

Is there a pathological way of ageing? Questioning ‘Alzheimer’s disease’

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Abstract

This think piece discusses ‘Alzheimer’s disease’ from a critical anthropological perspective. I aim to challenge the taken-for-granted biomedical framing in four steps. First, a brief genealogical account shows that Alzheimer’s disease as a biomedical category has only recently become a public and global health preoccupation. Second, the concept of medicalization is mobilized to illustrate the construction of and the uncertainty around this new medical object. Third, I build a case for analysing this medical category within a sociocultural context. Finally, a brief account of the relevance of social intervention is given.

Keywords

Alzheimer’s disease, ageing, anthropology

Background

In the spring of 2013, I organized an international workshop on Alzheimer’s disease among older people in Barbados to establish collaborative research relationships between Caribbean and Canadian institutions. The workshop was aimed at increasing knowledge and improving care in relation to Alzheimer’s disease, and was part of the 57th Annual Caribbean Health

Research Council and Caribbean Public Health Association's Scientific Conference. The workshop participants included public health officers, nurses, medical doctors (in primary health care, neurology, geriatric, family medicine, internal medicine), and members of Alzheimer's societies. Participants were from Barbados, the Commonwealth of Dominica, Trinidad and Tobago, Jamaica, and a number of Canadian universities. I knew some of the participants since I had previously worked as chief medical officer in Dominica. I also collaborated in the late 2000s in a study on ageing in the Caribbean (Cloos et al. 2010).

Oral presentations from Canadian and Caribbean participants and working groups were organized to facilitate the exchange of knowledge on the topic and to identify dementia-related regional needs to initiate research. All presentations but one focused on Alzheimer's as a disease from a biomedical perspective, without questioning the framework. The alternative perspective, which I proposed, was grounded in critical anthropology and aimed at deconstructing the framing of Alzheimer's as a disease. At the end of my presentation, I was emphatically reminded by a medical doctor: 'You have to understand that Alzheimer's is a disease!' During the conference, Alzheimer's was mainly seen as an unquestioned and unquestionable universal medical category with no consideration for context and meaning, a medical category that calls for a medical response. This think piece is my response.

My views cannot be separated from my international and interdisciplinary background: as a humanitarian medical doctor I became increasingly interested in the historical link between health, medicine, and colonialism and therefore the political and historical context in which medicine and public health operate. My doctoral thesis and the book that followed (Cloos 2015) looked at the way US public health uses, transforms, and reproduces racial difference and the racialized other, ideas that can be seen as grounded in racism to justify colonialisms, as suggested by Foucault (1997).

A few years before I wrote the thesis, my mother was living in Belgium and had been diagnosed with 'probable Alzheimer's disease'. Living in Montreal, I was in regular telephone contact with her. Although communications became very limited during the final year of her life, I continued to speak regularly with my brothers, who lived in Belgium, and my mother's home care staff in an effort to follow her situation. She died in the month of September 2015.

I had visited her at least twice a year during the previous five years, spending sometimes entire days with her for weeks and even two months at a time in the private home care residence where she had initially lived with my father and where he too died in April 2011. This allowed me to practice and experience participant observation as both a son and as a medical doctor with backgrounds in public health, social science, and medical anthropology.

I took notes on my discussions with the home care staff (nurses, cleaning and restaurant employees, and nursing assistants), on their interactions with my mother, and on my discussions with the medical staff including the neurologist.

These notes were a way for me to try to connect the dots between her situation and my immigrant life living in Montreal. They helped me to put some kind of order in what otherwise had come to seem fuzzy and tumultuous over the years. I also saw these notes as a way of staying close to her, thinking they could also serve as biographical notes that my own son could read later in his life to learn about his family. My own thinking about the multiple purposes of these notes demonstrates how an account of an illness can relate to many relationships and life events.

In attempting to make sense of the situation I occupied different and sometimes conflicting positions during these years. As a way of protecting her, I sometimes mobilized medical discourse to apologize for behaviour of hers that was deemed aggressive. One day she threw a piece of cutlery at someone in the home care restaurant. After that event she was not allowed to eat there anymore. Knowing that socializing contributes to memory and health status more broadly, I argued (without any success) that she should not be excluded from the restaurant. Furthermore, as a son, it was sad to imagine her eating alone in her apartment, where she never felt at home (she was always asking to go back home). The interpretation of these kinds of events and the associated attitudes we, as sons, could have, along with the myriad difficult decisions and tasks required in such a situation, often provoked tensions within the family. Of course, my own perspective and feelings about the disease and her situation cannot be delineated from my own condition as an immigrant living far from her, or from my own intellectual approach to dealing with the situation. On several occasions I was reminded by my brothers that I was the doctor of the family and the only one to understand medical issues. I repeatedly told them not to medicalize her and urged them to treat her as a human being, but their point was that she was losing her mind because of her disease and that health professionals were the best people to take care of her.

During my last visit in the summer of 2015, I realized that she was short of breath and dehydrated. The weather was very hot in Belgium and the staff did not always ensure that all residents drank regularly. We took the decision not to hospitalize her despite the on-call doctor's request and I stayed in her apartment at the home care residence to assist the (limited) nursing staff. She recovered within one week from this acute stage of dehydration. My contribution was mainly that of a son who took care of his mother in giving her food, drink, and attention. Less importantly, I think, my medical contribution was to ensure she got oxygen and subcutaneous rehydration. Reflecting on this experience, I've increasingly wondered what the use is of the medical category 'Alzheimer's disease' beyond the domain

of biomedicine. What is the use of this category for those suffering from the disease and for their loved ones?

Making up ‘Alzheimer’s disease’: The uncertainty of a biomedical category

Until recently, Alzheimer’s disease was almost unknown to the public, and this is still the case in some parts of the world. In societies like Canada or France, Alzheimer’s is hypermediatized and there is a tendency to be afraid of it. It is often portrayed in terms of memory loss and deficit, lack of initiative, problematic or asocial behaviours, regression, depression, and incapacity. In the biomedical discourse, Alzheimer’s is presented as a pathological process of ageing that leads inexorably to death, as opposed to a healthy form of ageing. I certainly do not want to refute the biological dimension of memory loss (and more broadly ageing) here, but I do not see a disease as a fact of nature; instead I see it as a social construction that engages practices and negotiations, meanings and experiences, as already suggested (Conrad 2010; Fassin 2005).

To paraphrase Hacking (1992), who proposes that specific kinds of people come into existence with the category that describes them: were there Alzheimer’s patients before the twentieth century? The answer is most probably no, at least not before the German psychiatrist Kraepelin – based on his colleague Alois Alzheimer’s microscopic examinations of postmortem brain tissue of demented patients – wrote in 1910 about a disease affecting the cerebral cortex in one of his medical treatises (Lock 2013). It was presented as a rare ‘presenile dementia’ affecting relatively young people that associated deterioration of cognitive abilities with some lesions of the cerebral cortex. Interestingly, till the 1970s, dementia in old age (or ‘senile dementia’) was mainly viewed as a psychosocial problem. However, with the continuing development of neuroscientific research and colouration techniques in microscopy, the organic explanation of dementia grew. No difference was made anymore between ‘presenile dementia’ and ‘senile dementia’: both were seen as pathological and, progressively, the medical category ‘Alzheimer’s and other dementias’ came to encompass various forms of dementia (Ngatcha-Ribert 2012). The amyloid hypothesis is still the dominant explanation: plaques and tangles in the brain characterize the neuropathology of Alzheimer’s, leading to clinical symptoms of dementia. In about a century, senile dementia, which was previously seen by the medical field as normal ageing, became pathological (Lock 2013).

Both the presumption that Alzheimer’s disease can be predicted and the value of making such predictions have been questioned, even from within biomedicine. Pimplikar (2010), associate professor in the Department of Neurosciences at the Cleveland Clinic’s Lerner

Research Institute, has questioned the value of early detection, arguing that because the disease is not yet well understood, there is a risk of overdiagnosis; he also notes that tests such as spinal fluid analysis are expensive and/or can be painful, and that there is no known cure for Alzheimer's. In a 2010 *New York Times* opinion piece, he reminds that 'the presence of plaques cannot predict with any accuracy or specificity that an individual is going to acquire the disease' and that 'roughly one-third of all elderly adults have such plaques in their brains yet function normally'. Following Lock (2013), we could argue that the frontier between the normal and the pathological is blurred in such cases. Alzheimer's disease was 'made up' in the context of biomedicine as a result of expanding diagnostic technology and criteria, and then by expanding the category to include risks. Barnes and Yaffe (2011, 819) suggest that 'up to half of Alzheimer's disease cases worldwide are potentially attributable to modifiable risk factors such as hypertension, diabetes, obesity, depression, low educational attainment, smoking and physical inactivity'. Beyond the creation of the category, we must consider how the disease is socially produced; Fassin (2005) argues that an illness is not only a social construction but is also produced by social circumstances that shape its social distribution.

'Alzheimerization': The creation of otherness

The limit between normal and pathological ageing cannot be delineated from broader representations of old age that relate to cognitive performance and deficit. 'They do not feel like us anymore', the director of the home care in Belgium told me, when talking about my mother the day after my father died, six years ago. The person with dementia is seen as losing autonomy and the capacity to think and speak in a rational manner. This is often seen as a return to childhood or even as a deterioration of humanity, a kind of otherness. Any interpretation of the world is attached to (positive, negative, or neutral) values that legitimate (in)action (Godelier 2011, 15). In the context of productivity and consumption values in capitalist societies, there is a binary opposition between positive symbols related to youth (strength, beauty, productivity, and capacity to work) and negative ones associated with older people. Older people are generally not seen as important assets; they are often viewed as a burden. Current conceptions of ageing cannot be delineated from modernity and social changes, no more than dementia can be separated from these negative social images and loss of identity (Goldfarb 2009).

The loss of subjectivity that goes with a diagnosis of Alzheimer's disease is associated with a loss of power for older people, especially in home care. Here I refer to the way medical doctors participate in disciplinary actions, often requested by the home care staff, toward individuals who do not act in a 'normal' way and those seen to be disturbing the smooth functioning of the institution in which they reside. In this sense, medicine, as a practice, as a

knowledge and as a power, participates in the labelling of residents in home care who do not exhibit expected behaviour. One can be labelled and stigmatized as ‘aggressive’ or ‘violent’, a label that a medical doctor will eventually confirm through medical decisions, notes, and prescriptions (for example, the start of neuroleptic drugs that are given to control what is seen as agitation or disturbing behaviour).

The importance of meaning, experience, and context

Kleinman (1995) suggests that meaning (other than the medical one) is not a concern for biomedicine, whose practices move toward dehumanization since the focus is on the disease as an object of study and practices and not on human experience. Medicalization can be seen as a reductionist process that does not tackle personal, family, and social issues. However, dementia and Alzheimer’s disease cannot be reduced to memory tests and other methods of diagnostic and medical treatment. They are also about making sense of lived daily suffering and isolation, not only for the directly affected individual but also for the family members who try to make sense of the situation. The medicalization of this way of ageing therefore neglects important aspects of the human experience of suffering.

I tried to make sense of my mother’s ‘loss of memory’, desire, and (mis)conduct. She could blow a kiss to someone, and then turn around and hit someone else with her cane. One morning caregiving would go smoothly, the next day, not at all. She became very sensitive to many things (cold, heat, wind) and she could hit someone (even me) when she felt discomfort. For the medical staff, the disease explained everything. However, anyone who spends some time in home care can lose contact with time and space and become irritable. You have to be a very strong person to not lose your mind in such circumstances. Several times the staff proposed that my mother be relocated to the dementia wing, an option I always battled against, convinced that this would be more for the convenience of the institution than the well-being of my mother. Then again, the staff in the specialized wing was probably more sensitive and better trained than some of the staff in the section where my mother was residing.

I always tried to identify contextual circumstances and biographical elements to explain a situation that was shifting rapidly. To me, there was never a fixed frontier between her life before and her life after, with the so-called disease. I prefer to see her condition as a continuum. Things – like her way of reacting to events or to people including us, were not completely different from before but they were expressed in another way, more intensely and with less – or no – inhibition. For example, she could tell one of her sons or grandchild: ‘You are just so fat!’ Was she to a certain extent instrumentalizing her own memory? She was not powerless. She could say ‘yes’ or, more often, ‘no’. But what can be done if the doctor

orders physical and/or chemical restraint? And if the home care staff comply (or even ask for that measure)? Was her memory loss an expression of the many trials and challenges she experienced in her own life, as a mother who probably felt certain abandonment by her own sons and became very lonely? Family members of a person labelled as having ‘Alzheimer’s’ and medical professionals do not necessarily have the same explanations for the disease (or perceive the same symptoms or behaviour thought to be associated with it), and therefore may not advocate for the same response.

I am currently conducting an exploratory study among Haitians immigrants living in Montreal about their meaning of memory loss among older people. Most participants partly rely on biomedical explanations of loss of memory in ageing. Many of them definitively assert that memory loss is a sign of Alzheimer’s and that Alzheimer’s is a disease. However, participants also commonly explain that people who are losing their memory have usually also experienced stressful events during their lifetime, such as living under the Duvalier regime in Haiti. Although they know there is no cure, diagnosis seems to serve a purpose: if memory loss occurs, participants told me, the family should visit a doctor with the elderly person to confirm the diagnosis and plan for the future.

The divergent perspectives of family members and health professionals are discussed by Enjolras (2005) in his study in La Réunion, an island nation in the Indian Ocean. He quotes a family member of a person who received the diagnosis of Alzheimer’s disease:

Then the neurologist told us she had Alzheimer’s. All family members did not understand anything about this diagnosis. They did not understand Alzheimer’s disease. In the family we never talked about it in these terms. They did not know. Her husband did not want to understand. He did not want to admit she had the disease. According to him, he knew everything and the doctor did not know anything and was ignorant. He did not want to know. (Enjolras 2005, 86)

The absence of any symbolic meaning in explaining the disease and its brutal enunciation by the doctor were quite destabilizing for the family, according to Enjolras. The family consulted a priest to seek out an explanation for the memory problems, but did not receive a satisfactory answer. They were caught between biomedical explanations, which were accepted by some of the family members, and other kinds of explanations such as life story events. This shows that what is qualified as ‘dementia’ is much more than a disease affecting an individual. It can disturb family interactions and has broad social implications in that many people are involved and affected.

This think piece raises important questions in the domain of global health and ageing, and for anyone involved in research and policy making when decisions have to be taken in terms

of resource allocation. I suggest that we should not reduce what is qualified as ‘dementia’ to a universal, static, and biomedical entity. Scholars from anthropology and sociology point to the constructed dimension of Alzheimer’s disease and blurred frontiers between ageing and Alzheimer’s, between the normal and the pathological. Critical questions have been raised about medical preventative practices that identify some people at risk of Alzheimer’s, legitimizing early detection.

It seems that Alzheimer’s disease is embedded in uncertainty. Despite this, a great deal of resources fosters biomedical research, pharmacological developments, and medical responses, while social interventions, policies, and support suffer a relative paucity of resources. This disparity is curious given that memory – taken as essential for maintaining cognitive function – relates to social relations such as integration, engagement, and family ties (Béland et al. 2005).

According to Lock (2013, 15), ‘biomedical discourse shifts attention away from political, social and environmental factors’. She suggests that efforts to reduce dementia worldwide should include the reduction of exposures to toxins, inequality, and poverty; the increase of community support; and the reduction of other factors such as discrimination and racism that are known to cause disease.

Furthermore, the understanding of individuals and group perceptions of ageing and dementia are important to inform appropriate knowledge of age-related problems and practices to alleviate them. From an anthropological perspective, it is important to recognize the person and to reconstruct their biography to relocate the person in their specificity and unity. Finally, the diagnostic process should consider the environment, including family dynamics and other interactions, in order to interpret any changes in ageing (Enjolras 2005)

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Patrick Cloos became a professor at the Faculty of Arts and Sciences (University of Montreal) in 2011 after completing his PhD in Applied Humanities. He was trained as a

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