



6 REVISITING MCI

On Classificatory Drift

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IN THIS CHAPTER, I INVESTIGATE the evolution of a diagnostic category—mild cognitive impairment (MCI)—in the last two decades. My point of departure is a comparison between two “practice parameters” or guidelines on MCI published in 2001 and 2018. Published in the journal *Neurology*, the official publication of the American Academy of Neurology, both guidelines’ collection and consideration of evidence were led by Ronald C. Petersen, the Mayo Clinic neurologist who systematized the category, drawing on earlier uses, at the turn of the 2000s (e.g., Petersen 2003). Further, both guidelines were developed by a team of academics that included not only neurologists but also psychiatrists and psychologists, as well as academics with expertise in clinical epidemiology and neuropathology. Contrasting these two guidelines—taken as public statements of a wider “professional consensus” on the meaning of current scientific and clinical information—provides a window into the transformation of the social, epistemic, and technological networks that support diagnostic practices concerned with memory problems.

On the first, defining guideline on the category, the justification for focusing on MCI is clearly placed on the emerging diagnostic requirements of promising therapeutic approaches to Alzheimer’s disease (AD):

Basic research, such as the identification of secretase inhibitors and the development of an immunization model for the prevention of amyloid deposition, underscores the importance of developing techniques for early detection (of AD). Parallel with these endeavours, clinical research aimed at identifying the earliest signs of cognitive impairment has progressed. . . . Mild cognitive impairment deserves recognition and further study because, as preventive treatments for AD become available, it will become incumbent on clinicians to identify persons at risk of AD and those with the earliest signs of clinical impairment. (Petersen, Stevens, et al. 2001: 1133)

By contrast, in the 2017–2018 revision of the guideline, the explanation given for using the diagnostic category is considerably less future oriented:

Mild cognitive impairment (MCI) is a condition in which individuals demonstrate cognitive impairment with minimal impairment of instrumental activities of daily living (IADL). Although MCI can be the first cognitive expression of Alzheimer disease (AD), it can also be secondary to other disease processes (i.e., other neurologic, neurodegenerative, systemic, or psychiatric disorders).

. . . Persons with MCI are at higher risk of progressing to dementia than age-matched controls. . . . Persons diagnosed with MCI may remain stable, return to neurologically intact, or progress to dementia (. . . 14.4 percent–55.6 percent reverting to normal). (Petersen, Lopez, et al. 2018: 127–128)

It goes on to make recommendations, including the following:

Although subjective cognitive complaints alone are insufficient to diagnose MCI, such complaints from either patients or their close contacts are core to most major MCI diagnostic criteria, as they may reflect a change in cognitive function.

. . . For patients for whom the patient or a close contact voices concern about memory or impaired cognition, clinicians should assess for MCI and not assume the concerns are related to normal aging. (Petersen, Lopez, et al. 2018: 132)

Between 2001 and 2018, MCI has shifted from being defined as the major risk condition for Alzheimer’s disease to being demarcated as a category loosely associated with a variety of possible etiologies, with a significant proportion of “persons diagnosed with MCI . . . reverting to normal.” In addition, while clinicians’ attention to MCI in 2001 was linked to wider processes of biomedical research on AD and the therapeutic possibilities attached to the amyloid hypothesis, by 2018 MCI had lost most of its connection to strategic biomedical innovation, grounding its continued existence on the importance of clinically legitimizing subjective memory complaints. At the start of the twenty-first century, MCI encapsulated the techno-economic promises of Alzheimer’s disease research (Moreira 2009; Lock 2013). Two decades later, MCI is proposed to clinicians as an opportunity to discuss “diagnosis, prognosis, long-term planning, and the lack of effective medicine options” with patients (Petersen, Lopez, et al. 2018: 128)

How did this happen? How can we understand the transformation—the drift—of the MCI category? In earlier work on MCI, I have proposed that its stabilization at the turn of the century was due to its ability to work as a *politico-epistemic scaffold*, enabling the exploration of possible equivalences between biomolecular markers, neuropathology staging systems, and com-

monly used clinical dementia rating scales (Moreira, May, and Bond 2009). In this process, MCI became temporarily settled as a hybrid “risk category” at the boundary between normal and pathological aging, and the laboratory and the clinic, articulating the experience of “memory problems” with neuroscientific standards. One consequence from this analysis is that MCI’s transformation from being a distinctively bioclinical category to becoming mainly defined by its clinical utility in the 2018 practice parameter requires not only an increased misalignment between research and clinical practice, but also an enduring necessity to enact and manage “memory complaints” in the clinic. In what follows, I address these two processes.

First, I explore the mechanisms leading to the increased misalignment between what Jutel (2011) labeled the “engines of diagnosis” in MCI. In particular, I focus on the evolving disconnection between existing clinical dementia classification systems, on the one hand, and dwindling expectations attached to therapeutics strategies and diagnostic technologies—biomarkers—on the other. Next, I suggest that the survival and classificatory drift of MCI can be explained by the role ascribed to “subjective memory complaints” not only in the consolidation of MCI as a category but also in bringing to bear a particular configuration of health care driven by choice and the “logic of the market” (Moreira 2012) in this domain. To do this, I draw on interviews with international biomedical and clinical scientists, originally collected in 2004–2006. My contention is that the significance of the data is not related to its “historical” interest but to how it provides insight into the reality-making, durable categorical politics invested into MCI, which have held to the present day. In the concluding third section, I consider the possible “torquing” effects (Bowker and Star 1999) of MCI’s classificatory drift for people experiencing memory problems.

The Rise and Drift of MCI

One of the reasons AD has generated steadfast interest in the social studies of medicine is that it is generally seen as an exemplary case to understand the dynamics of biomedicine in the late twentieth and early twenty-first centuries. Although formulated originally by Alois Alzheimer within the scientific and institutional context that historians usually describe as “laboratory medicine” (e.g., Pickstone 2000), it was only in the turn of the 1980s that a renewed concern with the condition emerged, supported by the converging sponsorship of the US National Institute of Ageing (NIA), the National Institute of Neurological and Communicative Disorders, and the Alzheimer’s Association. Through this process, AD became articulated as both a political issue—linked to demographic aging—and a medical/scientific problem.

With the establishment of the Alzheimer's disease research centers by the US NIA in 1984, the condition gained an institutional foundation from which it was possible to coordinate the relationship between research, therapeutic experimentation, and clinical practice. Such coordination is embodied in the development and publication of what came to be known as the "McKhann criteria" (McKhann et al. 1984). As a conventional standard, the McKhann criteria aimed at setting the procedures through which existing techniques and tools could be used to identify a new illness, thus enabling the transit of cases and materials such as brain tissue between laboratories and clinics. Recognizing that there was "insufficient knowledge about the disease" (McKhann et al. 1984: 939), McKhann and his colleagues proposed that diagnosis of "possible" or "probable" Alzheimer's disease required a harmonization between clinical, neuropsychological, and laboratory investigations that should be used in the clinic, and further research on the condition. This, I would suggest, can be seen as a major turning point in the establishment of Alzheimer's disease as a bioclinical entity.

Embedded in this conventional standard was a technological expectation, the promise that distinguishing between normal and pathological aging would be the best route for "finding a cure" for AD. This technological expectation was underpinned by the assumption that therapeutic development was propelled by a combination of standardized diagnostic criteria and the application of new biomolecular techniques and instruments. Importantly, this promise related not only to the personal troubles experienced by people living with dementia and their care givers, but also to the social and economic problems associated with aging populations. Crucially, the proposition was that such problems could be redefined as opportunities for innovation and the creation of economic value, affiliating AD research with what Felt and colleagues (2007) have called the regime of techno-economic promises. In this regime, research is justified by reference to the capacity to address a societal "need," arguing that this aim is best achieved by competitive market arrangements between researchers, universities, and companies, underpinned by strong intellectual property rights regulation. These arrangements, in turn, delineate strong boundaries between researchers and nonexperts, who assume the role of users or consumers of technologically enhanced health care.

One of the defining features of the field of AD research has been the cognitive and financial investment in this innovation model, helping to define its structure, and associated narratives such as "rational drug development" or "translational medicine." Its rootedness in the field is evidenced by the fact that the attachment to this innovation model persisted even after the first trials of therapies that "translated" the cholinergic hypothesis

showed modest results in the late 1990s, gaining new support as a strategy to “test” the amyloid hypothesis (Moreira 2009) within the new “preventative” approach for AD that became established in the 2000s. Thus, in ethnographic fieldwork in AD conferences in the beginning of the 2000s, I would often hear the argument that it was the understanding of the causes of the disease that needed addressing, not the innovation model. In many respects, it was as if the introduction of an alternative disease model reinforced the commitment of researchers, pharmaceutical company strategists, and policy makers to the regime of techno-economic promises.

As research groups and companies became increasingly interested in finding pharmacological agents that would target the molecular mechanisms that precede neuronal death, one of the strategies to implement this “preventative paradigm” was the creation of new risk categories that could serve as a bridge between normal aging and AD. This approach is evident in the 2001 MCI “practice parameter” extract provided in the previous section, where the proposal is to identify a population for research on the bioclinical antecedents of dementia and to test the effectiveness of preventative therapies for AD. As such, in its original formulation, MCI defined a transitional stage between normal cognitive aging and dementia (Petersen, Smith, et al. 1999), intended to work as a new “biomedical platform” (Keating and Cambrosio 2003) coordinating between different types of laboratories—molecular biology, neuropathology, neuropsychology, neuroimaging, etc.—and a new type of clinical setting, the memory clinic. In this regard, MCI could be seen as “nested”—in the sense proposed by Lampland and Leigh-Star (2009)—within the previous AD conventional diagnostic standard (the McKhann criteria), but only to extend and modify it.

During fieldwork in a memory clinic in the mid-2000s, I observed how the category of MCI was invested in by practitioners as a means to articulate “hope” and link individual diagnostic work to a wider techno-economic collective. This was possible because the clinic where I conducted the fieldwork had a strong research tradition, being associated with a major international academic program on dementia. Indeed, as the normative, population-based parameters for tests such as the Mini-Mental State Examination (MMSE) or MRI were not fully established for MCI or preclinical dementia, clinicians viewed their work as both care and science, and related to patients according to whether they thought they were a straightforward case—of depression, for example—or one that required further investigation. Persons with memory complaints became either “patients” or “research participants,” and their engagement with the clinic was significantly shaped by their bioclinical identity—their data and commitment being routinely maintained. There was a sense—even among staff that did not “buy into the Mayo Clinic view of things”—that characterizing, in the

clinic, early signs of dementia was a pathway to scientific discovery and therapeutic development. They were part of a bigger picture, a wider bioclinical assemblage.

In the following years, there was a weakening of the coordinating practices between standards in this assemblage. Nowhere is this more evident than in the attempts to develop, validate, and implement biomarkers of AD. As researchers and their sponsors increasingly advocated the use of MCI mostly as a point of entry to more detailed, biomarker-based investigations (Leibing 2016; also Boenink 2016), the fragility of “circuits of translation” on which MCI relied became paradoxically more discernible and unsettling. One of the key reasons for this is that, although proposed as crucial for investigators to draw equivalences and conserve passageways to more easily available—and accepted—diagnostic standards such as dementia rating scales, reliance on biomarkers has proved challenging because these are only available in very selected clinics. This, in effect, means that it has become increasingly difficult to maintain the coherence of the AD bioclinical collective, with memory clinics working with “old” diagnostic technologies, classification systems, and categories such as MCI (Hillman and Latimer 2019), and research projects deploying complex, “innovative” biomarkers for AD.

This disjointing between the clinical category of MCI and the world of AD research has been compounded by a series of negative trials of amyloid-based therapies in the last decade (Metha et al. 2017; Garde 2018). This and the difficulties inherent in coordinating the longer large clinical trials that are required by a disease-modifying, preventative approach to AD might be behind the current withdrawal of key pharmaceutical companies from the AD market (see, e.g., “The Brain Drain” 2012). Such disinvestment is significant because it destabilizes not only the assemblage of economic and biomedical actors gathered around AD as an entity, but also the model of innovation that AD research was supposed to embody and represent. The techno-economic promises of AD research and innovation now carry less weight than a decade ago. MCI and the diagnostic practices associated with it—“informant interview,” MMSE, etc.—are less easily linked to a collective investigation, and become primarily related to “personal troubles.” In other words, and drawing on the conceptual model I proposed for my analysis of memory clinics (Moreira 2010), current diagnosis of preclinical dementia individualizes memory complaints without providing a horizon of “hope.”

Meanwhile, interest in MCI at the turn of the century motivated a series of community-based population studies that attempted to validate the category or provide it with a more nuanced etiological understanding (Ritchie and Ritchie 2012). As is well documented in the 2018 MCI practice parameter, there was a multiplicity of criteria used to identify MCI in the com-

munity (Petersen, Lopez, et al. 2018: 135), leading to the reflowering of the dementia-continuum controversy. This is because even those studies focusing solely on amnesic MCI have found that while there is increased risk of developing dementia compared to age-matched participants, longitudinal data also show that persons diagnosed with MCI might also remain in that condition or revert to normal. It is not only that the boundaries between dementia categories are becoming increasingly blurred, but also that the transit of person between those categories is not unidirectional. This challenges both the usefulness of the categories in determining illness trajectories, but also the relationship between MCI and the “preventative paradigm” in AD research. Furthermore, compared to accuracy envisaged by biomarkers, MCI has progressively lost the ability to identify with some degree of certainty “persons at risk of dementia.” What it is doing instead, however, is not at all clear.

Research on the psychosocial consequences of being diagnosed with MCI has consistently found that the diagnosis has particular implications for the identity of persons experiencing memory problems. Corner and Bond (2006), drawing on Goffman’s concept of stigma, suggested that MCI’s association with dementia has led to feelings of worthlessness and increased anxiety. Beard and Neary (2013), more recently, have found that MCI diagnosis leads to a form of “courtesy stigma,” where others’ expectations of the evolution of the condition positioned persons experiencing cognitive impairment outside of full social membership. Others have found, however, that this loss of social membership and participation rights was balanced by the advantages of being able to “put a name” to the difficulties experienced in everyday life, and to thus devise coping and mitigating strategies (Lingler et al. 2006; also Joosten-Weyn Banningh et al. 2008). Noticeably, the 2018 MCI practice parameter excluded analysis of the literature on “the potential psychological distress of a diagnosis of MCI” (Petersen, Lopez, et al. 2018: 132), focusing instead on the provision of lifestyle advice and long-term planning (living wills, etc.).

Despite not providing clues on etiological causes, and being unable to identify treatment options or predict outcomes with some certainty, MCI continues to be proposed as a diagnostic category enabling clinical engagement with patients and care givers. This is justified, as suggested in the previous section, by the significance of “subjective memory complaints” for the person and his/her caregiver. But what is the meaning of this significance if, as argued above, the link between MCI and the disease model of dementia, and the bioclinical collective that enacts it, has been extensively weakened?

One possible answer to this question is that the expression of memory complaints is a signifier for a mode of health care organization that config-

ures persons experiencing such troubles as consumers of health care. This possibility overlaps fully with the regime of innovation that dominated the field of AD research and policy in that it positions individuals as consumers of technologically enhanced health care. However, the suggestion is that this attributed role can persist despite a fragile link to innovation practices because of how it is also attached to a regime of coordination of health care that relies on market implements and practices. In the next section, I develop and evidence this hypothesis.

Market Memories

Between 2004 and 2006–2007, within a multimethod study that aimed to understand the social, political, and biomedical mechanisms leading to the establishment of MCI as a diagnostic category, my colleagues and I conducted thirty-seven interviews with experts in dementia research, care, and policy in the United States, United Kingdom, Canada, and two continental European countries. These were qualitative semi-structured interviews on the scientific, clinical, and societal meanings of MCI and/or early diagnosis and prevention of dementia. Our analysis of this dataset indicated that participants saw the emergence of MCI not only as a consequence of changes in the biomedical and epidemiological knowledge base about dementia, but also as related to the social organization of health care, leading to differences in the use of MCI across the countries included in our study (Moreira et al. 2008). Indeed, one of the key findings was that experts saw the adoption of the MCI label as a function of how “marketized” the health care system was. For our participants, this was made evident in the way in which health care systems were responsive to “demands” expressed in the clinic.

This was a surprising result in our data analysis because while, at the time, the debate in the literature revolved around the possibility of moving MCI to the clinic, our participants seemed to suggest that the need for a category such as MCI originated partially in the clinic. This differed significantly from science-push explanations of the emergence of MCI, where scientific and technological changes would have led to the implementation of the category at the clinical level. In our interviews—confirmed by fieldwork data—the needs of patients and of their families were seen as essential to understanding the scientific relevance of MCI. For example, in an interview with a US neurologist, experiential knowledge of subjective memory complaints and the needs they entail were rendered as the source of the search for a new diagnostic category:

Neurologist (N): My opinion, I am unusual in being so bold: those patients and even more importantly their families know something is wrong and they

don't want to wait to see if they are going to get worse before they start therapy (hmm) so yes they are interested in clinical trials, I mean does that make sense?

Tiago Moreira (TM): Yes.

N: I mean they know something has changed.

TM: So would you say . . . that the fact that people are demanding, the patients are demanding other forms of treatment is also moving the field forwards in preclinical Alzheimer's disease?

N: Yes absolutely.

In this exchange, the neurologist's suggestion was that the need of persons with memory complaints to "put a name" to their troubles and attempt to do something about it had driven the field toward a focus on preclinical AD. Interestingly, the emergence of memory troubles is seen as underpinned by a change in their daily experience, whereby "patients and even more importantly their families" are able to ascertain the appropriateness of remembering or the inappropriateness of forgetting in specific familiar situations (the location of car keys when leaving the house was an oft-mentioned example). This knowledge that "something had changed" had not only an epistemic authority but also an ontological reality that appeared obvious to interviewees.

In establishing this authority and reality, participants made reference to established ways of enacting experience and symptoms. The solidity of experience of memory complaints came from it being enacted in clinical practice but also in clinical research over a period of time. As one US geriatric psychiatrist I interviewed put it,

Erm (pauses, laughs), people know, I mean this is not news for us, so, er, all these years, twenty five years [ago, we did a study, and], I don't think it's changed, also those people always knew (laughs), er, what was going on and, y'know, and we published [research paper about that a few years ago]. In other words this is not new, the people, y'know, er, and especially today . . . the patient (laughs) patients know, they're afraid and they don't need to be convinced (laughs) at all.

So, here there are two versions of knowing that, according to the extract, reinforce each other. On the one hand, the familiar, everyday knowledge that "something has changed," and, on the other, the gathering, processing, and analysis of those different experiences as one shared experience. This transformation of dispersed experiences into an equivalent category

is crucial because it exactly relies on the use of an epistemic instrument to assign reality to a particular phenomenon (Latour and Woolgar 1979). Furthermore, the repeated use of the same instrument—the interviewee was referring to a dementia rating scale—enables the production of a stable object that was known already “twenty five years ago.”

This stability refers to the diagnostic category itself—and its clinical referent—rather than how it is distributed in the population and across years. Such epidemiological characterization relies, in fact, on the permanence, the unchangeability, of the category, supporting the experts we interviewed to develop what could be conceptualized as a *members’* historical sociology of diagnosis (Garfinkel, 1984), identifying the constitutive elements that brought MCI to bear in the clinic. A common element in this historical sociology was the growth of the number of persons complaining of memory problems; one example from my interviews follows:

Well, I’m head of the [Alzheimer’s clinic] and, em, our research is aimed at early diagnosis and treatment of early Alzheimer’s disease, and in that sense we are interested in MCI. We see, compared to five years ago, we see more and more patients that enter in the memory clinic actually that have only memory problems. So they will be classified as MCI.

A neurologist in an international clinical research center located in Netherlands, he perceived that there had been an increase in the number of people who “have only memory problems” in the five years before the interview. We found also that clinicians in all the five countries where we conducted interviews shared this perception. It is thus at the aggregate level that the clinic can be seen to be mediating the knowledge need articulated by patients. In this, it was perhaps decisive that all clinicians we interviewed also had research responsibilities. Thus they saw themselves as spanning the boundary between the laboratory and the clinic. The language of consumerism enabled clinician-researchers to maintain authority in the research community.

People experiencing “only memory problems” were problematic because they did not display all the other markers of AD, yet presented with a pressing problem. This change, and its moral weight, had been, according to the same interviewee, one of the main drivers of the clinic’s reorientation toward MCI, responding to a demand that was not there previously. Such responsiveness was a critical element in the process of remaking clinical practices. As another US geriatric psychiatrist put it,

I do think the views on MCI are moving here though, in that, um, people are seeing the patients, I mean people are getting referred now, and you know we’re all seeing a group of people in reasonably large numbers that we didn’t

tend to see before, and I think realizing that you can't just send them away and say there's nothing wrong with you, you're normal, because they're not actually normal, and what do you call them? What do you with them? And there is increasing awareness of that.

In this participant's case, the story was that while he was at first resistant to MCI on scientific grounds, his views had moved because of the "reasonably large numbers" that were being referred to the clinic with "only memory problems." These patients were not only different from those presenting with AD but had a unique, distinctive quality to their experience. The same geriatric psychiatrist described this uniqueness thusly:

The patients that we see in a hospital setting, or go to their GPs and come here [to the memory clinic], they're the ones . . . whose lives are being really kind of wrecked by this worry that they've got a brain tumor and they can't really get on with their life until they get that sorted out, and I think they are a completely different type of person, and you know they should be seen and dealt with and assessed.

Being a "completely different kind of person" justified a different approach to health care. For the interviewee, this worked through a typification of a set of practices of engagement with health care practitioners and institutions: these were people that experienced memory problems, however minor, and were concerned with the possible causes of such troubles; they wanted reassurance and to be able to "put a name" to it, a legitimization of the concern (Freidson 1970). Most importantly, they actively sought the diagnosis and the reassurance. That is to say, they are defined, or configured, as active agents in seeking information and help about their forgetfulness. Crucially, participants in our study described this process typically by drawing on a market vocabulary, where the concepts of "need," "demand," and "expectations" were articulated. Clinical practice as well as research in MCI was thus framed by our participants as being a response to these requirements.

This is because participants' views emphasized how users' needs were channeled by the clinic. Participants highlighted how significant the memory problems were for patients presenting at their clinics. This significance was associated with the levels of worry and fear that were attached to forgetfulness by patients and their families. While this might lead to questions about whether patients can act as consumers because these emotional and personal attachments would prevent the patient from acting according to an ideal of rationality, our interviewees viewed these emotions as motivating the act of information seeking that characterizes consumers. Not being able to offer a long-term therapeutic solution, clinicians saw their role as

providing information individually to patients. In this respect, clinicians were able to use the language of consumerism to reinforce their professional roles and identities.

Our analysis of the data suggested that it was because clinicians are dealing individually with members of what they saw as a specific social group that they are able to both reinforce their professional identities and to reinforce their authority in a research field that is becoming increasingly biomedicalized. In our ethnographic fieldwork, informants consistently characterized the social status of MCI patient as white, middle-class “baby boomers,” also sometimes described as the “worried well.” Social research on “baby boomers” has shown that this generation ascribes strong value to self-actualization through consumption, which is one of the key driving forces in the changing health dynamics of contemporary societies. As one of our interviewees jokingly put it,

I mean what one worries about is the baby boom generation that’s in its, in its infant narcissism (laughs) and as it gets older and starts to worry about replacing its keys then, then, one can imagine that studies to look at misplaced keys will be very high in priority (laughs).

This typification is significant for our purposes not only because of how it accurately reflects reality but also because it enabled participants to further detail the social process underpinning the construction of MCI as a category. For example, in an interview with a female psychiatric epidemiologist, a linkage between MCI and the transformation of American society was offered:

The US has really developed into a society with very high expectations, er, very high entitlements, um, and you know the belief that we should take enough vitamins and exercise enough, you can avoid getting any diseases at all. And you know it’s sort of not realistic, but I think the medical profession and the pharmaceutical industry have, in a way, contributed to these beliefs. Um, so that nobody accepts aging as a process of, of, you know, incremental losses any more. . . . But because of this very high expectation people have and then also because we have a society where people are not living in an extended family and don’t have great support systems, there is such a fear of becoming disabled and dependent and not being able to maintain autonomy. Because this is a society that really, really values autonomy. . . . Um, you know, I think that trickles down to things like whether they want to hear about every breakthrough and, you know, want it implemented immediately and at the same time we’re going to turn round and sue somebody if it doesn’t go well. And there’s no question that that affects the way clinicians react to patients, the way the government reacts to the public, the way, what the public expects of the government.

In her view, expectations about maintenance of health and functionality across the life course, significantly shaped by the medical profession and pharmaceutical industry, had led to situation where “nobody accepts aging as a process of incremental loss.” This she linked to the core American value of autonomy, whereby aging is seen as a threat to defining qualities of agentic personhood—an analysis that echoes that proposed by key sociologists of aging (e.g., Cowgill 1974). Technological innovation, the interviewee suggested, has been promoted as a way to extend health span and maintain autonomy, making persons experiencing memory problems expectant consumers of possible medical “breakthroughs.” One thing distinguishes her view from most of the other experts we interviewed: that the ability and willingness to act as consumers was embedded in a cultural and technological background. Interestingly, her view was that the consumer role was enacted as part of a wider technological regime, one where investment in biomedicine is justified by possible “compression of morbidity” and a reduction in health and social care budgets (Moreira 2019).

The person with memory troubles becoming a health care consumer was a historically contingent outcome of a variety of elements: health promotion programs, fiscal and economic policies, demographic projection, technological forecasts, changes in health care provision, and a generational culture. In this regard, the sociological analysis of diagnosis offered by the interviewee adds an important layer to the one proposed in the previous section, in that it links the regime of techno-economic promises to a specific political context, and defines the outcome in terms of expression of expectations on the life course and consumer behavior. Out of this assemblage, participants produced a typical individual—an ideal type—who seeks medical help relating to forgetfulness and memory problems. This idealized person, because of his/her high standard of wealth and education, his/her ability for self-assertion and expression, requires a different form of diagnostic practice, one that, as suggested above, is centered around the provision of information tailored to specific individuals, as described in this interview extract:

Yeah, well for me it's the amount of information that you have available to you, so you know you have it within the context of the individual past life history, so obviously the retired professor in mathematics you need to operate a slightly different standard when you see him in the office than with seeing the man who cleaned his office, and so you need to be able to [take in consideration things] like that.

It would not escape any social scientist how class markers were used by the interviewee, a US neuropsychiatrist, to explain his different approach to the diagnosis of MCI. The implication is that with a more educated patient

you are operating at a cognitively “different standard,” with emphasis on explicit information and content, possibly linking advice to evidence-based protocols. Clinicians responded to this new type of expectant consumer by transforming the basis and structure of the clinical consultation on memory problems. “Responsiveness” to new demands and needs of patients was seen as crucial in maintaining professional authority in a marketized health care. In this, the value of medical diagnosis was linked not only to the legitimation it produced, but more importantly to how this legitimation led to the deployment of a form of disposal, a prognosis:

Er yeah, that’s sort of what I meant and my understanding in the seventeenth century was that your quality as a doctor was, um, boiled down to pretty much how good you were at predicting the death of your patients, and that was pretty much, you know, your role really, and in the dementia it’s, we do more than that obviously, but an important part of our role is seeing people with memory and other cognitive problems talking about prognosis, what’s likely to happen to them. And that’s valuable to patients, it’s valuable to caregivers, and it’s not to be, er, dismissed as a trivial thing. It’s an important thing.

In this extract, the interviewee—a UK geriatric psychiatrist—makes an interesting historical analogy between the work of seventeenth-century doctors and those providing diagnosis and prognosis for people with memory problems. Characterized by patronage and close relationship between doctor and patient, seventeenth-century medical practice valued prognosis but lacked therapeutic tools to change the course of most illnesses. In the same way, clinicians in memory clinics are able to provide a close and detailed diagnosis, excluding possible alternative diagnoses, and to provide patients with an assessment of “what’s likely to happen to them.” This information is, he argued, valuable to patients and caregivers, enabling them to imagine possible future selves and the arrangements they will require.

Diagnosis and prognosis of MCI enrolled patients in practices that Clarke and colleagues (2010) see as characteristic of biomedicalized conditions: new forms of bodily engagement whereby individuals are provided with information of their genetic or biomolecular makeup so as to tailor their own form of health maintenance. In this regard, the category of MCI served as a form of “standardised differentiation” (Busch 2011), where value is produced by the close alignment between specific needs of a particular group and the type of service that is provided to that group. The same UK geriatric psychiatrist further specified what constituted value in this exchange:

TM: Yes, yes. When you say that it’s nice to put someone in a category, what do you mean by that? What are the advantages of doing that?

Psychiatrist: I guess it would allow one to say, em, right, you know, you don't have dementia, you might get dementia, but so might I. But you don't have dementia at the moment, but you're not normal, so I'm not saying the complaints of your memory are in your head and you should go away and forget that; there is something there. Um, and, you know, your risk of Alzheimer's disease has increased, you know, you could do this and that to try and prevent, you could think about this. You know you should live a bit of a healthy life, everything like that. So these are the kind of things that, em, we can say to people. If we didn't have the category, I don't know how we could try and take things forward.

The suggestion was that the MCI category enabled a form of work that went beyond usual practice in dementia clinics. Being in the category positioned the patient between the normal and pathological boundary—"you don't have dementia at the moment, but you're not normal"—a space where it was then possible to engage the patient on prevention work. In this, the role of the clinician was seen as being mostly related to the provision of information, as already suggested above, and guidance on how to tailor general health advice to one's particular situation. This information was valuable exactly because it was "personalized." It took into consideration the persons' somatic makeup and lifestyle. Indeed, the focus on health advice, as opposed to technological interventions, was seen as a signifier for this practice of "personalization." One US neurologist expressed this in the following way in response to one of my questions:

TM: But at this point those interventions are mainly lifestyle interventions or, let's say, nonpharmacological, i.e., more exercise etc. . . .

Neurologist: Those are very important yes, absolutely. But I wouldn't, and I wouldn't minimize those; I think they have tremendously important significance for all of us and, er, but it can be a diagnosis of mild cognitive impairment of one form or another could be a wake-up call for somebody who's, you know, involved in a lifestyle that has, er, that is basically going to exacerbate the rate of progression of the illness, um, and so, um, making that diagnosis can have a major impact, not only in planning [for the future], as I said earlier, but also in the rate of progression of the disease.

In this is expressed the paradox of MCI: that while the configuration of persons with memory problems as expectant consumers results from the technological expectations invested in AD research, in the clinic, the exercise of consumerism was mostly deployed through ordinary, nontechnological health advice, albeit tailored to specific persons with a specific life history. However, this paradox also offers a solution to the problem posed at the outset of this chapter: how to understand the transformation—the

drift—of the MCI category from being a key vehicle in the delivery of therapeutic solutions to AD, to being solely a way to discuss “diagnosis, prognosis, long-term planning, and the lack of effective medicine options” with patients (Petersen, Lopez, et al. 2018: 128). In the clinic, MCI was, from the outset, a form of personalizing, of tailoring, health care to particular persons. There were two related ways this was articulated.

First, clinical diagnosis of MCI could give the patient the possibility of modulating the rate of progression toward dementia. In this, the main role was attributed to lifestyle interventions. It was reflexively understood by the participants in our study that those practices are imbued with moral meanings about one’s relation to one’s body and others around oneself. Thus class and education typifications of the person experiencing memory problems reinforced the relevance and appropriateness of lifestyle advice. There was a degree of elective affinity between consumers and the advice provided.

Second, participants in our study argued that clinical diagnosis of MCI could provide patients the opportunity to plan better for a trajectory of probable future cognitive decline. Because of the legal implications of a diagnosis of dementia, they viewed MCI also as offering patients “time,” a decision point in their trajectory to ensure that arrangements in the future will be organized according to one’s wishes. What is striking about this is how it appeals to the values of autonomy, cognitive agency, and control that epitomizes the baby boomer generation, as was recognized by many of our interviewees. Participants saw their role as providing the means through which patients could retain control over their lives by giving them a temporal horizon to which they should orient themselves. Overall, participants were aware of the different character of diagnosis entailed by MCI. While they conceptualized it mainly as information giving, they were also aware of social, cultural, and moral meanings of the information given, as well as of the information-giving situation. They were aware that MCI was a market making device, in that it constituted a specific relationship between providers and users of health that was shaped by consumerism.

On Classificatory Drift and Torque

In the chapter, I have investigated the evolution of MCI as a diagnostic category in the last two decades. Originally defined as the major risk condition for AD, MCI has become a much looser category associated with a variety of possible etiologies, with a significant proportion of “persons diagnosed with MCI . . . reverting to normal.” In addition, while in the beginning of the 2000s, MCI was proposed as a politico-epistemic platform, invested

with the capacity to move AD therapeutic research toward finding and validating “disease-modifying drugs,” two decades later, it is mostly seen as a useful categorical instrument to legitimize subjective concerns and provide personalized health advice.

In the first section of the chapter, I explored how it has become increasingly difficult to maintain the “circuits of translation” that uphold the AD bioclinical collective. I suggested that the assembling of this collective had relied on the power of conventional standards such as the McKhann criteria to facilitate the circulation of materials between clinics and laboratories. I then argued that with focus on biomarkers, memory clinics are increasingly working with what can be labeled “old” diagnostic technologies, classification systems, and categories such as MCI. Whereas memory clinics and their diagnostic work used to be easily linked to the wider, promising domain of AD, now this field of research is characterized by deep uncertainty about the value of existing therapeutic solutions and the restructuring of a pharmaceutical market. The question that then arises is, why is the category of MCI still used if its link with the disease model of dementia has been extensively weakened?

In the second section of the chapter, I suggested that the survival and classificatory drift of MCI can be explained by the role ascribed to “subjective memory complaints” in enacting a particular configuration of health care driven by consumer choice and the “logic of the market.” Drawing on interviews with researchers-clinicians in North America and Europe, I proposed to analyze interviewees’ reflections on MCI as a *members* sociology of diagnosis, as these were and are constitutive of the epistemic, technological, and institutional apparatus that brings MCI to bear in the clinic. I focused on how practitioners identified a “completely different type of person,” an idealized new sort of patient whose characteristics facilitated their reasserting of clinical authority. The generational, educational, and social positioning of this new type of person with memory complaints justified a new form of clinical “responsiveness.” These were “expectant consumers,” looking for technological solutions for extended functionality and health across the life span. Paradoxically, what MCI diagnosis entailed was non-technological, but nonetheless commodified, advice on lifestyle and health. MCI was, I argued, from the outset, a form of tailoring health care to particular persons. In this respect, it worked to enact market identities and entities such as “subjective memory complaints” in dementia care.

What are the possible consequences of this classificatory drift for persons diagnosed with MCI? As discussed above, in research on MCI diagnosis from the perspective of patients and caregivers, there is uncertainty about whether the stigmatizing outcome of the diagnosis can be balanced by the legitimizing protection it offers. However, as MCI loses its capacity to

identify a specific etiology and is increasingly unstable as a categorization, with a significant proportion of “persons diagnosed with MCI . . . reverting to normal,” it is likely that diagnostic uncertainty will impact patients’ self-concept and wellbeing, enhancing the liminality of their experience (Lock 2013), and constituting persons with memory problems as what Timmermans and Buchbinder (2010) conceptualized as “patients-in-waiting.” Such reclassification raises crucial ethical questions, the justification for uncertainty experienced by patients in the present hinging on the possibility of future technological developments (Schermer and Richard 2019). However, as the link between MCI diagnostic work and AD technological expectations appears to be weakened, the trade-off between current patients and future therapies has lost most of its leverage. Where once was hope, persons diagnosed with MCI may now find themselves increasingly outside the network, defined by a classificatory box that no longer connects to the wider grid, grappling with continued medical surveillance and the mundane complexities of managing their own condition.

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