A PERFECT STORM: THE ETHICAL CHALLENGES OF SIMULTANEOUS INCREASES IN THE NEED FOR LONG-TERM CARE, USE OF DIRECT-TO-CONSUMER GENETIC TESTING, AND RISK OF GENETIC DISCRIMINATION IN THE U.S.

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Abstract

The phrase ‘a perfect storm’ is an expression first derived from the novel *The Perfect Storm* by Sebastian Junger, meaning three concurrent circumstances colliding to create a poor outcome. The United States is approaching a current day Perfect Storm between the healthcare, healthcare technology, and legislative spaces. This paper begins with a case study to ground the discussion before diving into the Perfect Storm’s three elements; an increased demand for long-term care due to the rapidly aging population and increased life expectancy, an increased use of direct-to-consumer (DTC) genetic testing used for determining genetic risk of disease, and an increased risk of genetic discrimination and lack of adequate legislative protections. Ethical and moral principles will be connected to the Perfect Storm showing how many identified ethical aspects are, or will be, in violation of principles as these three factors continue to converge. This paper is not meant to outline a solution to the Perfect Storm, but suggestions for ways to think about alleviating burdens from these elements will be discussed. The United States is reaching a critical breaking point where these three factors are set to have serious consequences if appropriate actions are not taken.

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Introduction

Sebastian Junger's 1997 novel *The Perfect Storm* is the grounding story behind a commonly used idiomatic expression today. Junger wrote of a fishing boat and its crew becoming caught in a once-every-hundred-years simultaneous occurrence of three weather systems that resulted in a violent hurricane, wreaking havoc on the crew at sea.[1] The perfect storm is an idiom meant to represent the "rare combination of events of circumstances creating an unusually bad situation".[2] In America today many circumstances can be combined for poor outcomes, however, the Perfect Storm in this paper will focus not on weather systems, but on the healthcare and legislative systems. The issues of increased need for long-term care, increased use of direct-to-consumer (DTC) genetic testing, and increased risk of genetic discrimination are converging and setting the stage for an impending Perfect Storm in the US.

There is a growing literature on each of these topics and sometimes two in combination, but there is no discussion of the important triad set to make up the Perfect Storm. Publications on direct-to-consumer testing and the aging population are able to relate tests for neurodegenerative diseases and other diseases of aging to trends of increased incidences as the Boomer generation ages.[3,4,5] There is also extensive literature discussing the interactions between aging people and long-term care from numerous angles. Long-term care is described by the National Institute on Aging as services designed to help people live safely and as independently as possible when everyday activities become difficult to do by oneself.[6] These papers mainly aimed to acknowledge that diseases of aging and dependence on long-term care provisions are only growing and more solutions for dealing with diseases of aging are

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[1] Sebastian Junger, *The Perfect Storm: A True Story of Man against the Sea* (London: Harper Perennial, 2010).

[2] "Perfect Storm," (Grammarist, February 2013).

[3] J. Scott Roberts and Wendy R. Uhlmann, "Genetic Susceptibility Testing for Neurodegenerative Diseases: Ethical and Practice Issues" *Progress in Neurobiology* 110 (2013): pp. 89-101.

[4] J. Scott Roberts, Anne K. Patterson, and Wendy R. Uhlmann, "Genetic Testing for Neurodegenerative Diseases: Ethical and Health Communication Challenges" *Neurobiology of Disease* 141 (2020).

[5] Jill S. Goldman et al., "Genetic Counseling and Testing for Alzheimer's Disease: Joint Practice Guidelines of the American College of Medical Genetics and the National Society of Genetic Counselors" *Genetics in Medicine* 13, no. 6 (2011): pp. 597-605.

[6] "What Is Long-Term Care?" National Institute on Aging (U.S. Department of Health and Human Services, (2017).

needed.[7,8,9,10] Lastly, the connections made in the literature between DTC genetic testing and long-term care have mostly focused on genetic discrimination and legislative details of protections and limitations.[11,12] Each of these issues has been discussed in specific settings, but there is not an analysis of all three. This synthesis is important because of the burdensome threat the United States will encounter in the coming years and the actions that will need to be taken to keep the storm at bay.

In this paper, I will elaborate on and provide additional context for the Perfect Storm of long-term care needs, DTC testing, and genetic discrimination. Then I will discuss the ethical issues and challenges raised by the Perfect Storm. Finally, I will offer some suggestions for addressing these issues. I will begin with a case study to set the scene for the discussion that follows.

Case Study

Mary is a 55-year-old female from Indiana. She decided to take a direct-to-consumer genetic test after seeing a commercial for it online. It seemed easy even for her, an English teacher who never enjoyed the sciences. She followed the kit instructions, mailed her sample to the lab, and waited to learn her results. Mary was eager to get the results because she was hoping to learn more about her genetic risk of developing a disease of aging in particular. Her great aunt had Alzheimer's disease and Mary didn't know much about her family's health history. She

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[7] Terry Fulmer et al., "Actualizing Better Health and Health Care for Older Adults" *Health Affairs* 40, no. 2 (January 2021): pp. 219-225.

[8] Sławomir Tobis et al., "Needs of Older Persons Living in Long-Term Care Institutions: On the Usefulness of Cluster Approach" *BMC Geriatrics* 21, no. 1 (2021).

[9] Benjamin Plackett, "Tackling the Crisis of Care for Older People: Lessons from India and Japan" *Nature* 601, no. 7893 (2022).

[10] Efraim Jaul and Jeremy Barron, "Age-Related Diseases and Clinical and Public Health Implications for the 85 Years Old and Over Population" *Frontiers in Public Health* 5 (2017).

[11] Pascal Su, "Direct-to-Consumer Genetic Testing: A Comprehensive View" *Yale Journal of Biology and Medicine* 86, no. 3 (2013): pp. 359-365.

[12] Jessica Tenenbaum and Kenneth Goodman, "Beyond the Genetic Information Nondiscrimination Act: Ethical and Economic Implications of the Exclusion of Disability, Long-Term Care and Life Insurance" *Personalized Medicine* 14, no. 2 (2017): pp. 153-157.

wondered if Alzheimer's ran in her family and wanted to know if she was at increased risk so she could plan ahead.

At the same time Mary sent in her DTC test, she began the process of applying for long-term care insurance. She had no children and had lost her husband in an accident some years ago, so she wanted to make sure she could age comfortably with adequate support. The long-term care insurance company had sent her comprehensive paperwork to fill out, which she was slowly working her way through.

During this time Mary received an email informing her that her genetic test results were available. She logged onto her laptop and was directed to enter a code on the DTC company's website which gave her instructions on how to access her results. Before gaining access, a blank screen appeared with a pop-up window asking for her consent that said "Please take a few moments to read the terms and use agreement. If you agree to the terms you will be directed to your test results, if you are unable to agree, please X out of the web browser. You will not be able to see your results". The pop-up looked like every other cookie use agreement Mary had seen on websites, so she quickly scrolled through it, assuming it was a bunch of software lingo, and clicked "agree".

Her test results showed a few interesting pieces of genetic information, with the most important being that she was an *APOE*-ε4 homozygote. The *APOE*-ε4 allele is a well-studied risk factor for developing Alzheimer's disease, with potential to increase someone's risk of developing the disease by 15-fold when homozygous, like in Mary's case.[13] This disease of aging, Mary remembers from seeing her great aunt go through it, was ruthless in erasing memories and even her aunt's general process of thinking. Grateful to have this information, Mary went to work finishing her paperwork for the long-term care insurance application. The application required all health records including at-home tests to be provided to the long-term

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[13] Amanda L. Lumsden et al., "Apolipoprotein E (APOE) Genotype-Associated Disease Risks: A Phenome-Wide, Registry-Based, Case-Control Study Utilising the UK Biobank" *EBioMedicine* 59 (2020).

care insurance company for review. Failure to do so may result in risk of a void policy in the future, so Mary had her doctors send over her medical files, and she sent in her DTC test results.

Two weeks after submitting her long-term care insurance application, she was shocked to learn she had been denied coverage. Mary was told that because of her predisposition to developing Alzheimer's disease the company decided not to take her on as an insuree. Mary spent hours on the long-term care insurance company's customer service line angry that they had clearly discriminated on her application even though she knew the Genetic Information Nondiscrimination Act (GINA) was supposed to protect people from genetic discrimination. After being on hold for some time, Mary was able to state her case to the insurance representative, who cut her off halfway through the long-winded statement she had rehearsed with "I'm sorry ma'am GINA doesn't apply to long-term care insurance, we have the right to use your test results to determine coverage eligibility. Have a nice day". Mary, with her ear to the phone listening to the dial tone, was confused and shocked. How did she not know this? What happens now?

This case example is not unique. Many eager consumers take a DTC genetic test excited to see their results and to learn more about their health. With these results also come very real risks to the consumer, like vulnerabilities to genetic discrimination when the consumer does not understand the repercussions. There are people like Mary who don't realize their risks during the consent process, or who are unable to understand the often inaccessible language used in DTC companies' consent forms. Sure, if Mary had scrolled through the user agreement pop-up window more carefully she may have seen in tiny fine print there was a statement warning the consumer about the risks of genetic discrimination. These easy-to-access products do not necessarily provide easy access to clearly written information about the potential risks, or allow for a fully informed consent process. The situation that Mary experienced is likely to become more prevalent. A report by the National Poll on Healthy Aging asked older adults about interest and willingness to take DTC genetic tests and 70% of respondents aged 50-64 expressed interest in testing for genetic risk of developing Alzheimer's, with slightly less interest in other diseases of aging like Parkinson's.[14] These numbers are independent of other types of DTC testing capabilities like ancestry. This report points to a large population of Americans who are willing to, or already have, utilized DTC genetic testing to learn more about their genetic risk of diseases of aging, contributing to the Perfect Storm.

Contextualizing the Perfect Storm

The Increased Need for Long-Term Care

The first factor of this Perfect Storm is that there is an increased need for long-term care options in the US. The population is aging rapidly and with aging comes changes to physical, sensory, and cognitive abilities, and often diseases of aging emerge.[15] By 2030, the Baby Boomer generation will have reached age 65 or older, a phenomenon called the Gray Tsunami.[16] In addition to a rapidly aging population, life expectancy is increasing.[17] Life expectancy for individuals at age 65 is increasing from 11.9 years to 19.1 years.[18] This means that someone who is 65 years old is now estimated to live 19 more years, or approximately 84 years compared to 77 previously. The extension of life years is partly due to societal advances in public health initiatives, healthcare improvements, and new uses of biotechnology. Although the increased life expectancy means more time to spend with aging loved ones, it also creates more opportunities for diseases of aging to develop.

With the rapid increase of older individuals and diseases of aging becoming more common, more resources are needed per person to maintain a high quality of life in old age. The surge in the aging population will have a direct effect on the demand for long term care because of the

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[14] Scott Roberts, "Older Adults' Views on Genetic Testing" National Poll on Healthy Aging (2018).

[15] Jaul and Barron, "Age-Related Diseases and Clinical and Public Health Implications for the 85 Years Old and Over Population" (2017).

[16] "2020 Census Will Help Policymakers Prepare for the Incoming Wave of Aging Boomers" U.S. Census Bureau, (2019).

[17] Ibid.

[18] Wan He, Daniel Goodkind, and Paul Kowal, "An Aging World: 2015" U.S Census Bureau, (2016).

nature of many of these diseases. Options for long-term care vary, but the most common types are in-home and facility-based care, where multiple services are offered based on personal needs.[19] Currently the American Association for Long-Term Care Insurance has data showing in 2020, 7.5 million Americans had some form of long-term care insurance, either traditional long-term care or linked-benefit products, with only 7% of policy holders being people over 50.[20,21] The 7.5 million statistic has not changed since 2008 despite the population becoming older and more dependent on care options later in life.[22] An estimated 7 out of 10 individuals will require some form of assistance for personal care tasks such as bathing, dressing, and eating, in addition to other tasks like cooking, cleaning, and shopping over the course of their elderly life.[23] Long-term care is not the only solution for dealing with an aging population and their increasing healthcare needs. Other options, like living in multigenerational homes or receiving care from family exist but, at least in our culture, are hard to find or are unsustainable.

The United States and many Western cultures have certain views and norms that make caring for the elderly more challenging. It is most common to *not* live in a multigenerational home in the United States today and to *not* care for an aging family member full-time.[24] Data reveals that only 3.1% of US family households are multigenerational currently.[25] The care of an aging family member is often outsourced to long-term care options like nursing homes and assisted living facilities, or in-home nursing care. Care in some capacity is still done by family though, with aging Americans receiving unpaid support often through an adult child.[26] This unpaid care can be related to doing errands, housework, small personal care tasks, or assistance with end-of-life planning. A study from 2002 identified a pattern of informal elder care and a reduction in

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[19] "What Is Long-Term Care?" National Institute on Aging (U.S. Department of Health and Human Services, (2017).

[20] "2019 Long Term Care Insurance Facts - Data - Statistics, Long-Term Care Insurance Costs 2019 - Long-Term Care Insurance Claims & Buyers" American Association for Long-Term Care Insurance, (2019).

[21] Alexander Sammon, "The Collapse of Long-Term Care Insurance" The American Prospect (2020).

[22] Sammon, "The Collapse of Long-Term Care Insurance".

[23] Richard W. Johnson, "The Strains and Drains of Long-Term Care" Journal of Ethics American Medical Association, American Medical Association, (2008).

[24] Sally Vyain et al., "Chapter 13. Aging and the Elderly" Introduction to Sociology 1st Canadian Edition, BCCampus, (2014).

[25] Ibid.

[26] Johnson, "The Strains and Drains of Long-Term Care" Journal of Ethics American Medical Association".

nursing home admissions which could be telling about the benefits of once-common multigenerational living.[27] This study showed that informal care to an aging parent by an adult child was successful in reducing nursing home admissions by 60% over a two year study period.[28] So if data suggests that multigenerational living and greater care interactions with loved ones are beneficial, why is it not the primary means of caring for our elderly? Two possible explanations include the cultural norms in the United States and a shift in population demographics.

In Asian societies among others, there are cultural norms of filial piety, which consist of caring for parents and family members in old age.[29] The practice of caring for aging members of society within the family and through regular intergenerational support is common. Studies of elderly Taiwanese adults showed there were positive impacts that multigenerational living situations had on cognitive function as well as reducing feelings of depression and loneliness.[30] East Asian societies are most associated with the practice of filial piety because of the historic influences of Confucianism, which taught children they owe their parents care and respect in old age, as well as love and obedience, as a matter of duty.[31] Across the globe and within many religious and cultural niches there are versions of filial piety. This is not to say that the United States has no attitudes of respect, love, and care for parents, but younger individuals in Western countries such as the US have reported less obligation and even negative feelings toward elderly relatives and those who require assistance in old age.[32] In the United States, there are values of raising children to lead independent lives and this is reflected in how family-

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[27] Anthony T. Lo Sasso and Richard W. Johnson, “Does Informal Care from Adult Children Reduce Nursing Home Admissions for the Elderly?” *INQUIRY: The Journal of Health Care Organization, Provision, and Financing* 39, no. 3 (2002): pp. 279-297.

[28] Ibid.

[29] Akiko Hashimoto and Charlotte Ikels, “Filial Piety in Changing Asian Societies (Chapter 5.5) - the Cambridge Handbook of Age and Ageing” Cambridge Core Cambridge University Press, (2016).

[30] Feng-Jen Tsai, Sandrine Motamed, and André Rougemont, “The Protective Effect of Taking Care of Grandchildren on Elders’ Mental Health? Associations between Changing Patterns of Intergenerational Exchanges and the Reduction of Elders’ Loneliness and Depression between 1993 and 2007 in Taiwan” *BMC Public Health* 13, no. 1 (2013).

[31] Hashimoto and Ikels, “Filial Piety in Changing Asian Societies (Chapter 5.5) - the Cambridge Handbook of Age and Ageing”.

[32] Ken Laidlaw et al., “Attitudes to Ageing and Expectations for Filial Piety across Chinese and British Cultures: A Pilot Exploratory Evaluation” *Aging & Mental Health* 14, no. 3 (2010): pp. 283-292.

focused parenting is. A 2000 study examining parenting styles showed results of "Chinese parents more strongly endors[ing] traditional Chinese values and exert[ing] more parental control over their children than did American parents".[33] This conclusion is a generalization of results, the styles and experiences parents raise children with are all unique and valuable, but for the purposes of this paper it is important to note this difference when thinking about beliefs of filial piety and family-oriented values. Due to this societal reality in the US, outsourcing the majority of elder care to long-term care facilities will continue.

The second reason multigenerational living situations are unlikely to become a common model of care in the US is because of the shrinking number of younger people in the population, and the shifting composition of people able to provide support. Many aging adults in the coming generations will not have younger family to rely on as part of their aging process. According to the Census Bureau, "Older adults are projected to outnumber children under age 18 for the first time in U.S. history by 2034".[34] The overwhelmingly older population will be aging, but the young people who theoretically could be there to support them, like adult children with whom they could live or from whom they could receive care, will be in short supply. Elderly people in their 90's or older may have adult children in their 70's who, themselves, may have their own health problems and diseases of aging to deal with. They might be unable to care for their parents even if they wanted to because they need care of their own.

Birth rates of US women are currently not sufficient to replace the population, with the fertility rate being 1.7 children per woman, and 2.1 children per woman is needed to sustain the current level.[35] Dr. Grace Whiting, the president and CEO of the National Alliance of Caregivers, put it simply when she said, "We aren't having enough children to take care of us in our old age".[36] The ability to have a family caretaker is diminishing, but even if a younger family member exists to care for an aging adult, their caregiving capabilities may be limited. The role

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[33] Paul E. Jose et al., "Parental Values and Practices Relevant to Young Children's Social Development in Taiwan and the United States" *Journal of Cross-Cultural Psychology* 31, no. 6 (2000): pp. 677-702.

[34] "2020 Census Will Help Policymakers Prepare for the Incoming Wave of Aging Boomers" U.S. Census Bureau, (2019).

[35] Ibid.

[36] Ibid.

of caregiver, especially to someone with a neurodegenerative disease like Alzheimer's or Parkinson's, requires substantial commitment and resources. The nuances of providing care in later stages may be outside the knowledge limits for someone without formal healthcare training.[37] Regardless of the reasons why care cannot be given within a family unit, it is clear the current long-term care systems do not have the capacity to take on aging Boomers.

An estimated 1 million new senior living units will be needed by 2040 to accommodate the surge in demand as the Boomer generation ages into this living landscape. This aging will result in a 42% increase in the United States' 65 and older population, and there will be a 111% increase in people aged 85 and older.[38] Diseases of aging in these age ranges are common and the risk of development only increases over time. For Alzheimer's alone, the population of adults living with the disease doubles every 5 years after 65, and the rate is expected to triple to a total of 14 million people by 2060.[39] Diseases of aging such as this can progress rapidly, and long-term care is needed as the later stages claim memory and thinking ability.[40] Federal programs that serve aging Americans will feel the strain of the increase of all care needs.[41]

The federal programs in place, Medicare and Medicaid, are already stressed and overwhelmed by demand.[42] Medicaid is the health insurance program for low-income individuals, including those who are 65 and older, and the eligibility requirements vary by state.[43] Funding for Medicaid is determined and reevaluated based on census data, and in 2020 Medicaid spending was reported at $671.2 billion, or 16% of the entire National Health Expenditure.[44] To date, Medicaid is the largest payer for long-term care services, accounting for 57% in 2020.[45]

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[37] Committee on Family Caregiving for Older Adults, Board on Health Care Services; Health and Medicine Division, and National Academies of Sciences, Engineering, and Medicine, "Families Caring for an Aging America: Chapter 3 Family Caregiving Roles and Impacts" ed. R Schulz and J Eden, *National Academies Press*, (2016).

[38] Emma Rubin, "2021 Assisted Living Statistics: Current Data Trends and Projections" ConsumerAffairs, (2022).

[39] "What Is Alzheimer's Disease?" Centers for Disease Control and Prevention (Centers for Disease Control and Prevention, (2020).

[40] "Older Adults" The National Council on Aging, n.d.

[41] Rubin, "2021 Assisted Living Statistics: Current Data Trends and Projections".

[42] "2020 Census Will Help Policymakers Prepare for the Incoming Wave of Aging Boomers" U.S. Census Bureau, (2019).

[43] Ibid.

[44] "NHE Fact Sheet" Centers for Medicare and Medicaid Services, (2021).

[45] "2019 Long Term Care Insurance Facts…" American Association for Long-Term Care Insurance, (2019).

Medicaid eligibility is not universal across low-income elderly adults, and many are ineligible due to financial or health criteria.[46] Medicare is the other publicly funded branch of coverage, specifically for adults 65 years or older.[47] Medicare spending in 2020 reached $829.5 billion, which accounted for 20% of the National Health Expenditure and 19.7% of the GDP. Estimates show that from 2019 to 2028 Medicare will have the fastest spending growth of the entire National Health Expenditure because of the projected increase in enrollment rates.[48]

In sum, the United States' aging population is growing due to longer life expectancy. This means there are more people who will need to be supported with various forms of long-term care over a prolonged span of time as various diseases of aging develop. Many of these people do not have family members or caregiver support due to cultural norms and values here in the US. To prevent putting economic burden on relatives, more people will need long-term care insurance to offset the costs of these care options as current programs like Medicare and Medicaid alone are not sufficient to fill this gap. Accessing long-term care insurance is an option to supplement these saturated programs, however the booming DTC genetic testing industry is attracting consumers who can gain information about their genetic risk of disease without fully understanding the implications of the results. The second factor in the Perfect Storm is the increased use of direct-to-consumer genetic testing among the elderly.

Increased Use of Various Consumer-Driven Genetic Testing Kits for Diseases of Aging

Direct-to-consumer genetic tests first gained traction in the early 2000's when tests hit the market with the advertisement that consumers could learn about their genetics without the direct involvement of a physician.[49] Direct-to-consumer genetic tests are more available and more accessible than ever due to their affordability, ease of use, and broad public interest. Test kits on the market today range from $99 to several hundred dollars which means they are

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[46] MaryBeth Musumeci and Rachel Garfield, "Medicaid's Role for People with Dementia" Kaiser Family Foundation, (2016).

[47] "2020 Census Will Help Policymakers Prepare for the Incoming Wave of Aging Boomers" U.S. Census Bureau, (2019).

[48] "NHE Fact Sheet" Centers for Medicare and Medicaid Services, (2021).

[49] Karen Norrgard, "DTC Genetic Testing for Diabetes, Breast Cancer, Heart Disease and Paternity" *Scitable by Nature Education*, 2008.

accommodating to a range of budgets and socioeconomic groups.[50] Appealing aspects of DTC tests include reducing barriers to access that traditional healthcare facilities may have for consumers such as time, transportation, and cost. Being able to take the test in the comfort of your own home with no set appointment time is likely appealing. The elimination of some burdens associated with obtaining traditional clinical genetic tests such as getting time off for the test appointment, and potentially having to find childcare can also make a huge difference in access for some Americans.

DTC genetic tests differ from clinical genetic testing because they are not done in a healthcare setting. The tests are obtained and results are reported to the patient directly. Clinical genetic tests are mostly used for the purposes of learning about risks, such as determining carrier status, or to identify a disease diagnosis.[51] Most DTC genetic tests are able to highlight the possible genetic risk of disease as well as test for other areas of interest like wellness, allergies, or genealogy.[52] DTC genetic tests are requested by the consumer themselves as opposed to clinical genetic testing which is ordered by a healthcare provider when it is deemed necessary.[53] The purpose of clinical genetic testing is to diagnose or treat a patient with a genetic disease or cancer.[54] DTC genetic tests are not able to diagnose a patient but can provide insight about lifestyle concerns and predictive risks of diseases.[55] These genetic predispositions are useful to know for some individuals so they can be vigilant in screenings and other prevention measures throughout the life course.[56] Just because a genetic test result indicates a genetic predisposition it does not mean that the disease will actually manifest. Factors including lifestyle and environment can vastly impact the development of disease, so genetic tests merely point to an increased risk of disease in the patients' future.[57] Test results are not something that should

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[50] Oh, "Direct-to-Consumer Genetic Testing: Advantages and Pitfalls".
[51] Kenneth Wysocki and Nicole Osier, "Direct to Consumer versus Clinical Genetic Testing" *Journal of the American Association of Nurse Practitioners* 31, no. 3 (2019): pp. 152-155.
[52] "Direct-to-Consumer Tests: Center for Drug Evaluation and Research" (FDA, 2019).
[53] Bermseok Oh, "Direct-to-Consumer Genetic Testing: Advantages and Pitfalls" *Genomics & Informatics* 17, no. 3 (2019).
[54] Ibid.
[55] Ibid.
[56] Ibid.
[57] Ibid.

dictate health-related procedures or decisions on their own.[58]

Our population is living in an age of technology, and in a time where many have taken a DTC genetic test. A 2020 Consumer Report revealed that 1 in 5 Americans have taken a DTC genetic test in their lifetime.[59] This report does not give statistics specific to the test type and population of Americans that are the focus of this paper since the tests in the report included ancestry and trait DTC testing, and used a "nationally representative survey of Americans" with no specific data identifying the subset of aging people.[60] Many older adults are drawn to ancestry and genealogy DTC tests, so the statistics for just health-related tests are expected to be different than the report's number.[61] Even without the specific population and test type being identified, it is clear that the trends of DTC testing are strong and influencing many Americans.

The proliferation of DTC genetic tests is empowering consumers and changing the landscape of how people can access their genetics. Many of these tests give insight into the genetic risk of developing diseases of aging as well as other comorbidities, which can help individuals plan for later in life or brace for what's to come.[62] The idea of searching for a sense of self in the modern world is a topic of discussion that philosophers and consumers alike are considering in their own ways, but some consumers are keen to learn about genetics to feel more in tune with their bodies.[63] Knowledge about a genetic risk can also be a useful reminder to stay vigilant in regular check-ups and doctor's appointments. Knowledge of a predisposition could help motivate preventative measures by the consumer or their physician in earlier years before aging progresses. Regular screening, in general, could also help reduce preventable comorbid conditions so Americans are in a better state of health as they prepare to take on aging.

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[58] Ibid.

[59] "Home Genetic Testing: A Nationally Representative Multi-Mode Survey" Consumer Reports, (2020).

[60] Ibid.

[61] Kara Gavin, "Older Adults Have High Interest in Genetic Testing - and Some Reservations" University of Michigan (2018).

[62] Su, "Direct-to-Consumer Genetic Testing: A Comprehensive View".

[63] Ibid.

Even with notable benefits, the current landscape of DTC testing can be harmful. Genetic information, regardless of how it is obtained either with a DTC or clinical test, is being used against people in various contexts, such as long-term care insurance, without protections. Privacy and data risks are real and can have serious consequences to the consumer.[64] To be clear, the DTC genetic testing technology isn't inherently bad, but the current context and guidelines of American long-term care insurance do make its limits more prominent.

Increased Risk of Genetic Discrimination

The last component of the Perfect Storm is the increased risk for genetic discrimination in the long-term care space. This is due to gaps in current legislative protections. The Genetic Information Nondiscrimination Act of 2008 (GINA) was enacted to provide Americans with protection from genetic discrimination in employment and health insurance.[65] While GINA prevents personal genetic information from being used in these specific settings, the expansion of direct-to-consumer testing capabilities in the past fourteen years has revealed shortcomings in these protections. Genetic discrimination is known to happen in long-term care insurance as well as other spaces such as housing, education, and mortgage-lending.[66] GINA does not protect individuals who already have a genetic disease, they would have legal protections through the Americans with Disabilities Act.[67] However, the ADA does not extend protections to *possible future* disability, even for diseases with a strong genetic basis like some cancers.[68] An example of this distinction is in the case of Darby v. Childvine, where a woman argued she had a disability due to having a BRCA I genetic mutation for breast cancer, even though genetic risk of disease does not equate to a disability according to the legislation.[69] The most relevant area of genetic discrimination, and the focus for this discussion, is in long-term care insurance.

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[64] Tenenbaum and Goodman, "Beyond the Genetic Information Nondiscrimination Act: Ethical and Economic Implications of the Exclusion of Disability, Long-Term Care and Life Insurance" 153-157.

[65] "Genetic Information Discrimination" U.S. Equal Employment Opportunity Commission.

[66] Slewan, "The Genetic Information Nondiscrimination Act Allows for Too Much Discrimination" Public Health Genetics, (2021).

[67] "Americans with Disabilities Act" United States Department of Labor, n.d.

[68] Ibid.

[69] U.S. District Court for the Southern District of Ohio, "Darby v. Childvine, Inc." Judicial Caselaw (2019).

In long-term care insurance applications, knowledge of genetic predispositions has been shown to increase premiums, limit benefits, or justify denying coverage altogether.[70] The insurance industry works in a way where companies need to make a profit in order to pay for claims and stay in business.[71] This means there needs to be a balance of risky insurees who have a higher chance of developing a disease of aging, with less risky insurees in order to afford to pay claims. Long-term care insurance companies do not want to insure a large number of individuals who are at a higher likelihood of developing conditions requiring long-term care because they would be expensive and take away from company profits. Insuring someone who is at risk for a disease like Alzheimer's would be risky because their cost of care and the length of time that long-term care is needed would be quite high. This is likely what happened to Mary when she applied for long-term care insurance after her DTC test had indicated she was an *APOE*-ε4 homozygote. When GINA was becoming enacted, insurance companies lobbied for life insurance and long-term care insurance coverage to be excluded, which it was.[72] This created the opportunity for companies to be selective in who they covered without legal repercussions. Since long-term care needs are becoming more common with the aging population, genetic discrimination in insurance applications will only continue with the current policies in place.

Long-term care insurance is a good that not everyone can afford. However, just because access to long-term care is limited to wealthier populations doesn't mean we shouldn't care about it. And further, if these people are not able to get long-term care due to genetic discrimination then that will put more of a burden on the already-overwhelmed federally-funded systems in place. So, we want as many people who can afford long-term care insurance to have it, but genetic discrimination reduces that number drastically, or creates higher premiums for those at greater risk of diseases like Alzheimer's. Individuals who have taken a DTC test that provides

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[70] Karen Pollitz et al., "Genetic Discrimination in Health Insurance: Current Legal Protections and Industry Practices" *INQUIRY: The Journal of Health Care Organization, Provision, and Financing* 44, no. 3 (2007): pp. 350-368.

[71] Ibid.

[72] Ayanna Alexander, "Peeking at Your Genes Can Raise Red Flags for Life Insurers" Bloomberg Law, (2019).

health risk information are vulnerable to genetic discrimination based on information from their test result, including in the long-term care insurance space.[73]

In situations where medical information is needed for insurance or mortgage purposes, there would be a less direct pathway to access genetic results in DTC form than if they were filed at a doctor's office. This is because after taking a DTC test, the results are not be automatically linked to personal medical records like clinical genetic test results would. This is unless DTC test results are voluntarily added to a medical file by the patient. The consumer may choose to keep the results to themselves unless reporting it is required on applications like for long-term care insurance. The consumer may also choose to talk about their results in other settings.

Telling a primary care physician about DTC results can also be a pathway for results to be entered into medical records and accessible to insurance companies, but only if the provider chooses to document it and if the patient chooses to talk about it. Some physicians are mindful of these current issues and will not document the discussion about DTC results unless necessary. Insurance companies can contact primary care physicians for medical records, which is one risk of talking to a primary care physician about DTC tests and something for consumers to consider. If DTC test results are withheld on an insurance application form there could be a void of insurance coverage or insurance fraud issues later on, which means the 'gatekeeping' of these results can only go so far to protect a consumer.

Currently, DTC genetic testing companies have large databases of all test results of consumers. In order for genetic discrimination to be an issue in the Perfect Storm, the test results need to actually get to the long-term care insurance companies. Many long-term care insurance companies ask if you have ever taken a genetic test and require the results to be included in the application. Failing to disclose genetic test results can cause a void of the policy or repercussions including insurance fraud if found out. Clinical genetic tests are automatically sent in because they are tied to medical records, so they would not have the same process. It would be helpful to know the pathways by which DTC test results can be acquired in order to

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[73] "Home Genetic Testing: A Nationally Representative Multi-Mode Survey" Consumer Reports.

identify where these risks are stemming from. There is currently no literature citing if this is possible, but that type of access would be catastrophic. What makes a DTC genetic test result database concerning from a long-term care perspective is if insurance companies have really easy access to the results. If this was possible they could create a highly selective market and eliminate anyone with certain disease risks from their coverage.

Ethical and Moral Challenges Arising in Light of the Perfect Storm

In the face of the Perfect Storm - increased need for long-term care, increased use of DTC genetic testing, and increased risk of genetic discrimination - several ethical issues and challenges arise. These can be linked to Beauchamp and Childress's *Principles of Biomedical Ethics*.[74] First, the principle of autonomy is invoked in competing ways. On one side, autonomy can be enhanced by consumers exercising personal choice to take a test and gain more information about themselves for empowerment. This could be to inform healthcare decisions or strengthen views about who they are. Consumer autonomy is interrupted by DTC companies who are claiming to promote this empowerment, even though consumer autonomy is only being partly exercised due to the consent process not adequately informing consumers about risks.

A relevant example of DTC testing disempowering consumers is when permission is taken for granted. In January 2022 the DTC company 23andMe renewed its data-sharing deal with GlaxoSmithKline (GSK), in which 23andMe allows GSK to use its consenting customer's results in an effort to develop new drug targets and therapies.[75] This deal has been in place since 2018 and the data used are from consumers who have consented to the 23andMe research program.[76] The issue is that consumers who were asked if they wanted to opt in to the research program were not asked if they specifically wanted to opt in to the GSK data-sharing deal.

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[74] Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics* (New York: Oxford University Press, 2019).

[75] "23andMe Announces Extension of GSK Collaboration and Update on Joint Immuno-Oncology Program" 23andMe, Inc., (2022).

[76] Connie Loizos, "23andMe Underscores That Privacy-Loving Customers Need to Opt out of Its Data Deal with GlaxoSmithKline" TechCrunch, (2018).

Instead, they were told they could opt out if they wanted to, but it seemed to be taking these consumers' consent for granted. Informed consent is a fluid process that continually has to be reevaluated given changing circumstances. In the GSK and 23andMe data agreement, reconsenting consumers to have them opt-in would have been much more empowering and appropriate with respect to informed consent and exercising personal autonomy.

On the other hand, autonomy can be violated by inadequate informed consent. Even though consumers want to exercise personal autonomy and take a DTC test to feel more empowered, the consent processes of companies are actually suppressing it. Autonomy is violated if consumers don't have full informed consent about the test's risks and benefits, which is the case for many individuals who take a DTC test. Many DTC genetic test companies use a form of wrap consent, which is a common website-use agreement that can be easily overlooked.[77] Wrap or clickwrap consent appears when entering many websites, and it requires clicking "I agree" or "I understand" to the listed terms and conditions of the site before continuing.[78] These agreements are often written at the college reading level, yet 7th to 8th grade is the recommended literacy level for companies to use when creating written content.[79] In addition, the clickwrap style often requires the reader to scroll or click through multiple pages, decreasing the chances of the pages actually being read. The website ProPrivacy.com conducted an experiment to see how many people actually read the clickwrap 'terms and conditions' of websites.[80] After including outlandish terms in their experimental agreements like the 'naming rights to your firstborn child', the results showed "only 1 percent of technology users in a social experiment actually read the terms and conditions".[81] Similar findings were shown in a Deloitte survey, which showed 97% of people ages 18-34 agreed to online terms and

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[77] Rachele M. Hendricks-Sturrup and Christine Y. Lu, "Direct-to-Consumer Genetic Testing Data Privacy: Key Concerns and Recommendations Based on Consumer Perspectives" *Journal of Personalized Medicine* 9, no. 2 (2019): p. 25

[78] Andelka M. Phillips, "'Only a Click Away — DTC Genetics for Ancestry, Health, Love…and More: A View of the Business and Regulatory Landscape'" *Applied & Translational Genomics* 8 (2016): pp. 16-22.

[79] Hendricks-Sturrup and Lu, "Direct-to-Consumer Genetic Testing Data Privacy: Key Concerns and Recommendations Based on Consumer Perspectives".

[80] Tim Sandle, "Report Finds Only 1 Percent Reads 'Terms & Conditions" Digital Journal, (2020).

[81] Tim Sandle, "Report Finds Only 1 Percent Reads 'Terms & Conditions" Digital Journal, (2020).

conditions without reading, this data did not specify if it was a clickwrap style agreement, however.[82] Often there are no ways of ensuring comprehension for an online agreement, so consumers can consent without fully understanding what companies may do with their information.[83]

DTC wrap agreements are formatted similarly to the agreements on Amazon and Twitter, which are informal and show as a pop-up on the screen.[84] This form of consent is quick, as well as legally binding and enforceable which is why it is so commonly used.[85] A 2016 study concluded that DTC consent agreements consistently did not meet international expectations for transparency thresholds in confidentiality, privacy, and secondary use rights.[86] Risks are an important aspect of consent that are necessary to know about before making an autonomous choice. Individuals taking DTC genetic tests are not explicitly told the limits of GINA or their vulnerabilities to genetic discrimination. This is all to say that consumers of DTC genetic tests are at risk of violations of their autonomy because the informed consent they give is not meaningful and they are unempowered with respect to their ability to obtain life insurance among other goods. Informed consent is just one aspect of the principle of autonomy that is acutely relevant in the case of DTC genetic testing, but it is not the only manifestation of autonomy.

A second ethical principle at play in the Perfect Storm is justice. Genetic discrimination in long-term care insurance where GINA protections do not apply, as well as ageism, are two key justice issues. Discrimination of any form is a violation of justice because one party is restricting certain benefits or exposing unnecessary risks to another. Justice acts to ensure there is an

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[82] Caroline Cakebread, “You're Not Alone, No One Reads Terms of Service Agreements” Business Insider, (2017).
[83] Hendricks-Sturrup and Lu, “Direct-to-Consumer Genetic Testing Data Privacy: Key Concerns and Recommendations Based on Consumer Perspectives”.
[84] Phillips, “Reading the Fine Print When Buying Your Genetic Self Online: Direct-to-Consumer Genetic Testing Terms and Conditions”.
[85] Hendricks-Sturrup and Lu, “Direct-to-Consumer Genetic Testing Data Privacy: Key Concerns and Recommendations Based on Consumer Perspectives”.
[86] Linnea I. Laestadius, Jennifer R. Rich, and Paul L. Auer, “All Your Data (Effectively) Belong to US: Data Practices among Direct-to-Consumer Genetic Testing Firms” *Genetics in Medicine* 19, no. 5 (2017): pp. 513-520.

equal distribution of costs, benefits, and risks.[87] The imbalance of risks in the case of a long-term care insurance company would be discriminating against consumers whose genetic test results indicated increased risk for serious disease. The benefits that the long-term care insurance company gets are being able to choose to insure the people who look the healthiest on paper, and in the end being able to maximize profits. This is a difficult comparison to make when there is a person on the other side of the paper who is planning for their future health needs and who wants to make sure their quality of life is as good as possible, while also not incurring financial burden on other family members. Long-term care insurance could vastly improve someone's ability to afford this care.

The American Academy of Actuaries stated that, "Underwriting for disability insurance and long-term care insurance is more concerned with the predisposition rather than with the diagnosis of diseases".[88] This means that the genetic predisposition indication on a medical record or test result that is sent in with a long-term care insurance application can be weighed quite heavily, and it is not surprising that people who are already in need of care will be denied. Although the practice of genetic discrimination in underwriting is not illegal, it is unjust. Additionally, the accessibility of these DTC tests makes them more widely used, opening a door to more people being vulnerable to genetic discrimination. DTC genetic tests are known to be less expensive and faster to get results than a clinical genetic test.[89] This means they can be distributed throughout society more equally than other less accessible goods. Risks to this would include the potential for an already vulnerable or marginalized person to be exposed to more harm through genetic discrimination that they aren't aware of or aren't educated about.

Another aspect of justice is ageism, which includes stereotypes, prejudice, and discrimination based on someone's age.[90] The risk of discrimination based on age is more common than ever

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[87] Beauchamp and Childress, *Principles of Biomedical Ethics*.

[88] "The Use Of Genetic Information In Disability Income And Long-Term Care Insurance" *American Academy of Actuaries Issue Brief*, 2002.

[89] Oh, "Direct-to-Consumer Genetic Testing: Advantages and Pitfalls".

[90] "Ageing: Ageism" World Health Organization, (2021).

and only growing as the population ages.[91] A report in 2020 synthesized data from 5 continents to learn about patterns in ageism on the structural and individual levels, which concluded that there was a negative impact from ageism on individuals' health outcomes.[92] This is a justice issue because the aging population is one that is more likely to be living with multiple comorbidities and who may need more medical care than younger populations.[93] If they are being treated differently due to their age and their health outcomes are reflecting this, it does not reflect a just system of values and policies. Justice considerations are relevant because the elderly population is growing, and they are being exposed to a greater risk for poor health outcomes than younger individuals with ageist views.

In a way, those who are motivated to learn about their health risks and genetic risk of diseases of aging are penalized for doing so. Thinking back to the case of Mary, there are Americans who have an increased risk of developing Alzheimer's like her, but if they don't take a test or are oblivious to their risk, they could end up in a better situation when it comes to things like applying for long-term care insurance. It is important to note that the risk of genetic discrimination in long-term care settings is not limited to those who have taken a DTC test. It also impacts individuals who seek genetic health information in a clinical setting. A key distinction between these testing settings and their risks is that individuals receiving clinical testing are more likely to be made aware of their limited protections because they would be counseled before the test with a geneticist or genetic counselor. The discussion about risks of genetic discrimination in a clinical setting may also allow individuals to back out of the testing process before it is too late. In a DTC setting the consumer is likely to be less informed. Those who choose to learn more about their genetic risk of disease will have to face repercussions that individuals indifferent to learning about their genetic risk of disease will not. Even if

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[91] Austin S. Kilaru and Rebekah E. Gee, "Structural Ageism and the Health of Older Adults" *JAMA Health Forum* 1, no. 10 (2020).

[92] E-Shien Chang et al., "Global Reach of Ageism on Older Persons' Health: A Systematic Review" *PLOS ONE* 15, no. 1 (2020).

[93] Louise Aronson, "Necessary Steps: How Health Care Fails Older Patients, and How It Can Be Done Better" *Health Affairs* 34, no. 3 (2015): pp. 528-532.

motivation to learn about personal health is indicative of being more health-conscious, there are drawbacks that may make some believe ignorance is bliss.

The third ethical principle to highlight is non-maleficence. Non-maleficence commands people to do no harm or to avoid actions that would cause harm.[94] The lack of long-term care is a clear harm to the aging population that will continually increase as quality of life becomes harder to maintain. Actions that prevent this long-term care from being accessible, like making it harder for someone to obtain long-term care insurance or long-term care, are contributing to unnecessary harm. Non-maleficence is also an issue on the DTC side of the Perfect Storm. DTC companies are attracting people to their products, but are not able to fully inform potential customers about risks for harms. The DTC companies are not clear and upfront about harms to the consumer, which like in the case of Mary, can be detrimental for future planning and well-being. The lack of true informed consent is causing consumers to take a DTC test sometimes without knowing all of the potential consequences and it is resulting in very real harm. Even before the informed consent process, the advertisements and commercials for this product don’t discuss harm and only highlight benefits.[95] There is also potential for DTC companies to do harm in the future which can’t even be predicted yet. With advances in technology and the capabilities of science, a new technique may be practiced that leaves consumers’ test results even more vulnerable to types of genetic discrimination.

The flip side of non-maleficence is beneficence which Beauchamp and Childress define as maximizing benefits, improving outcomes, and acting in an individuals’ best interest.[96] We have an ethical obligation to care for the aging people in our society, yet there is current knowledge that there isn’t going to be enough resources to support this rapidly aging population. We know that there are harms being done through genetic discrimination and the increased use of DTC testing without full informed consent. One could argue that the harms done to aging adults by

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[94] Beauchamp and Childress, *Principles of Biomedical Ethics*.

[95] Sara Chandros Hull and Kiran Prasad, “Reading between the Lines: Direct-to-Consumer Advertising of Genetic Testing” *The Hastings Center Report* 31, no. 3 (2001): p. 33.

[96] Beauchamp and Childress, *Principles of Biomedical Ethics*.

not providing them with adequate care and facilities would greatly outweigh the benefits of saving federal funds or allowing private companies to continue making large profits. The principle of beneficence can be related to the ethics of care.

The ethics of care perspective, which originates from the nursing profession, is relevant to the Perfect Storm if we focus on the well-being of our elders.[97] The ethics of care is about acting in a patient's best interest which, in the case of long-term care, may be difficult to achieve if there are not enough resources in the form of facilities, staff, and funding for all those who need it. Similarly, if a patient doesn't have the right coverage or isn't on a certain type of federal health plan, does that mean they deserve less effective care? Taking away services that would improve daily outcomes and quality of life would be a violation of beneficence. The converging issues of the Perfect Storm are not going to improve outcomes or create more benefits for elderly Americans unless changes are made to meet those needs.

Lastly, and distinct from Beauchamp and Childress's ethical principles, is a moral argument from the Universal Declaration of Human Rights (UDHR). One article in particular relates to the Perfect Storm because it mentions having a right to healthcare and quality standards of living. Article 25 of the UDHR states:

> Everyone has the right to a standard of living adequate for the health and well-being of [them]self and of [their] family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond [their] control.[99]

With the UDHR highlighting that a standard of living adequate for health and well-being is a basic human right, one may argue that the denial of eldercare options in the future does not align with this. If the federal programs in place simply cannot provide enough care and some

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[97] Chris Gastmans, Paul Schotsmans, and Bernadette Dierckx de Casterle, "Nursing Considered as Moral Practice: A Philosophical-Ethical Interpretation of Nursing" *Kennedy Institute of Ethics Journal* 8, no. 1 (1998): pp. 43-69.
[99] "Universal Declaration of Human Rights" United Nations, n.d.

elderly individuals slip through the cracks, they are not able to enjoy a basic human right. It is important to acknowledge that the general infrastructure and privileges that the United States does have in comparison to lower and middle-income countries are much more robust, and to classify the predicament outlined in this paper as a human rights violation would be extreme. However, the point in highlighting the UDHR is to show that a standard of living and healthcare has been laid out for all people in the world to claim, and in the context of the United States' aging population, actions need to be made to accommodate these rights within American society. There are groups of aging adults that will not have access to care and services that they need due to being denied long-term care coverage or because the current system is overwhelmed with need and can't provide an adequate level of care. With many ethical and moral issues circulating the Perfect Storm one thing is made clear, actions must be made to create changes to these impending societal issues.

Suggestions for Tackling the Perfect Storm

Although the purpose of this paper is not to suggest a specific policy response to these issues, here are a few suggestions for mitigating the Perfect Storm. Possible pathways could include strengthening the consent process for DTC genetic testing. This suggestion is specific to DTC testing because there is no genetic counselor or healthcare provider going through a consent process about the risks and benefits like a clinical genetic test would. This is not to say that all DTC companies are the same, each company has its own unique consent process.[100] Some are more thorough than others in consenting and educating potential consumers, and many companies have modified their consent processes over time.[101] The general format of clickwrap agreements, which are used in varying forms by different companies, are not comprehensive enough and do not highlight the risks and benefits clearly.[102] Society today encounters so many clickwrap agreements whether on social media or the internet, so the knee-jerk response of many would be to click 'agree' without fully reading the terms. This response is dangerous in

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[100] Eline M Bunnik, A Cecile Janssens, and Maartje H Schermer, "A Tiered-Layered-Staged Model for Informed Consent in Personal Genome Testing" *European Journal of Human Genetics* 21, no. 6 (2012): pp. 596-601.

[101] Ibid.

[102] Ibid.

the DTC genetic testing context because there isn't enough space for acknowledgment of risks. It is particularly high-risk among elderly populations who may have less computer literacy or are intimidated by technological aspects of the DTC process. Having a consent process that clearly highlights the risks and benefits of the test should be standard for all DTC companies. The limits of GINA would be important to emphasize, as well as the risk of genetic discrimination the consumer may encounter in various spaces.

Another viable pathway would be to strengthen and expand GINA to include areas where genetic discrimination is known to happen, like in long-term care insurance. Some individual states have state-level legislation, such as California's CalGINA, that prohibit genetic discrimination in a broader range of areas including long-term care and life insurance, education, housing, and mortgage lending in addition to health insurance and employment.[103] Drawing from state legislation such as the CalGINA could be a useful guide for expanding protections at the federal level. Currently, each state has its own legislation regarding genetic discrimination, but it varies widely. The CalGINA extends some of the most comprehensive protections in the US, but a state like Maryland has nothing more to add to its legislation than what GINA outlines, and only mentions health insurance and employment protections.[104] The option of expanding GINA to protect against genetic discrimination in long-term care insurance spaces would be an opportunity to brace against the Perfect Storm.

Lastly, the US needs to increase long-term care options. Our population is aging and we don't live in a society where it's common to care for our elders in a family setting. Because of this, we have federal systems in place that allow older adults to get the care they need. The issue is that a large number of aging people rely on this system and if it is not working properly, or if it gets overwhelmed with the number of people it can take on, then the mass of people who rely on it are stranded with no alternatives. To appropriately combat this issue, expansion of long-term care and availability of more care choices could make a huge difference for elderly adults.

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[103] "Genome Statute and Legislation Database,"National Human Genome Research Institute, (2020).
[104] Ibid.

Conclusion

The aging population has an increased need for long-term care because they are living longer, and diseases of aging are becoming more prominent. Our cultural norms are such that eldercare is outsourced and not done within a household or by family members. The increased use of DTC genetic testing is allowing Americans to learn more about their genetic risk of developing certain diseases of aging and about their health as a whole. The information gained from these tests poses an increased risk of genetic discrimination because there currently aren't adequate legislative protections in place for these test results. The gaps in GINA allow some types of companies to be selective of their consumers without consequences. Long-term care insurance companies are one of the entities excluded from GINA, so their coverage practices allow for discrimination. Genetic risk for developing a disease of aging can impact someone's ability to get long-term care insurance. Since long-term care insurance companies are able to discriminate on who to cover, there will be more people in need of long-term care coverage than those who are actually able to get it. These three factors are approaching a breaking point where all won't be able to be sustained. Adjustments will be critical in the coming years.

Although this Perfect Storm isn't about fishermen at sea encountering the convergence of violent weather, the current issues highlighted regarding an increased need for long-term care, increased use of DTC genetic testing, and a heightened threat of genetic discrimination, may just have a catastrophic result of an even larger magnitude if no actions are taken to deal with America's impending Perfect Storm.

"Meteorologists see perfect in strange things, and the meshing of three completely independent weather systems to form a hundred-year event is one of them. My God…this is the perfect storm".[105]

- Sebastian Junger, The Perfect Storm: A True Story of Men Against the Sea

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[105] Sebastian Junger, *The Perfect Storm: A True Story of Man against the Sea* (London: Harper Perennial, 2010).

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