

Mind Matters: A Sociological Study of Dementia Diagnosis, by Alexandra Hillman. London: Palgrave Macmillan, 2025. Pp. 210.; €139 (hardcover); €109 (ebook).

Reviewed by Anurag Rakesh, Case Western Reserve University (anurag.rakesh@case.edu), Cleveland; Daniel George, Penn State University, Hershey (dgeorge1@pennstatehealth.psu.edu); and Peter Whitehouse, Case Western Reserve University, Cleveland (peter.whitehouse@case.edu)

For the past several decades, dementia diagnosis has been viewed through the limited biomedical frame as a scientific evidence-based clinical process with approaches focused primarily on early detection and treatment. Running counter to this, an expanding body of critical scholarship has emerged to problematize this view, arguing that diagnostic categories should not be disproportionately based in individual memory and cognition when they are deeply intertwined with cultural norms, ethical concerns, and social forces. Moreover, the movement has sought to counter the ways in which contemporary diagnosis can subject people living with memory loss to undue stigma and social exclusion.

Alexandra Hillman's *Mind Matters: A Sociological Study of Dementia Diagnosis* contributes to this ongoing conversation with an ethnographic investigation of two memory clinics in the U.K., encompassing a study spanning a year. Her focus is on the everyday practice of clinicians, the interactions between patients, families, and staff, and the ethical and emotional factors that arise within diagnostic encounters, which she covers extensively across seven chapters. Through close observation of consultations and interviews within the embedded reality of modern memory clinics, Hillman shows how dominant biomedical discourse and technologies of diagnosis and treatment converge in the process of "constituting persons," i.e., the production of subjectivities, and explores the challenges for patients, families, and clinic staff (3).

Hillman's sociological exploration finds common ground in critiques such as Tom Kitwood's *Dementia Reconsidered* (1997), Margaret Lock's *The Alzheimer's Conundrum* (2013), Jesse Ballenger's *Self, Senility, and Alzheimer's Disease* (2006), and Whitehouse and George's *The Myth of Alzheimer's* (2008), in highlighting the

reductionist tendencies of the biomedical model. Her focus is on care-seeking experiences of patients and families that are nuanced, relational, and often resistant to the biomedical model and its emphasis on rigid categorization. Drawing on her ethnographic observations, she reveals the inescapable ambiguity present in conversations of diagnosis. She explains how clinicians, operating without definitive tests or treatments, offer labels such as Mild Cognitive Impairment (MCI) that act as a sort of mask of medical certainty. Hillman shows how such labels—which blur the line between aging and disease—can cause unnecessary anxiety and medicalization without offering clear benefit. Through careful attention to language, metaphors, and silences in clinical encounters, Hillman reveals the moral and emotional labor required to “stage” diagnosis in a way that balances honesty, hope, and social expectations.

Hillman’s sociological critique extends further to ethics. She devotes Chapter 4 (titled “Moral Reasoning and Everyday Ethics in the Memory Clinic”) to challenging the assumption that a discourse promoting autonomy and informed consent—especially in an area lacking diagnostic certainty and effective therapeutics—is clear-cut and stable, and that these concepts deserve a guiding principle position, particularly when early or so-called timely diagnosis is encouraged. She focuses on the voices and perspectives of those living with dementia and their caregivers, explicating the experience of diagnosis as more dynamic (rather than straightforward and purely medical) and as socially mediated through institutional norms, technological tools, and interpersonal negotiations.

While Hillman illuminates the clinical ambiguity and stigma of diagnosis and provides push-back against dementia diagnosis as delineated by the biomedical model, she does not fully engage with the larger, external forces beyond the memory clinic that impinge upon the dominant discourses of care. Expectations of constant biomedical progress, promises of scientific fame and fortune, pressure from the pharmaceutical industry and biotechnology companies, and influences from financially-driven care systems would all have been useful areas of critical focus beyond the institutional setting that she so capably explores.

PERSONAL EXPERIENCE: IMPLICATIONS FOR PRACTICE

Diagnosis shapes how individuals with dementia are seen, engaged with, cared for, and positioned in the culture. Thus, understanding power dynamics among social actors is key. For those of us who have lived this reality with family, a reality where the diagnosis risks defining and debilitating our loved one rather than helpfully orienting them, Hillman's findings go beyond scholarship—they resonate personally.

One of us (Rakesh) remembers his grandmother as incessantly active—cooking, cleaning, gardening, teaching, problem-solving. She was the one everyone turned to when things grew difficult, her capability a kind of anchor for the whole family. Rakesh was around 10 when he noticed changes: repeated questions, lapses in certainty, and his grandfather's sharp, dismissive responses, "How can you be so forgetful?" At that time, Rakesh did not fully understand, but as time progressed, he found himself mirroring the same tone, one not borne of cruelty but out of helplessness. More than the forgetting, it was the seeming loss of those qualities which had once centered her as a pillar of the household, the seeming loss of who she was, that frightened him.

This feeling of dread, of dawning helplessness, is precisely the emotional response Hillman cautions against. Drawing on her ethnographic encounters, she explains how dementia diagnosis can cascade into becoming more than a label, often turning into organized decline, where the individual's present state is disproportionately reframed through the lens of what has been lost.

Hillman elucidates in Chapter 7, "The Sociology of Dementia Diagnosis and the Constituting of Persons," how relational dynamics can shift with diagnosis, how the individual plays a diminishing role, how the individual's present experience is filtered and silenced, how memory lapses become pathological, and how loss becomes the defining frame. Her critique resonates with Margaret Lock's *The Alzheimer Conundrum: Entanglements of Dementia and Aging* (2013), which asserts that Alzheimer's is as much a problem shaped by culture, politics, and market forces, as it is a pathological one. In both accounts, there is a call to resist the seduction of neuro-reductionism and to see dementia not simply as a

cognitive collapse but as a dynamic, relational, and socially mediated condition laden with moral, emotional, and political implications.

Hillman's work acknowledges the difficulty in shifting to this model, particularly in systems oriented around biomedical risk and prognosis. She invites familiarity through resistance in small, tangible ways: noticing moments of emotional connection, loosening the compulsion to correct, and acknowledging who the person is *now*, rather than just who they were.

Like many families, Rakesh's turned to medications, memory-building activities, and rigid routines—aids that were supposed to offer a sense of control in the face of uncertainty. Yet the promise of control is often where hope and reality part ways. In recent years, research has only sharpened this tension between lived experience and false hope. Aducanumab was controversially approved by the FDA in 2021 despite essentially no evidence of cognitive benefit, revealing how biomedical hope often outpaces therapeutic reality (Knopman et al. 2021; Whitehouse, et al 2022). Ultimately, it is those families who are desperate for solutions that chase these medical and market-driven promises.

We must probe, then, what alternative scripts are available? Hillman points to narrative resistance as one possibility when families and clinicians push back against deficit models and insist on seeing the person beyond the diagnosis. She notes examples of this in her ethnography, where family members reframe clinical assessments by emphasizing enduring traits or relational cues—one, where a daughter affirms her mother's conversational skills, in opposition to test scores reflecting cognitive decline. It is these moments that resist the authority of standardized metrics, that reassert personhood as something contextual, emotional, and alive in interaction.

Hillman emphasizes how memory clinics too often focus on simply placing a label rather than ensuring that emotional and social connections can be fostered, and she argues that this is exactly where care must shift: toward a psychosocial approach that sees purpose, dignity, and personhood as co-constructed through everyday moments and not preserved only in memory but rather sustained through ongoing relationships.

Hillman's critique of biomedical approaches could be extended by considering the role of care relationships between humans and the rest of nature. Ecopsychosocial models of health consider the role of ecological connections, which can include spiritual dimensions of care. Appreciating humans as a part of nature and engaging in activities such as walking, gardening, or others have been demonstrated to provide benefits in health and quality of life (Parrill 2023).

Indigenous world views and other integrative approaches to health are based on harmony with natural systems rather than dominating and manipulative human hubris. As changes in the environment intensify, because of the climate crisis and other factors, people with dementia and all of us will do better if we integrate care perspectives from nature, including from ecopsychology, transdisciplinary science, evolutionary biology, environmental bioethics, and Indigenous epistemologies. The mind is not an isolated entity, rather one profoundly shaped by embodied experience, social context, and ecological connection. What we attend to is critical. Music, dance, ritual, and other artistic practices enrich cognition, emotions, and healing. By incorporating such practices, we can push back against the contemporary biomedical framework, which Hillman repeatedly urges us to challenge, to foster deeper connections with the world around us. Adopting community and public health approaches in dementia care requires structural investment, collective support, and a rethinking of the systems that shape how care is imagined, valued, and delivered.

Therefore, we come to *intergenerative ethics*, which is grounded not in preserving autonomy at all costs, but in fostering dignity and connection across generations, communities, and cultural beliefs. Hillman warns against the quiet cruelty of neoliberal narratives, where "living well" becomes a moral expectation and where the responsibility is placed on individuals with dementia and their families. Such expectations, which imply that good outcomes are earned through good behavior, i.e., early detection, healthy lifestyle, cheerful resilience, etc., ignore the material and emotional exhaustion of caregiving as

well as access to support that is so often determined by systemic, built-in inequalities.

As authors of this review, we believe that alternative narratives reframing the experience must therefore operate on cognitive, emotional, and community levels. Stories based on conceptions of holistic health should advocate for structural change in our long-term care systems disrupting existing power dynamics. We should push for friendly urban design, for systems of community-based care, and for public health approaches based on recognizing brain aging as deeply tied to socioeconomic and environmental factors. This re-storying must include more than awareness of cognitive decline and labeling people; it must affirm the socially and ecologically embedded self. It must challenge society to respond not with fear or avoidance, but with validation and political action.

IMPLICATIONS FOR POLICY

Hillman's insights on diagnosis, personhood, and relational care are not just relevant to clinicians and families—they echo the need for change in how entire health systems are designed. A recent *Lancet* Commission report identified 12 modifiable risk factors for dementia, among which are low education, social isolation, environmental toxins, and air pollution. It estimates that up to 40% of dementia cases could be preventable (Livingston et al. 2020). Yet few memory clinics, including the ones Hillman studied, integrate these risk factors into care plans or advocate and organize around them politically, leaving these sites as deserts of medicalization and pharmacological hope.

We now find ourselves with one of the book's main limitations, one that may also be an opportunity. Hillman extensively interacts with the "politics of selfhood," however much less so with the politics of world-making, thus leaving us to imagine a society wherein dementia is not regarded as the end of the self, contrarily, it is understood as a shift in how the self may be sustained, whether through community, environment, and/or shared stories (183).

The work of aging well cannot be only medical, it must also be moral, ecological, narrative, and political (Whitehouse 2014). There is emphasis on the importance of guiding patients toward a greater sense of purpose and belonging

in communities; one must ask how the concept of quality of life may be better integrated into the conversations at memory clinics in order to shift away from a focus on diagnosis and treatment and toward one on helping patients and families ponder bigger, deeper questions about the human condition.

Hillman opens the door to these questions but leaves the reader to imagine walking through. For those of us who have traversed the hallways of memory clinics, who have loved someone slowly forgetting, the call is clear: look closer, stay present, and refuse tidy biomedical narratives. But in looking closer, another even more provocative question may arise: is Alzheimer's disease a failed biomedical project? Billions have been spent, and research priorities have been misdirected, all in the pursuit of distorted theories occasionally even built upon fraudulent data (Piller 2022). As Hillman shows, the results of decades of the biomedical pursuit of treatment and cure amount to very little, leaving those working in memory clinics almost nothing to offer in real therapeutic support.

If we succeeded in shifting “brain health” from a biomedical framework to a more sociologically imagined, public health-informed, and humanities-inspired one, how might the field evolve? Might we start thinking less about degenerating brain structures and more about the deteriorating social structures and safety nets of contemporary societies? Lack of access to healthcare, declining access to K-12 and higher education, widening income and wealth inequality, heavy metals in drinking water, etc.—these are the trends that continue to precipitate poorer cognitive health. Engaging with the systems, structures, and processes that diminish brain health seems a vital direction for the dementia field to move toward. Hillman notes herself that dementia “is embedded in and entangled with the political,” but she does not suggest much about the way forward (191).

Can we leverage the understanding that cognitive aging occurs on various spectra of changes to develop policies and practices that may build cognitive reserve and emotional resilience at the population level (something we have elsewhere termed “population reserve” (George and Whitehouse 2021)? We must understand that the impact of those initiatives on brain health would far surpass any current (and arguably even any realistically achievable) medical

intervention. In doing so, we might begin to build the collective modes of care that Hillman's work gestures toward—ones that say, yes, caring can be hard, but no, you are not alone, and there are rewards to be realized on the journey.

CONCLUSION

Ultimately, despite the understandable limits in the scope of her approach, Hillman has made an important contribution to dementia studies. She impressively synthesizes many perspectives in the critical dementia space, and adds ethnographic richness from observations and narratives of patients, families, and clinical staff that beautifully reveal the ambiguities of contemporary diagnosis, the role of technologies in reifying diagnostic categories, the delicate dance in the words, metaphors, and insinuations of doctors who must guide patients in the face of clinical uncertainty and the absence of disease-modifying therapies. Perhaps most importantly, in a field where the metaphor of “loss of self” is still employed, Hillman's work centers the narratives of people with dementia and their family members and allows their humanity to rise out of the forced formality of the memory clinic. If we learn these lessons from our thinking about and valuing of people with aging-associated cognitive challenges, we might discover a reinvigorated sense of our humanity that will be essential as we address the multiple interconnected ecological, economic, and political polycrises in the world.

WORKS CITED

- George, Daniel R., and Peter J. Whitehouse. *American Dementia: Brain Health in an Unhealthy Society*. Johns Hopkins University Press, 2021.
- George, Daniel R., and Peter J. Whitehouse. “The Alzheimer's Conundrum: Entanglements of Dementia and Aging.” *The Gerontologist*, vol. 54, no. 3, 2016, pp. 398–405.
- Knopman, David S., Joel S. Perlmutter, and John C. Morris. “Evidence for Aducanumab in Alzheimer's Disease.” *Science*, vol. 373, no. 6554, 2021, pp. 1016–17.
- Livingston, Gill, et al. “Dementia Prevention, Intervention, and Care: 2020 Report of the *Lancet* Commission.” *The Lancet*, vol. 396, no. 10248, 2020, pp. 413–46.

- Lock, Margaret. *The Alzheimer Conundrum: Entanglements of Dementia and Aging*. Princeton UP, 2013.
- Parrill, Fey. "Revisioning Cognitive Science Through Holistic Science, Biophilia, and Indigenous Ways of Knowing." *Ecopsychology*, vol. 16, no. 1, 2023, pp. 1–10.
- Piller, Charles. "Blots on a Field?" *Science*, 21 July 2022, www.science.org/content/article/potential-fabrication-research-images-threatens-key-theory-alzheimers-disease.
- Whitehouse, Peter J. "Intergenerative Transdisciplinarity in a Future of Aging Professions: New Words Are Not Enough." *Futures*, vol. 63, 2014, pp. 16–19.
- Whitehouse, Peter J., and Daniel R. George. *The Myth of Alzheimer's: What You Aren't Being Told about Today's Most Dreaded Diagnosis*. St. Martin's Press, 2008.
- Whitehouse, Peter J., et al. "Making the Case for Accelerated Withdrawal of Aducanumab." *Journal of Alzheimer's Disease*, vol. 87, no. 3, 2022, pp. 1003–07.