



Social and Cultural Insights into the Diagnosis and Treatment of Alzheimer's Disease

Hello and welcome to Alzcast.org. Today we have the privilege to hear from Jesse Ballenger. Jesse Ballenger has recently published a book titled, *Self, Senility and Alzheimer's Disease in Modern America*. Dr. Ballenger is assistant professor at Pennsylvania State University in the Science, Technology and Society program. He is a historian of science, medicine, and technology, whose research and teaching interests include the social and cultural history of biomedical science, biomedical research policy, the neurosciences, and aging.

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Jon Merril: Jesse can you speak to us about your experience as a nursing assistant and how the experience in caring for a patient with Alzheimer's disease translated into a lifelong passion for learning more about the history of the diagnosis and treatment of this disease?

Jesse Ballenger: I really liked these patients and I really wanted to understand some of the things I observed. For me as a nursing assistant it was kind of paradoxical that I really liked taking care of dementia patients even people who were pretty deeply, far into dementia and it was probably because, well that I could accept any sort of confabulation any sort of delusional language they would give me and I would just kind of go with it and as a caregiver who really didn't know their story it was very easy for me to accept that and it sort of made their lives easier and I would have somebody who would insist on going to work. Now I could either fight with them and insist they don't have to go to work and stay in bed etc. and you know I would give them a job out in the hall folding towels or something like that. Very easy for me, very easy to accept their losses because I didn't know who they were before. What was so striking to me even then was seeing how difficult it was and recognizing how difficult it was, really impossible it was, for families to accept these losses. For them to come and see perhaps their father or husband who might have been, who knows, a university professor, a business executive or whatever, reduced to folding towels out in the hall, you know could not be seen as anything but a horrible loss. So it really got me thinking how deeply this condition penetrates into our social life, our social world. So



Jesse Ballenger, PhD
Presenter
Author: *Self, Senility and Alzheimer's Disease in Modern America*



Jon Merril, MD
Moderator
CEO, Astute
Technology

that was kind of the animation of my book on the history of Alzheimer's disease. I really wanted to understand the fear of Alzheimer's. Have we always been afraid of it as we are now and my answer was "No". We look at this fear emerging and taking shape as the meaning of old age is changing in industrialized America as a traditional kind value placed on old age is eroding. There is all this anxiety about what does it mean to be old, what the use of being old in a world that's changing this fast and I would say to that as our families become thinner that is simply that there's less people around who know your story. You know our families have become thinner and widely spread. There's simple less individual who intimately know you and have to accept you tell your story as family members are further away and harder to reach. As that happens when someone who knows your story can't remember your name anymore that's you know becoming more and more devastating in the kind of society we been moving into.

So those who know really my experience of hospitals which fed me a lot of questions. I tried to answer in my book on the History of Alzheimer's disease.

Jon Merril: Jesse in speaking about your book on the history Alzheimer's disease can you give us some insights about the discovery of the disease and how its diagnosis and treatment has changed over the past few generations.

Jesse Ballenger: Right, part of what gerontologists' accomplishments is to advance the claim that the aging process should not entail the drastic losses of physical and cognitive abilities and that when you do have these losses when these losses do occur you should look for the disease process. So Alzheimer's disease which has been the distinction has been made between Alzheimer's disease, dementia and senile dementia was well we expect that, we expect dementia when people are older. And we don't expect it when someone is fifty-one which is the average age of the Alzheimer's first patient so therefore when it occurs in the early ages we will call it a disease. When it occurs in older people you sixty-five and over, we just regard it as part of the pathological process of growing old.

Gerontology you know post World War II project really of gerontology was to attack that assumption that there was inevitably going to be a drop in physical and cognitive abilities and insisting that when those drops did occur, when cognitive ability was impaired, it should be regarded as a disease. It should be assumed that there is a disease that we can identify and isolate and hopefully find a treatment and prevention.

Jon Merril: We have a hard time dealing with Alzheimer's disease in the United States. We're not diagnosing it as early as we can and we really don't want relatives to see a loved one as they decline in mental function. They really become isolated from society and it just makes it more and more difficult for caregivers. Do you see other countries handling Alzheimer's disease better than we are?

Jesse Ballenger: Like India or China in which social hierarchies still try to protect older people and give them a meaning to their life that's quite independent of productive work or self fulfillment.

Jon Merril: Jesse on a personal note you have direct experience caring for patients with Alzheimer's disease as a nursing assistant you've done your scholarly study of the history of the diagnosis and treatment of Alzheimer's disease. How would you cope with losing your ability to write and other abilities in living with a disease like Alzheimer's disease?

Jesse Ballenger: Ah do I want to define myself by my productivity, what I'm able to produce? If I lost the ability to write books, no study history. Would my life be over? I certainly hope not, so I, so I it's certainly you know like everyone I'm recognized to my work that I have to face the prospect of slowly losing these things as I age that's a possible outcome but you know I should hope so rethink where I am now actually and how do I want to forge my identity am I the sum of my abilities in my work or do I want to reach out and make connections with society kind of sustaining with the people I'm around and the place I'm living in. Do I want to recognize and strengthen my connections and try to take my identity from that? So no the short answer is there is no short answer but I guess it's given me kind of different ideal to work for. An ideal that is not rooted in my own productivity in my own ability in my own fulfillment but you know a broader connection to the world I'm actually in. You know that is made it you know my inquiries have made it apparent to me how important being part of a healthy society is.

Jon Merril: With the advent of the hospice do you think our views are changing about death and dying and the aging process and dementia where we no longer are holding on to this ideal of providing heroic care all the way through the end of life we're frankly letting go a bit. Is that changing the way we perceive death dying and dementia?

Jesse Ballenger: It's kind of demedicalising death and allowing people to experience it with less the sense of my God we have to prevent this you know, no matter what, no matter how absurd it may be. It sort of says well this person is dying and how can we make them most comfortable? How can we create an environment where we're most able to stay connected with them and talk with them to the very end? You know I think it's very positive. I think the call for the creation of these kinds of services, that's just not enough of them. I know here in central Pennsylvania it's kind of difficult to get hospice and a lot of people die waiting to get into hospice programs, they just don't get into them soon enough. But I think that it's part of the actual movement towards more with regard to Alzheimer's dementia they agree to say well let's not think about a cure or a kind of medicalized management of this but let's create a situation where we're all about making people comfortable and trying to have an environment where they can be with their family in a calm and accepting environment. I think that's actually very positive and its part of making kind of a

more normal state for dementia, I think it actually can and should be working to lessening the fear we have of it.

Jon Merrill: With the vast perspective that you have on Alzheimer's disease through the ages, what gives you the most hope for the future?

Jesse Ballenger: I would say I hope that people when looking at how others have dealt with Alzheimer's and how dementia builds in the past and the present I am impressed and I think we should all be impressed by people's courage and resourcefulness and so I guess the grounds for hope are simply in seeing people's resilience, seeing people's strength.

Jon Merrill: We wish to thank Dr. Ballenger for his insights into the history and underpinnings of our current views regarding the diagnosis and treatment of Alzheimer's disease.

We also wish to thank our sponsor of this program Elan Pharmaceuticals.

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