Thinking About Dementia

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Published by Rutgers University Press

Leibing, Annette and Lawrence Cohen. 
Thinking About Dementia: Culture, Loss, and the Anthropology of Senility. 
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Negotiating the Moral Status of Trouble
The Experiences of Forgetful Individuals Diagnosed with No Dementia

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

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

**Literature Review**

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

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

Several nondementia factors have also been associated with mild cognitive impairment, including fatigue, depressive symptoms, sensory impairments, and other physical disabilities, as well as social, cultural, and educational issues (Tuokko, Frerichs, and Kristjansson 2001). Among those factors, the relationship between depression and cognitive functioning has been best documented (Kahn et al. 1975; La Rue, Swan, and Carmelli 1995). In particular, depressive
symptoms have been associated with self-reported problems with basic cognitive processes, including memory and concentration (Bola et al., 1991; McGlone et al. 1990; O’Connor et al., 1990; Basset and Folstein 1993; Watts and Sharrock 1985). In a meta-analysis of studies on depression and memory impairment, Burt and Zembar (1995) found a significant association between depressed mood and memory impairment.

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

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

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

**Background Information and Methods**

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

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

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

Situating Memory Problems in Everyday Life

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

During that time, Claudia had several memory lapses that triggered fears about having the early symptoms of AD, a disease that had taken her mother earlier. For instance, she recalled how one day at school, she forgot about sending one of her pupils to the principal’s office and was reminded of his whereabouts by the other pupils when she started to look for him in a panicked state. On several occasions, she also forgot the names of colleagues at school functions and once misplaced important class preparation material. In another incident, Claudia canceled her credit cards, which she believed lost, only to
remember later that she had put them away in a safe deposit box to prevent overspending. As the following comment indicates, Claudia also experienced word-recall problems: “I said to my daughter one time, “Oh, get the milk out of the, uh, uh,” and I’m looking at her, “the cold thing, the cold white box, the, uh, fridge.” And I’m going, “Oh, God.” At the time of the interview, Claudia was concerned that she would be dismissed from her job as schoolteacher on the grounds that her memory lapses endangered the safety of her pupils in the classroom.

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

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

The other two participants, Sonia and Marilyn, reported similar memory problems. Sonia was working as a nurse at a local general hospital when she began forgetting to do particular care procedures for her patients. She eventually went on extended sick leave and received treatment for depression from a psychiatrist. She stayed at home, managing a hobby farm she co-owned with her husband. She continued to experience memory problems and requested a referral to the Clinic because of concerns about having an AD-like brain disease. As for Marilyn, she sought a referral to the Clinic because of concerns about having the early symptoms of AD. She reported forgetting the names of friends and colleagues, which she felt interfered with her ability to adequately carry out her
responsibilities as event coordinator for an evangelical mission. She was not receiving treatment for depression at the time of the study but reported having been on antidepressants for several years following the death of her son.

**Referral and Clinical Evaluation**

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

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

Each patient underwent a multidisciplinary assessment that included radiological and laboratory investigations. All were evaluated by NINCDS-ADRDA criteria for AD and by DSM-III-R criteria for dementia (APA 1987). Not only did all patients perform well within the normal range on all tests; their ability to consistently report instances of memory lapses on separate occasions naturally reaffirmed the intact nature of their memory function. In one instance, Claudia cited as evidence of her failing memory the need to purchase an alarm
watch to remind her about meetings, yet readily admitted being able to remem-
ber which meetings she needed to attend whenever the alarm went off.

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

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

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

**Negotiating the Moral Status of Trouble**

In accounting for why these women interpreted their memory problems as
symptomatic of dementia, I offer in this section an explanation that is based on
the notion that diagnostic categories do not simply describe underlying psycho-
pathologies but also serve to label the moral status of problematic behaviors.

More specifically, the argument is that these women considered the alternative
diagnosis of dementia as a way to resist the stigma they perceived to be attached
to the diagnosis of depression. Goffman (1963) defined stigma as an “attribute
that is deeply discrediting” and that reduces the bearer “from a whole and usual
person to a tainted, discounted one” (3). The discrediting nature of depression has been well documented in the literature on mental illness. Depression is one of several serious mental illnesses that continue to elicit generally unfavorable attitudes from members of the public (Bhugra 1989). Having one’s name associated with depression can be detrimental to one’s career and future. For example, Glozier (1998) found that personnel directors in a sample of two hundred U.K. companies were much less likely to hire an applicant described in a vignette as having depression over someone with diabetes. A famous example of discrimination is the case of former U.S. senator Thomas Francis Eagleton, who was dropped as running mate by presidential candidate George McGovern shortly after the 1972 Democratic Party convention when it was revealed that Eagleton had been hospitalized for depression.

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

As Gray (2002) remarks, the concept of felt stigma has two advantages. First, this concept acknowledges the precariousness of maintaining a normal identity once a stigmatized label is applied; and it underlines the importance of accounting for the ways a person manages the social presentation of his or her stigmatized condition in light of anticipated rejection. A common management strategy is to conceal the diagnosis and minimize one’s involvement in social situations where disclosure could occur. However, the experiences of these women suggest another strategy whereby an alternate and less stigmatized label is considered to explain problematic behaviors in a less discreditable manner. To better understand this process, it is crucial not to dichotomize between dementia and depression on the basis of their respective psychopathological features. Undoubtedly, being diagnosed with dementia is a much less desirable
option given the condition’s irreversible and ultimately fatal pathology. By contrast, depression is an eminently treatable and thus comparatively hopeful illness. However, these women were less concerned about the prognostic implications of being diagnosed with dementia and instead focused on the perceived positive societal reaction associated with this label. In that sense, the anticipation of being diagnosed with dementia can be understood as a heuristic device that conveys a lack of control (and thus responsibility) over discreditable behaviors and thus reduces the possibility of one’s being interpreted by others as being morally disreputable. This is possible because the label of dementia shifts the cause of personal problems away from the morally charged realm of psychiatry onto the more neutral ground of neurobiology. A dementia diagnosis points the finger at a pathology that is outside one’s control, thus diffusing moral responsibility for discredited behaviors in everyday life.

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

Thus, one can argue that the women described here attempted to secure a more socially accepted label for the distress they experienced while struggling with alienating work situations and traumatic life events. This was particularly
evident for Claudia, Sonia and Vivian, who clearly expressed in their interviews that they regarded the diagnosis of depression as inadequate for explaining the problems they were experiencing. For example, Vivian was convinced that her inability to operate her cash register resulted from a condition she described as an “organic brain disorder along the lines of a stroke, a lack of circulation to the brain causing some atrophy and subsequent memory loss.” Sonia attributed the errors she made while working as a nurse to a mild form of a brain pathology similar to AD but less severe. In the following comment, Claudia explains how her diagnosis of depression stirred fears of ending up like her first husband, who had bipolar illness.

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

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

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

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

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

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

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

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

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

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

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

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

NOTES

This study was supported by the Social Sciences and Humanities Research Council of Canada (SSHRC) through a doctoral and a postdoctoral fellowship (strategic grant number 12R57453). Many thanks are due to the director and staff at the Clinic, whose openness and cooperation are truly appreciated.


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