Aging as a Disease in the United States

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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Fable of Tomorrow

To the Aging,

You are one of us, or at least you were. It can all happen at once, in the blink of an eye. It can happen slowly, degrading day by day. No one knows when it will happen. One day you can be the poster child for good health. They say how amazing you look for your age, even if that's a purely superficial assessment. But then your luck changes, you fall. It was just to go to the bathroom in the middle of the night, as you have thousands of times before, but this time is different. Only when you are faced with the cold, hard, unforgiving tile floor do you realize how easy life as you know it can all slip away. Those superficial comments did not prevent your hip from fracturing. The subsequent hip surgery is routine, doctors say you will be fine. Three months of recovery and you will be back to normal, or so they said. The continuing struggle to walk makes you question how this was ever normal, taken for granted. They say it is like riding a bike, you can never forget how to walk, but riding a bike does not cause this throbbing pain throughout your body. So you stop following the recommendations. The hip is fixed, who cares if you walk as much as you did before. You're exhausted, and walking only becomes harder and harder. That is when most of what you thought you knew changes as well. You thought the hip was an isolated thing, a simple slip, a stroke of bad luck with an easy fix. But then the delirium set in, you were not the same, shedding light on the true menace that was slowly developing behind the scenes. You have dementia. The years slip by with an inevitable, slow progression. You move into an assisted living facility. Your family visits frequently as they promised, you think. The ailments that once were so rare become a part of you. The medications, and bills, are relentless. They are supposed to help, but the list of side effects is an illness in and of itself. The visits slow. Once familiar faces, they do not know whether you will know them or not when they

come because your recognition changes each time. You are not you anymore. The diseases and medications stripped that from you. You are a shadow of your former self. A living premonition. A reminder of what is to come. A real-time prophecy unfolding before their eyes. Each visit is a scene in a tragedy. The tragedy of slow decline, of falling, of life.

We are sorry that it had to happen this way. Now, all we can do is wish to hit rewind. To cherish the times we had before everything changed. But this future does not face us all. Some experience aging gracefully, welcoming it as a transformation rather than a degradation. They embody a positive experience that transcends purely the physiological aspects of the phenomenon. Aging is a multi-faceted issue without a panacea, incorporating philosophical, medical, social, and political dimensions. How do we assist individuals in their aging journey, creating a future that can be looked upon fondly? Replacing frailty with freedom, sickness with health, and mental degradation with wisdom; a future that can be viewed as an evolution, not a fall.

Introduction & Research Questions

With the number of people over the age of 60 projected to approximately double between 2015 and 2050 from 12% to 22%, questions arise regarding aging that range from the socioeconomic impact of this segment of the population to how we perceive aging itself¹. The aging of the baby boom generation, a growing number of people living with multiple chronic conditions, and the reform of the US health care system all are playing a role in fostering a discussion on aging in the United States².

The broad medical definition of aging is the process of becoming older that is genetically determined and environmentally modulated. Through previous studies on twins, researchers were able to determine that 20% of aging is related to genetics and 80% is dictated by lifestyle³.

Modern scientific research has developed our understanding of the aging process at the most fundamental level. At the cellular level, aging is the impact of the accumulation of a wide variety of molecular and cellular damages over time including, but not limited to, telomere erosion, epigenetic alterations, cellular senescence, and stem cell exhaustion⁴. The collective effect of cellular aging is believed to be a critical component leading to the overall aging of individuals. While additional research is needed to fully understand the fundamental mechanisms behind aging, the potential for novel therapies to combat the cellular processes underlying aging, previously seen as impossible, are coming into sight through the advent of biotechnologies such as regenerative medicine and big data.

Although fundamental cellular processes may underly aging, it is clear that the aging phenomenon goes beyond these biological events. Factors such as where one lives can majorly impact one's lifespan, which is displayed by the discovery of areas around the world where people routinely live to significantly older ages, known as 'Blue Zones'. These areas are demographically confirmed to have the highest percentage of centenarians with the chance of reaching age 100, 10 times greater than that of the United States as a whole. Residents of 'Blue Zones' were determined to have nine specific characteristics conserved across their residents, dubbed the Power 9, which include: moving naturally, having a sense of purpose, following caloric restriction, and eating plant-based diets. The Power 9 display that aging is related to biological processes and social processes to a somewhat equal extent.

Views of aging differ greatly between individuals, with the topic embodying different dimensions depending upon the individual's perspective. For instance, Ian Ground, a professor of philosophy at the University of Newcastle, believes life's meaning comes from its finitude stating, "To say we address the most profound problem of life by abolishing death is like saying

we'll solve world poverty by abolishing money"⁶. The philosophical aspect of aging presented by Ground and others explores the aging issue, pointing to potential flaws in scientist's approach to the issue. However, these emphasized perspectives do not fully characterize aging in the United States. The multi-faceted nature of aging in the United States necessitates a sociotechnical analysis considering the viewpoints of all actors shaping this topic.

With older individuals forming an ever-increasing segment of the population, aging is coming to the forefront of discussions from a health care, economic, and societal perspective. The desire to increase the number of healthy years within someone's life is central to biomedical research. However, processes, such as those that cause aging, are still treated as inevitable, which can hinder research and funding. The views of biomedical researchers are not the only aspect to view when considering the aging in the United States. The actors and actants such as government funding bodies, general public, scientists, medical technology, and ICD-11 play a critical role in defining aging. My STS thesis will focus on analyzing aging in the United States through the lens of actor-network theory. Specifically, I aim to understand the key actors involved in aging within the US and how these human and non-human actors interact to understand how they define aging.

Literature Review

As a new generation of scientists is emerging, the previously traditional views of aging as an inevitable and natural process are coming into question⁷. The idea that aging is a natural process has become intrinsically a part of society, without proponents of this belief employing a critical look as to whether or not it is truly the case. In order to best understand why aging was presented as a normal change for a significant period of time, it is necessary to review other

discrepancies where human behavior was considering a disease, or a disease was considered normal human behavior.

Perhaps the ubiquity in aging is a significant component in why the process is considered by many to be a natural one. In addition, numerous diseases used to be purely accepted as a natural consequence of aging such as osteoporosis, hypertension, and Alzheimer's disease. However, this cannot be the case considering physiological-level conditions; such as muscle atrophy leading to sarcopenia, reduction in bone mass and density leading to osteoporosis, etc. Atherosclerosis, dementia, and acne are nearly universal phenomena in humans and yet they are not considered to be natural processes⁸. These individual occurrences are often treated as departures from what is normal or natural in research labs focusing on these phenomena, but the cumulative effect of these underlying processes is viewed as natural. Progeria, the rapid aging of a child, is considered to be a disease, but if the same changes are to occur in an elderly individual, the changes are normalized as a natural process that does not require or deserve medical intervention⁹.

It is clear that diseases are characterized largely by the social/historical context of the times rather than purely its objective measures, thus we must consider the social dimensions of aging within the United States. There are several instances in history where human behavior is considered a disease that generally seem preposterous to modern society and scientists⁸. For example, drapetomania was considered to be a mental disease that caused slaves to run away in 1851¹⁰. Homosexuality was considered as a disease as recently as 1973, at which point the American Psychiatric Association removed it from the diagnostic and statistical manual of mental disorders with the latest print of DSM-II¹¹.

The historical context of a medical phenomenon must be considered to truly gain an understanding of the topic – and thus this process must be applied to aging in the United States. Throughout time, the general population's views of aging and its associated characteristics have changed drastically. The transition from the nineteenth century to the twentieth was largely characterized by a medicalization of aging and a shift away from the view that aging was inevitable and a part of "God's plan" Views of the course of life for individuals has changed throughout time and continues to be a socially constructed concept. For instance, the concept of an individual's adolescence lasts longer within industrial societies when compared to small-scale societies View old age through the lens of their physical capabilities and feeling old rather than purely a chronological age View old age through the lens of their physical capabilities and feeling old rather than purely a chronological and social context. Aging is not a purely static idea as it changes dynamically throughout time and space.

Medical anthropologist Margaret Lock's research has largely focused on the nature of medical knowledge and the social contexts inherently embedded within this knowledge. Within medical research there typically lies an inherent reliance on reductionist logic to explain phenomena¹⁴. Reductionist logic can lead to the trivializing of topics, such as aging, as critical aspects are neglected from analysis. While Western medicine has drastically increased lifespan, ailments such as Alzheimer's and other age-related diseases have increased in prevalence¹⁵. In Lock's *The Alzheimer Conundrum: Entanglements of Dementia and Aging*, she discusses the social context and political aspects of research on Alzheimer's disease¹⁶. Through her research, she found an inherent reliance on localization theory by biomedical researchers leading to studies supporting the most prominent current hypothesis of pathophysiology. These studies lead to a hunt for biomarkers and an understanding of epigenetic and genetic processes, rather than

expanding their analysis to consider neglected aspects such as environmental factors related to Alzheimer's and caring for those with the disease. Clearly without any successful treatment for Alzheimer's, these efforts have largely been unsuccessful and misguided at times. Dogmatic following of beliefs such as localization theory by medical researchers, without self-reflection, demonstrates a propensity towards reductionist thinking. Reductionist thinking leads to a neglection of social dimensions and a dissociation from the affected individual. Similarly, aging research adopts a reductionist mindset by linking aging processes to cellular processes rather than a broader cultural context. By painting aging in the light of something to be combatted against while championing youthfulness, researchers may unintentionally promote false promises that degrade at the elderly's sense of self-worth and contribute to a divide between generations¹².

Contextualization of aging through a social lens reveals a divide between different actors that play a role in defining aging within the United States. Debates arise from medical researchers and others opposed to the medicalization of aging as they consider the elongation of life spans⁶. Philosophers, opponents, who explore the different aspects of aging suggest life's meaning comes from its finitude as justification that life spans are long enough. Further, critics of medicalization raise concerns regarding political aspects of the problem – citing that having one generation replace another allows for the development of new ideas over time. Proponents of medicalization claim the societal problems associated with increased life span are valid, but do not represent an issue comparable to the level of suffering that comes from diseases of aging. Additionally, Aubrey de Grey, a biological gerontologist, believes there to be no conflict between an individual's desire to live longer and the collective good. It is clear that the aging debate is not a settled issue with actors voicing perspectives from both sides of the medicalization debate. Ultimately, aging within the United States is a multi-faceted issue which

cannot be understood without considering its social and technical dimensions as well as the relationships between key actors.

STS Framework

In order to understand the problem of aging in the United States, the STS framework of Actor-Network Theory (ANT) was selected due to the preliminary research revealing the involvement of a number of actors, both human and non-human. ANT is a sociotechnical framework founded by Bruno Latour that focuses on the relationship between actors and their resulting effect on social processes. Actors, in this context, are defined as anything that can be a source of action and influences other entities. A main aspect of ANT is the fact that actors can be either human or non-human, arguing that they should be treated equally for the purposes of analysis¹⁷. Moving forward, actors will be referred to as actants – the word actor refers specifically to humans, but ANT does not make this distinction. ANT considers the world in terms of networks of actants whereby the mapping of associations and relationships between actants allows for a deeper understanding of the constructed nature of that network. The culmination of actants into a network leads to the creation of new entities that do not necessarily represent the sum of its components. Further, within ANT, scientific knowledge is a social product which must be considered in terms of the actants involved¹⁸. ANT analyzes the mechanics of power through the construction of networks through the sociology of translation whereby actants translate their interests/materiality into the network.

Applying the ANT framework to the aging issue in the United States, specifically with regard to the construction of aging as a disease, first requires the determination of the key actants that play a role in this network. Key actors were determined through a variety of means mainly related to a literature review on the topic. Reviews of literature discussing aging as a disease as

well as literature that applies ANT to aging in other aspects were used to define key actors. First and foremost, the scientific community represents a significant actant within the network due to their role in defining critical aspects of aging at the biological level and theorizing means of altering these systems for the betterment of humans. Grant-funding bodies in the form of government institutes are further critical to the analysis as these institutes make up the majority of funding for research in the field of aging. Specifically, the National Institute on Aging (NIA), a subcomponent of the NIH, was selected to be analyzed due to their large presence in the field with \$3.08 billion dollars in funding, primarily dedicated to research grants¹⁹. In addition, the general public represents a critical actant within this network as they are directly affected by aging and thus impacted by advances within this field. The general public will largely be considered across all ages as medical advances in the field of aging now span across age demographics, but of course these advances disproportionately affect older individuals. Medical technology also plays a role as a non-human actant through which scientific advances are translated to the general public. The final actant considered is the International Statistical Classification of Disease and Related Health Problems (ICD-11), which is a key point of contention between various researchers in the field of aging. This diagnostic tool plays a vital role at the interface between researchers and grant-funding institutions as described earlier. The combination of these actants and their various relationships forming an actor-network will represent the basis for analysis of aging in the United States using ANT.

Methods

In order to understand the sociotechnical complexity involved with aging in the United States through the lens of ANT, various documents were gathered to understand actants' positions in the issue. Document analysis was conducted through the aid of a document analysis

form adapted from materials by the National Archives and Record Administration and put forth by Facing History and Ourselves. Document analysis is a systemic procedure for reviewing documents where one examines and interprets the document to gain an understanding of different questions of interests²⁰. Generally speaking, the document's different parts are observed, its main expressed points are summarized, the motivations of its authors are considered, and it is finally used as historical evidence. This technique can be utilized to understand the value and impact of different technologies and polices by taking into account who produced a document, who published it, and what position the document is trying to convey. Using document analysis, these questions and more were explored to develop an understanding of connections between actants within the actor-network that constitutes aging in the United States as well as to elucidate each actant's view of aging. Documents that are capable of being utilized in this analysis take a multitude of forms including but not limited to: technical reports, policy reports, advertisements, interviews, products, and news. Representative documents were gathered regarding each of these actants in various forms to then apply the document analysis form described above. Documents identified ranged from published literature for representing the scientific community, to websites' description of missions for the NIH, to published surveys of the public's view on aging. Once documents were identified, these documents were used to provide data for understanding an actants' views/roles in aging.

Data Analysis

Aging as a Public Health Problem

Analysis of opinion articles published in scientific journals display a divide between the scientific community with regard to aging in the United States. Researchers tend towards two sides, arguing that aging is or is not a disease. Further, there appears to be a degree of

disagreement on the medicalization of aging. Some scientists within the field present aging through the lens of a public health problem, rather than purely a biological phenomenon characterized by cellular degradation. Public health agencies largely were not involved in aging until 1987 when a provision within the Disease Prevention and Health Promotion Services mandated Medicare and Medicaid program officials consult public health officials in the carrying out of their programs². Public health officials further established an epidemiological model of "successful aging" in the 1990s, applying public health concepts to the field of aging and imposing their public health interpretation on the aging issue. The model's "successful aging" description includes maintaining physical and mental functioning, minimizing risk of disease and disability, and social inclusion as key components of the process. This model of aging emphasizes researchers' focus on the physiological changes that come with aging, while the social inclusion aspect highlights public health's ability to go beyond basic science researchers to recognize the social aspect of aging. Studies have shown a wide variation in the physical abilities of the elderly, representing a challenge for public health in improving the lives of older adults. Even though public health officials recognize the importance of social dynamics in aging, they typically only apply this social emphasis as a means to improve other aspects of older individual's lives such as mental and physical well-being. Community-based programs are presented as a means of increasing physical activity and preventing the physiological degradation of aging. This framing points to the underlying focus of public health officials on the physiological aspects of aging. The focus is positively intended, but opportunities exist for public health officials to interface with other fields to gain a broader understanding of the aging issue within the United States to develop more effective plans to embrace the needs of aging individuals.

Advancing biomedical research has impacted the way in which many stakeholders interact with aging, bringing what was once impossible into sight. Regenerative medicine involves treatments that restore damaged tissues in individuals. Recent advances within the field have shown remarkable progress in using induced pluripotent stem cells, opening the door for improved organ transplantation as well as the treatment of diseases of the aging brain²¹. Once adequately developed, these technologies have the potential to add decades to people's lives, which, while solving certain health issues, brings diseases of longevity such as cancer to prominence. Additionally, developments in artificial intelligence (AI) are improving the ways in which we understand aging. Through AI, researchers are identifying novel biomarkers of aging to create a systemic view of the aging process, which will aid in anything from pharmaceutical research to screening of patients²².

Researchers at the forefront of aging research tend to take a biological standpoint of aging, purely analyzing physiological impacts rather than broader impacts. Those who are of the opinion that aging should be treated as a disease typically refer to ICD-11, suggesting that aging should be incorporated as a disease with its own code within this framework. ICD-11 forms the basis for payment for health services and is used for the identification of health trends and statistics worldwide. In another opinion article from University of Chicago, researchers counter these arguments stating that, as Biodemographers, they consider claiming aging is a disease is equivalent to equating cause and effect. Biodemographers think recent efforts by researchers to push forth aging as a disease resembles a promotion rather than a scientific revolution⁷. ICD-11 represents a tool for global public health officials to define aging-related symptoms and employ these in the diagnosis of disease, typically prioritizing physical manifestations of aging in individuals. Aging represents a public health issue in which actants, in particular public health

officials and ICD-11, formulate the definition of aging and design strategies for improvement based upon their definition.

Aging as a Political Problem

Aging within the United States has implications across society and, as such, there are key implications for politics in the issue. An aging society poses various changes beyond the chronological age of its citizens. Aging workforces yield a less productive workforce, with every 10% increase in the fraction of the population greater than 60 years old resulting in a decreased growth rate of GDP per capita by 5.5% ²³. Additionally, increasing demands on social programs like Medicare and Social security necessitate changes in the budget of countries to compensate for deficits. As the number of elderly individuals increases, there is a rising demand for health care workers, which requires a modification of the workforce. These various aging-related societal changes all necessitate policy-level changes within the United States. The MacArthur Foundation Research Network on an Aging Society puts forth policy options to address agingrelated issues²⁴. The network effectively considers aging in the context of broader changes, expanding analysis to consider society as a whole rather than pitting generations against one another. Therefore, policy-makers represent a heterogenous group with regards to aging with some envisioning all aspects of the aging issue and others observing aging as purely a policy problem.

Scientists who make the case for classifying aging as a disease and medicalization of aging seems to stem largely from a point of view that doing so will allow for an increase in funding towards aging research and legitimization of medical efforts to do so⁸. Thus, one may regard these views as heavily biased towards those arguing for medicalization of aging, as they would be the actants who stand to gain a financial benefit. Budgets for scientific research have

historically been influenced heavily by the political climate and public support. As a result of increased public support for cancer research and the concerns of those in the medical profession, Richard Nixon declared a "war on cancer." Through this initiative, he requested an additional \$100 million to be added to the NCI budget²⁵. In 1971, he signed the National Cancer Act of 1971, which increased NCI funding and power²⁶. These developments have ultimately resulted in an increase in the relative survival rate for all cancers of 70%²⁷. Therefore, the interaction between different actants, in particular by scientists and the general public, is capable of driving change at a societal level through modified research focuses and federal funding. A change in view with regards to aging could result in increased funding through grant-awarding bodies for aging research and the development of therapies to combat the effects of aging⁸.

Discussion

Through an understanding of how different actants view the aging issue in the United States, one is able to understand the underlying relationships between them and how this network shapes the meaning of aging. Aging is not a purely biologically-defined process. It is a problem that transcends biology with political, social, and public health dimensions. The primary actants involved in aging are researchers who have shaped a discourse around aging while focusing on the physiological impacts. Political actors sometimes transcend these views to guide public policy towards a holistic view of aging, but these actors are largely heterogenous. Researchers are incentivized to increase their funding to increase their job security, and as such become biased when promoting medicalization of aging. Further, researchers' interactions with industry help solidify this mindset as medicalization leads to increased health spending. The act of recruiting individuals for clinical studies involving biological processes connected to aging further solidify the network forming the definition of aging in the United States. This process of

recruitment can come in various forms, but, due to the power dynamic between the general public and researchers, it can be predatory. For instance, pharmaceutical companies utilize families in Antioquia, Colombia due to their carrying of a specific gene mutation that results in early onset Alzheimer's disease²⁸. These families attend information sessions provided by the company which often present a one-sided view of the issue, strengthening the pharmaceutical company's depiction of aging. Margaret Lock points this instance out as a part of an "expanding universe of drug trials in which 'naïve' subjects... often living in economically deprived conditions are systematically recruited for trials" ¹⁶. The establishment of the meaning of aging within the United States is driven heavily by the partnership of researchers and pharmaceutical companies as they act to recruit the general public to both develop their research and solidify their views.

The medical advances such as AI and regenerative medicine promoted by the scientific research community do not work alone. A sociology of translation is developed by researchers as they recruit the general public into clinical trials for aging using these technologies. The resulting network is utilized to impact policy decisions at the highest level to solidify their network. The incentives driving researchers and pharmaceutical companies, such as financial security and the will to help end human suffering, do not always align, and a dichotomy often existing between these goals. Pharmaceutical companies more often take the form of daily pills to increase the commercial capacity of treatments, despite a potential optimum treatment that would occur more infrequently. These medical technologies and ICD-11 act as immutable mobiles through which scientists can act in a distance with power, further promoting the physiological aspects of aging as a whole. Debate still exists within the aging discourse in the United States regarding medicalization, and ultimately the answer must encompass a broad view of aging beyond the

biologically determined process. Research of aging must consider the broader societal and political aspects underlying the phenomenon.

Conclusion

The aging discourse is shaped by an actor network that successfully utilizes actants to recruit actors and establish the power to define the issue, without taking a critical look at all the different aspects of aging in the United States. Specifically, scientific researchers, public health officials, and pharmaceutical companies all utilize advancing medical technology and ICD-11 to legitimize efforts in the field and promote a physiologically-based argument for aging. However, these actors are innately heterogenous groups with individuals at both ends of the medicalization debate. It is important to note that additional actants are involved in the aging issue within the United States, such as health care workers, politicians, medical technology companies, assisted living facilities, and more. However, in order to constrain the complexity of this analysis, the above key actants were selected due to their critical relevance to aging in the United States. Follow-up studies could expand upon this work by including additional actants that play a role in aging within the United States to develop a more thorough understanding of network dynamics. Further, surveys could be utilized to question researchers' motivations directly to gain a better understanding of their views on aging.

Aging is a global challenge for every country – as medical technology advances and life spans increase, the demographic changes unfolding in the United States will occur across the globe. These changes have already impacted countries like Japan where demographics are consistently shifting towards older generations. Such demographic changes have impacted health care within Japan significantly, requiring both increases in health care and broader societal changes. There is no universal meaning to aging, with individual's experience of the process

varying widely. The United States must approach aging as such, considering all dimensions of the issues rather than a myopic view on purely the physiological changes that arise as a result of aging. Through a sociotechnical analysis of aging, the United States can hope to effectively move views of aging from a degradation to an evolution which it can embrace.

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