

Philosophy of Medicine

Perspectives

Dementia and the Boundaries of Secular Personhood

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Abstract

For many, dementia disrupts basic ideas about what it means to be human, raising profound philosophical and theological questions on the nature of personhood. In this article I ask what dementia might reveal about personhood in a “secular age.” I suggest that the ill-fitting relationship between Western bioethics, with its emphasis on autonomy, and dementia throws into relief the boundaries of a secular self, and I tease out the ethical implications of the limits of those boundaries by highlighting a biopolitics of secularism. Lastly, I offer a theological account of dementia that situates dependence as a central feature of the human condition, and enriches a secular biomedical understanding of this neurocognitive disorder.

Last scene of all
That ends this strange, eventful history,
Is second childishness and mere oblivion,
Sans teeth, sans eyes, sans taste, sans everything.

—William Shakespeare, *As You Like It*

1. Introduction

Depending on who you ask, Margaret “Marge” Warner died sometime between 2015 and 2017.¹ Everyone agrees, however, that she was born in Chicago on 5 February 1934. Although she would eventually settle down in the countryside with a family of her own, as a young woman, Marge was a proper city girl, spending summer evenings dancing and flirting with boys at the Naval Base—including the boy she would marry at just 18, to whom she remained married until her death some 60 years later. Yet, for some members of her family, when exactly Marge “died” became a source of considerable rumination. For years, Marge suffered from dementia. When she was “officially” pronounced dead in 2017, there were those who took cold comfort in the observation that, while her biological body may have stopped ticking on that day, the Marge they knew—the *person* they knew, strung together by bundles of life’s most defining memories—had in fact departed quite some time ago.

¹ This account draws loosely on personal encounters. Names, dates, and details have been changed.



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Second only to cancer, Alzheimer's is the most feared disease in the United States (Dresser 2017). For many, dementia represents a fate worse than death. Indeed, in some countries (the Netherlands, for example), a person with early-stage or advanced dementia can qualify for physician-assisted suicide (Gather and Vollmann 2013). Clearly, dementia, or the perceived experience of dementia, strikes dread into many minds, disrupting as it does basic ideas about what it means to be human, and thus raising profound philosophical, ethical, and theological questions about the nature of personhood. For these reasons, I use dementia as a case study to explore the boundaries of secular personhood. Put differently, I ask what dementia might reveal about personhood in a "secular age." After defining my terms and tracing a brief history of secularism and medicine, I consider the ill-fitting relationship between dementia and Western bioethics. I suggest that the dissonance of this relationship throws into relief the limits of secular notions of personhood, and I then parse out some of the ethical implications of those limits, highlighting in particular a "biopolitics of secularism" (Coviello 2019, 39). Lastly, I draw from theologian John Swinton's account of dementia for an alternative perspective on dementia that underscores the centrality of dependence for the human condition.

2. Secularism and Medicine

Although common wisdom may render the secular as an empty space that marks the absence of religion from public life, scholars in recent years have revealed that the ostensible neutrality of the public sphere is in fact a centuries-long sleight of hand, an illusion that the project of secularism itself produces and maintains. In *A Secular Age*, Charles Taylor (2007) argues that the concept of the secular emerged in the early modern period as a response to European religious wars, created as an effort to carve out an ethical register attuned to the universality of reason, rather than the particularity of religion.² Secularism was therefore central to the Enlightenment narrative, "in which reason progressively frees itself from the bonds of religion and in doing so liberates humanity" (Jakobsen and Pellegrini 2008, 2). Janet Jakobsen and Ann Pellegrini (2008, 7) define secularism as a "political project that deploys the concept of the secular" in an effort to establish a hegemonic modernity. Far more than mere separation of Church and State, then, secularism establishes the conditions within which religion and irreligion alike take shape (Warner and VanAntwerpen 2013, 9)—thus Peter Coviello's first two axioms of secularism: secularism "does not cancel religion, but redefines it," and secularism's enemy is not religion itself, but rather "bad" religion (2019, 26–29). For these reasons, Coviello (2019, 3) describes secularism as a discipline, one "wedded to liberal imperialism," which serves to mark the boundaries between acceptable and unacceptable beliefs, practices, and bodies—in other words, the boundaries between desirable and undesirable ways of being in the world. It is a discourse in the Foucauldian sense, say Jakobsen and Pellegrini (2008, 7): "a set of material and linguistic practices that work across multiple institutions" to instill the normative values of liberal rationality. One of these institutions is modern medicine.

While, in the West, the "separation between Church and medicine" (Shinall 2009, 747) has largely become the norm, only recently has medicine come under the jurisdiction of the secular. As historians like Gary Ferngren (2014) and Jeff Levin (2020) have adeptly shown,

² Sylvester Johnson (2015) offers a corrective to Taylor's account, noting that the rise of secular rule in Islamic polities such as Ottoman Turkey predates the emergence of the secular in Western Christendom by several centuries (110). It is therefore more accurate to say that Taylor's argument pertains to the emergence of a particular form of secularism.

medicine and religion have been deeply intertwined throughout human history. During the medieval period, for instance, the Catholic Church enjoyed a monopoly on most aspects of Western European culture, including the domains of health and healthcare. Monasteries not only served as places of ritual and prayer, but also as places of learning and healing. For several centuries, clergy were frontline workers in the battles against plague, suffering, and death, all of which were interpreted through the prism of Christianity. Thus theology, ethics, and medicine were located squarely within the domain of Church (Caton 1985, 493).

Around the seventeenth century, however, attitudes towards the practice of healing began to change. With the Enlightenment under way, there was growing optimism that scientific rationalism, exemplified by Francis Bacon's inductive method, would gradually disclose the mysteries of the natural world, including the nature of disease. At the same time, prayer increasingly appeared outmatched against relentless waves of affliction and plague. The masses grew suspicious that such a colossal amount of suffering could be chalked up to divine will alone, and started looking elsewhere for explanations. Thus throughout the seventeenth and eighteenth centuries, medicine experienced a crisis in confidence: on its way out of the doors of the Church, yet not quite fully in the halls of science, the practice of healing could not draw fully on either source of cultural authority (Branson 1973, 24).

Yet, in the nineteenth century, Western medicine steadily found its footing. The rise of industrialization, globalization, and science seemed to rationalize the world. Rationalization entailed the differentiation and professionalization of various sectors of society, including the practice of healing. Meanwhile, the emergence of biblical criticism and evolutionary theory weakened religion's epistemic authority. By the end of the nineteenth century, healing had arguably become more science than art—a trend that, propelled by the development of new medical technologies, rapidly accelerated in the twentieth century (Ferntgren 2014, 177).

Indeed, in the decades following World War II, the Western biomedical establishment came to embody the secular dogmas of scientific rationalism and bureaucratic efficiency.³ And physicians, as defenders of the prevailing secular consensus, became the new arbiters of orthodoxy. Medicine, in other words, emerged as a central apparatus in the project of modernity, endowed with the right to define health and illness, to mark bodies as normal and socially productive, or as abnormal and unproductive, rendered deviant to society. And for a society that prizes autonomy and its accompanying virtues—reason, intellect, individualism—is there anything more deviant than a disease that strikes at all three? (Branson 1973)

3. Dementia and Secular Personhood

For Marge, dementia, at first, crept slowly. Slips of the tongue, a forgotten conversation or two, fleeting moments of disorientation—nothing that set her apart from your typical octogenarian. But steadily her symptoms became more pronounced. Memories of old friends dispersed, memories of new friends arrested in development. Soon, mundane tasks—cooking, cleaning, turning on the television—became difficult, confusing. Marge's family took careful note of these concerning signs, but for Marge, they were nuisances at most. She lived in her own home, walked to her own mailbox, fed her own cat, and, each

³ As Jeff Levin notes in *Religion and Medicine*, the field of bioethics largely emerged in the 1970s in response to the perception, shared by popular and academic writers alike, that modern medicine had become too technical and impersonal, and that modern physicians had become “specialists without spirit” (2020, 141).

night, eased into bed with her lifelong partner. A few memories dissolved, to be sure, but all things considered, she was happy, and life was good. As she would so often say, she felt like going dancing in the city. But when pancreatic cancer took Marge's husband of so many years, it seemed that the floodgates, which had been holding the tides of dementia to a steady but manageable stream, burst. First went the names of grandchildren. Then their faces. Then brothers, sisters, parents. Eventually went the memories of her husband. And ultimately the awareness of space, time, and self.

A biomedical understanding of dementia says that dementia is pathological and individual, that it is caused primarily by deterioration in the brain (brought on, for example, by a disease like Alzheimer's), and that the most effective treatment is based on this medical understanding, such as medications that target specific areas in the brain (Spector and Orrell 2010, 957). There is, of course, nothing wrong about this understanding, and neurological research in recent years has afforded tremendous strides in uncovering the pathology of dementia. There does, however, seem to be something missing. From this perspective, when someone dies from dementia, they die from deterioration of the brain (or, as is often the case, a comorbidity that is hastened by dementia). But such a perspective does not give us a sense of the deterioration of life before death, which is of such a nature that many feel as though it is a fate worse than death itself. In other words, it does not help us understand the *terror* of dementia, the tragic absurdity of a disease that thoroughly erodes the very pillars that seem to uphold one's sense of self: knowing, remembering, and the freedom of self-determination.

Indeed, the rhetoric of freedom has long been a siren song to American ears. As Willard Gaylin and Bruce Jennings (2003, 4) write in their book *The Perversion of Autonomy*, the words "liberty, freedom, autonomy, choice, personal rights, voluntarism, and empowerment are now the most often used and revered words in our moral and civic discourse." This reverence for freedom is reflected in American bioethics, where the principle of respect for autonomy, broadly speaking, reigns supreme.⁴ Autonomy in this context refers to an individual who "acts freely in accordance with a self-chosen plan, analogous to the way an independent government manages its territories and sets its policies" (Beauchamp and Childress 2009, 10). Behind the exhalation of autonomy stands a particular vision of what it means to be a self, as well as a vision of what types of social arrangements ought exist in accordance with that self (Gaylin and Jennings 2003, 7). And both visions, as we will see, have been deeply colored by the project of secularism.

The Foundations of Christian Bioethics (2000), a book by H. Tristram Englehardt, Jr., illuminates with particular clarity how the normative project of secularism has shaped basic assumptions about the nature of personhood and therefore the values that underpin Western bioethics. Echoing Taylor, Englehardt argues that the bloody religious wars of the seventeenth century prompted Enlightenment philosophers to work towards a singular, content-full morality—one that could transcend volatile religious differences by being grounded in the ostensibly universal category of reason. Thus, a secular ethics, as others have argued, emerged out of an effort to remedy the difficulties posed by the fragmentation of Christianity—namely, pluralism and particularity. But as Englehardt persuasively illustrates, secular ethics is just as plural and particular as Christian ethics. Whether steeped in moral intuitions, senses, or rationalities, as soon as a secular ethic possesses content, it

⁴ This is indeed a broad generalization, made for the purposes of this article. No shortage of thinkers over the past few decades, however, have offered critiques of autonomy-based bioethics, as well as principlism as a whole—some of the most influential coming from, but not limited to, the perspectives of feminist ethics (Gilligan 1982), virtue ethics (MacIntyre 1981), theological ethics (Engelhardt 2000), critical race theory (Threadcraft 2016), and the social sciences (Haidt 2001)—to just cite a few.

becomes one moral vision among many. Moreover, one cannot establish the secular vision one selects as being canonical without lapsing into circular argumentation or infinite regress. In short, there is no impartial secular perspective, and it is impossible to have a singular, content-full secular ethic. As a result, the only grounds for justifying collaboration between moral strangers is a content-thin, procedural morality based on consent—the defining feature of what Englehardt calls a “liberal cosmopolitan ethic” (2000, 1–44).

But Western minds and hearts, Englehardt continues, aspire for something deeper than a morality grounded solely in consent. So, those encased within the horizons of a liberal cosmopolitan ethic confuse consent, as a source of moral authority, with individual choice, as a cardinal moral value. This confusion forms the basis for claiming that individual choice and the concepts it encompasses—liberty, autonomy, equality—are universal, taken-for-granted values, when in fact they are associated with a particular, secular normative agenda. In turn, individuals or communities who do not or cannot comport with the norms of liberal cosmopolitanism are rendered morally suspect, deviant, and feared (Englehardt 2000, 134–43).

While the precise details of Englehardt’s far-reaching diagnosis can be disputed, most observers do agree with his general conclusion that the West, and in particular the United States, displays a peculiar reverence for autonomy, where the respect for autonomy prevails over a morality of interdependence.⁵ “The idea of autonomy,” affirm Gaylin and Jennings (2003, 22) “permeates the thoughts and feelings, the hopes and concerns, of our whole worldview and way of life.” Autonomy, moreover, is inextricably tied with other premium liberal values, such as independence, reason, and intellect, generating what Stephen Post (2013, 349) calls a “hypercognitive” culture. Thus the veneration of autonomy thoroughly informs notions of personhood: namely, that it is those individuals who exercise self-determination who are considered and accommodated as persons (Post 2013). It follows that those lacking self-determination—and its accompanying attributes, such as reason, memory, and intellect—are viewed as less than persons, and treated as such. “To become deeply forgetful and intellectually vulnerable within liberal Western cultures ... has quite a specific meaning,” writes John Swinton, “and that meaning is deeply negative” (2012, 80).

4. The Biopolitics of Secularism

As Marge’s brain deteriorated, so too, it seemed, did the relationships with the people around her. After her husband died, Marge was alone in the countryside, tucked away at the end of a long, willow-wrapped street. Although family and friends would continue to visit, and some suggested that she leave and go to stay with them, Marge loved her home, and had no intention of leaving. The more dementia progressed, however, the more Marge retreated further into her own world. While once boisterous and the center of any conversation, she became shy and soft-spoken. Her behavior became more unpredictable, her moods more melancholy. Some visitors kept coming, but Marge seemed increasingly

⁵ This reverence for autonomy is especially apparent when contrasted with certain traditions of African bioethics, where values like relationality, community, and harmonious relationships hold central importance (see Behrens 2013; Metz 2018). And while some North American bioethicists have charted communitarian approaches—both of the religious and secular type (Emanuel 1998; Engelhardt 2000; Galarneau 2016)—such approaches, I would argue, remain sidelined in favor of the individualist consensus described here. Lastly, it is worth noting Albert Jonsen’s intriguing observation that, in the nascent years of the American bioethics movement, there were three distinct issues that could have easily pushed the emerging field into the realm of social ethics—research ethics, population growth, and genetics—but such issues ultimately settled bioethics within the familiar territory of the individual (Jonsen 2001).

unwelcoming to them. Eventually, Marge was no longer able to take care of herself, and living alone was unfeasible. The last root keeping her grounded to the life she once lived and loved so much, her home, was decidedly cut. In her final home, a nursing home, the trend of isolation and deterioration only continued. On her deathbed, whether she processed, cognitively, that the eyes welling with tears before her, and the hand clutching hers for one last time, belonged to her daughter, or just a friendly stranger, is unknown. “Last scene of all that ends this strange, eventful history,” Jaques says in Shakespeare’s *As You Like It*, “is second childishness and mere oblivion, / Sans teeth, sans eyes, sans taste, sans everything” (2.7.170–174).

Tom Kitwood has a name for the mechanism that drives this trend toward deterioration: “malignant social psychology.” In brief, this concept refers to the social processes—such as disempowerment, infantilization, and banishment—that harm someone with dementia (Kitwood 1993, 542–43). As neurological impairment takes its course, so too does the impairment of relational networks. “The social life of people with dementia tends to dwindle away,” Kitwood writes. “The result is that people with dementia often have no group to belong to—not even the family of which they were once a part” (Kitwood 1997, 20). Evidence suggests that impaired relationships can exacerbate the physical deterioration of the brain (Swinton 2012, 75). Physical deterioration of the brain can in turn exacerbate impaired relationships. And so goes the vicious cycle. On the flip side, however, some research has shown that when the psychosocial needs of someone with dementia are met—love, attachment, inclusion—stabilization can occur, which is when the process of dementia seemingly grinds to a halt (Swinton 2012, 74). This sheds light on cases of rapid decline, when deterioration accelerates much more quickly than neurological damage can explain, and often happens when a person with dementia loses a loved one or is taken out of their home and moved into an unfamiliar caring facility (Swinton 2012, 74). Sounds familiar. Kitwood’s research underscores the very tangible impact that the normative values built into assumptions of liberal personhood can have on the bodies of those affected.

In other words, Kitwood’s research illuminates the workings of what Coviello calls the “biopolitics of secularism” (2019, 39). Coviello explores the biopolitics of secularism by attending to the lived religion of early Mormons, and in particular how Mormon theology was translated into modalities of practice. “The unceasing attacks on Mormonism,” he writes, “bring into exceptional focus a contrary rendering of secularism as a normative and disciplinary force,” one intimately linked to “redemptive liberalism” (39). More specifically, the biopolitics of secularism works to “integrate the body into a system of economic productivity” (46) and “adjust populations to economic processes” (175). Bodies that are unfit for economic productivity frustrate societal norms, and therefore must either be disciplined to align with those norms or remain marginalized—socially, politically, or otherwise.

Precisely because it so thoroughly resists these norms, dementia begins to throw into relief the processes by which secularism disciplines ways of being in the world to the premises of liberal rationality, as well as the negative consequences of such disciplinary processes. And although I have been mostly interested here in the relationship between dementia and secular constructions of the self, the phenomenon of dementia can challenge certain religious and theological accounts of personhood as well. What does it mean, after all, to be known by God when one cannot remember who God is? (Swinton 2012, 3)

5. Stories of Dependence

In his wonderful book *Dementia: Living in the Memories of God*, Swinton, a Scottish theologian and former nurse, develops a theological account of dementia. The basic premise of his book is that “the standard neurobiological explanation for dementia is deeply inadequate for a full understanding of the nature and the experience of dementia” (2012, 9). Bringing together biological, psychosocial, and theological perspectives, Swinton tries to foster an understanding of “what it means to be a person with dementia living in God’s creation.” By doing so, he aims to move beyond a secular-liberal conception of personhood that views cognition as the necessary qualification for personhood. “Knowing God,” Swinton writes, “involves much more than memory, intellect, and cognition” (15).

The starting point for Swinton’s “theological redescription” (2012, 154) of dementia is that the world is a place that is created by God, broken by sin, and in the process of being redeemed. As creatures created by God, our fundamental condition is one of radical dependence. Although this is a straightforward point, it is one that most Americans, says Stanley Hauerwas (2010), tend to forget. Americans are a people who believe that they “should have no story except the story [they] chose when [they] had no story,” he writes. Liberal democratic culture cultivates the illusion that we are authors of our own stories. According to Swinton, however, our story is chosen for us. To be human is to be contingent—on God at a divine level, and on other humans at a temporal level. One’s identity is not fashioned out of autonomy and freedom, but rather “envisioned, created, and held by God” (Swinton 2012, 177). All of our stories, says Swinton, are stories of dependence.

On this account, then, it is our ideas about what it means to be a person, ideas that are fundamentally shaped by secularism, which need to be dissolved—not the person with dementia. As I have suggested here, the experience of dementia marks a site where different modes of agency may be revealed, thereby highlighting the limits of secular personhood. Put differently, dementia serves as a site for a critique of the ongoing project of secularism.

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