Thinking About Dementia

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Introduction

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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 Mitteness 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,” “BRRRRR!” 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 re-enter 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 Furiai 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 interdependence. *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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