7 THE PREVENTIVE UNCERTAINTY OF MILD COGNITIVE IMPAIRMENT (MCI)

The Experts, the Market, and the Subjects of Diagnosis

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Mild cognitive impairment, or MCI, is a predementia condition considered a risk for Alzheimer's disease (AD). As such, its diagnosis and study has become a primary opportunity in research and practice for prevention and intervention. However, a growing literature of debates and critiques has also revealed the inherent uncertainty and instability of MCI as a diagnostic category that sheds light on the etiology of Alzheimer's disease itself. This chapter contributes to this literature by drawing together and juxtaposing data from the experts, the market, and subjects of diagnosis as three social realms where brain health, aging, cognitive impairment, and caregiving are assembled.

In "The Experts," we summarize the problems and issues about MCI articulated by experts in the field, supported by some of the interviews with nine leading researchers published by authors Stephen Katz and Kevin R. Peters in a special issue of *Dementia: The International Journal of Social Research and Practice* (2015).[1] In reviewing the MCI field, we highlight where researchers, experts, practitioners, and critics share common concerns about diagnostic inconsistencies, biomarker uncertainty, and pharmaceutical capitalization, all central themes to discussions about AD prevention as well. In "The Market," we look at selected rhetorics and products representing a new and lucrative memory market promoting "cognitive fitness" as a lifelong pursuit against the risks of dementia. The commercialization of memory products, foods, games, and exercises, and the incorporation of lifestyle intervention in health science and policy, both create and fill the gaps for hope and optimism for those seeking to manage their brain health. In "The Subjects of Diagnosis," we develop an interpretive analysis of data with twelve focus groups that were led by author Peri J. Ballantyne with people affected by MCI and AD diagnoses, highlighting their metaphorical

and narrative skills at making disruption and apprehension meaningful and coherent. Here we are also concerned with the relationship between the professional landscapes of MCI and dementia-related diagnoses and subjective and lay experiences.

These three parts of the chapter together raise the question of what MCI and other predementia categories actually mean and accomplish in a medical culture that, through diagnostic testing and preventive interventions, goes beyond the clinic to connect biographies, families, communities, services, and networks. If AD has become one of the most dreaded diseases of our time, then practitioners should be encouraged to consider how diagnosis is an ethical, as well as a clinical, process, observable in lived situations where personal resources are called upon to make sense of it. Thus, the experts, the market, and the subjects of diagnosis are purposively juxtaposed in this chapter not only as social locations of MCI and prevention knowledge-making, but as part of a wider diagram of uncertainty by which MCI, early detection technologies, and dementia campaigns are redrawing the health politics of aging. Conclusions consider the relationship between these politics and new divisive states of vulnerable, at-risk, and unsettled life.

The Experts

Katz and Peters titled their special issue of *Dementia: The International Journal of Social Research and Practice* "Voices from the Field: Expert Reflections on Mild Cognitive Impairment" (2015) because MCI and dementia are not just disease categories, but constitute a social field of networks of experts, research agencies, policy agendas, pharmaceutical interests, medical practices, popular images, and public social media that converge to mark out new cognitive and life-world boundaries between normal and pathological, functional and dysfunctional, and successful and unsuccessful aging.[2] As background, there have been many different MCI-type labels put forth over the years, with Kral's (1962) distinction between "benign" and "senescent" forgetfulness being one of the earliest.[3] Today, the common definition of MCI is that it presents a measurable degree of cognitive impairment that does not meet the diagnostic criteria for dementia. Thus, individuals diagnosed with MCI fit somewhere between normal and pathological, depending upon the diagnostic interpretation of descriptive and clinical criteria. And it is precisely this in-between status and liminal space that lay behind the uncertainty of MCI.

Currently, the most popular MCI clinical criteria are those put forward by Ronald Petersen and his colleagues (Petersen, Smith, et al. 1999). These initial criteria focused exclusively on memory impairment. These research-

ers subsequently expanded the MCI construct beyond just memory impairment by proposing the following three MCI subtypes: "MCI-Amnestic," "MCI-Multiple Domains Slightly Impaired," and "MCI-Single Nonmemory Domain" (Petersen, Doody, et al. 2001). The amnestic subtype became the major one in MCI research. In the spring of 2011, three important papers were published in the journal *Alzheimer's and Dementia* by American working groups established by the National Institute on Aging (NIA) and the American Alzheimer's Association, whose tasks were to revise diagnostic criteria for "dementia due to Alzheimer's disease" (McKhann et al. 2011), "mild cognitive impairment due to Alzheimer's disease" (Albert et al. 2011), and "preclinical Alzheimer's disease" (Sperling et al. 2011). These papers reified a place for MCI and preclinical AD along a proposed continuum of cognitive function, thus serving to legitimize the research push into early AD diagnosis, along with promoting the potential benefits of diagnostic biomarkers (e.g., MRI brain scans and cerebrospinal fluid [CSF] testing).

Although the fifth *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* (American Psychiatric Association 2013) replaced MCI with "mild neurocognitive disorder," MCI has remained a highly popular clinical label as an underlying cause of AD, in part because of its relevance to prevention, even as important questions have emerged regarding its detection methods and the validity of associated biomarkers (Brown et al. 2011). Other critiques have focused on how MCI has been constructed through language and biased by scientific enterprise (Visser and Brodaty 2006; Whitehouse and Moody 2006), and have pointed out the ethical risks of MCI diagnoses and biomarker testing at increasingly younger ages, since AD is a late-onset disease (Corner and Bond 2006; Leibing 2014; Lock 2013a; Manthorpe et al. 2011; Moreira et al. 2008). At a macro-social level, MCI detection and dementia prevention are mediated by health-care policy, pharmaceutical interests, and public demands for better treatment.

Given this controversial background about MCI and its diagnostic uncertainties, why does it persist as such a successful disease entity? Our interviewed experts and others in the field offer three main reasons.

First, there is a need for some kind of diagnostic stage that precedes dementia in order to allow for early intervention, since a significant number of individuals with MCI progress to dementia, although neurodegenerative conditions such as AD itself can be slow to progress. One does not just wake up one day with AD; there must have been earlier signs. But conversion rates vary—not surprisingly, they are higher in clinic-based than in population-based samples—as do reports that between 14 and 41 percent of individuals with MCI revert back to "normal" cognitive functioning (Ganguli et al. 2004; Gao et al. 2014; Kaduszkiewicz et al. 2014; Manly et al. 2008; Ritchie, Artero, and Touchon 2001). Other inconsistencies have

divided the MCI field as some researchers, such as Mary Ganguli (2014), recommend refining MCI definitions since not all studies use the same ones, while others, such as Ronald Petersen (2015), continue to see MCI as a promising anchor for more precise data, although questions remain as to when and what kind of early testing is optimum for supporting intervention. As Carol Brayne and her colleagues have argued, we need to stop confusing "early" with "timely" diagnosis, because "there is currently no high-quality evidence that diagnosis before the usual point of clinical presentation leads to long term improvements for people with dementia and their families" (Brayne et al. 2013: 1). The medical logic that assumes "the earlier the better" can also overlook the aggressive imposition of medical screening with neither timely reason nor researched justification. And, as Constantine Lyketsos (2015: 323) told us in his interview, "If screening is applied to detect dementia at an early stage, then it needs to be related to helpful interventions for people."

Second, MCI satisfies a biomarker hypothesis, since diagnosed individuals have been found to have intermediate biomarker scores/values linked to AD (e.g., see De Santi et al. 2001; Pennanen et al. 2004; Xu et al. 2000). These results support the notion that MCI is a transitional phase between normal aging and dementia, as well as theories that the underlying factors associated with AD are the two neuropathological features of plaques (composed of the amyloid protein) and tangles (involving the tau protein). Predictive research also suggests that biomarker changes indicating features of AD can occur ten to fifteen years before the onset of any cognitive or clinical symptoms. However, the biomarker hypothesis in MCI and preclinical AD has been challenged in cases where no clinical symptoms are present (see Rockwood 2010; Sperling and Johnson 2010) or where biomarker abnormalities may not be specific to AD and amyloid and tau abnormalities may not be the cause of AD (Lock 2013b; Whitehouse and George 2008; Wright et al. 2009). Such debate challenges the use of biomarkers in diagnosing milder conditions such as MCI and preclinical AD, even as reliance on biomarker measures is becoming paramount in cases of asymptomatic preclinical AD. Epidemiologically, as Carol Brayne (2015: 356) comments, "until we have studies which are in truly unselected populations and follow them up for long enough, we will not know whether they [biomarkers] are actually predictors of dementia outcomes. . . . So the question is what is the value added of the biomarkers over the things that we already know enhance the risk for dementia just through education or family risk."

One particularly interesting finding has been that up to 30 percent of individuals who are cognitively "normal" have been found to have AD-related pathology, and this number has been found in postmortem studies as well

(see Aizenstein et al. 2008; Knopman et al. 2003; Price and Morris 1999; Snowden 2001). In addition, some studies have documented the deposition rate of amyloid in the brain of individuals who are initially cognitively normal, suggesting that cognitively normal individuals who are biomarker-positive may or may not be in the preclinical stages of AD or other types of dementia. Future research, therefore, more closely needs to examine the actual connections between biomarker results, prognostic reliability, and levels of care for people with AD.

Third, there is the critical issue of connection between MCI and pharmaceutical influence and capitalization. According to the website clinical trials.gov, there are hundreds of pharmacological and nonpharmacological registered trials related to MCI and Alzheimer's disease, indicating sizable investment in intervention. (At the time of our study, there were 233 trials open.) The cholinesterase inhibitors (i.e., donepezil, rivastigmine, and galantamine) and memantine are drugs already being prescribed for MCI, even where reported benefits are modest at best. In fact, there is some evidence of an increased risk of adverse events with these drugs (Russ and Morling 2012). Of the current drugs under development for AD, most are aimed at lowering amyloid levels in the brain. However, health research mandates for prevention fuel a pharma sector geared to narrowing the boundary between MCI and normal cognitive status and expanding the pool of "at-risk" older populations. The drug companies are racing ahead with growing the capitalization of dementia, even as the measurement and meaning of biomarkers have yet to be fully standardized across laboratories and clinics. Further, many drug trials involve very large sample sizes, which increase the chances of obtaining a statistically significant result. Yet even these small statistically significant effects may not be clinically meaningful (see Graham 2008; Peters 2013). While the research community agrees that early identification of MCI would be ideal if there were a safe and effective treatment for it, at this point there is no drug for MCI nor AD, and looking to the pharmaceutical industry for dementia care may well turn out to be an expensively flawed pursuit, as critical researchers predicted (Ballenger et al. 2009), especially if nonmedical approaches are excluded (see Basting 2009). In the end, as David Healy admonishes, we should think about what harm treating every illness for older people with drugs can create. "What we need is a new framework with guidelines for people, not illnesses" (Healy 2015: 365).

These three areas of research debate and contention regarding the uncertainty of MCI and predementia testing, the reliability of the biomarker hypothesis, and the influence of pharmaceutical capitalization support our conviction that understanding the strengths and weaknesses of the MCI disease model requires interdisciplinary breadth and plural sources of

knowledge, especially if preventive cognitive testing will be a pervasive part of our aging futures. The MCI and predementia field, as it continues to grow in research, funding, and technology, has also left unaddressed questions of improved care and attention to the everyday consequences of diagnoses. As Holly Tuokko (2015: 315) asks, "So what if I say that someone has MCI or dementia? We still have to provide support for this person after they leave the clinic or GP's office." And while research on MCI seems like a reasonable scientific response to public anxiety about protecting the aging brain from memory loss, it exists in a culture that has turned AD into a calamitous epidemic. The promise that medicine can intervene in the progress of AD at increasingly earlier points of life and at least prevent some of its risks—as it has done with diabetes, cancer, hypertension, and other chronic diseases—needs to be gauged against this cultural background. Part 2 of this chapter explores how a market of anti-aging industries has filled the gaps around hope and care left largely vacant by the health and medical sciences and created its own forms of commercialized expertise on managing brain health and cognitive "fitness" in relation to preventing dementia.

The Market

Today, cognitive health, a vague term in itself, is increasingly added to other health statuses (physical, functional, sexual, etc.), as evidenced by a growing focus on brain care in the lifestyle literature on exercise, diet, stress, sleep, and work-life balance. Such literature acts as a public pedagogy to educate readers about the wonders of brain-"boosting" foods, vitamins, daily exercises, and optimizing mental "workouts." Most importantly, it provides a sense that AD might be preventable; thus, the markets share a language with public health promotion agencies that mandate active lifestyles as disease preventive regimes. For example, the Alzheimer Society of Canada (2011), in the authors' home country, advises older people to "keep your brain active every day" and "that a healthy brain can withstand illness better." But how can we really know when our brains are "active" or "healthy" or "fit," let alone keep them that way? As Stephen Katz and others have investigated, the commercial inundation of products, programs, and advice about maintaining brain health and preventing age-related memory loss are based on contestable and culturally fabricated meanings of cognitive life itself (Katz and Marshall 2018; Williams, Higgs, and Katz 2012).

These meanings also have a political dimension. While there is a long history of mind and memory training with deep roots in theology, philosophy, and science (Danziger 2008; Katz 2013), today there is a cognitopolitics that reaches out to what Rose and Abi-Rached (2013) call "futurity,"

the governance of the future by way of controlling population risks in the present. For example, in 2009, the American National Institutes of Health (NIH) was spending nearly 20 percent of its total budget on brain-related projects (Carey 2009). In the United States, Humana and MetLife have programs to encourage clients to optimize brain health (Thornton 2013: 9), as public expectations for cognitive performance and boosting "mental capital" (cf. Foresight Report 2008) align to other market-driven standards of productivity, efficiency, speed, and unerring memory. The evidence of a coalescence between the brain sciences, futuristic cognito-politics, the neurocommodity market, and lifestyle preventive practices appears in overarching discourses about the brain that represent a new human nature (Rose and Abi-Rached 2013) and create what Fernando Vidal (2009) calls "cerebral subjects," who learn to express their identity in neuroscientific terms (see Pickersgill and Van Keulen 2011). Yet a key feature of these discourses is their lack of clear distinctions between states of cognitive improvement, enhancement, optimization, and wellness, even as these terms are ubiquitous in the promotion of brain-based marketing.

Scientific researchers advise caution about the marketed promises of an exciting lifestyle frontier aimed at preventing cognitive decline, especially where it is tethered to misunderstood appropriations of *brain plasticity*, an attractive idea that the brain can change itself or can be trained to do so. Plasticity signifies human character as flexible, mobile, dynamic, and adaptable, traits that also articulate human capacity and labor with neoliberal and global capitalist strategies (Pitts-Taylor 2010, 2016). As with physical fitness training and its metric quantification, brain training "is based mainly on recent neuroscientific findings that the brain is less like a blank slate or a computer-processing center (as metaphors of old would have it) and more like a muscle that can undergo atrophy or hypertrophy depending on its stimulation" (Millington 2014: 495). Images of the plastic brain-as-muscle permeate the commercial field of cognitive advice, "neuro" stimulants and protectors (e.g., LifeExtension's Cognitex, BrainStrong's Memory Support), "brain-boosting" programs (e.g., BrainAge 2, HAPPYNeuron), and brain "gym" and "spa" memberships (e.g., Mindspa). This is a hugely lucrative field that was forecast to become a $6 billion market in 2020 and expected to entice increasing numbers of consumers interested in cognitive fitness and influenced by the dictum that aging is inevitably accompanied by cognitive decline unless an individual does something about it (Fernandez 2013).[4] Thus, brain-fitness marketing language "renders the 3-pound organ in our heads both an object of alterity and veneration" (George and Whitehouse 2011: 591).

The lifestyle marketing and health politics around the aging brain overlie a deep anxiety about aging with dementia, again buoyed by apocalyptic

media images of "tides," "tsunamis," "storms," and "bombs" that depict growing older populations as social threats (Behuniak 2011). While it is often wrongly assumed that older people self-rate their memory more negatively than younger people (Shmotkin et al. 2013), the fear of dementia has become as explosive as the number of diagnoses reported for it. And, if older individuals choose not to buy into the commercialized promises of brain work, they become stigmatized as vulnerable to cognitive decline, poor health outcomes, and entry into the "fourth age" (Gilleard and Higgs 2010), just as do those who refuse to be physically "active" and remain "sedentary." Further, the public is aware that currently available drugs, treatments, and tests, despite the inflation of research funding and pharmaceutical investment in dementia-related diseases, are hardly proving effective to prevent them, let alone provide definitive cures. What, then, are the subjective experiences of people who have been or might be diagnosed with MCI or dementia and must incorporate this culture of fear, risk, and confusion into their own ways of interpreting and narrating their lives. These are questions we now turn to address in part 3 of this chapter.

The Subjects of Diagnosis

As discussed above, preventive diagnoses of predementia associated with the risk of progression to AD are riven with uncertainty, especially as biomarker research in some countries, such as Germany, are becoming increasingly part of common clinical practice (Schweda et al. 2018). As Gomersall et al. (2015: 907) discovered in their qualitative study of patients' accounts of ambiguity created by an MCI diagnosis, "It was not only the perception of MCI as a prodromal form of dementia that led to future-oriented anxiety; concerns were also raised around the uncertainty of the label." In some everyday encounters between patients and practitioners, the uncertainty of cognitive testing in memory clinics can be advantageous, as Swallow and Hillman (2018) investigate in their ethnographic research in the United Kingdom. Here "tinkering practices" around testing technologies and the "thickening of time" purposively used to slow down diagnostic disclosure become ways for professional staff to diminish patient anxiety about diagnosis. The authors conclude that, "as well as drawing on uncertainty in the diagnostic process, routines and mundane practices of clinical work can also be utilised to manage and traverse the presence of fear and anxiety and perhaps to protect practitioners from 'too much' emotion" (Swallow and Hillman 2018: 12). Thus, a more flexible diagnosis and less determinate labeling might also benefit people who are motivated by it to make

healthy changes in their lifestyle or work habits. MCI, in such cases, can be diagnosed in the sense of an alert, a warning sign to encourage healthier aging practices.

However, where clinicians might provide this more positive potential of diagnostic uncertainty, they still encounter their patients' dread of such testing if it portends an AD-foreclosed future, especially if exacerbated in poor communication practices about informed consent, disclosure practices, and false-positive results. Although dementia research demarcates MCI from AD, an MCI diagnosis is *experienced* as inseparable from AD because it carries the threat of it and already detours memory problems into a pathological state. As Renée L. Beard argues in her book *Living with Alzheimer's: Managing Memory Loss, Identity, and Illness* (2016), the MCI label is part of the same clinical and service worlds as AD. Indeed, someone complaining of memory problems and then diagnosed with MCI is already suspected of mental incompetence (Beard 2016: 56). Margaret Lock (2013a: 91) also emphasizes that an MCI diagnosis becomes a liminalizing and stigmatizing experience since the person becomes neither normal nor demented. Whether or not their MCI progresses to AD, a model of progress is insinuated. And as a person becomes a case for MCI and a clinical patient with cognitive problems, they must revise their personal identity and biography accordingly.

Hence, for people who are tested and diagnosed with MCI or at risk of AD, it is difficult to bridge the gap between the medical world, with its technical terms and uncertainties, and their subjective identification with cognitive decline labels (Campbell et al. 2016). Yet they are obliged to make sense of their age-related memory loss and come to terms with the likely need to depend on others for support and care. Since there is a woeful lack of research in the dementia field on the personal effects of diagnostic labeling or how it spreads and affects other spheres of life, there is little emotional counseling for diagnosed individuals to draw on or read about outside of commonsensical and marketed advice about prevention, diet, exercise, sleep, and stress reduction (although support groups can help). Yet such advice hardly considers how deeply disturbing and isolating the consequences of an MCI diagnosis can become (see Parikh et al. 2016; Stites et al. 2017) or how women and men can respond differently to their diagnostic status (Tolhurst and Weicht 2017).[5]

In our research with twelve focus groups of selected older individuals, family members, caregivers, and professionals, conducted by author Peri J. Ballantyne at Trent University (Canada), we learned how the ambiguities and uncertainties of MCI and dementia diagnoses are negotiated and rendered meaningful in the conversations, relationships, identities, and

routines of the people affected by it. These observations accord with gerontological research on metaphor (Kenyon, Birren, and Schroots 1991), discourse (Nikander 2002), narrative (de Medeiros 2014; Hubble and Tew 2013), and everyday sense-making (Gubrium and Holstein 2009) that shows how wider cultural ideologies and expert knowledges are fractured, translated, recombined, and adapted within people's everyday vocabularies and interactions.[6] Thus, in the remaining part of this chapter, we concentrate on examples where participants inventively use metaphor and narrative to account for their living with cognitive impairment. In particular we focus on recurring themes of what we classify as diagnostic "it," biographical disruption, and narrative collision.

This Diagnostic "It"

MCI and AD diagnoses happen largely in brief, anxious meetings with little attention given to postdiagnosis consequences. When people come to a clinic because of a memory complaint and learn they might have a serious medical condition and a possibly threatened future, the impact and uncertainty of the diagnosis can be experienced as an intrusion by an overpowering but amorphous "thing" in their lives. This is similar to the accounts offered by participants in Cox and McKellin's (1999) powerful study of Huntington's disease, where predictive genetic testing created a new affective entity within households around which family obligation, responsibility, routine, and care were organized. While, on the one hand, MCI or AD and Huntington's disease are obviously very different conditions, on the other hand, there are parallels in the language and affective presence of the disease(s) for those diagnosed. Just as the reference to Huntington's disease risk was expressed as "this thing in our family" in Cox and McKellin's study, in our research, an MCI or AD diagnosis produced a new and fearful presence marked by contradictions between the known and the unknown. The following excerpts are examples of how our focus group participants created a workable and lay relationship with this diagnostic presence and its contradictory nature by using the referent "it" (author emphasis italicized).

> Patient Mr. M: I didn't think too much about *it* until my wife realized that I was starting to forget a few things and we decided we would get diagnosed, to see if *it* actually was there. And of course, *it* proved positive, so it was just a matter to find out as much as we could, to postpone *it* . . . because there really isn't any cure. I don't try and hide *it* . . . I'm trying to get on with life. Now that I'm more aware of *it* I try and explain *it* to people . . . I don't think we need to be in denial about *it*.

Spousal caregiver Ms. G: The doctor had given him [spouse] an x-ray . . . I met with his doctor, "what was the result of that x-ray?" He says "he has dementia." I said, "well what can we do?" He says, "oh nothing much, you can't do anything about *it*."

Spousal caregiver Ms. D: He [spouse] arranged for a meeting with Dr. X and she confirmed *it* was Alzheimer's. I didn't call it Alzheimer's with him, I just said "oh you've got a bit of memory loss." And then slowly I worked the Alzheimer's in with him until he accepted the fact that he had *it*.

Spousal caregiver Ms. S: He [spouse] got fired from a job and he was extremely upset, but when I think back . . . maybe that's when *it* started, but when I really first noticed *it* we had belonged to a club and had a speaker there about the Alzheimer's Society . . . they said look at specifics . . . if they do things that they've never done before, and Mr. A. started to do things that he'd never done before. That was a good thing because that was in the early stages.

Volunteer caregiver Ms. T: I don't believe there is anything you can do to stop *it*. I think *it* is programmed in, I think it is a genetic thing and if you're going to get *it*, then you're going to get *it*. Maybe something to slow *it* down, but I don't think can stop *it*.

Biographical Disruption

The use of metaphorical language such as "thing" or "it" to refer or adapt to the onset of disease and suffering is connected to biographical disruption, a problem well documented in medical sociology. In her book *Disruptive Lives*, Gay Becker (1997: 60) points out the importance of metaphors in narratives of disrupted lives for linking the present to the past and reconnecting a person to their community or family by providing a "transforming bridge between the image of the old life and the new one." Even in cases where life becomes permanently disrupted and unpredictable, metaphors can be a resource for narrative sense-making by integrating suffering and loss into coherent explanatory patterns. In their study of strokes, Faircloth et al. (2005) examine the various metaphorical and narrative practices that stroke survivors use to come to terms with their experiences of sudden and massive disruption. MCI or AD diagnosis can be also particularly disruptive because it can reset the narrative flow of biographical life between the before and after of diagnosis. Here diagnosis is multifaceted, both predicting a potentially terrifying future as well as inspiring changes in health behaviors. However, when disruption follows from the diagnostic moment itself, it is often shocking and unmediated, as the following excerpts portray.

> Patient Mr. M.: I was up at the clinic and being diagnosed, then I had my sleep test and after three days, and it was just boom, boom, boom and they diagnosed *it*.
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> Spousal caregiver Ms. G.: It was just sheer accident. I happened to be there seeing my own doctor, because we didn't have the same doctor. I bumped into him and asked him and he said, "Oh, he's [husband] got dementia."
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> Spousal caregiver Ms. M: I noticed that he [husband] wasn't remembering things. We went to his doctor who said "I'll do a mini mental test." He also wanted to do some blood work. The doctor called soon after and said, "yes he has some the beginning of Alzheimer's." He said that he would give him Aricept. He really didn't talk about it too much. The next day there was a mail delivery to the house with Aricept in it.
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> Older women's community focus group member Ms. M.: There was a woman who lived across the street and she was maybe 50-something, really fit and alert. I saw her outside, working in the yard or something. I called over, "how are you doing," and she went into the house and came out with this piece of paper that said that she has early Alzheimer's disease, she couldn't remember exactly what it was called. And then she lost all her vocabulary almost right away.

The following excerpts are related examples of how biographical and family history is recounted to help mollify disruption (authors emphasis of metaphorical language italicized).

> Spousal caregiver Ms. M: I think we can all look at our family histories, our extended family histories and say, you know grandma had *it*, you know my mother's *dingy*, great Aunt Mabel had *it* for sure, Uncle Harold had *it*, I probably got *it somewhere in there*, so we already at a gut level know that *we're marked*, down the road.
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> Spousal caregiver Ms. C: On reflection the disease must have started years ago . . . the family always thought it was all his [spouse] arguments and idiosyncrasies, but as time unfolds you realize this was the beginning of Alzheimer's. I knew he had Alzheimer's long before the doctor said . . . you just know . . . you lived with the person all these years and you see the changes; you know something's up.
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> Daughter Ms. P: [Talking about her mother's experience with memory loss]. It's the little *shift*, she says I've lived a full life and I have a wonderful family and I'm content with my life now.

In comparison, when we talked to a physician about diagnosis, he had his own way of narrating and dealing with biographical disruption for patients.

Dr. R: Typically, if I identify a patient with early cognitive changes and I'll bring the family in even if they're at an early stage. I'll introduce or give them insight *into the progression and having an idea of getting prepared right*. So it won't just be, well you know you're slowly going to decline, no; you need to get ready, right? So I'll instruct them on getting their will together, finding out who is going to be the POA [Power of Attorney], a substitute decision maker, ensure that there's safety in the home, the driving issue, and then further down the road, where are you going to live?

Because those things . . . *you plant the seed early right so people have a chance to prepare*. The crisis is when people ignore all of that and they end up in a hospital, right, because they're too far along. Then I'll have a follow-up visit and I'll say "so how far along have you come with the suggestions I made the last week?" And they'll say "not very far" or some will say "well at least we went to the lawyer and got something done."

Narrative Collision

If diagnosis can create disruption, sometimes the narratives through which it is expressed diverge and collide with each other and the diagnosed subject's own experience, due to the different interpretive strategies of family members, friends, and spouses. Here we borrow the term "narrative collision" from Tolhurst, Weicht, and Kingston (2017), who describe the differing and colliding accounts between friends and family members in cases of dementia-related diagnoses. As in the above focus group excerpts, the narrative work we listened to here was about creating composite and livable accounts of uncertain conditions (author emphasis of metaphorical language italicized).

Daughter caregiver Ms. M: My brother is my mother's major caregiver. He doesn't think there is anything wrong with her, but for those of us who don't see her every day, *we see the decline happening*. He insists she's fine, but she no longer socializes and she can't find words to speak when she wants to talk, maybe part of that is the mini strokes part . . . It's just sort of a *general slowdown*, she can watch the same documentary on TV over and over and thinks it's brand new.

Mother caregiver Ms. S**:** My other son has prostate cancer and when I see things that he's doing, I think more of the cancer. He downsized his home, his backyard, he's too tired to do all the work. My other son sees it as dementia. He's afraid, he's 58 and my other son is afraid that it is dementia starting. I would be worried more about the cancer than the dementia.

Spousal caregiver Mr. J: I've been married 34 years to a terrific girl who has a phenomenal memory, and because she's got a phenomenal memory, I frustrate the hell out of her with my memory loss, so I'm starting to feel depres-

> sion because if I said to her, "what does that cognitive mean," she would say "J., I already told you yesterday." I wish I didn't ask the question.

> Spousal caregiver Mr. G: I noticed my wife starting to use strange language about 15 years ago. It was just one or two little items and a few little choices that she made here and there. [After I went to meetings for caregiver support,] she thought I had betrayed her . . . it took a long time to convince her that I was coming for my own reasons. . . . She knows she *has decline* . . . but she won't buy it if I use words "dementia" or "Alzheimer's," so I don't use those words.

Doctors and diagnosticians in their practice face colliding narratives as well.

> Dr. A: A man appeared for the appointment with his wife; I asked "why are you here?" and the man said, "I'm doing fine" and the wife said "I'm a little concerned about what's happening to my husband, his memory is not so good." The man says, "I don't forget things" and his wife says "remember you came to pick me up at the mall the other day and you couldn't find me." It's the unawareness of the person who's afflicted, they're not looking for information because they think they're fine.

The import of our focus group data is to remind us that clinical testing, assessment, and diagnosis of cognitive decline may tell us what it is, but not how to reconcile ourselves to it. This gap creates a kind of ethical fallout, an absence that must be filled outside the clinic in everyday life where subjective and narrative resources are called forth to settle such unsettling circumstances. Even if diagnostic labeling is uncertain, it still creates a troubling aftermath. As one respondent told us, "My concern is if I were to end up with Alzheimer's, I would be dumped into what I call a dumping ground . . . that what scares me the most, because if I did get Alzheimer's I would want to be treated with dignity, right to the very end, treated as a person. Maybe I won't understand things . . . but I still have a heart, I still have a soul."

Conclusions

This chapter has juxtaposed the three social spheres of "the experts," "the market," and "the subjects of diagnosis" to present a sense of the complexity of "early" and "mild" dementia not only as disease categories of aging brains, but also as social assemblages of spaces, relationships, discourses, technologies, labels, products, statuses, ethics, authorities, and hopes. These assemblages are opportunities to consider how and why certain knowledges,

modes of care, and styles of life have become problems for older people. We have focused on the uncertainties of MCI labeling and preventive intervention because they effect service gaps between the clinic and the community, resulting in a postdiagnostic ethical fallout of personal support. The haste to develop tests and therapies of prevention and intervention for dementia and the rapid growth of sciences of "early," "pre-," and "mild" stages, has meant that younger but larger groups of people become categories of risk within the AD epidemic imaginary and as subjects of what Leibing (2018) calls the troubling "new dementia" of preventable risk.

If posed as an ethical and collective question, what does living with the uncertainties of cognitive impairment mean? One response comes from writers such as Judith Butler (2016), who advocates that we reverse the objectification and alienation of uncertainty, vulnerability, and dependence and see these as shared human conditions. Indeed, for Butler (2016: 14), what makes life sustainable and livable is the recognition that it *is* uncertain and precarious for all of us, and that we all depend on others and on social supports. Grenier, Lloyd. and Phillipson (2017: 325) adapt Butler's work to argue for an interdependent and relational model in dementia care practices that contest "the social and political conditions which shape a devaluing of subjects by means of their physical or cognitive impairments." These ideas offer a shift in critical perspective about the nature of fragility, dependency, and impairment that may come with aging, since these are or will be probable challenges for all of us. Taken to the domain of cognitive testing and diagnoses for MCI and dementia, this perspective also suggests how we might better humanize dementia as a collective responsibility through diagnostic practices that include support, dialogue, and compassion as bulwarks against the rising fears and risks promulgated by the coercive politics of self-care and regimes of prevention. To this end, this chapter has explored the value of sociological research into the subjective and narrative practices of individuals, families, and communities whose various journeys from memory complaint to dementia diagnosis wind across the debates of the experts, the prognostications of the clinic, the promises of the market, and the dilemmas of uncertainty.

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Notes

1. This special *Dementia* journal issue consists of nine interviews conducted during 2012–2013 as part of a project at Trent University (Canada) funded by the Canadian Institutes of Health Research (CIHR) on "Perceptions and Realities of Mild Cognitive Impairment: Diagnosis and Treatment of Older Individuals." The interviewees are neuroscientists Ronald Petersen, John C. Morris, and Peter J. Whitehouse, psychiatrists Constantine Lyketsos and David Healy, psychologist Holly Tuokko, epidemiologist Carol Brayne, sociologist John Bond, and Humanities scholar and dramatist Anne Davis Basting.
2. See Katz 1995 and Moreira 2017 for field histories of gerontology, and Whitehouse and George 2008 on the field of Alzheimer's disease.
3. There are recent predementia categories based on subject memory complaints and behavior, such as subjective cognitive decline (SCD) and mild behavioral impairment (MBI), which this chapter does not examine. However, these and related conditions share with MCI problems of vague definition and inconsistent predictive testing (Canevelli et al. 2016), as well as having become targets of pharmaceutical intervention (Leibing 2009).
4. The scope of this chapter does not permit a fuller elaboration of the growth in alternative regimes and movements emerging around cognitive health. While most involve dietary restrictions, physical exercise, and mental stimulation, others, such as Dale Bredersen's protocol and "cognoscopy" testing, signal a more comprehensive and biotechnological regime (see Marsa 2018).

5. The general exclusion of sex and gender factors in AD research, prevention, detection, and treatment is a significant bias; for example, the neglect of the impact on cognitive decline of hormonal differences between men and women (see Nebel et al. 2018)
6. While not theoretically applied here, the anthropological subfield of narrative medicine and its emphasis on patient stories and experiences is well established (see Charon 2006; Frank 1995; Kleinman 1988).

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