectly preserved from earlier decades and wore their best dresses and jewelry. Gold necklaces and bracelets studded with diamonds and pearls were worn in

place of the usual beaded jewelry that had been made in the creative arts program. Scarves and colorful hats brightened the women's faces. Men wore tidy suits over frayed but neatly pressed shirts.

The concert began with piano music and a strong alto that filled the room with Yiddish song. As I stood listening and watching, I noticed Dora. Her eighty-five years had been kind to her face, leaving a smooth and creamy complexion. Her lips were full and pink, and her eyes unclouded by cataracts or glaucoma. The backs of her hands were blotched with brown spots and her fingers crimped by arthritis. Even Dora, within her limited financial resources, rose to the occasion by wearing a faded floral polyester dress with an old green heavy-knit cardigan-sweater set that matched. Her feet, resting on the pedals of her wheelchair, looked painful as her calluses and bunions protruded from her plastic sandals.

Somehow, while sitting in her wheelchair, Dora was dancing. She created a sense of fluidity and abandon, moving her arms above her head elegantly and delicately wiggling her fingers while slowly lowering her hands to each side of her wheelchair. Dramatically tossing her head back, she extended her arms above her head as though performing an arabesque. So choreographed were her movements that I wondered if she was reenacting a performance from another time. When the song finished, applause erupted in appreciation of the singer and pianist, and Dora moved her upper body forward in her chair as if to take a bow for her own performance.

Jelly doughnuts, brought out by staff and volunteers, were served to the residents on plastic plates with a napkin. Dora ate her doughnut as she continued to listen to the music. Licking the jelly from her fingers, she moved her head from side to side. With her hands busy with the doughnut, she struggled to stretch her legs out in front of her. Her swollen feet looked almost delicate as she gently brought her toes and then her heels together, alternating these movements to the rhythm of the music.

Following the concert, there was to be a ceremonial lighting of the menorah. As it was the eighth day of Hanukkah, all eight candles would be lit. Mrs. Allen, the program coordinator, invited a resident from the audience up to the menorah, located at the front of the room on a small table that had been carefully covered with a white cloth. Mrs. Allen lit the candles and the resident recited the appropriate blessing while bowing her body forward over the small flames. Although Dora watched with intense interest from across the room, it was difficult to determine how much of the ritual she was able to see. The lighting of the menorah marked the end of the program, at which point the staff and volunteers began the task of taking the residents back to their rooms.

A health-care aide approached Dora, released the brakes of Dora's wheelchair, and announced, "It's time to go." Dora immediately clutched the woman's arm and shook her head vehemently, indicating that she did not want to go.

Dora's insistence on staying was inexplicable amid everyone's eagerness to return to their rooms. The aide did not have time to question Dora's resistance, for she was distracted by another resident who had considerable difficulty in walking and required immediate support. I watched Dora as she struggled to make a path for herself through the crowd, manually navigating her wheelchair around walking aides, other moving bodies, and chairs. Following a slow and laborious process, she finally reached her destination, the table where the menorah stood in glorious full flame.

Dora unfolded the napkin she had used when eating her jelly doughnut and, ensuring that the jelly side was facing upward and not touching her hair, she placed it with utmost care atop her head. She then held her palms up to the menorah, embracing the warmth of the candles. I was close to her but she did not see me. She then raised her hands to her face, covering her eyes, and prayed privately. Dora had seemingly slipped into another time, subsumed by an inner experience that was strangely sheltered from the ongoing commotion in the room. Tears streamed through her fingers. When she removed her hands she looked up at me and smiled with a transformed visage. I saw in her face a deep pleasure, and I smiled at her. Dora removed the napkin that had served as her head covering and smoothed her soft white hair. The aide who earlier had tried to take Dora to her room returned for her. This time Dora did not resist. Dora's hands were gently clasped in her lap and her face was peaceful as she left the room.

## Discussion

The ethnographic data here clearly demonstrates that the residents of Chai Village exhibited selfhood *in the face of even severe cognitive impairment*. It is a notion of selfhood that speaks of a complex interrelationship between the primordial and the social characteristics of the body, all of which reside below the threshold of cognition, grounded in the prereflexive level of experience, existing primarily in the corporeal. My discussion in this chapter will suggest that selfhood resists the ravages of Alzheimer's disease precisely because it resides in corporeality.

I turn now to Merleau-Ponty's analysis of motility as basic intentionality in order to begin to understand the role that the body plays, at the most fundamental level, in selfhood, as expressed by the residents of Chai Village.

### *The Primordial Sources of Selfhood*

Merleau-Ponty argues that embodied consciousness, which he refers to interchangeably as "embodied significance" or "nonrepresentational" and as "basic intentionality," is a fundamental level of existence that does not involve a cognitive form of consciousness. Merleau-Ponty's *basic intentionality* is the body's concrete, spatial, and prereflective directedness toward the lived world. The

prereflective moving body is in and of itself intentional by virtue of being naturally invested with a certain perceptual significance, a bodily know-how or practical sense. He argues that the body in movement is not limited to submitting passively to space and time, for the body actively and intentionally takes them up in their elemental significance. In Merleau-Ponty's words, "[A] system of possible movements radiates from us to our environment" (1964, 5), giving us at every moment a practical and implicit hold on our body, a hold that situates us as subjects perceptually, linguistically, and through motor activity. I understand *selfhood* as inhering in what Merleau-Ponty describes as corporeal and nonreflexive intentionality, and as such, it is my claim that selfhood must be understood as being enacted in the actual movements of the body.

Within this "system of possible movements," the body possesses, according to Merleau-Ponty, a coordinating power in relation to itself, what he refers to as the primary perceptual level, which is prior to any explicit act of intellection on our part. He cites the following example to illustrate the prereflective nature of the coordination of visual, tactile, and motor aspects of our body: When bitten by a mosquito, we do not need to look for the part of the body where we have been bitten. We find it straight away by reaching for the itchy spot on our phenomenal body. For us there is no question of locating it in relation to axes of coordinates in objective space. In the natural system of our own body, we experience a direct relationship between our hand as an instrument of scratching potentiality and the part of our body that has been bitten as a spot to be scratched. The whole operation takes place, according to Merleau-Ponty, in the domain of the phenomenal (1962, 105–106).

Similarly, it can be seen in the example of Ethel's stitching, in that when the needle and thread were placed between her thumb and finger, she did not need to look for her hands or her fingers when she began to sew, because they are not objects to be discovered in objective space. The task to be performed, the stitching, immediately elicited the necessary movements from Ethel as she took hold of the objects, assimilating their structure into her body, without any calculation on her part. Ethel's example makes apparent the spontaneous method of perception, what Merleau-Ponty describes as a kind of living system of meanings, which makes the concrete essence of the object immediately recognizable. As soon as Ethel took hold of the needle and thread, these objects meant something, without the meaning having to be established through cognition. In other words, there was an immediate familiarity with, and an effortless use of, the needle and thread.

Ethel was able to sew without any cognitive awareness of her ability to do so. The disjunction between cognitive impairment and the coherent expression of talent or skill draws attention to Merleau-Ponty's example of one who knows how to type *without having to think out* the location of each letter on the keyboard (1962, 144). Even more than this, though the typist *does not know where the keys*



are in a reflective sense, he or she—to make any attempt to provide a reflective and discursive account of the keyboard layout—would have to imagine typing in order to see the direction in which his or her fingers moved to hit the appropriate keys. Knowledge of typing, Merleau-Ponty argues, is *in the hands* and manifests itself only when bodily effort is made and cannot be articulated in detachment from that effort.

Merleau-Ponty does not intend for knowledge to be understood in an intellectualist fashion in cases in which it would be associated with the supposedly self-transparent activities of a reflexive subject. Indeed, the kind of knowledge of the keyboard that the typist has is a practical, embodied knowledge, quite remote and distinct from discursive knowledge. Knowledge, as Merleau-Ponty understands it here, is the capacity for acting, the know-how belonging to a subject whose primary relation to the environment is that of prereflective, active, and practical involvement. He speaks of how the perception of our body functions as a *logic lived through* that does not rely upon reflective-discursive thought, and thus the meaning of that which is perceived becomes fully elucidated only through bodily movement (1962, 49). In the absence of practical involvement, stitching did not register any significance for Ethel, as evidenced by her protest of “I don’t know how.” Ethel’s knowledge of sewing was forthcoming only when she herself took hold of the needle, thus highlighting precisely the distinction that Merleau-Ponty draws between intellectual and practical significance. The relevance of *practical significance*, which for my discussion of selfhood has the same meaning as *nonrepresentational intentionality*, is that this primordial level provides the foundational structure for selfhood. In this sense, Ethel’s stitching renders visible how selfhood resides in, and is manifested through, the ways of the body. Conceptualized in this way, selfhood is supported by and emanates from the existential expressiveness of the body.

However, there is an obvious difference between the example of Ethel’s stitching and Merleau-Ponty’s example of the typist. The typist, though unable to describe the layout of the keyboard, is fully aware of his or her ability to type. Ethel, however, claims to be unable to sew, demonstrating a lack of cognitive awareness of an ability that she in fact possesses. Despite this difference, the relevance of Merleau-Ponty’s example of typing to my analysis of Ethel’s sewing is that in both instances, bodily movements are *not* dependent upon cognition in order for the necessary tasks to be performed, but rather rely upon what Merleau-Ponty refers to as motor intentionality. Ethel’s ability to sew is guaranteed by her body itself as a “motor power,” a “motor project” (1962, 110), in the absence of which the instruction to sew, as given to Ethel by the coordinator of the creative arts program, would remain unfulfilled. This is to say that Ethel’s ability to sew is completely dependent upon her having incorporated the meaning of the needle and thread and the rhythm of stitching into her bodily



schema, just as the typist incorporates the keyboard space into his or her bodily schema.

Embodied selfhood can be further explored through additional examples of basic bodily movement. In Chai Village, when Molly reached behind her neck to pull her pearls from beneath her bib, she “knew” where her hand was and how far and at what angle she had to reach to grasp the pearls. Similarly, when Dora performed her seemingly choreographed dance at the Hanukkah party, she, like Molly, desired a certain outcome of her actions, and the necessary tasks were spontaneously distributed in the appropriate parts of her body. Their movements were perfectly suited to the exigencies of the circumstances without Dora’s having to think of how to make them or to articulate reflectively the principles upon which their actions were based. Neither Molly nor Dora launched their bodies into blind attempts to perform an action; every movement was inextricably *movement* and embodied selfhood. That is, selfhood can be observed *in* movement where movement itself attests to the hold the residents have on the general synthesis of their bodies, a hold that emanates from the primordial unity of the body.

### ***The Primordial Depths of Sociability***

Chai Village residents are not operating in their own private worlds. On the contrary, they are participants in a common world and communicate with one another. In performing social interactions, in order that we understand the words of another person, a vocabulary and syntax must be previously known. Merleau-Ponty argues, however, that words do not do their work by arousing representations associated with them (1962, 183). Language certainly has an inner content, but the meaning of words is not contained in the words themselves such that their intelligibility is finitely self-subsistent, but rather emerges in the flow of intercourse. As Merleau-Ponty argues, it is in the context of interaction that words assume their conceptual meaning, grasped by a kind of deduction from gestural communication (179). Thus, even with language, Merleau-Ponty detects certain existentialist tendencies, underscoring the primacy of embodiment in speech itself.

Merleau-Ponty’s intention is to restore to the act of speaking its corporeality through an analysis of the embodiment of speech in the lifeworld. Merleau-Ponty’s argument that speech is a gestural system is perhaps most apparent where no linguistic meaning at all is conveyed by speech itself. This is so because in such instances we are still able to communicate with one another by virtue of the expressive dimensions of the gesticulating body, which are fundamental to communication in human interaction. The following exchange between Anna and Abe is noteworthy.

Abe sat down in the dining room and shouted, “Bupalupah.” Anna twisted around in her chair so that she could see Abe (his table was behind hers). Abe’s

face opened up. His eyes grew wider, his mouth eased into a broad smile, and he shouted, “BRRRRRRR!” with a rising and then falling pitch. Anna imitated him, shouting back, “BRRRRRRR!” following the same change in pitch. Abe then shouted, “Bah!” and paused while looking at Anna. Anna shouted, “Shah!” and then waited for Abe’s response. Abe shouted, “Bah!” and Anna, “Shah!” as they established a repetitious pattern of exchange. Anna eventually turned back around in her chair, with her back to Abe. Abe shouted, “Bupalupah!” as if wanting to initiate another exchange with Anna, but instead of responding verbally, she raised one arm above her head and lowered it in a swift motion with a sharp flick of her wrist. With this gesture, she terminated their interaction, and they both began to eat their breakfast quietly.

Even when speech is incoherent and void of linguistic meaning, in face-to-face interaction there is a smooth and appropriate alternating pattern of vocalizing, as well as gesticulating, back and forth. With the utterance of only “Bah,” “Shah,” “BRRRRRRR!” and “Bupalupah,” Abe and Anna were able to communicate without any recourse to intellectual interpretation. There was a fittingness and a meaningful relationship between the rise and fall of their pitch, their pauses, and their postural shifts. Their gestures had a melodic flow and fluent form, rather than appearing as a composite of bodily movements strung together in a mechanical way. What this example illustrates is Merleau-Ponty’s argument that communication dwells in corporeality or, more specifically, in the body’s capacity to gesture (1964, 7). Because of the fact of speech impairment, the force of their speech acts derived not from semantic content but rather from the meanings that their bodies directly indexed. Communication, Merleau-Ponty argues, is a continuation of the corporeal schema. As such, it is my claim that selfhood persists in and through the body’s power of natural expression, that is, the body’s inherent ability to apprehend and convey meaning.

### *Limitations of Merleau-Ponty’s Perspective*

We saw with Merleau-Ponty that the body naturally lends itself to movement and gesture because of the body’s primordial essence, which functions as a form of generality, giving embodied consciousness an impersonal quality. However, there is a certain style or content to bodily movements and gestures, the source of which cannot be attributed solely to a primary level of signification. Bourdieu’s concept of *habitus* is pertinent here because unlike the generality of the primordial, Bourdieu addresses the sociocultural sources of bodily practices.

Habitus consists in dispositions, schemata, forms of know-how and competence, all of which function below the threshold of consciousness, enacted at a prereflective level. As Bourdieu states, “The schemes of the habitus, the primary forms of classification, owe their specific efficacy to the fact that they function below the level of consciousness and language, beyond the reach of introspective

scrutiny or control by the will” (1984, 466). Wacquant (1992), perhaps Bourdieu’s best commentator, has noted that Bourdieu is clearly drawing on Merleau-Ponty’s idea of the body as the source of practical intentionality and of intersubjective meaning grounded in the preobjective level of experience. The body is treated as having a “generative, creative capacity to understand” (Wacquant 1992, 20)—a kind of corporeal awareness—a practical reason, with reason existing primarily in corporeal ways. However, with the concept of *habitus*, Bourdieu takes us beyond the elements of essentialism and the subjectivist grasp of practical sense in order to investigate practice in the context of the social genesis of its conditions of operation. Thus, Bourdieu’s exploration of competence, know-how, skill, and disposition moves him into the sociocultural horizon in which, according to Bourdieu, bodies assume their embodied significance.

It is my argument that selfhood, in addition to having a primordial source, consists in the dispositions and generative schemes of *habitus* and thus, in the same way that dispositions are embodied and materialize in practice, selfhood is embodied and manifested in a socioculturally specific way of being in the world. I will continue to explore communication in the following section but with a shift in focus to the sociocultural sources of selfhood.

### *Communication in Sociocultural Context*

Bourdieu’s argument that cumulative exposure to certain social conditions instills in individuals an ensemble of durable and transposable dispositions is evident when we consider that Chai Village residents have a habitual state, “a tendency, propensity, or inclination” (Bourdieu 1977, 214n1), to gesture in a particular manner. Voice, facial expressions, and body movements were distinctive and predominant manifestations of selfhood in communication among my participants. When the residents of Chai Village interacted with one another, so identifiably Jewish were their intonation patterns and nonverbal forms of communication that a person of Jewish heritage did not need to know that Chai Village is a Jewish facility to recognize instantly that the residents were Jewish. Following Bourdieu, we could say that their Jewishness is actually embodied in their arms, hands, feet, and head underscoring the essence of *habitus*, which is the embodiment of culture-specific conditions of primary socialization.<sup>4</sup> I would add that selfhood resides in the embodiment of culture-specific conditions of primary socialization, and thus, Jewishness is a manifestation of my study participants’ selfhood. Typical Yiddish gestures include flinging one or both hands in front of the body in a swift downward motion, with elbows close to the body and turning head away slightly; holding hands with palms facing outward, elbows kept within a very narrow area, close to the body, while turning the head all the way to one side, lifting the opposite shoulder slightly. Efron (1972) has described the various aspects of such gestures and argues that East-

ern European Jews who have maintained their Old World traits or mannerisms have a propensity to accompany their speech with lively bodily motions, a propensity, Bourdieu would claim, that is determined by their cultural heredity.

In addition to gestural communication, discursive expressions equally reveal a dispositional character that emerges from the internalization of a socio-cultural environment through the primary experiences of the body. For example, the Yiddish language has an expressiveness that is manifested in the rhythm of speech. There was a great deal of emotion in the highs and lows of my participants' voices. As the sounds went up and down in melodious directions one could feel the words as much as hear them. One is not born with a culturally distinct intonation pattern but acquires it "by the childhood learning that treats the body as a living memory pad" (Bourdieu 1990, 68). The way my participants spoke and used their bodies to express themselves are examples of cultural aspects of selfhood "given body, *made* body" (69; emphasis in original).

### ***Ritual and Ceremony***

Jacob's prayer at the *bimah* and Dora's before the menorah were ethnic ritual gestures that captured a sacred moment by bringing the past into the present. However, I would argue that such rituals are not a matter of bringing into the focus of consciousness a picture of the past. Reenacting rituals that were part of one's early childhood is not a matter of delving into the past through a cognitive operation. Following the logic of the concept of habitus, these rituals underscore the *active presence of the past in the body itself*. We could say that the rituals are "embodied history, internalized as a second nature and so forgotten as history" (Bourdieu 1990, 56). "Embodied history" here suggests that past experiences persist in the body in the form of transposable dispositions that collectively function as a matrix of perceptions and actions. They are embodied in the sense that the memory of them is not confined to the brain but is actually encoded in the muscles, nerves, and sinews of the body. Following the logic of habitus, we could say that what propels such ritual practices are dispositions inculcated by early pedagogy that is part of a child's primary learning and constantly reinforced through socialization in a Jewish home. Thus having knowledge of the *broche* and the meaning of the menorah is akin to having acquired the mother tongue, in that the subject is unaware of the associated learning and is thus ignorant of all that is tacitly granted through socialization. In this respect, Jacob and Dora did not embark upon the practice of ritual as a conscious act, for they were born into the practice.

The emotion that is commonly expressed by Eastern European Jews in gesture and speech is similarly expressed in prayer through bodily movement and melody. In the Jewish faith, gestures, movements, and melody are essential ingredients in the life of prayer, enabling worshippers to put the whole of themselves into the act of worship (Jacobs 1972; Rosenberg 1997). On Simchat Torah,

as Jacob prayed, he swayed deeply, stepping forward and back, bowing and striking his chest with clenched fists, his movements reflecting an intense and vital bodily force that is common in Jewish prayer. As he rejoiced with the Torah in dance he was highly enthusiastic, passionate, and emotional.

Following Bourdieu's thought, Jacob's movements are "learned" by the body, but it is not a kind of knowledge that one *has*; rather, it is "something that one *is*" (1990, 73; emphasis added). This means that what the body learns is *never* detached from the body; it is prereflective and thus can be activated only by its being evoked in practice. To be even more precise, it is a "practical reactivation" (73) whereby the knowledge that the body reproduces is not a memorization of the past but rather an *enactment* of it. Bourdieu refers to this knowledge as "practical sense" (69) that constitutes the world as meaningful by spontaneously anticipating its immanent tendencies (Bourdieu and Wacquant 1992). As I have already argued, practical sense does not derive from rules, principles, or calculations, or from a premeditated goal, which, for Jacob, would in any case be excluded by the urgency or spontaneity of his actions. And in his case, reflective thought and calculation would be further excluded by the fact of his advanced dementia. Neither could Jacob's movements be mistaken for pure imitation, particularly if we consider that his precise and passionate recitation of the blessing before the *bimah* was a solo performance.

There is an apparent contradiction between Jacob's coherent performance in the synagogue and the fact of his cognitive impairment, manifested in his inability to speak coherently beyond monosyllabic utterances. This apparent contradiction can be resolved if we approach Jacob's ritual gesture as the application of a practical logic, produced without any conscious intention by a structured, structuring body that functions as a generator of a symbolic act. His prayer was not an intellectual effort of meditation and contemplation. Bourdieu would say that it is practical sense that, for Jacob, brought an instant appreciation of the meaning of being before the *bimah* and enabled him to produce at once the appropriate ritual gestures. That Jacob was in such command while standing before the *bimah* attests to Bourdieu's argument that schemes of perception, appreciation, and action are not only acquired through practice, but also *implemented in a practical state* in which objective structures match those of which the schemes of habitus are a product. Bourdieu argues that habitus and the way in which it shapes perceptions, motivation, and action dispose the subject to recognize and engage in particular practices, which in turn perpetuates one's system of dispositions (Bourdieu 1990, 58–59). We can therefore understand Jacob's actions as being the result of the reactivation of his system of dispositions through involvement in a practice of similarly structured practices. The synagogue, its congregants, the presence of the rabbi, and the touch of the Torah scrolls were aspects of an organized event that exercised the pertinent incitement of the habitus. Jacob would not have succeeded in his performance

at the *bimah* had there not been a concordance between the opportunity and the disposition to grasp it.

As long as one ignores the notion of a “conductorless orchestration” (59), that is, *habitus* as a spontaneity without consciousness or will, one is left with no other unifying principle than conscious coordination and, consequently, no reasonable explanation for the coherent performance of ritual practices in the face of severe cognitive impairment. On the basis of my argument that selfhood resides in sociocultural bodily dispositions, we could say that selfhood is what propels the reenactment of these ritual practices. To say that selfhood is the generator of ritual practice is to stress the body’s prereflective capacity to express itself.

### ***Selfhood: Coherence and Improvisation***

We have seen in the discussion of the primordial source of selfhood that Merleau-Ponty’s notion of bodily schema gives us a practical and inherent hold on our body and its relation to things in the world. I have suggested that we should think of Merleau-Ponty’s notion of the perspectival unity of corporeal schema as providing the foundational structure for selfhood, a structure that itself consists in perception as embodied consciousness. Thus, fundamental to the coherence of selfhood is the unique totality achieved through the synthesis of movement and embodied perception, that is, through the body’s ability to seize upon and transform the perceptible into something meaningful. The way that my study participants unthinkingly carried and projected their bodies disclosed a coherence and unity in their directedness toward the world. It is this unity that, at a fundamental level, allowed my participants to converse with the world, in grasping external space, as well as in mutuality with others. Hence my argument that bodily schema, the primordial unity of the body, is foundational to the coherence of embodied selfhood.

However, embodied selfhood owes its coherence not only to the foundational unity of the body, but also to the embodiment of culture-specific conditions of primary socialization. This is apparent when we consider the ongoing interactions of daily life at Chai Village, where there was coherence and consistency in the residents’ mastery of their social world, in the ways that they embraced their daily routines and engaged in specific activities. The rhythm of ongoing interactions of daily life at Chai Village owed its regularity and predictability, its steadiness and persistence, to the objective structures that produced the dispositions of the residents and that continued to inform their interaction (Bourdieu 1990, 59). As a result of the internalization of external structures, the residents of Chai Village were able to react to the demands of their environment in a coherent and systematic manner.

We could say that selfhood is their practical sense operating at the pre-objective level and endowing their world with meaning. For example, there was

a particular logic to the meal experience, an observable coherent, consistent intelligibility to my participants' management of the demands of this social activity. Such consistency, which is a precondition of the coordination of the meal as a practice, presupposes on the part of the residents a mastery of a common code that functions as a kind of self-regulating mechanism. Thus, there is an immediate familiarization with, for example, the proper use of utensils, napkins, salt and pepper, and butter and jam. Furthermore, when the residents sit at the table they socialize with one another and, for the most part, respect table etiquette while they eat their meal. In other words, there is a harmony between practical sense and the socially objectified meaning of sitting at the dining-room table that creates a consensus in the meaning of the practice (Bourdieu 1990, 58). Their manner of interacting with one another at the table and the competencies that they clearly embody are what Bourdieu refers to as "a harmonization of the agents' experiences" that results from the homogeneity of conditions of existence. That is, their social history and culture are objectified in habitus, which harmonizes practices without any deliberate pursuit of coherence or conscious reference to a norm, and without any explicit coordination (58–60). We know that there is no explicit coordination through cognition because, to continue with the example of a meal, there were no two lunches, dinners, or breakfasts that were identical in terms of the interactions that transpired, thus militating against any notion of advanced orchestration or mechanical repetition. This suggests that practices are regulated without being the product of obedience to external rules because the taken-for-granted, prereflexive nature of practices flows from embodied selfhood.

Mastery of a common code was evident not only where there was regularity in social practice, but also when something happened that deviated from or contradicted the common code, such as when a resident who failed to adhere to proper etiquette was met with strong disapproval from others. For example, Abe, one of my participants, belched loudly in the dining room and Anna held her hands over her ears, yelling, "Tell the *meshugener*, stop it," in an indication that Abe's behavior was offensive to her. Anna's reaction can be interpreted as a negative sanction because Abe's behavior was too different from what she expected and from that to which she had objectively adjusted. As Bourdieu argues, "[H]abitus tends to favour experiences likely to reinforce it . . . to protect itself from crises and critical challenges by providing itself with a milieu to which it is as pre-adapted as possible" (1990, 61; emphasis in original). A similar disjunction between habitus and objective conditions occurred when Molly furrowed her brow and abruptly stopped eating when she saw Dody, who was sitting directly in front of her, using the twisted corner of a napkin to clean her nostrils. The behavior of Abe and Dody was deemed improper and intolerable, attesting to the persistence of embodied selfhood. Put simply, behavior is negatively sanctioned when it offends the sensibility of one's selfhood.



The disjunction between habitus and objective conditions that the preceding examples reveal points to a central objective of Bourdieu's work, which is to show how cultural practices are markers underlying class distinctions. Since habitus produces practices adjusted to the regularities of the conditions of existence, taste and etiquette, according to Bourdieu, are markers of social orientation and thus provide a "sense of one's place" (1984, 466). For example, the class distinctions between the residents of Chai Village, at the corporeal level, is evident if we consider that Dora's polyester dresses and plastic shoes would never be confused with the elegant silk blouses, slacks, and low pumps favored by Molly. Similarly, Anna's oversized, tarnished Star of David is in marked contrast to the refined, pure white pearls that adorn Molly.

However, it is not jewelry and garments alone that distinguish residents from one another; differences can also be gleaned through social etiquette and physical manner. Edna is aggressive and boastful, characteristics that are in marked contrast to Dody's propriety and modesty and her general objections to the indecorous, even brazen manner of Edna. There is an excessive swing of the hips that comes from Edna's heavy stride and even when seated there is a constant movement of her hands and feet. In contrast, when Molly walks her steps are delicate, and when she is seated, her legs are always crossed and her hands clasped in her lap. Molly's delicate manner is also apparent when she uses a paper tissue, softly wiping the tip of her nose, whereas Edna, in contrast, blows sharply and loudly, covering her entire nose and clenching it tightly with the tissue. When eating, Goodie is prone to putting large portions of food into her mouth at one time, using her hands as much as she does her utensils, and will invariably drop food down her front. Molly delicately puts food between her lips with reserve and restraint, always being careful not to get stains on herself.

All these propensities and movements of the body are socially qualified. This is so because, according to Bourdieu, each habitus embodies both the material conditions of existence of a class and the symbolic differentiations that categorize and rank its relation to other classes. Individuals are then predisposed to make lifestyle choices characteristic of their class habitus (1984, 172). Molly's refined clothing, jewelry, and table etiquette, in contrast to the aggressive, brash behavior of Edna, clearly are reflective of her different social origin. We see in the preceding examples a practical expression of class distinction, and to this extent, there is a practical equivalence between the different divisions of the social world and selfhood.

The class distinctions between the residents of Chai Village should not obscure the fact that the totality of each participant's manifestations of selfhood discloses internal consistency and coherence such that *all* manifestations are congruous with and representative of the particular social class of the individual. This is apparent when we consider, for example, the connection between Molly's wearing her pure white pearls; crossing her legs and clasping her



hands in her lap when seated; delicately placing food between her lips with reserve and restraint, always exercising care not to let food fall on herself; and finally, politely using her tissue to wipe the tip of her nose. There is a similar connection between Edna's excessively swinging her hips while walking; aggressively salting her food; loudly blowing her nose while covering her entire face with a tissue; and wearing a pedestrian style of dress, demonstrated by her loose-fitting sweaters and dated costume jewelry.

Coherence in the distinctiveness of embodied selfhood is not confined to bodily expressions of social class. Distinctiveness is also evident when we consider how spontaneity, and the ability of the residents of Chai Village to go with the inspiration of the moment, produced diverse practices that were relatively unpredictable, just as were their corresponding situations. The residents have the use of their bodies not only insofar as they are involved in a concrete setting but also to affect actions that go beyond the specificity of concrete tasks such as sipping a cup of coffee or removing one's shoes at the end of the day. Dora, for example, sang on her own accord; Edna often stopped to look at the paintings on the wall while strolling down the hallway; and Anna would glance at her wedding band and engagement ring while quietly sitting alone. There was spontaneity in the residents' openness to situations, whether this was of their own accord or prompted by others. Abe slow danced to a song playing on the radio with a health-care aide when prompted to take her hand; and when a Styrofoam ball was playfully tossed to Anna, she threw it back. In all these instances, the body puts forth beyond itself meanings that can be read as providing a framework for a whole series of experiences. In this regard, selfhood does not reside in organic processes but in human gestures and movements that issue from these processes. This is most apparent when we consider that the preceding examples are incomprehensible if selfhood is treated as a machine governed by natural laws, or even as a cluster of instincts.

The examples render visible how selfhood emanates from the body as a generative spontaneity that asserts itself in an *improvised engagement with the world*. The idea emphasized here is that the engagement of the self with the world consists primarily in the residents' intrinsic corporeality of *being-in-the-world*. This implies that self is grounded in the prereflective level of experience, providing "practical sense" (Bourdieu 1990) or "practical competence" (Merleau-Ponty 1962) for the residents to engage with the world. Selfhood animates their presence and endows with coherence and spontaneity their interactions with the world.

## Conclusion

In the literature on Alzheimer's, the implicit reference to a presumed loss of agency is a product of the Western assumption that only the mind relates us to

the world and gives it meaning, rendering silent and inconsequential the lived materiality of the body. Central to this perspective on the body is a concept of personhood that hinges exclusively on cognition and rationality, ignoring the significance of Merleau-Ponty's bodily schema and Bourdieu's notion of *habitus*. However, as I have argued, following Merleau-Ponty and Bourdieu, the existential and social aspects of the body are indispensable to the articulation of selfhood. The coherence of selfhood and its generative spontaneity reside in our embodiment, which is a synthesis of primordial and social being. It is an argument that challenges the current conviction that selfhood is tied exclusively to cognition, by treating the body as a primary source of selfhood and a facilitator of its articulation. This is not to suggest that the prereflexive body exhausts selfhood; however—and this is the crucial point—even if the residents of Chai Village were not as cognitively impaired as they were, or not impaired at all, still the prereflexive body would continue to be fundamental to the whole of their selfhood.

Although embodied selfhood is a concept I use to articulate and theorize findings drawn from a particular ethnographic setting, it is a concept that invites inference of larger scope. This is because, as I have argued, the primordial unity of the body as well as specific sociocultural dispositions, all of which sustain the self at a prereflective level, are fundamental to our existential being. In other words, the interrelationship of the primordial body, sociocultural bodily dispositions, and selfhood transcends cultural distinction. This is not to suggest that selfhood would manifest itself in uniform or identical fashion irrespective of the sociocultural context. On the contrary, the sociocultural specificity of selfhood, as expressed in one's habitual state and in one's tendencies and inclinations to act in a particular way, would be different from culture to culture. However, it is for further ethnographic research to explore what these differences are and what they mean in the context of the interrelationship between selfhood, the primordial unity of the body, and specific sociocultural bodily dispositions. Embodied selfhood by no means concludes the matter of body-self, body-world relations; nor is it intended to resolve the debate about the self in Alzheimer's disease. Thinking of selfhood as embodied provides new insight and direction for future investigation of the localized symbiosis of prereflective intentionality and structures of the social world. It is a symbiosis that is "enacted at every instant in the movement of existence" (Merleau-Ponty 1962, 89), rendering the animated, living, experiential body as of paramount importance for understanding the nature of human agency, selfhood, and embodiment.

#### NOTES

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1. The name of this facility is a pseudonym.
2. Cognitive impairment was measured with the Mini Mental State Examination (MMSE), a widely used method for assessing cognitive mental status (Folstein, Folstein, and McHugh 1975). Within my sample of study participants, the mean MMSE score was 11.3 and the range was 1–15 (mild, 19–24; moderate, 10–18; severe, 0–10) (Jones et al. 2004). MMSE scores have not been adjusted to remove the effect of age and education, which are said to be of etiological significance in dementia (Crum et al. 1993). However, by virtue of the fact that all participants resided on a secured Alzheimer's Support Unit because of the degree of their cognitive impairment, even if scores were adjusted for age and education, the adjustment would not have altered in a meaningful way their assessed degree of cognitive impairment.
3. The names of residents living in Chai Village, as well as any names of Chai Village staff referred to throughout this chapter, are pseudonyms.
4. Bodily discourse has played a significant role in the history of anti-Semitism, with claims of there being a differentiated Jewish body (for a discussion, see Gilman 1991). My analysis is in no way an attempt to essentialize a primordial Jewish set of bodily characteristics. On the contrary, I am demonstrating how the culture-specific conditions of socialization become, for my study participants, an important resource for bodily expressions of *their* selfhood.

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## Normality and Difference

### Institutional Classification and the Constitution of Subjectivity in a Dutch Nursing Home

ROMA CHATTERJI

In an influential essay on dementia care, Kitwood (1993) uses the notion of *culture* to orient caregivers to the communicative aspects of care on psychogeriatric wards. By talking about a “culture of dementia” he provides a new perspective on the way in which dementia sufferers are usually represented, that is, in terms of a loss of voice and of the possibility of constituting a lifeworld (Leering 1967; Chatterji 1998). He tries to think of the ward in terms of an intersubjective space that can be shared by both caregivers and patients, that offers possibilities for the development of a lifeworld. Kitwood’s work is important not only in the sphere of dementia care—he is one of the few scholars who represents dementia sufferers as intentional subjects who are responsive to community life—but also because he shows us what is at stake in achieving this sense of community. For him dementia becomes a way of problematizing the very idea of communicative sharing, for it points to the singularity of individual experience and to the fact that intersubjective relations may be built on differences rather than on commonalities. Thus, for Kitwood *dementia* means more than just a category of psychobiological pathology. It points to a special kind of care relationship and to a model of nonverbal communication in which there is a “heightened awareness of body language” (Kitwood 1993, 64).

In this chapter I shall use dementia as a thematic to talk about bodily disposition and the way in which it inflects the construction of ‘normal’ everyday life on a *verpleeghuis* (nursing home) ward in the Netherlands.<sup>1</sup> A term such as *the culture of dementia* allows me to think of the medical institution as a local moral world and to ask what is at stake in constituting the *verpleeghuis* as a discursive entity (Kleinman 1988). I try to problematize dementia by using it as a lens through which to reflect on the notion of normality as a mode of standardization produced through ward routine (Goffman 1961). Problematization is itself a

somewhat tricky exercise. As Rabinow (2003) says, it means that something must have already happened to introduce uncertainty in the familiar modes of engagement with the world. In this chapter I shall describe one such event that threatened to disrupt the routine on one particular ward and that led to the transfer of one of the residents to a ward that specialized in the care of behaviorally disturbed (*gedraags gestoord*) persons. This allows me to destabilize dementia as a taken-for-granted category and shows how it participates in other ensembles of knowledge and practice.

To this end I juxtapose a number of different discursive sites through which the verpleeghuis is materialized. Thus I begin with a brief account of the concept that was given to the firm of architects that designed Regina Pacis by Dr. Cornelius Leering, the first medical director of the institution. I then go on to describe the ward routine and finally the case conferences that preceded the transfer of the patient that I just mentioned. In the process I hope to show how dementia offers a vantage point from which medical practitioners in the verpleeghuis can reflect on conceptions of self and normality that structure regimes of work and knowledge. The particular ward that I have chosen to focus on is a somatic ward and does not offer dementia care. I do so deliberately, as there is a fine line that separates somatic from psychogeriatric groups as far as the verpleeghuis is concerned. For the organization, such divisions often function as modes of normalization, as disciplinary regimes for the management of the verpleeghuis population. But first, a brief account of the institution is in order.

The verpleeghuis, Regina Pacis, on which my ethnography is based is a “combined” geriatric facility that offers intensive nursing and medical care to elderly persons suffering from both somatic and psychogeriatric illnesses. *Dementia* as a term has very little operative significance in the organization of verpleeghuis work. Instead it is subsumed within more functional categories that are able to discriminate quantitatively between different kinds of corporeal capability. Instruments that measure corporeal capability, such as the Activities of Daily Life (ADL) rating scale, and quantify the extent of nursing care that a patient requires help to disaggregate the verpleeghuis population on the basis of a differentiated set of therapeutic goals.<sup>2</sup> *Dementia*, too, can be used to refer to a kind of corporeal capability but only in moral or evaluative terms. Thus, psychogeriatric wards are sometimes thought of as enclaves of tolerance where norms regarding bodily disposition that are crucial in sustaining the notion of a ward community can be interrogated.

### **The Verpleeghuis as Community: Architectural Design and Intersubjective Space**

In the Netherlands, verpleeghuis medicine is premised on the idea that diseases in old age are part of life and have to be managed as such. It is also recognized

that such disabilities often make normal life in the family and community difficult to sustain. This means that the *verpleeghuis* defines itself in terms of two major goals. First, it must offer specialized, long-term care for old persons suffering from multiple chronic pathologies; second, it must be a “complete community” that has to cater to all dimensions of a patient’s life (Leering 1970).<sup>3</sup> The fact that these two requirements can have contradictory effects is part of the problematic that I hope to address and is recognized as such by the practitioners themselves.

Cornelius Leering, a pioneering geriatrician in the Netherlands and, as noted earlier, the first medical director of *Regina Pacis*, tried to create a concrete structure that would fulfill both requirements. This involved restructuring the organization at several different levels—beginning with nursing activity, the coordination of different services such as medical and paramedical services, recreational services, spiritual services, and so on. It also involved a specialized architectural design—the construction of a new building whose spatial organization would reflect the primary orientation of *verpleeghuis* medicine, that is, a focus on the lifeworld of the individual resident.

Through a combination of fortuitous circumstances, such as the establishment of the Exceptional Sickness Costs Act in 1968, which helped finance treatment and paid for long-term stay in medical institutions such as the *verpleeghuis* and which in turn led to an increase in the number of *verpleeghuis* beds; the economic boom in the late 1960s; and new theories of architecture that tried to relate spatial design with concerns of the lifeworld; Leering was able to restructure *Regina Pacis* in terms of this new vision of geriatric care. Leering’s report elaborating these new ideas was submitted to the firm of architects in charge of constructing the new building in 1970. It is worth discussing here, since it not only gives a detailed account of geriatric medicine but also offers a specific representation of bodily being in old age and of invalidity as a crucial feature of this experience.

An account of Leering’s conception of invalidity, which relates the embodied being to an environment that is made palpable by the very fact of this embodiment, is necessary for an understanding of *verpleeghuis* culture. In the 1950s, when the first geriatric facilities were being established in the Netherlands, old-age impairments came to be seen in new ways. Active engagement with the environment came to be viewed as a form of therapy. Interestingly, this had ramifications for the treatment and nursing of patients with chronic disease as well. It was felt that such patients must learn to actively participate in societal processes and were encouraged to overcome the limitations of their disease. Bodily mobility came to be associated with well-being and became a sign of active engagement (Blommesteijn 1990).

Central to the relationship between bodily movement and well-being, in Leering’s work, is a particular understanding of invalidity. Leering (1968) de-

scribes the state of being invalid as a form of damaged embodiment (*geschonden lichamelijkheid*), that is, an inability to experience one's body as a coherent whole. This appears because the body is always other to one's self; it is made one's own through the process of socialization. Leering says that this form of invalidity has a particular connotation for the elderly that is not generalizable across generations. Thus a dependency on others for one's bodily movement, "giving oneself to the gaze and practice of another," as Leering puts it, is exacerbated in old age because it is coupled with a form of infantilization (1968, 23). In terms of bodily function this translates into a "disturbance" in the ADL, especially in those activities that are associated with personal grooming.<sup>4</sup>

What is the relationship between the ADL, the mode by which one experiences one's body as uniquely one's own, and the experience of the *verpleeghuis* as a "lived environment" (*leef klimaat*)?<sup>5</sup> For Leering, the experience of one's body, the capacity to make it one's own, involves both work and learning. The ADL scheme, which has to do with the constitution of the inner space of the self, involves purposive activities that transform external bodily space into one's private intimate space. The ADL functions are also the first step in the creation of a personalized public space. Thus, it is the responsibility of the *verpleeghuis* to organize its space in such a way that the potential for experiencing bodily coherence is restored. Wards are supposed to be color coded so that they can be easily recognizable by memory-impaired residents. Corridors connecting different parts of the building are broken up by points of interest and points of rest where residents can meet as if they were on a public street. Leering thought that color was an intrinsic part of the architectural design and suggested that it be used to direct movement within the building. "Light spaces," which were supposed to be accessible to residents, for example, doctors' examining rooms, or which were points of greater interaction, were demarcated from "dark spaces," which were meant for introversion but also for the performance of ADL, spaces such as bedrooms and lavatories but also others where technical services were carried out and that were kept out of sight. Thus, bedrooms and lavatories were sparsely decorated, in contrast to public spaces such as the living rooms on each ward, which were marked by distinctive colors and decorations. The shopping area and the café were located near the entrance to the *verpleeghuis* to give the residents the sense that they could go out with their visitors even while still being inside *verpleeghuis* space. There were even streetlights and benches placed in the shopping area, to reinforce the impression of a public square.

In an earlier work I described how Leering was influenced by the European phenomenologists, among them Merleau-Ponty and Minkowsky, who thought of space and bodily movement as crucial aspects of intersubjectivity (Chatterji 1998). A detailed discussion of this influence is beyond the scope of this chapter. Suffice it to say that Leering was aware of the architectural debates in the Netherlands and the influence of phenomenology on some of the postwar



trends in building design. However, he was following the principles of modernist architecture when he divided the living environment into spheres for the performance of different functions (Rabinow 1996). But for him these functions were mapped onto the phenomenological body of the invalid resident.

This account is clearly oriented to the somatic patient. Leering was primarily interested in revalidation therapy, and the ADL rating scale was not just a tool for organizing the verpleeghuis population. Instead, he thought of it as a fundamental aspect of a purposive engagement with the world. Purposeless action, the repetitive gestures that are often thought to be associated with dementia sufferers, found no place in this scheme. However, he did write an article on dementia, a literary piece, in which he uses invalidity to analyze the plays of Samuel Beckett (Leering 1967). He says that the experience of dementia comes closest to describing the absurdity that Beckett sees as a part of everyday life. For Leering, dementia is a metaphor for life lived for the moment, without temporal depth, and dementia sufferers have the unique capacity to experience both intense joy and sorrow, a capacity born of an exclusive orientation to the present.

### **The Ward: Normality, Dependency, and Disturbed Behavior**

In the previous section I dealt with the representations of the patient in terms of his or her phenomenological experiences and the manner in which there is an attempt, through the architectural design of the institution, to create a space for a potential community of residents, an alternative community in which the impaired elderly can lead “normal” lives. In this section I deal with the interactions that take place on the ward and describe the work involved in the constitution of this normality. The ward has an important role in the creation of this ideal of community. Day-to-day life on the ward is supposed to approximate normal life in the world outside the verpleeghuis.

A brief description of the organization of ward activity will demonstrate what I mean. Ward space is organized in terms of a temporal division between day and night. Thus, daytime activities are thought of as being part of what Schutz (1970) would have called the “wide awake world,” the world of purposeful social activity, and the night as the time of withdrawal into oneself. Verpleeghuis residents are encouraged to get out of bed in the morning, to dress, and to sit in the living rooms that are attached to the wards. The living rooms are thought to be spaces for socialization, but they are also places where nursing activity occurs during the daytime. I was told repeatedly that, unlike in the hospital, verpleeghuis nursing was focused on the chair and not the bed. Thus, living rooms are multifunctional spaces in which residents spend most of their waking hours. They are furnished with easy chairs and tables at which they eat their meals. They are encouraged to decorate the living rooms with some of their personal possessions, a favorite painting perhaps, ornaments, or even

greeting cards from visitors. There is an attempt to decorate the living rooms in the style to which the residents were accustomed when they were setting up their own homes. Considerable thought is given to the seating arrangements in the living rooms, to encourage “contact” between residents, in keeping with Dutch norms of sociality. Yet this sociality has to be sustained in the face of severe impairment and dependency that at first sight seem to negate the values of privacy and autonomy that inscribe patterns of Dutch social interaction. The following section is a description of the nursing routine on a ward in which there is an attempt to create a façade of normalcy that will conform to a model of sociality, one that consciously maintains notions of autonomy, privacy, and volition and incorporates them into the therapeutic regime of the *verpleeghuis*.

However, the actual “bed and body work” that makes up a significant portion of the nursing routine is often at odds with the therapeutic goals of the *verpleeghuis* (Gubrium 1975; Datta Chowdhury 1991; Paterniti 2003). Bed and body work is formally organized around the ADL scheme. Patients are perceived in terms of their ADL functions as “bodies in need,” to quote Paterniti’s evocative phrase (2003, 61; see also note 4, below). Paterniti is justifiably critical of this way of approaching patients—in terms of their deficiencies and the time taken to care for them. The nurses with whom I worked in *Regina Pacis* were aware of this criticism. It was an aspect of their work that was frequently discussed in ward meetings. They felt that doctors and social workers did not adequately understand the nature of their work. They felt that bed and body work was often the only way they had of achieving contact with their patients. Indeed, communication with patients is often very hard to achieve. But there is more at stake in bed and body work, as most nurses know but are rarely able to put into words. Given the taboo on touch in Dutch society, especially between strangers in public places, and the valorization of personal autonomy, intimacy is expressed through bed and body work as well. Relations of care and dependency that threaten the ideal of autonomy are framed by a professional work routine and thereby made acceptable.

This section is divided into two parts. In the first I describe my first day as participant observer/nursing aid on the ward and, through this, the daily nursing schedule. In the second part, I detail the spatial organization of a living room on the ward in which patients spend most of their waking hours. Through this description I attempt to show the contradiction between institutional ideal and organizational practice, for it is in the space of this contradiction that dementia emerges—not as a disease category, but as an alternate way of doing and being.

### The Ward Routine

I arrived at the Peppel (Poplar) at half past seven in the morning—my first day of fieldwork on the ward. I had been assigned to the blue unit. (Each ward is

divided into units of three with twelve patients each.) The nurse I had been detailed to work with had already begun the distribution of medicine. I was three minutes late that first morning, and work had already begun. The nurses on the morning shift usually arrive ten to fifteen minutes earlier. They drink what will be the first of innumerable cups of coffee together and smoke their cigarettes. At 7:30 A.M. on the dot, coffee cups are drained and cigarettes stubbed out, and one of the unit heads reads out the evening and night reports of the previous day. The day's roster is also read out, as well as any special appointments that a resident may have—to visit the hairdresser, go for physiotherapy, and so on. Then the bustle begins—people must be got out of bed, washed, and dressed, made ready to meet the day as it begins. The nurses working in the units pick up the washbasins from the storeroom attached to the ward. There are two for each patient, green for the upper part of the body and red for the lower. Each nurse also takes a tray, on which are cotton wool swabs, disinfectant, and nail clippers. If she is new or has no experience with the particular patients she has to take care of, she takes the ADL cards with her.<sup>6</sup> They will tell her what functions the person can or cannot perform.

I was sent off with a student nurse to help get people out of bed. The student nurse had a brisk and breezy air. She wasn't experienced enough to have developed the touches of intimacy that the more mature nurses use to soften the work technique. She kept up a cheerful patter as we worked. She would say to me, "Give me a hand here, catch hold of the shoulder like this . . ." or, "This one needs the lift . . . she's too heavy!"<sup>7</sup> She left me with a woman who had "a light demential image" (*licht dementieel beeld*). We were introduced to each other. She was lying flat on her back with her night dress rucked up. But she was wide awake and said, "Pleased to meet you," with great courtesy. The student nurse, now called away, left hurriedly, saying that I could manage on my own. Mw. Fokke (the patient) was easy to manage and would tell me what to do in case of problems, she said.<sup>8</sup> Mw. Fokke and I stared at each other rather uncertainly and I began the washing routine. Mw. Fokke kept saying, "I think I can do that myself—I do live alone, you know, so I must be able to do that on my own." But she spoke somewhat hesitantly and I decided to carry on. Then she said, "Things are a little different today, aren't they? Is there a shortage of staff?" The nurse whom I was originally supposed to be helping came up just then, and I asked her if Mw. Fokke could really manage on her own. She said, "Yes, that is true, but you weren't to know," and she delicately covered Mw. Fokke's chest with a towel. I realized at that point that it had been exposed.

I saw that I had been doing everything the wrong way. Nurses take great pains to ensure that the privacy of the body is maintained while performing invasive activities. The private parts are covered with towels when the washing is done—white for the upper half of the body and yellow for the lower. One starts from the face and moves downward, in stages. After each part is washed it is

quickly covered up with the towel. Most nurses carry on a conversation with the patient while they wash and dress them. Patients are encouraged to take an interest in their appearance—to choose their own clothes, comb their own hair, and so on.

There is a conscious effort to maintain the status of patients as “normal,” as I noted earlier. Nurses are taught to “frame” invasive activities so that patients’ privacy is not violated. Officially, the relationship between patients and caregivers is supposed to be that of strangers, signaled by normal-status behavior emphasizing distance and respect.

The nurse introduced me to each patient on the unit. She told them that I was here to see things and asked them if I could watch. The patients who could talk gave varied responses. Some were genial, others confused, and some rather sarcastic. One woman said, “She can watch my face, but not here,” pointing to her genitals. The ward-in-charge took the patient to task on this later: “Mw. We all look the same over there.” She turned to me, laughing. “She feels ashamed.” Another patient, Mw. Roosevelt, commented on the fact that there were two people beside her bed. The nurse told her that I had to learn and that I was here to write a book about the residents. Mw. Roosevelt muttered that she didn’t care if I was Sinter Klaas and was writing in my golden book.<sup>9</sup> She had Parkinson’s disease and her limbs were stiff and her movements awkward. At each stage of the process of dressing she would give us instructions: “You haven’t cleaned my eyes.” “I will do it last, with this ointment,” the nurse replied. “My back hasn’t been dried properly. Do it again!” This was directed at me; I had been scared of hurting her. Mw. Roosevelt wore elasticized support stockings for the edema in her legs. She was always anxious when the stocking was fitted over the bunion on her foot. She rapped out, “Bunion!” The nurse pressed the bunion to show that the stocking was safely over it. She resisted slightly when she was told that I was to do her hair, but she did so more as a matter of form. Her instructions to us were in the same spirit, to show us that she was still in control of the situation at hand. We held out a selection of necklaces and she chose one that matched her dress. The nurse deftly sprayed her with perfume and complimented her on her dress. She unbent sufficiently to say that her son had chosen it. Then the wheelchair routine began. The nurse and I put an arm under each armpit while Mw. Roosevelt gave us rapid instructions—“Turn me to the left . . . no more . . . now move the chair closer . . .” and so on. She wanted to visit the restroom first. We wheeled her there and left her with the calling bell in her hand. The nurse made a cross on the defecation chart under Mw. Roosevelt’s name. We rushed through the next job, breaking off for a quick cup of coffee, standing in the kitchen. It was 9:30 A.M.—the time when nurses take a five-minute break.

We got back in time to wheel some patients into the living room. Mw. Roosevelt, whom we had left in the restroom, was already ensconced in her

chair, at her place at the table. I wheeled in a rather mournful woman, Mw. Timmers, who sat at the same table. Mw. Roosevelt supervised the process. I got her breakfast from the kitchen. It was on a small plastic tray, covered with cellophane and with her name written on it. Mw. Roosevelt supervised the placing of the cup of Nutramel that she was supposed to drink: "On the right side; she can't see from the other side." Mw. Timmers whimpered softly. I asked her what the matter was. "She always does that!" Mw. Roosevelt said.

We broke for a fifteen-minute coffee break at 10:20 A.M. All the nurses gathered in the living rooms to drink coffee with the patients. After this we spent the rest of the morning cleaning the washbasins, the urinals, and the bedpans, as well as changing the bedsheets. As one of the nurses told me, "We give first priority to the people, the rest can come later."

Most of the nurses take their lunch break from one to one thirty. A few stay behind to receive the lunch wagon, which comes in at about this time. Lunch-time is another period of intense activity. Many of the patients have special diets, while some are part of the *eet tafel* project; that is, they are served food in the "normal" way—they eat from bowls, and they can serve themselves and choose what they want to eat. The other patients eat from prepared trays. The afternoons seem more relaxed after the hectic pace of activities in the morning. Patients doze in their chairs. Some go for activities to Het Stekje (the central activities room). The nurses write their daily patient reports and drink coffee with the patients. At 4:00 P.M. the day shift ends. There are fewer nurses on the evening shift because there is less work to be done. Patients eat a *brood maaltijd* (bread meal) and then go to bed. Nurses prepare patients' clothes for the next day—setting out a range of outfits from which patients can make their own selection if they are in the mood—match accessories, wash pantyhose, and so on.

The ward is very different at night. Most nurses hate the night shift because, unlike the day shift, which is filled with activity, it is monotonous. It is for this reason that it is called *de wacht* (the wait). There is only one nurse in the ward and she sits in the nursing station to attend to the bells that patients can ring from their beds to summon her. Most of the summonses are for bedpans. A student nurse called *de zwerf*, or "the rover," rotates between the three somatic wards in the verpleeghuis and helps to lift and turn patients who are given bedpans, incontinence mats, and related items.

The nursing schedule reflects contradictions in the identity of the organization at large. Relations between nurses and patients are supposed to be modeled on the service contract so that patients are seen as clients who are recipients of a specialized service (care), the modalities of which they are, ideally, free to negotiate. However, given the extent of impairment that marks the average verpleeghuis patient, which makes it difficult for patients to enter into the details of their care contract, and the bureaucratic constraints of large organizations, which turns patients into objects to be worked on, this is not usually

possible. Doctors sometimes complained about the “medical model” that nurses on the somatic wards seemed to have internalized. The doctor in charge of the Peppel would tell the head of the ward that her nurses should spend quality time with difficult patients and worry less about the work regime. He told me that nurses were trained to be task oriented and found it difficult to shift to a people-oriented approach. However, nurses on the somatic side felt that it was only through actual bed and body work that they achieved contact with patients. They are aware that nursing often involves activities that may violate patients’ privacy. (After all, touch is usually restricted among strangers. Ideally, nurses and patients are supposed to meet as polite strangers or as service renderers and clients.) It is only by channeling all physical contact through the ADL regime that they are able to maintain the facade of a service relationship.

The work schedule creates a rationally ordered structure on the ward, a structure that is supposed to have therapeutic value for the patients because it gives them a sense of continuity with the world outside. But it is also the only mode that the staff has of communicating with patients. The daily ritual of washing, dressing, and the choosing of accessories can also become the moment of contact, of renewing ties of affection between the nursing staff and the patients. In an earlier section I said that there was a contradiction between the specialized service that the *verpleeghuis* is supposed to offer—long-term care for patients with chronic disease—and the aspiration for it to be a community in which patients will be able to experience themselves as normal persons. Values such as autonomy and independence are central to the constitution of self and to participation in social life in the Netherlands. Perhaps the emphasis on a task orientation among the nursing staff was a response to this dilemma. Bed and body work may be the only mode that nurses have of relating to patients while still respecting the values that make the patients persons in this society. Respect for personal privacy is also possibly the reason why the ideal of normalcy is applied only to the public spaces on the wards. Patients are dressed as if they are ready to go out, and indeed they interact with one another as polite strangers in the ward living rooms. In fact, all interactive spaces in the *verpleeghuis* are organized as public spaces.

### **The Living Room at the Peppel**

In the preceding section we saw how Leering’s conception of corporeal intentionality is translated into a ward regime. Merleau-Ponty, from whom Leering borrows this idea, discusses corporeal intentionality in the context of the humdrum or routine aspects of everyday life. Institutional taxonomies, such as the ADL scheme, tend to literalize this, turning habitual routines, necessary for creating an intersubjective world, into regimented practice. In this section I move from the regime of bodily care and considerations of self that emerge from this

practice, to the ward community and to the potential of a shared lifeworld that may materialize within it. In phenomenological terms, intersubjective relations assume a notion of shared space. It is the animate or sentient body that becomes the common measure for this sharing. For Schutz (1970) there is a continuity of perspectives among actors in interactive situations based on the assumption that their bodily experiences are similar and therefore transparent to one another. He calls this the “reciprocity of perspectives,” subjunctively attributed by the self to the other. The self experiences the other through a unified field of bodily expression that reveals the other’s conscious life.

The reciprocity of perspectives is modeled on face-to-face interaction, which involves symmetry between the actors, as well as a certain spatial distance (cf. Berger and Luckmann 1967). In the *verpleeghuis*, a reciprocity of perspectives, as Schutz conceived it, is difficult to achieve. Intersubjectivity is made possible within the care relationship but not through the assumption of a symmetry between self and other. The care relationship is based on dependency and is therefore asymmetrical. Spatial distance is an important aspect of the self’s experience of its actions as intentional and for a sense of its autonomy. Whether or not this remains an aspect of one’s experience as a *verpleeghuis* patient is a question that will be explored in this section. Is the living room an intersubjective space? Do patients experience it as an aspect of their lifeworlds? I describe the living room (*woon kamer*) of the blue unit of the Peppel—the interactions between patients and the spatial arrangements that configure those interactions—in an attempt to address these questions.

Let me begin with a description of the seating arrangement. There were three small dining tables that divided the room into two segments. All three tables were positioned in such a way that residents sitting at them had a clear view of the park outside; the outer wall of the living room is made of transparent glass. Mw. Roosevelt sat with her two companions, Mw. Timmers and Mw. Fokke. As mentioned earlier, Mw. Roosevelt and Mw. Timmers sat in wheelchairs, which neither was able to maneuver independently. Mw. Roosevelt was a Parkinson’s patient and was not able to perform the arm movements required for pushing a wheelchair. She had refused the offer of an electric wheelchair. Mw. Timmers had hemiplegia and suffered from chronic depression. During my time on the blue unit I never heard her speak. She would communicate through groans and whimpers and, at times, through gestures. Mw. Fokke was becoming demented, as noted previously, but her condition was not considered advanced enough for her to be moved to a psychogeriatric ward. Adjacent to Mw. Timmers and Mw. Fokke were two other women, who also sat in wheelchairs, with legs outstretched. Their limbs were so rigid and so painful for them to move that they could not be maneuvered under tables. In the other half of the room, three women sat at a rectangular table near the picture window. Two of these women, Mw. Diekema and Mw. Smit, had their backs to the round table.



Mw. Diekema was severely diabetic and had had her right leg amputated, in two procedures; Mw. Smit had a complex set of somatic problems, but over and above this she had also been diagnosed as manic depressive. The three remaining women in the room were all stroke patients. However, Mw. Van den Berg, who sat at a small square table adjacent to the rectangular table, also showed signs of Alzheimer's disease. All attempts at fixing a daily routine for her had failed. Her food was left at her table and she picked at it intermittently. Other than the rhythmic movement of her jaw, she showed very few signs of animation. Mw. Klasen, her table companion, had a bulbar syndrome, her throat was partially paralyzed, and she was hemiplegic in her right side.

All the occupants of the room suffered from severely impaired mobility. The people whom they knew and talked to were the ones with whom they had eye contact. Mw. Smit once said to me, "I know Mw. Diekema and Mw. Guillet" (who sat opposite her at her table). "I know Adrienna Klasen and Mw. Van den Berg. I know when their birthdays are and where they used to live before coming here. But I don't know those ladies," and she turned her head, indicating the table behind her.

There was very little conversation in the room. Apart from the customary "Good mornings," silence reigned. This was broken by the cheerful voices of the nurses asking, "Mw.—? Tea?" Mw. Fokke would try her best to keep the conversational ball rolling at her table by reading out gory anecdotes from the local newspaper to which she subscribed. "The body of a teenage girl found in a highly decomposed state. Tsk, tsk, I wonder what happened to her? Perhaps she didn't get enough to eat. These young girls—always dieting!" Her comments were often rhetorical and did not require a response. The people in her vicinity would murmur something now and then. They tended to adopt a somewhat indulgent attitude toward her, because they knew that she was "confused" (*in de waar*). Mw. Fokke was one of the more active residents on the unit. She would go regularly for "activities" and to the gym, for physiotherapy. She participated in all the festivities that took place in Regina Pacis. Mw. Guillet, who was hard of hearing, kept herself occupied with her knitting and embroidery, but the others just sat silently at their respective tables.

Does the ward constitute an intersubjective community? At first sight it would seem not to be the case. It is only the seating plan that brought residents together into some kind of a relationship. Otherwise they all seemed to live in different worlds.

Mw. Klasen's presence in the living room acted as some kind of catalyst for the group. She threatened to disrupt the fragile structures of normality. She was a relatively young woman—in her early sixties—and had come to the verpleeghuis as a result of repeated strokes after she received radiation treatment for a tumor in her brain.<sup>10</sup> She had been a woman of considerable ability in her past life, a musician and a poet, and an intensely emotional person, according



to her sister. She had felt herself “disintegrating” long before she came to the verpleeghuis.<sup>11</sup> Her life was a tragedy, one of the many in the ward. The difference between her and the other residents was that she had not become resigned to this loss. She could neither speak nor write. Her right side was paralyzed and her spirit too tormented for her to be able to concentrate on learning to write with her left hand. She did have a mechanical communicator when she first came but could not bring herself to use it. Her anguish expressed itself in screaming that was considered unreasonable and unbearable by residents and nurses alike. She presented a bizarre picture—saliva dribbling down her chin because she could not swallow and skirt rucked up over her knees so that her catheter tube was visible. She was very restless, fidgeting with whatever lay within her reach, wheeling herself all over the ward, even going outside. The nurses felt helpless. They could do nothing for her, could not understand what she wanted. I found that her bouts of screaming ended immediately if she was held and caressed—if she was given undivided attention by one person. But it was difficult to do this within the confines of a somatic ward. Physical gestures are restrained. The extravagant physicality that Mw. Klasen was wont to display was considered threatening. She had to be transferred finally, to a psychogeriatric ward, not because she was thought to be a psychogeriatric case but because the norms of behavior there are different.

Why was Mw. Klasen’s presence so threatening to the others on the ward? Was it because she upset their notion of spatial order? As I have shown, interactive space in the living room is largely delimited by where one sits and with whom one has eye contact. It is as if the rim of the table becomes the boundary demarcating intersubjective space. The notion of intersubjectivity assumes a conception of bodily intentionality that is based on norms regarding locomotion, object manipulation, and communication. It is largely through bodily intentionality that subjects acquire the kind of individuation required for participation in communicative relations. It is by positioning our bodies freely vis-à-vis other bodies and objects that our environment is made habitable. Thus, image schemas of the body organize the kinds of worlds in which we live (cf. Merleau-Ponty 1962). In the verpleeghuis, patients rarely conform to the bodily norms that are required for the kind of intersubjective relations that the phenomenologists describe. Norms of spatiality and motility are imposed externally, as patient’s bodies are often not capable of free and independent movement. Body images are fractured because patients are not capable of achieving the expressive unity that would give them the freedom to command the space that they require for making their own worlds.

The living room, as I have described, gives the impression of rigid spatial order, externally imposed. Patients are dependent on others for locomotion; they rarely move around the ward on their own—except Mw. Klasen. Her move-

ments, however, were not perceived as intentional. They were threatening because they were enigmatic. She did not conform to the norms required to sustain the kinds of communication that was possible on the ward. Most of the patients whom I have described did resort to gesture to communicate their wishes to the nurses; conversation was minimal other than as responses to the nursing staff. Some of the patients used words very effectively, but they tended to do so in an attempt to affirm their presence on the ward or to express their autonomy. The patient who was capable of movement and who did use speech to establish communicative relations with others in the living room was Mw. Fokke, and she was considered to be confused, though quite harmless, by the others. It was only Mw. Klasen who moved around the ward constantly—and who screamed. It was as if she breached the norms of spatial distance that people felt was necessary to sustain their own conceptions of personhood in the ward.

It was thought that a psychogeriatric ward would be more suitable for Mw. Klasen, because such wards tolerate a wider range of differences. It would also be able to provide her with a form of therapy that was difficult to find on the somatic side—that is, close physical contact. As I have already said, the loss of inhibitions caused by cognitive disturbances among psychogeriatric patients allow the nurses to communicate with them through touch. This is usually not possible on the somatic side, where the Dutch inhibitions on touch between strangers are observed. The nurses touch patients only when washing and dressing them, and this touch is kept impersonal to ensure respect for the patient's autonomy. The self of the patient is constituted differently on the two sides of the *verpleeghuis*. In the case of Mw. Klasen, as we shall see, the change of residence also resulted in a change of identity.

In this section I have tried to show how selves emerge in the complex imbrication between institutional ideals and organizational imperatives. Public order is internalized to produce a certain conception of the disciplined self. The division between the somatic and the psychogeriatric wards does not only arise from the taxonomy of disease but also assumes different orientations to care. Theoretically, patients in somatic wards are capable of being rehabilitated. Patients in psychogeriatric wards are not. As we have seen, this division is not strictly maintained. There were at least two patients with dementia in the blue unit. They were tolerated because their presence was not overly disruptive. Mw. Albers was thought to be still aware of her surroundings and to have too much of a consciousness of self to be transferred to a psychogeriatric ward. Mw. Van den Berg's presence on the Peppel was more difficult to justify. Her daughter insisted that she was not demented and therefore did not belong in a psychogeriatric ward.

There is a sense of fear regarding the psychogeriatric side that is shared by both nurses and patients. As will be shown in the following section, nurses

resist sending their patients to such wards. There is a fear of infantilization, of regression from the somatic ideal of rehabilitation and the hope of the recovery of a social self.

### **The Remaking of the Self: Transfer to a Psychogeriatric Ward**

In organizations, entrances and exits carry a symbolic charge. They reveal the limits of organizational discipline and threaten the fragile order negotiated from day to day (Goffman 1961; Strauss et al. 1973). However, the decision to transfer Mw. Klasen to a psychogeriatric ward was not taken lightly. It took several months and many anguished meetings between the nursing staff, the doctor, and the verpleeghuis psychologist before the final decision was taken. Even then, there was a certain amount of anxiety among the nursing staff about the outcome of the transfer but also a helplessness, as if Mw. Klasen's conduct represented an insurmountable barrier that their professional training did not allow them to cross. Here I provide an extract from the case conference.

DR. HUUB: And now Mw. Klasen—who wants to begin?—you, you, you. (*He points in turn to the two nurses from the blue unit who are present and then to me.*) You, too, have something to do with her. (*He does not follow the usual style of conducting a case conference. These usually begin with a brief introduction giving the patient's medical status.*)

JENNIE, THE UNIT HEAD: Her behavior has been changeable [*wisselend*]. There is a mental deterioration. Earlier, there was more contact with her. She responded to us more. It is not as if she doesn't now. But then, it was as if she was actually going to say something. And now she behaves in this strange fashion—the crazy screaming, the contortions in bed—she even had her head stuck in the bed frame last week. And the weeping. It is difficult to know what is going on with her—yes, one can guess, I suppose.

DR. HUUB: She looks better though, physically, than when she first came here.

ELIZABETH, THE WARD HEAD: When she is physically weak, she is more tranquil. Now that she is better she has become more restless.

DR. HUUB: She sits facing Mw. Van den Berg—couldn't be much for her there.

JENNIE: That's why we position her wheelchair in such a way that she can look out the window.

JUDITH, A NURSE: She enjoyed the singing in the recreational therapy room last Friday.

ELIZABETH, A NURSE: We have been asked not to send her again. She started to scream and the other residents were frightened. Why she does it we don't know.

DR. HUUB: (*Turning to me*) You told me that she liked music.<sup>12</sup>

ANNIE, THE SOCIAL WORKER: She used to play the organ and the recorder.

DR. HUUB: This is a woman with severe cerebral injuries, but with moments of clarity. She needs individual care. She was an intelligent woman once, she made something of her life and then this . . . I know you all have too much to do. Try and get a volunteer.

*(At this point there is no discussion regarding her transfer to a psychogeriatric ward. The staff is still working with a model of rehabilitation and hopes to help her acquire a social disposition that is in conformity with the normative expectations of the ward.)*

Three months later at another case conference . . .

DR. HUUB: Last month, on January 6 to be precise, we had asked the psychologist to examine Mw. Klasen to consider the question of transfer [*overplaatsing*]. *(He summarizes her medical history.)* She has had a meningioma and a number of CVAs. She has always been hysterical—according to her sister, that is.

MARTIJN, THE PSYCHOLOGIST: Her actions and thoughts seem unconnected. At least there is a fluctuating connection. She is easily distracted.

DR. HUUB: Is she conscious of her failings?

MARTIJN: I hope not, for her sake.

DR. HUUB: . . . and the unstoppable screaming?

MARTIJN: I don't know what's going on in her head. Transfer to the other side has ethical problems. It won't help her—but it depends on the other thirty-five people. *(He is referring to the other residents of the ward.)*

DR. HUUB: The change has no advantages for her. She is very sensitive to atmosphere. *(Turning to me)* You have spent a lot of time with her. Do you want to say something?

ROMA, THE ANTHROPOLOGIST: She can't communicate.

DR. HUUB: Yes, yes, I understand. That's why she screams—because she can't.

ROMA: And she isn't demented.

MARTIJN: Yes, but there is a fluctuating chaos in her head.

DR. HUUB: *(Summing up)* A woman with organic injuries whose behavior is disturbing for others.

ELIZABETH: I know that she is disturbing—but we have invested so much energy in her. We have spent hours feeding her—Roma has as well. What if she gets worse? Can we get her back?

MARTIJN: No. There is a discrepancy between her pattern of expectations and that of the ward.

DR. HUUB: We don't have any other choice. We have the whole institution to think of, not just one individual. But we have to be careful about the choice of ward.

The theme that strikes me as most significant in this discussion is the attribution of agency to the patient. Mw. Klasen's behavioral anomalies are attributed to her communicative incapacity and to personality quirks rather than to her illness per se. Her behavior was thought to be opaque. She was not capable of internalizing a discipline that would produce a socially embodied self in alignment with institutional norms. The logical way out was to transfer her to a ward where opaque behavior was the norm, where action was not thought to be an outcome of will or intention.

As it so happens, she was much happier in the psychogeriatric ward and, as is the case with many verpleeghuis residents, she expressed this through her body. The image of her in the somatic ward had been that of a woman tottering on the edge of chaos, restrained with great difficulty. She had limp, dank hair falling from a point in the center of her head (the rest had fallen out as a result of radiation treatment). This set her apart immediately in a room full of perms and well-groomed buns. She sat in a wheelchair with a restraining belt around her, a catheter tube visible on the side. The nursing staff, in all fairness to them, did try their best to turn her out neatly, but her mental state was such that she did not care about her appearance.

After she was transferred to the new ward, the nurses began a series of normalizing experiments. They began by removing the belt. She did fall once or twice, but on the whole this experiment proved successful. She no longer sat in a wheelchair. She had already begun to walk, supported by a nurse, while on the somatic side. Now she was given a stick. (This also made her more immobile, of course.) Her hair was permed and she was encouraged to eat on her own. She was more at peace with herself and her surroundings. She developed a special friendship with a fellow resident; he gave her a new name, "Mien," and she seemed to prefer it to her own. There was a new desire to communicate and to establish links with what she had been before. Her sister described how she had asked for her old books and the poems that she had once written. She said that she had noticed that Mw. Klasen was scribbling something with her left hand. There was a scribble, then a *g*, another scribble, then a *d*, and she suddenly realized that Mw. Klasen was writing *gedichten* (poems). When I visited her she would show me pictures from her childhood, the books from her nursery school, and some of the poems that she had written.

She was happy in this ward, as expressed through the new relationship she was trying to establish with the past. But there was also a dislocation from, a renunciation of, another part of it—the torment and suffering that had dominated at least a part of her adult life. I sorted out her papers with her. She would laugh at the old schoolbooks and the children's poems that she had written, but turned her face away in distress when we came across some short poems, almost jottings, in which she had expressed her despair at the meaninglessness of passing time.

Forgetting is not always something that overtakes one. It does not just simply occur; it can also be a deliberate choice, not just a loss, but a renunciation. For Mw. Klasen, the past was in a way embodied in the family and the community from which she had to be dislocated after entering the institution. In the somatic ward, she expressed this dislocation through screaming and her disheveled appearance. After being shifted to the psychogeriatric ward, she seemed to calm herself down by bracketing away a certain part of her past and to begin inhabiting a different region, that of her childhood. The tolerance in the psychogeriatric ward of childlike behavior and the liberty to be different, since norms establishing and representing the ordered body were less strictly adhered to, allowed a temporary equilibrium.<sup>13</sup>

However, it is inappropriate to attribute Mw. Klasen's transformation simply to a process of infantilization. As a result of the normalization experiments that were being tried out on her, she developed a new consciousness of self and an awareness of her presence on the ward vis-à-vis the other patients. Paradoxically, the psychogeriatric ward was able to achieve what the somatic ward could not. Mw. Klasen was redefined as a socially embodied self. As I have said, Mw. Klasen's transfer was an acknowledgment that the goal of rehabilitation—that is, the reconstitution of social embodiment for selves who are damaged in this regard—could not be achieved in her case. It was acknowledged that it was a result of the social dislocation in the ward, a dislocation in interpersonal relations, rather than of any biological disturbance caused by her illness. The psychogeriatric ward was able to instill an inner discipline precisely by accepting her on her own terms. However, the process of resocialization did involve the sacrifice of some part of Mw. Klasen's biography, of the passions, emotions, and intellectual concerns that marked much of her adult life.

She died a few months later. Her anguish on the Peppel had had a positive side. She had not given in to her illness completely; her restlessness had been a sign of her effort at orienting herself to her new environment in the verpleeghuis. It is as if she gave up on life after her transfer—not in despair, because she seemed happy, but as a conscious choice.

## Conclusion

In recent years, dementia studies has made a significant contribution to strengthening the relational perspective on the self by describing the influence of intersubjective processes on its preservation and dissolution. Cross-cultural ethnographies have made us sensitive to the importance of culture in understanding personal and institutional responses to dementia (Sabat 2001). However, cross-cultural comparisons of institutions, especially medical institutions, are not so common. Such endeavors are complicated by the diversity of institutional arrangements that are present in any given society. Particular

institutions have cultural patterns, norms, and expectations that are specific to them, even if they all tend to conform to the general normative structures of the wider society. Cultural plurality can exist even within an institution. Thus, the two wards in the medical institution that I describe seem to embody different kinds of cultures, such that demented persons are viewed somewhat differently in each of them.

There is a danger, however, in analyzing institutions through the prism of culture, as I have done. Cultural relativity, when inscribed in self-referential bureaucratic systems such as the one I describe, can be used strategically as a justification for the perpetuation of such systems. Contradictions within the system are perpetuated, as there is no outside source to which it is accountable. Thus in the context of the verpleeghuis, the ideal of verpleeghuis medicine—individualized norms, which establish a unique relationship between the subject and the verpleeghuis environment—seems to be in a contradictory relationship to the reality of organizational functioning, which is based on “dividing practices” that classify and distribute patients in terms of externally imposed norms (cf. Rhodes 2000).

From this perspective, Leering’s references to the work of Merleau-Ponty and his discussion of the embodied self can be viewed as an attempt to “naturalize” this contradiction by locating it within the person rather than in the techniques of normalization instituted by the verpleeghuis (cf. Leering 1968, 1970). However, a careful reading of Leering’s proposal to the architects who designed the new building reveals a more complex picture. Leering took pains to define the two central concepts that he used in talking about the individual norm in relation to the environment of the verpleeghuis. One was *leefbaarheid*, the quality of habitability; the other was *menselijke functioneren*, human functioning. *Leefbaar maken*—to make habitable—that is, to create an environment in the verpleeghuis that would allow the self the possibility of true embodiment, the ability to offer itself to the subject’s senses and intentions so that the patient could function as a complete human being (cf. Leering 1970, 6). This allows us to consider the dividing practices in the verpleeghuis—the division into somatic and psychogeriatric sides—as an attempt to realize this ideal.

Clearly, this division has more than a diagnostic or a therapeutic basis. As we have seen, a person’s location in a particular ward may sometimes be based on nonmedical criteria. Dividing practices also produce subjectivities. Patients become who they are in the process of interactive reflexivity with others in the ward, as well as through their sense of where they are, as we saw in the case of Mw. Klasen—a nondemented person in a ward for people suffering from dementia. Why did she accept the normalizing practices here, when she had rejected them earlier, on the somatic ward? Is it because on the psychogeriatric side, differences are accepted as the norm? Or alternatively, one could say that



both sides operate within the same disciplinary regime. They merely use different strategies.

Rhodes (2000) thinks of medical taxonomies as offering possibilities for organizing “the many forms of otherness that mark the limits of . . . manageability”—of the self and of discipline in total institutions. While the specific forms of classification in the *verpleeghuis* may partake of this logic, I prefer to think of the somatic and psychogeriatric sides as alternative to each other—each one representing a different kind of normality and offering a particular form of normativity (cf. Rabinow 1996). However, it is only from the vantage point of psychogeriatrics that it is possible, within the *verpleeghuis*, to reflect seriously on the idea of differences and to accept the challenge of constituting new norms in new environmental contexts.

#### NOTES

1. The term *nursing home* is not really a correct translation for *verpleeghuis*. Caregivers stress the fact that inmates *reside* in the *verpleeghuis*. It is not their home. However, until the late 1960s the designated term for such institutions was indeed *verpleegthuis*, which can be translated as “nursing home.” This was officially changed to *verpleeghuis*, “nursing house,” in keeping with the medical goals of the institution and an emphasis on its professional functions. However, there is also a normative dimension to this change of designation. In the Netherlands, the home is considered to be part of one’s private sphere and cannot be substituted by formal institutions of any kind.  
My ethnography is based on fieldwork in Regina Pacis, a *verpleeghuis* in Arnhem in 1986–1988 and again for a short period in 1989. I was able to pay a brief visit to Regina Pacis again in 2000. The fieldwork was funded by the Indo-Dutch Programme for Alternatives in Development.
2. The instrument that quantifies extent of nursing care is the Behavior Rating Scale for Old Patients (Beoordelingschaal voor Oudere Patientten [BOP]).
3. *Verpleeghuis* medicine is distinguished from the kind of medicine practiced in hospitals. It operates with a chronic-care model in opposition to the acute/cure model that characterizes the medical regime in Dutch hospitals.
4. Leering defines function as goal-oriented action (cf. Leering 1970). The ADL functions are as follows: bathing/washing, clothing oneself, ability to use the toilet, eating, and continence. Leering thought of the ADL in terms of activities that were concerned with the private space of one’s own body. He chose not to include walking in this scheme because it involved more than this private space. He thought of it as an activity that involved public space (cf. Leering 1968).
5. Interestingly, Leering never talks about the capabilities of patients when he discusses the need to make the *verpleeghuis* a personalized space. The onus is on the designers and the caregivers. This is in marked contrast to the emphasis he gives to patient initiative while discussing revalidation and the ADL (cf. Leering 1968, 1970).
6. I use the feminine form deliberately. Even though there were five male nurses in Regina Pacis at the time when I was doing my fieldwork, there were none on the Peppel.
7. The lift is a crane that is manually operated to lift up people who are very heavy from their beds on to their wheelchairs.



8. Mw. is the abbreviation for *mevrouw*, meaning "madam." Verpleeghuis residents are always addressed formally by the staff as if to stress their autonomy. Since the nurse-patient relationship is often invasive, this is one of the ways in which formal distance is sought to be established.
9. Sinter Klaas is a figure of folklore who distributes gifts to children at Christmastime. He records the good deeds of children in a golden book and the bad deeds in a black book. I think Mw. Roosevelt was responding to an implicit infantilization that was taking place. She was used to the fact that she needed help with the ADL but she probably felt that more than one person helping her diminished her status as an adult with an attendant claim on privacy. Before I had started work in the ward I had circulated a note on what I proposed to do on the ward and in my discipline, cultural anthropology. In India my designation is that of a sociologist, but since I am one of the rare breed of sociologists who have studied a society other than their own, it was easier to call myself an anthropologist while I was in the Netherlands.
10. The average age of the verpleeghuis patient more than seventy years.
11. *Disintegrating* is the term Mw. Klasen used to describe her condition in a letter she wrote to one of her previous doctors before she was treated for the tumor in her brain. Patient records are supposed to be as complete as possible. Considerable effort is taken to collect documents from all medical institutions with which the patient has had contact. Even personal correspondence between the staff of such institutions and patients are gathered together for the patients' dossiers.
12. On my first day on the ward, someone switched on the television while I was feeding Mw. Klasen. A recording of Vivaldi's symphony *The Four Seasons* was being broadcast. She looked up immediately with an arrested expression on her face. I remembered reading in her case file that she had been an accomplished musician before her illness. I asked her, "Mw. You played an instrument, didn't you?" She nodded and her face broke into a radiant smile.
13. Els van Dongen (1997) speaks of infantilization as a way of relating to the ungovernable body. It invites the imposition of disciplinary techniques—the imposition of external rhythms of work and patterns of bodily care—but also allows trust and intimacy between caregivers and patients. It is one way of overturning norms of autonomy and bodily discreteness.

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## 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).<sup>1</sup> This was one of my field sites for my study of the psychiatry of aging.<sup>2</sup> 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.<sup>3</sup> 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).<sup>4</sup> 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.<sup>5</sup>

### Divided Gazes

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.<sup>6</sup> 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).<sup>7</sup>

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.<sup>8</sup> 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.<sup>9</sup> 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.<sup>10</sup> 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).<sup>11</sup> 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.<sup>12</sup> 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).<sup>13</sup>

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.<sup>14</sup> 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.<sup>15</sup> 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.<sup>16</sup>

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.<sup>17</sup> 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.<sup>18</sup> 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.<sup>19</sup> 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.<sup>20</sup> 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).<sup>21</sup> 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.<sup>22</sup> 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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## Being a Good *Rōjin*

### Senility, Power, and Self-Actualization in Japan

JOHN W. TRAPHAGAN

During the summer of 2000, six women and three men gathered at about ten o'clock in the morning at the Furiiai Puraza (Contact Plaza), a senior center located in the town of Yonegawa in northern Japan. The group assembled for the first day of a cooking class that would meet six times over the following three months. As the participants, all of whom were in their late sixties and early seventies, waited for the class to commence, the director of the center spoke briefly about his hopes that all the students would learn not only to cook, but also about proper nutrition. The class, he said, fit within the “goal of having zero people using the *kaigo hoken* system”—the long-term-care-insurance scheme initiated in 2000 as a comprehensive social program aimed at helping people cope with frailty and disability in old age (Campbell and Ikegami 2000; Traphagan, forthcoming). He then went on to inform everyone, “There are various kinds of uneasiness [*fuan*] that the elderly encounter: economic uneasiness, social uneasiness, and so on. This sort of class should help prevent this uneasiness, at least at the social level.”

After the introduction, the women in the group headed for the kitchen and began managing the process of cooking, using as a guide the recipe they had been handed by the instructor and largely ignoring the few directions she gave. All the women, having used the facility for a previous class, knew where all the pots and pans were located and were adept at food preparation. The men, in contrast, were for the most part uninvolved with the preparation of the food. Two of them helped with peeling some of the vegetables and then went to the adjacent room to smoke. The one man who participated in the entire process of preparation was seventy-five years old and lived alone, having lost his wife about a year earlier. As the women boned the fish and made a mayonnaise



dressing for the salad, I asked him if he enjoyed cooking and he quickly replied, "No, but it's better than eating at restaurants all the time."

For this man, there were practical consequences of taking the course in terms of learning something about cooking so that he could take care of himself, but for most who were involved, instruction in cooking was virtually irrelevant. Throughout the morning, there was no specific instruction in the preparation of the food; instead, the "class" seemed to be an opportunity for the participants to get together and cook. The one time that the instructor did offer advice was during a brief summation of the day in which she went over the nutritional value of the meal that the class had prepared. She indicated that fish is very high in calcium, a point that she had made casually several times during the preparation, and that it was very important for the elderly to have calcium to strengthen their bones. She also commented on the high nutritional value of using mayonnaise in the salad dressing because of its plentiful calcium, ignoring the various drawbacks to mayonnaise, such as its high fat content.

In many respects, the cooking class had little to do with nutrition or learning to cook. As noted above, there was virtually no instruction in how to prepare the meal, and the men, all of whom lacked knowledge of cooking, either stayed out of the process or simply observed the activities of the women, who already knew what to do. Rather than being centered around learning to cook, the class had as its focus two key issues that are closely tied to conceptualizations of growing old in Japan: (1) being involved in group activities is essential for a good old age, and (2) maintenance of health in old age, in part accomplished through such group participation, is a social and moral responsibility that is fundamental to being a good *rōjin* (old person). The placement of the class within the context of the senior center and the center director's characterizing the class as a means for the participants to avoid the *kaigo hoken* system are intertwined with the moral discourse on old age and senility in Japan. Local governments use a narrative that emphasizes the moral concepts of effort and self-cultivation in the project of being a good *rōjin*.<sup>1</sup> Engagement in these practices is presented not only as positive behavior for personal reasons, but also as a moral responsibility, to be carried out by being involved socially in contexts such as the cooking class. Social interaction forms a valued "object" (Bell 1975, 82) that is implied through the manner in which government officials strategically deploy rhetoric and manipulate the discourse on growing old. The context of the Furiai Puraza, and numerous other, similar contexts in which elders come into direct contact with government officials, form a matrix of power relations, structured not only in terms of dominance, but also as a strategic field through which the concept of a "good *rōjin*" is both conceptually and practically defined by both government officials and those who are potential users of the social services and government facilities (Foucault 1978, 94). At the center of this strategic field

of power is senility, which in certain forms represents a basis for differentiation, distinguishing the good rōjin from the bad.

Foucault's conceptualization of power having been invoked, it is important to point out that while I think that Foucault is largely correct in his notion that power and resistance are typically found together (1978, 95), in the example discussed here, it will become clear that the object toward which the use of power is directed—maintenance of physical and mental well-being through social interaction—is valued both by those who make use of such facilities as the Furiiai Puraza and by the government officials who invest their time and sometimes political careers in the development and use of those facilities, even if this object is valued for different reasons. Thus, there is little call for resistance.

Power, as it relates to the discourse on old age in Japan, is conceptually structured in terms of the notion of *ikigai*, which translates loosely as “one's *raison d'être*” but which is better understood as signifying a moral ideal that emphasizes self-actualization and self-discipline. *Ikigai* is employed by government officials as a means of encouraging older people to focus their primary attention on maintaining physical and mental health. While this is certainly beneficial to the elderly themselves, its use can also be understood as a subtle form of coercion in which old bodies are directed to become (self-) disciplined bodies through the exploitation of the moral force contained in the concept of *ikigai*.

### Northern Japan

The Furiiai Puraza, described briefly above, is located in the center of a town of about eight thousand people and to which I have given the pseudonym Yonegawa. Like most such facilities in Japan, the Furiiai Puraza is little more than a kitchen and a few rooms that can be used for many different types of activities. On the day of the cooking class, another group of women was using an adjacent room for a sewing group that met on a regular basis. This particular facility was built specifically as a location for older people to gather in, and one of the town officials explained that its construction was made possible by funding connected to the *kaigo hoken* program and that the center was specifically intended to be part of that program as a means of helping people be active and, thus, hopefully maintain physical and mental health further into old age. This, in turn, would mean less drain on other resources for elder care, such as nursing visits, home helpers, or more expensive needs such as nursing home residence.

Yonegawa is an agricultural community devoted to rice farming, situated a few kilometers outside of Akita City, the capital of Akita Prefecture, on the northwestern side of Japan's main island of Honshū. Yonegawa is one of three

locations where I have conducted fieldwork since 1994, the other two being in the neighboring prefecture of Iwate. In each of these locations, I have held numerous discussions with people about their ideas, perceptions, and attitudes concerning senility. The region's heavy orientation toward agricultural production defines it as one of the most rural areas of Japan; and, indeed, many of the older people who live in the region have spent at least part of their lives engaged in agricultural production. The toll of the hard labor involved in rice farming is evident in the bodies of the elderly, particularly the women, who often have bowed legs and severe osteoporosis that leaves many permanently bent at the waist at a ninety-degree angle. Moving around to do simple household chores or errands about town is difficult for these women, as they struggle to hold their heads upward as they walk. Locals often attribute these back problems in women to years spent in the rice fields bent over for planting, weeding, and harvesting, but it seems equally likely that a lack of calcium in the traditional rice diet also played a significant role.<sup>2</sup>

Throughout the region, broad expanses of checkerboard rice paddies stretch out to meet a dark green mountain range, whose peaks are snow topped from September until June. While rice is the central agricultural product, apple orchards and dairy farms are also common throughout the region, particularly in Kanegasaki, where dairy farming plays a major role in the town's economy. Although agriculture is important economically and the region is viewed as rural, the presence of industrial society is unavoidable. Along with the rice paddies, mountains, and winding rivers, there are automobile factories, semiconductor-production facilities, high-speed rail lines, and shopping centers. The region is closely linked to Japan's high-tech economy and is tightly integrated into modern society. Satellite dishes are a common sight on houses throughout the area, and sport utility vehicles are a ubiquitous mode of transportation to the area's supermarkets, shopping malls, discount stores, and video arcades.

### Senility, the Japanese Version

Elsewhere, I have presented detailed discussion of the cultural construction of senility in Japan (Traphagan 2002, 2000, 1998a, 1998b); here I will offer only a summary of the main issues, emphasizing the manner in which senile bodies are differentiated from healthy bodies and the linkages between concepts of individual and communal well-being (cf. Cohen 1998). Although the concept of senility in Japan overlaps with the North American version, important differences shape the way in which Japanese think about functional decline in old age and the ways in which people react to the potential onset of senility. Three categories of senility obtain in the Japanese context: Alzheimer's disease (*arutsuhaimā*); other forms of dementia associated with old age (*rōjinsei chihō*),

such as vascular dementia; and *boke*, a polysemous term that is difficult to translate directly into English but in the broadest sense connotes “being out of it” or a combination of physical and mental disorientation (Traphagan 2000, 135). The first two categories are primarily thought of as biomedical or clinical categories of disease, understood in terms of a pathological cause that is largely outside the control of the individual. When people refer to these conditions, they often use the phrase *shikata ga nai*, a kind of shrug of the shoulders meaning “there’s nothing one can do.” Long (1999, 19) argues that this phrase indicates a sense that circumstances are beyond one’s control, but also may index attempts to maintain personal control over the process of dying and the sense of self in the face of terminal illness, which is in many ways not differentiated from death itself. Similar to terminal illnesses such as many forms of cancer, there is a belief with these types of senility that when control is lost, “existence is no longer thought of as a truly human life” (Long 1999, 19). For the victim of Alzheimer’s or other biomedical categories of senility, the victim and those around him or her are beyond the point of being able to exert effort to change the circumstances of life caused by the onset of the disease.

The third concept, *boke*, is typically viewed as a social category of illness over which people have some degree of control. Although the idea of *boke* is nothing new in Japan, the concept emerged as a central feature of public discourses on aging in the 1970s, after the publication of Ariyoshi’s (1972) novel *Kōkotsu no hito* (Person in Ecstasy), which describes the tribulations of a woman attempting to care for her senile, and increasingly difficult, father-in-law. Ariyoshi’s work pointed out not only challenges faced by those who must care for elders experiencing dementia but also the horrors of losing one’s capacity to function normally and interact with others—the capacity to be socially involved representing a key element of a good self and a normal life in Japan. In relation to its onset and progression, *boke* is conceived in terms of a narrative that elaborates a theory of selfhood in which selves, as Dorinne Kondo notes, are not separable from the contexts in which they are constructed and maintained through active involvement in “culturally specific forms of pedagogy” related to self-building and enacted through social participation (1990, 77). This pedagogy of self-enactment, as I will discuss below, is consciously developed and encouraged by government officials and is particularly important when it comes to the elderly, who are at risk of losing the ability to engage in self-building because, as a result of their age, they have greater potential to experience or allow a reduction in activity. *Boke* symbolically represents the disintegration of an intersubjective self and loss of the ability to engage in the pedagogies of self-actualization that are critical to creating ideal selves (Traphagan 2002).

It is important to point out that it is impossible to draw a line that would clearly mark the distinction between biomedically defined forms of senility and *boke*. Meanings associated with the term *boke* are both ambiguous and

polysemous. The symptoms of boke are largely indistinguishable from those of Alzheimer's disease as it is understood in the North American biomedical context, although the categorization of the symptoms reflect Japanese notions of the person (Traphagan 2002). In one book on the subject, the author divides the symptoms into three areas: bodily disorientation, social disorientation, and inner (*kokoro*) disorientation (Kikkawa 1995). Bodily disorientation includes symptoms such as difficulty with walking, short steps, balance problems, difficulties speaking, stiffening of the hands, incontinence, weakness, and appetite loss. Social disorientation includes doubting others, lacking energy (*ki*), aggressive behavior, jealousy, overdependence, irresponsibility, and inability to take one's roles in family, society, and so on. Inner disorientation is associated with forgetfulness, inability to organize ideas, being quick to anger or cry, lacking patience, lack of perseverance, vagueness, and unwillingness to meet others.<sup>3</sup> In some cases, the word is presented as simply a lay term for biomedically defined diseases such as Alzheimer's. For example, in one book about how to prevent boke, Alzheimer's and vascular dementia are equated with boke, this last being divided into these two forms of dementia, with vascular dementia, in contrast to Alzheimer's, presented as being preventable through exercise and diet (Gonda n.d.). This approach to the concept of boke clearly taps into broader cultural concepts of the category as representing a controllable form of dementia.

But the term also has connotations that diverge from Alzheimer's and other biomedically defined forms of senility. For example, at times the condition is used as a source of humor by comedians and, in representations of people in a boke state, on television shows. Boke elders who are experiencing relatively minor symptoms are sometimes depicted in the public media as cute in a way similar to that of a dependent child. In one television drama I observed, the boke Grandpa of the household consistently had a pleasant smile on his face, did silly things, and was forgetful, but was presented as generally enjoyable to live with. Even when he wandered off, it was an opportunity for joviality when he was ultimately found.<sup>4</sup>

Older people themselves sometimes joke about forgetfulness by stating that they are already starting to become boke. This joking indexes deep fears about the onset of the condition, fears that are rooted in culturally circumscribed ideas about the importance of self-building and effort as fundamental to being a good person. Indeed, the implication of having some degree of control over the onset of boke is that one should make efforts to prevent the onset of the condition. While this is perhaps not surprising—in American society, for example, there is value placed on keeping oneself fit—it is particularly poignant in Japanese society, where being active and giving one's all are highly valued moral concepts; idleness is represented as the antithesis of activity and, thus, is endowed with moral import. As Margaret Lock points out, for Japanese the idle person is anathema because he or she fails to participate as an active, socially

viable, member of society and, thus, as a contributing member to the public good (1993, 230–231; Traphagan 2000). In short, the boke person is viewed as having failed to have made sufficient efforts, through being active in hobbies, sports, study, and other pursuits, to have staved off the condition.

Engagement in activities intended to delay or prevent boke is not simply a matter of individual activity; it also carries moral weight as a social responsibility. The moral component of boke is related to Japanese notions of reciprocity and interdependence, which are themselves closely connected to the Japanese conceptualization of selfhood as intersubjective. As a person enters into more severe states of boke, he or she becomes removed from the interdependencies and social relations that define one as a human being in the Japanese context (Plath 1980, 217). Being removed from the context of these interdependencies is particularly frightening to Japanese because the individual is unable to reciprocate those favors he or she receives. With boke, interdependence degenerates into a state of unidirectional dependence in which the individual receiving care, because of his or her cognitive and physical condition, is unable to reciprocate. While any form of disability takes on this character to some extent, the boke condition is particularly problematic because it is viewed as something over which people have at least some degree of control (Traphagan 2000).

In short, the basic consequences of becoming boke include not only the specific difficulties associated with cognitive decline, but also the fear that one may be perceived as not having made sufficient efforts to prevent that decline from occurring. When combined with strong concerns about avoiding overburdening others with care provision, this forms a strong motivation to engage in activities aimed at avoiding the onset of boke, and these activities are typically conceptualized in terms of the notion of *ikigai*, as will become clear below.<sup>5</sup>

### Contexts for Self-Actualization

On the cover of the brochure for a facility known as the Center for Lifelong Learning (*shōgai kyōiku sentā*) in the town of Kanegasaki, the following description is printed prominently at the top in a section that refers to the Agricultural Village Environment Improvement Center (*nōson kankyō kaizen sentā*), part of the Center for Lifelong Learning: “For the purpose of residents to carry on an abundant and bright life, an institution where one can be healthy through study, learning, sports, and recreation.”<sup>6</sup>

This slogan sums up the basic idea behind the government rhetoric that presents these kinds of facilities as contexts for self-actualization—activity directed toward self-actualization is viewed as synonymous with being healthy. Health is generated and maintained through a combination of activities that involve both the mental and the physical aspects of the person and that are carried out primarily in concert with others. Facilities such as this center, and

the senior center discussed at the beginning of the chapter, broadly fall under the rubric of *kōminkan*, government-run community centers that are found in most municipalities in Japan and that manage a wide range of cultural activities (see Tamanoi 1998, 3). These centers typically consist of an office and several large rooms in which local residents come to engage in group activities, such as lessons on the tea ceremony, music, exercise, calligraphy, or even magic. In recent years there has been a fair amount of improvisation on the *kōminkan* theme, with facilities directly aimed at older people cropping up on a regular basis.<sup>7</sup>

The *kōminkan* in Kanegasaki is more than simply a public facility in which people pursue hobbies and cultural activities. It is also a focal point where government officials and local citizens interact and a context in which government officials disseminate official ideas about what constitutes a good community and good people within the community. Some of the ways in which one maintains a good self, and by extension a good community, are expressed in the charter of Kanegasaki. The charter is read aloud, sometimes solemnly and sometimes with a lack of attention, at most public gatherings, including meetings of government officials and gatherings at the start of some classes in the facility. Many in the town can recite the charter from memory, or at least know the primary bulleted points. Below is a translation of the charter:

Let us increase the level of education and culture, and make a cheerful town

- Increase education and raise the hopes and dreams for all generations
- Throughout one's lifetime, enrich (nourish) an abundance of education and hobbies
- With broad vision, act with good judgment
- Make our cultural assets important and volunteer to devise a new culture
- Defend morality, erect good customs, and make the natural features of the town beautiful

Let us make this a town of spiritual and material richness and work in health

- Lead a healthy, safe life with cheerful mind and body
- Make a hygienic, beautiful, rich environment
- Hold on to happiness and pride in work and increase production
- Learn advanced technology and modernize industry
- With originality and invention, have a life of material and spiritual richness

Let us tie our warm hearts together in love, and make a wonderful town in which to live

- Make cheerful, happy, sound families



- Support courtesy and live harmoniously with kindness and generosity
- Live with consistency by respecting our responsibilities and keeping promises, and living a decisive life
- Take good care of children, the elderly, and unhappy people and defend the happiness of all people
- Make public morality and public property important and volunteer for the betterment of society

Several relevant themes emerge from an examination of the charter. First, health is defined and contextualized not only in terms of the individual, but also as an aspect of a community that is progressing and productive. The second section, which deals explicitly with health, indicates not only the importance of physical and mental health, but also a healthy (hygienic) environment, pride in work, increased production, and advancement in industry. Of course, the entire charter emphasizes the idea of community and community building, which is not surprising, since it is intended as a means of focusing the attention of townspeople on improving the town. However, that community is achieved through focus on an active approach to *making* individuals and, through that, making a community—more specifically, a *moral* community—in which individuals are dedicated to the communal good. The emphasis is not on what the community is or should be, but on what people should *do* to make it *become*. The charter emphasizes self-actualization as a central means to building a good community, and these ideas form the basis for a pedagogy of creating disciplined selves. The contexts in which these ideas are promulgated are the venues through which individuals and groups engage in that activity (Traphagan 1998a).

Indeed, there is a broad label under which these ideas are generally expressed. This concept, known as *machizukuri*, is part of a community-development drive encouraged and, in part, financially supported by the national government (Robertson 1991; Knight 1994). In Kanegasaki, the concept of *machizukuri* (town making) forms the central narrative for self-actualization that bureaucrats employ to encourage the creation of a sense of community and citizenship, reflecting the values of modernity and democracy (Bestor 1988, 430). This is articulated at the individual level through a second concept, known as *hitozukuri* (person making). Government officials argue that through *hitozukuri* individuals will cultivate their own interests, hobbies, businesses, and so on, and through that the community as a whole will be improved—as one government official put it, as “individuals continue to better themselves, this will be reflected in the children of the community. If parents better themselves, children will also become better people. If everyone studies it will bring in experiences and ideas to the town, improving the community as a whole” (Traphagan 2000, 170). This rhetoric reflects the core concept of a pedagogy



that is aimed at constructing disciplined selves through building and maintaining relationships with other members of one's community (Kondo 1990, 107).

Essentially, the individual selves who become involved with activities associated with facilities such as the center are objects of power aimed at transforming and improving not only themselves, but also the community as a whole. As Foucault notes, discipline is "a technique for the transformation of arrangements" (1977, 146). Discipline organizes individual bodies into a network of (power) relations in which people engage, or are compelled to engage, in actions associated with an idealized form such as a good student or model prisoner. To be (self-) disciplined is to align one's own behavior as closely as possible with that of the idealized form of behavior, and the degree to which one is able to do this becomes a basis upon which one accumulates symbolic capital. The disciplined self is the symbolic representation of culturally circumscribed expectations about good behavior. Within the context of the center, disciplined individual selves are individual symbols of a disciplined community, just as a prosperous community (a disciplined community) is a symbolic reflection of the disciplined selves that constitute it.

In other words, the activities supported by local governments are designed as conduits through which people can engage in the discipline of self-actualization. And many of these activities are directly aimed at the elderly. Perhaps the most prominent of these are two games known as gateball and ground golf, which are popular among the elderly.<sup>8</sup> Other examples include exercise classes, group calligraphy lessons, and group instruction in traditional Japanese musical instruments such as *shamisen*. At some facilities women get together weekly to participate in group sewing or choral singing.

Certain activities, particularly exercise and sports, are strongly promoted by town governments. Under the auspices of the Center for Lifelong Learning in Kanegasaki, for example, the town sponsors a marathon and various athletic meets for people of different age groups, such as baseball tournaments, volleyball tournaments, and gateball tournaments for the elderly. During the initial introductions by town leaders (*aisatsu*), such events are usually placed into the framework of *machizukuri*. Many public, town-sponsored events that have at least a minimal physical element begin with group stretching exercises, and the town encourages residents of all ages and physical condition to participate in town-sponsored exercise classes, to attend health checks (for blood pressure, pulse rate, and so on) and to visit the town's sports center for physical exams that compare actual and physical age (Traphagan 2000).<sup>9</sup>

For older people in particular, use of these facilities and the activities related to self-actualization are organized around the concept of *ikigai*, an idea that "functions as a core notion for the expression of private and public identity" among Japanese (Johnson 1993, 232).<sup>10</sup> The term varies considerably in relation to the specific practice to which it refers, but it generally connotes one's

purpose in life or something that one does deeply and wholeheartedly. As I have pointed out elsewhere (Traphagan, forthcoming), a college student might describe playing mah-jongg as his or her *ikigai*, while a woman in her thirties might describe her children as her *ikigai*; a man in his forties might describe his work as his *ikigai*, or a woman in her fifties might describe flower arranging as her *ikigai*. Rather than emphasizing specific activities or specific kinds of activity, *ikigai* indexes activity itself. Furthermore, it indicates a sense of fulfillment or pleasure derived from pursuit of the activity in which one engages (Yamamoto-Mitani and Wallhagen 2002, 401).

Gordon Mathews (1996, 17; see also Traphagan, forthcoming) explains the concept as consisting of two forms. On the one hand, pursuing an *ikigai* usually indexes commitment to a group of people engaged in the same activity. Such a group might be one's flower-arranging class or the company where one is employed. In this sense, *ikigai* can be understood as implying connection to a social context in that it involves group membership and interaction with others. On the other hand, the term conveys a more inner and somewhat reflexive (or introspective) quality in that it implies activity that is directed toward self-realization or self-actualization and that is focused on the development of the individual. As noted above in the discussion of the charter of Kanegasaki, these two elements of *ikigai* are viewed as complementary. A fully realized self is one that is thoroughly capable of and involved in social interaction while also being self-reflexive and concerned with continual processes of self-improvement or self-actualization. The concept presented by town government officials in Kanegasaki and other locales is that if individual selves are engaged in self-articulation through the pursuit of *ikigai*, the entire community will benefit.

Although finding an *ikigai* can be important at any age, for the elderly it is often viewed as a matter of fundamental importance for avoiding a lonely, sad, and illness-ridden old age and, as such, is strongly advocated both by government bureaucrats and by younger family members (Traphagan, forthcoming). Having an *ikigai* is viewed as being the central method through which one may be able to avoid the onset of boke, although it is by no means seen as a guarantee. Mathews (1996) notes that the pressure on the elderly to have an *ikigai* is so intense that one may actually be brought to consider or commit suicide, and, indeed, older informants have told me that the lack of an *ikigai* is one of the primary reasons elders do commit suicide. Reasons for committing suicide among the elderly are, of course, more complex than lack of an *ikigai*. Fear of burdening family members with long-term care is also often cited as a reason older people commit suicide (Traphagan 2003, 32). However, the interpretation of elder suicide as being tied to a lack of *ikigai* is important, because it indexes the emphasis placed on social interaction as a basis for living a good old age. Insularity is viewed as a prescription for various forms of decline, both physical and mental, which may, in turn, lead to despair.

The rhetoric of *ikigai* is represented by the government through pamphlets and fliers that are available in most public offices and form a source of information intended to help people organize self-articulation, or self-discipline, around the idealized self dedicated to the pursuit of *ikigai*. These publications emphasize the importance of having an *ikigai* and often contain images of elders engaged in hobby activities along with such slogans as “*Ikigai* is the source of vigor,” a proclamation that appears on the front of a pamphlet that encourages older people to become “health millionaires” through having an *ikigai*.<sup>11</sup> This particular pamphlet provides numerous examples of potential activities that can form one’s *ikigai*. In figure 12.1, some examples of activities within the home that can form an *ikigai* are shown. In the top drawing, an older couple is shown doing pottery, and the caption encourages people to spend time pursuing an *ikigai* as a couple. This is interesting because, although mixed-gender activities, such as gateball and ground golf, are sometimes pursued by married couples, in general older people focus their attention on participation in groups that are either entirely male or female.

At the bottom of the page, a drawing shows an older man happily cooking and encourages one to take on the challenge of learning to cook. This is particularly interesting since, although not unheard of, it is atypical for men to involve themselves in cooking (or any other domestic work). Men, because throughout most of their lives work has formed their *ikigai*, are perceived to be at high risk of becoming *boke* following mandatory retirement at the age of sixty or sixty-five (depending upon one’s employer), unless they are able to find an *ikigai* to replace work. They are often perceived as a nuisance to their wives, because they have never been involved in domestic chores such as cooking and cleaning. Indeed, the pamphlet discussed here describes housecleaning as a potential *ikigai*. Cooking in this pamphlet is presented as one example of a way in which men can both find a suitable activity to bring fulfillment and contribute to domestic harmony in the process.

### Power, Senility, and *Ikigai*

How, then, are *ikigai* and senility (in the form of *boke*) linked? Both concepts index a third concept, that of effort (*gambaru*), or giving one’s all, which is a key element in the moral pedagogy associated with defining a good person in Japanese culture (see Singleton 1993). For older Japanese, concern focuses not simply on having an *ikigai* as a means of avoiding the onset of *boke*—in fact, there is a fair amount of angst about whether being involved in social activities actually will prevent or delay the onset of the condition. The salient aspect of the relationship between *ikigai* and *boke* is to be found in the idea that one should be constantly engaged in *efforts* to be active, particularly in contexts that involve other people. This emphasis on effort is widely evident in Japanese



FIGURE 12.1 A page from a brochure encouraging people that they can find an *ikigai* even within the home.

conceptualizations of self-building and self-discipline. As Kondo notes in her discussion of an ethics retreat at the company where she worked, the focus of the retreat rested far less on attaining specific goals than it did on strengthening one's ability to persevere and give one's full effort in the demanding tasks set forth in the curriculum of the retreat. She describes daily running in which the goal was to prepare for a 7.5 kilometer marathon set for the end of the program. The point was not to win the race. Instead, "the key was to finish and not to give up" (1990, 87). While Kondo points out that pressure to persevere in formal contexts such as the ethics retreat are not met without resistance, the basic lesson of much of the Japanese attitude toward self-discipline and, ultimately, toward being a good person rests on the notion of giving it one's all. Effort and perseverance are core concepts in Japanese notions of the good self, and effort

and perseverance are the focal points for the exercise of power in relation to *ikigai* and *boke*.

The exercise of power in relation to this complex of ideas is found in at least two ways. First, the doing that is associated with the pursuit of an *ikigai* is, itself, a source of power for older people. By engaging in the pursuit of developing an *ikigai*, older people are able to accumulate, or embody, symbolic capital associated with being a good *rōjin*. As noted earlier in the chapter, “the good *rōjin*” is a category of old person that is characterized by active engagement—that is, making sufficient efforts—in activities, largely social in nature, that help to maintain physical and mental health and, in particular, can be interpreted as being beneficial in preventing or delaying the onset of senility. The pursuit of an *ikigai* is a practice aimed in large part at avoiding the onset of *boke*, but the consequences of that onset are more than simply a matter of potentially staving off cognitive decline. To become a *boke rōjin* is to risk the implication that one did not make sufficient efforts to avoid that state. In other words, the pursuit of an *ikigai* is an explicit tactic in which power—which I am defining in this context as *doing* itself—is used to generate the perception that one is being a good *rōjin*. In other words, the simple fact of giving one’s full effort to avoid the onset of *boke* is a tactic used to manipulate potential positive and negative sanctions (Bell 1975, 26) in the form of social acceptance as a good *rōjin* or the stigmatization of being a *boke rōjin*.

I want to stress here that the accumulation of symbolic capital associated with being a good *rōjin* is by no means the only reason people engage in the pursuit of finding and maintaining an *ikigai*. Being active is viewed as inherently good in Japanese society—anyone, regardless of age, who is actively involved in self-improvement and engages in social interactions is looked upon in a positive way, and being interested in self-improvement is viewed as a very natural type of behavior (Lock 1993; Traphagan 2000). But for the elderly, there is particular significance found in the pursuit of an *ikigai*, because the free time associated with postretirement life, particularly for men, is viewed as putting the elderly at greater risk of sliding into inactivity and thus contributing to the social and individual circumstances that bring about the *boke* condition. In other words, pursuit of an *ikigai* is a use of power focused inward; it is power aimed at what Long describes as “directive control” intended to manipulate changes in self (physical and mental) that are associated with the aging process by manipulating the “most basic sense of who one is” (1999, 23).

The second sense in which power is used in relation to *ikigai* is seen in government officials’ concern with the potential costs of an illness-ridden elderly population. The Japanese government is acutely aware of the potential problems the country faces—both fiscally and in terms of service provision—as the population continues to age and as an increasing number of individuals face cognitive and physical decline. As of the 2000 census, the proportion of

people in the population who were over sixty-five had reached 19 percent, and in some areas, such as Tōhoku, it has already surpassed 20 percent (Ministry of Public Management, Home Affairs, Posts and Telecommunications, Japan 2002).

Although there are no formal sanctions in the event that an elder chooses not to pursue activities aimed at maintaining personal health, the strategic use of the concept of *ikigai* by government officials is a means of exercising power to guide or direct older people to build selves that accord with ideals associated with the good *rōjin*. Having a healthy mind and body is more than a matter of personal concern—it is a social responsibility, one that is particularly important for the elderly to recognize given that they are at increased risk of functional decline in comparison with other age groups.<sup>12</sup> Government officials strategically deploy the concept of *ikigai*, and the centrality of self-actualization through having an *ikigai*, as a moral frame through which the elderly can express—through doing—their own willingness to contribute to the social whole by being good *rōjin*. Old bodies in Japan are not simply subject to forces of dominance over which they lack control, but the doing of *ikigai* “generates social and symbolic capital associated with being a good, active person” (Traphagan 2000, 174). Symbolic capital associated with being a good *rōjin* is collectively constructed around the notion that healthy individuals form a healthy community.

Political leaders use the concept of *ikigai* not only as a means to encourage and help people to avoid individual functional decline in old age, but also as a way to avoid overburdening the social service system, particularly the fiscal burden of *kaigo hoken*. Facilities such as the *shōgai kyōiku sentā* and such classes as that in cooking, discussed above, function as an institutional structure for channeling self-actualization (*ikigai*). In other words, these contexts are locales where various forms of power are being simultaneously enacted—subtle forms of dominant power in employing the concept of *ikigai* to direct older people in their behaviors, and productive power in the form of individual and collective generation of symbolic capital associated with being a good *rōjin*.

In the Japanese context, *boke*, or perhaps more precisely the fear of the onset of *boke*, is tightly linked with moral, political, and economic discourse on aging. Facilities such as the senior center in Akita or the Lifelong Learning Center in Kanegasaki are presented as contexts through which individuals can engage in activities aimed at preventing or delaying the onset of *boke*. But they are also contexts in which power is strategically used by both government officials and the elderly who make use of the facilities. Although there is a subtle element of coercion in the manner in which the government uses the conceptual elements of *ikigai* as functions of individual and social responsibility to influence people’s behavior in ways that may limit use of social and health services designed for the elderly, this use of power is not unidirectional. Indeed, both those in political power and those using the facilities are confluent agents in the



field of power associated with senility. Power in this framework is not organized around a binary opposition of political structure and individual agency; rather, the political structure through which people wield power and the individual agents who engage that structure converge. In other words, structure and agency are isomorphic. The goals of individual agents and the political structure are two different expressions of the same fundamental set of social constructs, which emphasize activity and social interaction as fundamental to being a good person, and which underlie the basic assumptions that run throughout the field of power (cf. Margenau 1977, 330).

Furthermore, in the context of coping with senility in Japan, the exercise of power lacks an inherent element of resistance. While the elderly are subtly coerced into structuring self around the ideals associated with activity and effort, they participate in these activities willingly and are themselves enacting power, both in terms of their confluence with government rhetoric and in terms of their efforts aimed at preventing boke. Given that the elderly are faced with the seeming inevitability of functional decline in old age, it is in their self-interest to comply with these government-promulgated ideals. And, indeed, the ideals themselves are simply reflections of long-standing conceptualizations of what makes a good person in Japan—lifelong dedication to effort both as an individual and as a member of a larger social whole. Being a good *rōjin* means engaging oneself in the matrix of power relations that is used to organize the articulation of self around doing and effort.

#### NOTES

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1. I use the term *narrative* to indicate the context in which the processes of discourse and rhetoric generation are embedded. Narrative provides the basis of possible meanings that can be used to stimulate discursive and rhetorical activity (see Schrag 1997, 29).
2. Although fish was available, it was expensive in earlier times and thus not eaten frequently. In addition, following World War II, there was a considerable period of food shortages that also contributed to nutritional problems.
3. For a discussion of how Japanese conceptualize somatic and mental elements of the person in term of ideas about inner-ness (*uchi*) and outer-ness (*soto*), see Traphagan 2002.
4. This should not be interpreted as meaning that Japanese generally conceive of living with an individual suffering from dementia in these terms. Ariyoshi's (1972) novel portrays a very different picture, depicting sacrifice, emotional pain, and physical exhaustion as characteristic of the experience of caregivers for boke individuals.

5. Other consequences may also be related to the onset of the boke condition. For example, it is possible that families may be regarded as having been at least partially to blame for the onset of the condition, in a way similar to what Cohen (1998) finds in India, although in my fieldwork I have not encountered specific cases of this type of social stigmatization. One area that does appear to represent a negative consequence for elders who experience is in terms of access to some social services. At least in rural areas, it can be difficult for families with a boke member to actually find a nursing home willing to accept the individual; this is particularly problematic because of the shortage of nursing home beds in rural areas. Nursing homes will in some cases claim that they are unable to deal with the difficulties specifically associated with a person who has any form of dementia, boke or otherwise. This is an area related to the experience of boke that is in need of further research.
6. Jyūmin ga kenkō de akaruku yutaka na seikatsu o itonamu tame no kenshū, gakushū, supōtsu, rekurieeshon ga dekiru ba to shite sukoterareta shisetsu.
7. *Kōminkan* are not specifically intended for older residents, although it is typically older people who make the most extensive use of these facilities.
8. Gateball is a game similar to croquet that has been played by the elderly in Japan for many years, and ground golf is a recently developed game similar to golf. Both of these games are played primarily by the elderly (see Traphagan 1997).
9. Although these ideas have been promulgated and encouraged by the national government, not all towns buy into them with the vigor that has characterized Kanegasaki's use of these ideas. However, these ideas reflect a general concept that individuals hold responsibility for self-maintenance and cultivation and that self-cultivation is not that of an isolated self, but one of a self in community. The responsibility thus is not simply a responsibility to care for oneself, but a responsibility to care for the community as a whole by caring for oneself.
10. An earlier version of this discussion of the concept of *ikigai* appears in Traphagan, forthcoming.
11. I have discussed this particular pamphlet elsewhere in relation to the conceptualization of disability in Japan; see Traphagan, forthcoming.
12. As Akiko Hashimoto (1996) points out, unlike in most Western societies, in Japan the identification of the elderly as a class of persons in greater need and at greater risk of becoming a burden is a legitimate form of social differentiation.

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## CONTRIBUTORS

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**JESSE F. BALLENGER** is an assistant professor in the Science, Technology and Society Program at Penn State University.

**ANNE DAVIS BASTING** is the director of the Center on Age and Community and an associate professor in the Department of Theatre and Dance at the Peck School of the Arts, University of Wisconsin–Milwaukee.

**ROMA CHATTERJI** is a reader in the Department of Sociology, Delhi School of Economics, Delhi University, India.

**LAWRENCE COHEN** is a professor in the Department of Anthropology at the University of California, Berkeley.

**YVETTE FLORES** is an associate professor in the Chicana/o Studies Department at the University of California, Davis.

**CAROL FRANZ** is a senior analyst at the Center for Health Services Research in Primary Care at the University of California, Davis, School of Medicine.

**JANICE E. GRAHAM** is an associate professor of medicine and anthropology and Canada Research Chair in Bioethics at Dalhousie University in Halifax, Canada.

**ISABEL HERNANDEZ** is a postgraduate researcher in the Department of Psychiatry and Behavioral Sciences at the University of California, Davis, School of Medicine.

**LADSON HINTON, MD**, is an associate professor in the Department of Psychiatry and Behavioral Sciences at the University of California, Davis, School of Medicine.

**SHARON R. KAUFMAN** is professor in residence in medical anthropology in the

Department of Anthropology, History and Social Medicine; Department of Social and Behavioral Sciences; and Institute for Health and Aging, University of California, San Francisco.

**PIA C. KONTOS** is an anthropologist and a postdoctoral fellow at the Toronto Rehabilitation Institute, Toronto, Canada.

**ANNETTE LEIBING** is a professor at the Institute of Psychiatry, Federal University Rio de Janeiro, Brazil, and a visiting professor at the Department of Social Studies of Medicine, McGill University, Montreal, Canada. She is also a researcher at the Institute of Social Gerontology of Quebec, Montreal, Canada.

**STEPHANIE LLOYD** is a doctoral student in the Department of Social Studies of Medicine, McGill University, Montreal, Canada.

**MARGARET LOCK** is a professor of anthropology in the Department of Social Studies of Medicine, McGill University, Montreal, Canada.

**ATHENA HELEN McLEAN** is an associate professor in the Department of Sociology, Anthropology, and Social Work at Central Michigan University.

**LINDA S. MITTENESS** is a professor of medical anthropology at the University of California, San Francisco.

**JANALYN PREST** is a doctoral student in the Department of Social Studies of Medicine, McGill University, Montreal, Canada.

**ANDRÉ P. SMITH** is an assistant professor in the sociology of health and illness in the Department of Anthropology and Sociology at the University of British Columbia, Vancouver, Canada.

**JOHN W. TRAPHAGAN** is an assistant professor in the Department of Asian Studies and director of the Center for East Asian Studies at the University of Texas at Austin.

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