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An Ethics of Care Approach to Managing the Burden of Alzheimer's Disease

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AN ETHICS OF CARE APPROACH

TO MANAGING THE BURDEN OF ALZHEIMER'S DISEASE

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By

Carrie L. Stott

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ABSTRACT

AN ETHICS OF CARE APPROACH

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Dissertation supervised by Gerard Magill, PhD

Alzheimer's disease is a progressive, neurodegenerative disease for which there is currently no cure or effective treatments. The disease has devastating effects on the individuals whom it strikes and because its prevalence continues to rise, it significantly threatens the public good. Throughout its lengthy duration from diagnosis to death there are numerous ethical issues concerning patients individually as well as society generally. The management of the burdens of Alzheimer's disease presents a formidable ethical challenge from the perspective of patients and society. The ethics of care is adopted to address this problem because of its flexibility to integrate personal care needs with public good. An ethics of care approach can facilitate effective management of the burden of Alzheimer's disease when its two components, relational autonomy and social responsibility, are integrated and analyzed.

From the earliest stages to the most severe stages of Alzheimer's disease the ethics of care can help to incorporate personal care and the public good, providing high-quality care while enhancing public wellbeing. The ethics of care is attentive to the need to engage clinical ethics with organizational ethics for the proper management of the disease. From the perspective of clinical ethics, relational autonomy and social responsibility can address the ethical issues related to diagnosis in early stages to management in severe stages. From the perspective of organizational ethics, the focus upon relational autonomy highlights the organizational components underlying quality of care, and the focus on social responsibility highlights the need to control costs and improve access to care. The ethics of care approach combines clinical and organizational ethics to manage the burden of Alzheimer's disease in a manner that unites personal care and the public good in a sustainable and effective manner.

DEDICATION

To my husband Kyle, for turning my visions into reality. Your persistence and perseverance have made so many of my dreams come true. I am forever grateful for you.

To my children Ethan and Lucianna, for allowing my adventure into healthcare ethics to also be your adventure. You both make the world a better, brighter place.

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Chapter One: Introduction

Alzheimer's disease (AD) is a progressive, neurodegenerative disease for which there is currently no cure or effective treatments. The disease has devastating effects on the individuals whom it strikes and because its prevalence continues to rise, it significantly threatens the public good. Throughout its lengthy duration from diagnosis to death there are numerous ethical issues concerning patients individually as well as society generally. The management of the burdens of Alzheimer's disease presents a formidable ethical challenge from the perspective of patients and society. The ethics of care is adopted to address this problem because of its flexibility to integrate personal care needs with public good. The thesis of the dissertation is that an ethics of care approach can facilitate effective management of the burden of Alzheimer's disease. The ethics of care has two integrated components that are relevant for the analysis: relational autonomy and social responsibility.

From the earliest stages to the most severe stages of AD the ethics of care can help to integrate personal care and the public good, providing high-quality care while enhancing public wellbeing. The ethics of care is attentive to the need to engage clinical ethics with organizational ethics for the proper management of the disease. From the perspective of clinical ethics, relational autonomy and social responsibility can address the ethical issues related to diagnosis in early stages to management in severe stages. From the perspective of organizational ethics, the focus upon relational autonomy highlights the organizational components underlying quality of care, and the focus on social responsibility highlights the need to control costs and improve access to care. The ethics of care approach combines clinical and organizational ethics to manage the burden of AD in a manner that integrates personal care and the public good in a sustainable and effective manner.

It was in 1906 when Alois Alzheimer discovered a biological link to a seemingly psychological problem that was sporadically noticed in older adults. This condition became known as Alzheimer's disease.[1] Today, over a century later, AD continues to affect people worldwide and its prevalence has grown to epidemic proportions. On a personal level the disease robs people of their autonomy and independence, causing the cognition and behaviors of adults to revert back to those expected of children and infants. The disease does not progress quickly and its affects ultimately require those inflicted to be cared for around the clock. Anyone advancing in age is at risk for the disease. AD is extremely costly and places great financial burden on micro, meso and macro levels of society; patients, their family members and caregivers, and the healthcare system at large.[2] The disease is unique in that it occurs gradually over a long period of time where the individual losses the capacity for autonomy making personal care a main concern. The large number of people with the disease, the high cost of care and lack of medical treatment or cure has put public good at risk. From a bioethics perspective a unique approach to the management of this disease needs to be developed to lessen the burden and to ensure better care for individuals and society.

Ethical consideration has been given to different aspects of the disease but there is not a lot of literature addressing how to ethically manage the overall burden of this disease outside of medical treatment. The ethics of care is a modern moral theory that differs from traditional moral theories. One of the main differences is its views on autonomy and social responsibility. The framework of the ethics of care is being used in various ways to address issues in modern society. Although it has not been highly utilized in direct application with disease management as of yet, the ethics of care offers a framework that has the potential to readdress how the stages

of AD and organizational ethics are managed to ensure better outcomes on the personal and societal levels.

There is a great deal of literature supporting the assertion that AD is a growing burden that is negatively impacting patients, families and society at large as well as a federally supported action plan to address the far stretching burden has been put into place by the United States government. The country's current medical model is highly focused on developing an effective medication to cure, slow or delay the onset of its most debilitating symptom, dementia. While such a medical advancement would offer remarkable improvements to those affected by the disease, this has yet to be successful and the burden has continued to grow creating multiple problems affecting personal care and public good. In 2011 the United States government, in a bipartisan effort, enacted into the law the National Alzheimer's Project Act (NAPA) to address the rising burden of AD. NAPA will be carried out through the National Plan to Address Alzheimer's Disease. The Plan has five foundational goals; to prevent and effectively treat AD by 2025, to enhance care, quality and efficiency, to expand supports for people with AD and their families, to enhance public awareness and engagement and, to track progress and drive improvement.[3] A normative approach that seeks to address the National Plan will be adopted throughout this dissertation. Specifically, the dissertation thesis is that the ethics of care approach will facilitate effective management of the burden of AD. Although this method will be focused on care within the United States healthcare system, its use will likely be applicable to other nations as well.

I.   The Burden of Alzheimer's Disease

In chapter two the burden of AD will be explored. Since its recognition as a pathological disease it has become clear that while the biggest risk to developing AD is aging, AD is not the normal result of aging.[4] Despite countless research studies, what has not become clear are many other aspects of AD such as; its causation, its cure, an effective treatment, how to slow its progression or how to delay its onset.[5] While so many aspects of AD remain uncertain, the incidence and prevalence of the disease continues to rise significantly as does its negative impact on individuals and society.[6] According to the Alzheimer's Association, today 5.2 million Americans are known to have AD. Ninety six percent of these people are over 65 years old. Women over the age of 65 have a 20% likelihood of developing AD and men in the same age category have a 17% likelihood. The prevalence is predicted to grow to 7.1 million by 2025 and to over 13 million by 2050.[7] The progression of this disease is one which occurs over a long period of time, often a decade or more, altering the adults it strikes from independent members of society to people completely dependent on care for all activities of daily living.[8] The costs associated with the disease are astronomical. Estimates indicate that approximately two billion, US dollars were spent in 2010 on dementia care.[9] A new approach to treatment is necessary to accommodate the growing needs of individuals with AD as well as for the good of the public. To set the foundation for establishing a unique approach to its treatment based on care ethics, the correlation between mild and severe AD needs to be explored as does the need to develop organizational ethics to integrate personal care and public good into the healthcare system.

A. The Correlation between Mild and Severe Alzheimer's Disease

Over the years, several staging frameworks haven been devised to explain the various periods of decline typical to the AD experience. The most recent stages, derived in 2011, are;

preclinical AD, mild cognitive impairment (MCI) due to AD, and dementia due to AD.[10] The

course of AD covers a large spectrum of cognition and physical ability, from independence to

complete care dependence.[11] At the mild end of the disease, effected persons can express their

desires for care, at the severe end of the disease this is no longer possible. For this reason, it is

vital to embrace the mild stage in order to ensure the person with the disease receives the care

they want well after their ability to express their desires have been wiped away by the disease's

progression onto the severe stages.[12]

i.   The Mild Stages of Alzheimer's Disease

The preclinical stage is the earliest and mildest of stages. Only biomarkers are present to

indicate potential AD. No clinical symptomology is yet evident and without biomarker testing

most people would not be aware they possess the physiological potential to develop symptoms of

AD.[13] The stage referred to as MCI is characterized by evident symptoms of memory loss and

cognitive impairment but neither are severe enough to impact the overall daily functioning of the

individual experiencing them.[14] With MCI people are still able to function autonomously.

While both the preclinical and MCI stages can be associated with mild AD, it is imperative to

understand that neither of the first two stages ensures that an individual will progress to the more

moderate or severe stage of dementia due to AD.[15]

ii.   The Severe Stages of Alzheimer's Disease

When people are in the stage of dementia due to AD the disease has progressed from

mild symptomology to symptoms of a more moderate to severe degree. These moderate to

severe symptoms impact a person's abilities to function independently.[16] At the onset of the

dementia stage of AD, symptoms are moderate. People require some degree of assistance with

areas of daily living that include, but are not limited to, meal preparation, bathing and dressing.

At this time supervision may be required to ensure the person's safety. The person may be alert but only oriented to a certain degree.[17] As this stage progresses to advanced dementia, symptoms become more severe, depriving people of their autonomy as they eventually require complete care.[18] During this time symptoms are so severe that complete assistance is necessary for all areas of daily living including feeding, toileting and mobility. Increased amounts of supervision are also necessary as cognition will become so compromised that people may be alert but not oriented to any degree.[19]

B. Developing Organizational Ethics to Integrate Personal Care with Public Good

The promising news for the Alzheimer's population is that there are non-medical forms of treatments and services that show great potential to effectively improve quality-of-life and prolong the preclinical and mild period of the disease process.[20] However, the current model of American healthcare prevents these avenues from being routinely offered and well promoted to all whom may benefit. The American healthcare system is based upon a treatment and cure model of care. In this model people seeking care are most often prescribed medications or directed to surgery to cure or alleviate ailments.[21] Healthcare providers are reimbursed by Medicare, and other insurance providers based upon such services. Unlike patients with treatable conditions, people with AD bring little financial return.[22] This is because, in the current case of AD, there is no cure or effective treatment in the form of medication or surgery.[23] Proper diagnosis, care of AD patients and support to their caregivers has proven to be insufficient, time consuming and costly to the current primary care structure of American medicine.[24] The few specialist who focus their practice on AD do so in a fragmented system.[25] Organizational ethics can be developed to improve quality of life and enhance public wellbeing pertaining to AD.

i.   Improving Quality of Life

Organizational ethics has struggled to combine quality healthcare with care which is affordable and profitable since managed care was introduced to the healthcare system.[26] A restructuring of the current organizational model to address the needs of the Alzheimer population may better ensure patients with AD are provided appropriate care to extend a desirable quality of life, for as long as possible while also meeting the public's best interest with cost control and disease prevention.[27] This is not to imply that research efforts to find medical cures and treatments to AD should cease. The implication is that until such medications are found, or for the population who may not respond to future curative or treatment medications, a different approach will be beneficial. For people in the mild stages of AD this new organizational approach will facilitate improved care to make use of this time where autonomy still exists. Regular use of cognitive exercises, proper diet and exercise, among other factors increase the likelihood that cognitive and physical decline will be delayed.[28] This time is also crucial to plan for care when decline does occurs.[29] For people in the more severe stages of AD, changes in organizational approaches to AD will embrace care plans that promote dignity at end of life and provide support to families and caregivers.[30] Care ethics recognizes a unique perspective on autonomy and responsibility which may effectively incorporate improved approaches to quality-of- life improvements when its framework is used to establish organizational ethics.

ii.   Enhancing Public Wellbeing

Organizational changes will also enhance public wellbeing as it confronts the growing burden of AD. The vast prevalence of AD makes it a concern for public health. Organizations whose missions focus not only on curative measures of treatable illnesses, but also on

preventative aspects of chronic disease will help to lessen the public burden of AD.[31] It has been suggested that if the onset of AD can be delayed by just 5 years the prevalence of AD will be lessened by 50%.[32] If preventative measures are regularly promoted by healthcare organizations the onset of AD may be delayed.[33] Unfortunately such measures are not part of the current medical model of care. It is imperative that a new model, less focused on the use of expensive medical technologies and ineffective drug treatments be derived to lessen the public burden of AD.[34] The cost savings associated with delaying onset of AD would greatly impact healthcare spending which is a problem for America at large.[35]

AD has become an increasing burden over the past century. The disease steals older people's abilities to be autonomous. The inability for autonomy creates a need for care that demands much time, effort and financial support for those who will assume the caregiving role as well as the healthcare system. The burden of AD has been recognized by the United States government and a call to action is underway.[36] While the search for a cure and effective medical treatments for the disease should continue, a new approach to management of the disease is necessary to improve personal care and public good. The disease occurs over a spectrum of cognition, from full cognitive capacity to a complete lack of cognition. Patients experiencing the milder end of the disease spectrum are urged to utilize their autonomy to clarify their desires for care when autonomous action can no longer occur. Healthcare organizations can have a positive impact on disease management by reengineering their approach to the unique needs brought about by the Alzheimer's burden.[37] A revised organizational approach will not only enhance personal care for the Alzheimer's population but enhance the greater good of the public, which is greatly at risk of bearing the burden of AD. Ultimately, the analysis in chapter two will combine clinical ethics and organizational ethics to integrate personal care with public good.

II.   Systematic Analysis of the Ethics of Care for Alzheimer's Disease

The ethics of care is a theory which provides an effective framework to facilitate the task of managing the burden of AD by integrating relational autonomy and social responsibility. A systematic analysis of the ethics of care for AD will occur in chapter three. The ethics of care, or care ethics, is a moral theory which is based on the notion that the value and practice of caring relationships are the basis for human nature and human flourishing because all human beings are interconnected and dependent on one another and society for survival.[38] Development of the ethics of care began only recently, over the past few decades, making it one of the newer approaches to normative moral theory. Its development was conceived in the rise of feminist philosophy when the typical roles of women as nurtures and caretakers were for the first time being established as important and equal to the typical role of men in power, politics and economics.[39] What began as a theory to explain the importance of caretaking roles within the private spheres of home and family life has proven enough moral significance and implication to be expanded to less private spheres such as politics, economics and international relations.[40] This modern theory is different from traditional moral theories because it is not primarily based on personal rights and reason.[41] Rather, the ethics of care focuses on the importance of care between people and among communities.[42] Subsequently, care ethics has been used to suggest better methods of caring for people with physical disabilities.[43] It has also been suggested as alternative framework to curative care for an approach to better managing chronic illness.[44] The ethics of care also offers great potential as a framework to better manage the unique needs of AD. The two major components of the ethics of care; relational autonomy and social responsibility, better illustrate its significance to the management of AD.

A. Relational Autonomy

Autonomy is a very influential aspect of bioethics and has been claimed to be one of its main elements. Traditional models of autonomy derive from rights-based theories and assert that people are independent beings capable of making decisions for themselves without outside influence.[45] This model of autonomy is incompatible for those facing AD, especially those who will progress from early stages of the disease to the moderate to severe stages. The ethics of care offers a different model of autonomy in which the tendency for interconnection between people is recognized. The capacity for individual autonomy is not completely rejected by care ethics but relational interactions between people are viewed as more predominant in human nature than are independent actions.[46] Thus relational autonomy is the first major component of care ethics. The interdependence of people and a concept of universal vulnerability are key to understanding relational autonomy.

i. Interdependence

As one of its preliminary assertions, the ethics of care emphasizes that the human species would not survive without care. The classic example used to reinforce this premise is that infants would not survive infancy without the care of another human being. With care, most infants are able to grow into autonomous people. Despite the capacity for independence, care is still necessary at times throughout the lifecycle.[47] The inescapable, universal need for care has prompted care ethicists to foster a concept of autonomy which is based on the interdependence of people rather than a concept which views people as primarily independent individuals only entering into relationships voluntarily.[48] When the interdependence of people is embraced, moral emotions such as empathy and sensitivity are respected and a context of trust and mutual responsiveness is evoked.[49] Value is placed upon emotions because they result naturally from

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interdependent relationships.[50] Trust is essential to interdependence to ensure relationships are healthy and beneficial.[51] Although strong emphasis is placed on interdependency, care ethics never promotes relationships of harm or violence.[52]

ii.   Vulnerability

Human vulnerability is a concept commonly addressed in the area of bioethics but the field has been criticized for not articulately developing its meaning. Traditional approaches to bioethics have categorized people into groups that tend to be vulnerable; i.e. the poor, racial minorities or prisoners, and cautioned for careful attention to the avoidance of exploitation to such groups.[53] Within the ethics of care, a more broad explanation of vulnerability has been developed recognizing that all people are prone to vulnerability regardless of their capacity for independence. While some factors, such as those just mentioned, make people more prone to harm and exploitation, all people will experience some degree of vulnerability.[54] Vulnerability is a mere part of possessing human mortality and from this notion the ethics of care has embraced a unique concept of vulnerability that encompasses all people.[55] When vulnerability is viewed as universal, perspectives pertaining to equality and the value of care work change. Because relationships are not always between people with equal abilities, care ethics aims to promote fairness among unequals.[56] The value of care work, which has historically been under recognized, is acknowledged from this perspective of vulnerability.[57]

B. Social Responsibility

The second major component of the ethics of care, social responsibility, is based on the premise that society would not survive without the extension of the value and practice of care to its members.[58] For societies to be moral they must ensure adequate, basic provisions of care are available to their citizens. While this is not the only moral obligation of societies, it is an

essential obligation.[59] Care ethics establishes that care is the basis of a just society thus contradicting other moral theories that claim justice is the foundational element of a moral society. The ethics of care promotes a larger framework of care for societies within which rights have a place.[60] Care becomes the foundational value of society because without care, there would be no people to form societies and thus justice would be an unnecessary value.[61] Because so many people are, or will become, affected by AD either as patients, caregivers or eventually both, AD is an issue worthy of social concern. Social responsibility is essential in today's culture where the practice of care has expanded beyond the private boundaries of home. Care is the basis of the ethics of care but justice is still valued and incorporated into its framework.[62]

i.   **The Expanding Practice of Care**

In the past the practice of care tended to take place privately, at home and between family members. The structure of care in today's modern society however has eliminated much of the partition between private and public life. Care is sought not just at home by family members but in the community through paid services such as child care and elder care.[63] Either because of this shift or as a result, care and associated care work have become a major part of today's market economy.[64] Care providers are thus often strangers to those to whom they provide care rather than a loved one with a personal interest in their welfare. This does not change the fact that people still desire quality care. Society has an obligation to ensure these desires are met based on the interrelatedness and dependency of all people on care.[65] The expansion of care has even prompted prominent scholars such as Virginia Held, Joan Tronto and Fiona Robinson, to assert the relevance of care ethics on society's global level.[66] Social responsibility for the care of the ill and elderly in the United States has been highly criticized. Potential for improvements

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have been suggested to involve meeting more than just health and safety guidelines by emphasizing moral components of care.[67]

ii.   Care and Justice

Traditional moral theories, such as Kantian and utilitarian theories, focus on justice as the larger framework for morality because their view of human nature revolves around a concept of the independent and rational individual.[68] Because of the major contrast between these traditional perspectives of human nature and that of the contemporary care ethics perspective, it was originally presumed that justice and care were to be contained in different realms of society.[69] Recently, as care ethics has become more firmly established, this notion is rejected and justice is now seen as a necessary constituent of care.[70] Care is the larger framework within which justice should be considered because care is always necessary for the advancement of society while justice, although essential to maintain order and equity, is not needed by all people.[71] When justice is appropriately incorporated into the framework of care, it becomes clear that care should not become a commodity because it is a basic need for people and societies.[72] Trust and mutual consideration between people is built when care is the larger focus.[73] The focus on care works to reduce or eliminate hierarchies of power so they do not influence how and to whom care is provided.[74]

When explored systematically, the ethics of care creates a framework for morality based on relational autonomy and social responsibility. These two main components of care ethics have great potential to effectively be applied to the burden of AD. One of the first concerns to arise in a new diagnosis of AD pertain to loss of autonomy and the impending vulnerability created by the need to rely on others.[75] Relational autonomy refocuses the notion of autonomy and of vulnerability through its emphasis on interdependency. Social responsibility works to

protect societies from vulnerability by recognizing and accepting responsibility for the practice

of care which is no longer only a private matter. This is especially evident in the presence of AD

where patients and caregivers need public collaboration for various long-term and supportive

services.[76] Although care is the most essential element to morality, social responsibility still

embraces aspects of justice to ensure care is not commodified and relationships of power are

refocused.[77] These aspects are important to ensuring the AD population have access to the care

they need and are not marginalized by those providing their care. Together these elements create

a care ethics framework that should be applied to various aspects of AD.

III.   The Ethics of Care during the Mild Stages of Alzheimer's Disease

In chapter four the utility of care ethics during the mild stages of AD will be established.

The field of neuroethics examines how advances in neuroscience impact bioethics from

theoretical, empirical, policy and practical perspectives. Among the goals of neuroethics are to

examine how neuroscience; impacts notions of self, agency and responsibility, can advance

clinical practice and can be can adequately understood by the public. [78] Neuroethics has been

pertinent to AD throughout its history especially related to the concept of diagnosis disclosure.

For much of the disease's past, early diagnosis of AD was not possible.[79] People were most

often diagnosed as likely to have AD when they exhibited symptoms associated with dementia.

The disclosure of the diagnosis was an ethical area of controversy because of inadequate

diagnostics, lack of treatment options and the decreased capacity of the patient for understanding

due to the presence of dementia related symptoms.[80] Since the turn of the twenty-first century,

advancements in neuroimaging technologies have allowed for the detection of physiological

indicators, biomarkers, of AD. This has enabled more precise and reliable diagnosis of AD in

patients with moderate to severe symptomatic dementia.[81] These advances have also made it possible to detect AD in its preclinical stage, prior to symptom onset, or during the early stage of MCI. The ability to make such a diagnosis in the disease's prodromal period has signified an increased need for neuroethical consideration in the early diagnosis of AD.[82] Within a framework of care, the mild stages of AD should be embraced and utilized to ensure positive impact on personal considerations and public good despite the potential for progressing to advanced dementia.

A. Relational Autonomy: the Impact of Early Diagnosis for Patient Care

There is currently ethical controversy surrounding the disclosure of an Alzheimer's diagnosis during the prodromal period based on how it may impact patient care. Preclinical awareness of AD is currently only utilized for research purposes and thus there is not an obligation to disclose the presence of positive biomarker indicators of AD to individual participants.   MCI due to AD does currently have both clinical and research applications.[83] The current lack of effectiveness in treatment options and the uncertainty about whether MCI will in fact advance to dementia however often makes physicians hesitant towards early disclosure.[84] Unlike disclosure in the dementia stage of AD, disclosure in the prodromal phases takes place when competency is still intact and has not been compromised by the advanced symptomology of the disease.[85] Competency is a vital aspect of consideration in bioethics and is a requirement for ethical decision making.[86] When biomarkers reveal the presence of AD, patients and caregivers can prepare for their future but it must be clear that the potential for advancing to later stages of AD is less than 100% even when biomarkers are present.[87]   In addition to research potential, early diagnosis reinforces that medical models ought to include psycho-social considerations and allows more time for preserving quality-of-life.

Refocusing Medicalization to Include Psycho-Social Considerations

The contemporary goals of medicine, as established by the Hastings Center in 1996, include goals pertaining to cure, treatment and care. The goals clearly focus on the aspects of both cure and care, not separating one from the other although cure tends to be the more common focus of today's healthcare systems. Physicians and patients alike tend to place more emphasis on efforts to cure, or at least prevent, mortality for as long as possible.[88] This may explain why until only recently approaches to AD have focused heavily on the biomedical model which seeks pharmaceutical interventions to treat visible symptoms. Such approaches are negatively focused, placing emphasis on dysfunction and limited abilities. The alternative, bio-psycho-social approaches, are gaining attention because they are more positively focused on people's abilities by considering more than evident symptoms of the disease but rather intact aspects of personhood and self and how such aspects can improve care for those with AD.[89] Such approaches provide clarity that there is not extreme dualism between mind and body thus reinforcing the need for psycho-social considerations to coexist with biological considerations in AD research and clinical management.[90] Earlier diagnosis allows for more detailed research into aspects of AD related to personhood and identity based on first hand narrative accounts from people living with AD. Until recently, the dominant methods of understanding experiences of people with AD have been typically based on the second hand accounts of caregivers.[91] While understanding caregiver perspectives is necessary, firsthand accounts of how AD is experienced leads to unique understanding of coping strategies and how wellbeing ought to be augmented.[92] Ultimately psycho-social considerations will enable better care planning for later stages of the disease.[93]

ii.   **Preserving Quality-of-Life**

A common fear associated with the notion of early disclosure is that competent people who receive the information that they possess an increased chance of progressing onto the later stages of a disease that potentially destroys personal identity will be more at risk for anxiety, depression or suicidal ideation.[94] The REVEAL study (Risk Evaluation and Education for AD), conducted from 2004-2006, indicated that the disclosure of a genetic susceptibility to AD did not produce adverse psychological outcomes.[95] Other studies recognize a low, but not likely, risk of suicidal ideation resultant from a diagnosis of dementia and thus infer that preclinical and early diagnosis of AD may expand this risk.[96] The low risk of adverse psychological reactions to an early diagnosis of AD are outweighed by other factors that show potential to improve quality-of-life when early diagnosis is disclosed. In many instances when people fear AD due to a family history or the onset of symptoms of MCI, diagnostic confirmation provides relief of anxiety when biomarker testing either confirms or denies the presence of Alzheimer pathology.[97] Additionally, there is benefit for early disclosure for the family members of the diagnosed in that they can begin the transition into the informal caregiver role. With adequate time to prepare for this role, informal caregivers will experience less burden which can negatively impact their own quality-of-life.[98] The phenomena of cognitive reserve also shows evidence that lifestyle choices and activities may have a beneficial impact on prolonging the onset of symptoms of AD even when pathology is evident in the body.[99]

B. **Social Responsibility: Benefits of Early Diagnosis for the Public Good**

In 2005, the United Nations Educational, Scientific and Cultural Organization (UNESCO) published its Universal Declaration on Bioethics and Human Rights which established the first set of internationally recognized, morally binding principles that link

bioethics and human rights.[100] The Declaration introduced "social responsibility and health" as a new guiding principle with a wide scope making health not just an individual responsibility but the responsibility of governments and all other sectors of society.[101] Based upon solidarity, these societal obligations are aimed at promoting health, access to healthcare and reduction of factors that negatively impact health.[102] On a national level, the US government reinforced the importance of social responsibility and health when it approved the National Alzheimer's Project Act and set into motion the National Plan to Address Alzheimer's. The Plan recognizes the importance of early diagnosis as offering significant potential to identify strategies or treatments that may interrupt disease progression.[103] Social responsibility is upheld through early diagnosis when it is used to expand research efforts and reduce the stigma associated with the disease as both are ways to promote health and reduce negativity.

i.   Expanding Research Initiatives

For the past several decades research efforts have been unproductive in establishing a cure, prevention or effective treatments to managing AD. Today, researchers are becoming more hopeful that the key to such discoveries may be in interventions that occur in the prodromal phase of the disease.[104] Both pharmaceutical and non-pharmacological trials have been required by the Plan in effort to discover new interventions that offer hope in cure, prevention or treatment of symptomatic AD when administered in the early disease stage.[105] This push by the government for accelerated pharmacological research was reinforced when ten big pharma companies agreed to work in collaboration in these efforts.[106] Some believe that trials to determine the effectiveness on non-pharmaceutical interventions, such as reducing risk factors through diet and lifestyle modification, may show promise to prevent or prolong the onset of dementia due to AD.[107] Recruitment of participants in the prodromal stages of AD is an obstacle

for such trials.[108] Once established, research trials pose ethical risks that need to be considered

cautiously when participants are those who are vulnerable based on their potential for

development of later stages of AD. Specifically, the informed consent process and the potential

for therapeutic misconception require careful consideration.[109] When a more patient-centered

model of trial recruitment and informed consent are used in research efforts, obstacles and risks

posed by clinical research may be lessened.[110]

ii.   Reducing Stigmatization

AD is a well-known condition to most of the American public however, misconceptions

about the disease are widespread thus warranting better public education.[111] Misconceptions

about AD has led to stigmatization that negatively affects both patients and caregivers, especially

those in the early stages of the disease.[112] Stigma is a negative attribute placed upon people

which leads them to be viewed as less valuable than those without an associated stigma. Stigma

associated with AD is commonly linked to the moderate to severe stages of the disease when

devastating symptoms are evident resulting in compromised competency and moral agency.

There is lack of understanding among the general public about the scope and span of AD and the

autonomy that is still possessed by those with preclinical AD or MCI.[113] This misunderstanding

leads to problems for those diagnosed with early AD as well as their family members who may

likely become their future informal caregivers. Among the potential issues are misuse of clinical

information for insurance or employment purposes. Policy and legal protections may be

necessary and are ethically merited to protect the rights and privacy of the early diagnosed.[114]

Public health initiatives, such as The Healthy Brain Initiative, act to increase public awareness

about the stages of AD.[115] Such initiatives if carried out properly will provide promise to reduce

the stigma associated with early diagnosis of AD resulting in societal benefits.

The ability to detect AD in its earliest and mildest stages has become possible since the turn of the 21st century as the result of advances in neuroimaging and genetic technologies.[116] Early diagnosis has raised various ethical concerns and disclosure continues to be inconsistent among medical providers. Concerns surrounding disclosure usually involve compromising personal wellbeing when advancement of the disease is not certain to occur.[117] Early diagnosis of AD however offers various benefits for both patients and the public. When relational autonomy is embraced, psycho-social considerations are incorporated into the medical approach to care resulting in a more positive focus on personal care for patients' present and potential future needs. Personal benefit may also occur from early diagnosis as various lifestyle options show promise that quality-of-life will be maintained for longer lengths of time when incorporated into regular routines.[118] Public good is enhanced when research initiatives are expanded to include participants in the prodromal or early stages of the disease because it is now believed to provide a more optimal opportunity for discovering effective treatment or prevention modalities and/or pharmaceutical interventions.[119] The public will also benefit from better understanding of AD to reduce stigma through the realization that the disease spans a varying degree of competency levels, and physical as well as mental abilities.

IV.   The Ethics of Care during the Severe Stages of Alzheimer's Disease

Death and dying have changed dramatically over the past few centuries. What was once an event that primarily occurred privately and peacefully within the home, in which little could be done to control or prevent its occurrence is today less private, less peaceful, and often times more controllable.[120] As a result of advancements in science and technology since the mid-twentieth century, people now tend to die in hospitals relying on the hope that skilled physicians

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can prevent death.[121] Debates now occur about the value of compassion in medicine and that

perhaps these advances have replaced the need for a compassionate physician with the need for

only a knowledgeable physician.[122] While advancements have been remarkable at preventing

early death and extending the average life span, death remains a fact of life. The Institute of

Medicine (IOM) has recently identified that end-of-life care in this country is not optimal and

more should be done to improve it for patients, families and society at large.[123] For the large

number of people who will develop AD and progress to its severe stages death will in-fact occur

as advanced dementia is a terminal condition and is the sixth leading cause of death for

Americans.[124] Despite this inevitability, at least 16% of AD deaths occur in hospitals where

aggressive treatments tend to occur despite claims by patients' family members that their goals

of care are for comfort.[125] Chapter five will explore issues associated with how relational

autonomy may account for why this is the case and how notions of social responsibility may

indicate where improvements to care issues associated with advanced dementia at the end-of-life

ought to be made.

A. Relational Autonomy: Vulnerability during Complete Care Dependence

According to the Global Deterioration Scale (GDS) severe dementia consists of two

stages, severe cognitive decline and very severe cognitive decline. Respectively these stage are

characterized first by loss of awareness of recent events, necessity for assistance in bathing and

toileting, progressing next to an inability to speak more than a few words, inability to ambulate

and complete incontinence.[126] The latter stage, marked with the need for complete care

dependence, is also referred to as advanced dementia, a terminal condition despite difficulties in

prognostication.[127] Despite the clarity of the scale, in reality it can be difficult to identify exactly

which stage of the GDS individuals may be and with an indefinable prognosis, exactly when the

end-of-life phase begins may be difficult to define.[128] The on-set of AD may not exactly indicate

that end of life is near but the disease does promise to be present, to some degree, throughout the

remaining life span until death occurs. When AD progresses to its severe stages, enduring the

decline creates a vulnerability that captures all people who face the situation including both

patients and caregivers. Universal vulnerability tends to increase when the disease process

threatens the physical and psychological integrity of self.[129] In the severe stages of AD this

integrity is compromised increasing the importance of cohesive relational autonomy for

caregiving issues and medical decision making.

i.   **Caregiving**

Caregiving, either formal or informal, is necessary prior to the severe stages of AD but it

is in the severe stages when the needs of those with AD are most intense and demanding.[130]

Choices will be made along the trajectory of the disease regarding how one will receive the

necessary personal care as the disease progresses. Caregiving can be informal, unpaid services

provided by a close family member or friend, or formal, provided through paid services either in

the home or within long term care facilities. Regardless of the type of care selected, issues in

caretaking continue to be evident and cause for concern. Both formal and informal caregivers

are at risk for burnout and caregiver fatigue, and both are associated with exuberant costs. [131]

The burdens associated with informal caregiving has recently suggested caregivers are at risk for

vulnerability and their need for support is becoming acknowledged as a public health issue.[132]

Training about AD among formal caregivers in assisted living varies greatly among facilities and

improved training is linked to improved quality of care.[133] New models of long term care are

showing promise for the improved quality of care for people with AD but barriers still prevent

access to such forms long term care.[134] Reducing issues associated with caretaking for people

with severe AD is essential to ensuring harmony within the relationship of autonomy between patient and caregiver as well as for the overall wellbeing of both patients and caregivers.

ii.   Medical Decision Making

Medical decision making tends to be a complex process in today's healthcare system where people are required to make crucial decisions about issues they often are not trained or educated to make.[135] When advanced dementia is present the process is more complex as capacity for traditional autonomy is lost and decisions must be made by surrogate decision makers. Lost capacity for autonomy emphasizes the necessity for cohesion between patients, their healthcare agents and physicians through advanced directives. Healthcare agents and physicians however often do not carry out patient wishes. This trend is evident even in the small portion of the population who have completed advanced directives.[136] Vulnerability becomes heightened when people find themselves in moral dilemmas regarding treatment options associated with common complications of advanced dementia.[137] Such complications include; issues pertaining to nutrition and hydration, tendency for infections and increased prevalence of pneumonia. Although treatments for such complications are clinically indicated or beneficial in numerous medical conditions, they have limited to no effect on improving or prolonging the life of people with advanced dementia.[138] Physicians of all specialties and personal healthcare agents require improved education about advanced dementia to ensure treatment decisions are being made ethically and that personal and professional harm is avoided.[139]

B. Social Responsibility: Benefits of Hospice and Palliative Care for Public Good

The IOM highlighted the importance of societal responsibility at end-of-life in the introduction of its report *Dying in America* by claiming all Americans are stakeholders in ensuring and expecting the provision of adequate care at life's end.[140] The report indicates that

palliative care programs offer an effective model of care aimed at improving all aspects of care at end-of-life, though its use is not yet standard or consistent throughout the nation.[141] Palliative care is a multi-disciplinary approach to enhancing quality-of-life for people with serious or chronic illnesses appropriate for patients regardless of disease prognosis or whether or not curative or non-curative treatments are being sought. Within the US healthcare system hospice is a more specific service falling under the palliative care umbrella that offers palliative services to people who are no longer seeking curative treatments and have a disease prognosis of six months or less.[142] Because of the large and growing population in the severe stages of AD, the benefits of hospice and palliative care are experienced on both a personal and public level when provided to this population. The benefits include a multidisciplinary approach to care and reducing unnecessary hospitalizations.

i. A Multidisciplinary Approach to Care

Hospice and palliative care seeks to enhance quality-of-life during life's final stages by providing physical, social, spiritual and emotional supports through a multidisciplinary approach in collaboration with patients, their caregivers and family members. Such an approach prepares patients, caregivers and family members for the impending death as well as providing bereavement services to survivors.[143] The multidisciplinary hospice team functions to enhance quality-of-life though various tasks including; proper physical and psychological pain management, providing caregiver education and support, ensuring smooth transitions and communication between care settings, and ensuring that adequate disease management occurs through realistic goal setting and regular follow up.[144] All of these aspects when left untouched have been indicated to hamper quality-of-life in the face of progressive AD.

## ii.	Reducing Unnecessary Hospitalizations

Hospice use is shown to reduce hospitalizations in the last few months of life for people with advanced dementia. Hospitalization of patients with advanced dementia often results in poor end-of-life experiences because often there is lack of familiarity with patients, less time is taken in explaining benefits and harms in the decision making processes, and services are often fragmented resulting in the provision of care which is not in accordance with patient or surrogate wishes. For patients with advanced dementia, the majority of reasons for hospitalizations at end-of-life are avoidable.[145] Hospice and palliative care providers offer education and counseling surrounding decisions against the use of non-beneficial medical interventions and their services enable hospitalizations to be avoided when appropriate.[146] Thus, valuable and limited medical resources are savored for those who will truly reap the benefits of their use.

Adequate end-of-life care is an essential element of human morality and it has been recently identified as an area where America can afford improvements.[147] When AD progresses to its most severe stage it is undeniably a terminal condition. People with the disease are vulnerable because of their complete dependence for care and their family members are vulnerable due to issues associated with caregiving and medical decision making.   When left unaddressed, high levels of vulnerability on both ends of the caring relationship can jeopardize the effectiveness of relational autonomy.[148] The far reaching societal implications of the disease also implies risk of vulnerability for society. The notion of social responsibility in care ethics works to overcome societal vulnerabilities by promoting responsibility.[149] Responsibility for people with advanced dementia is not able to be contained only within the confines of privacy. People who are effected by advanced dementia either as patients or as caregivers or family members need the support of public goods, services and financial assistance. Medical care is

needed, long term care is essential and supportive services are necessary to get through the extended period of time this terminal condition tends to last.[150] Palliative care and hospice services can positively impact societal responsibility to those affected by advanced dementia. The ethics of care should be integrated into organizational ethics to manage AD.

V.   Integrating Ethics of Care with Organizational Ethics to Manage Alzheimer's Disease

Since the turn of the twentieth century, healthcare in America has become a major enterprise in the market economy, one which has seen great profits as well as increasingly high associated costs.[151] Healthcare is unique to other types of business because of its vast array of stakeholders and the incongruencies between consumers and payer sources.[152] Healthcare organizations (HCOs) are considered to be moral agents just as are individuals.[153]   Because HCOs are comprised of many individuals, moral direction and outcomes are often difficult to remain focused on and attain. For these reasons, organizational ethics is a new component that has recently been introduced to healthcare over the past few decades. The purpose of organizational ethics is to incorporate aspects of clinical ethics, professional ethics and business ethics into the overall operation of the organization to effectively influence issues related to quality, cost and access.[154] While various theories can be applied to organizational ethics, the ethics of care offers a relation-based approach which focuses on the particularities and complexities of relationships which are manifest within the HCO.[155] Chapter six will examine how the two may be integrated effectively. Relational autonomy ought to be emphasized to improve quality-of-care for the Alzheimer's population and social responsibility ought to be emphasized to contain costs and improve access associated with AD for the public good.

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A. Relational Autonomy: Improving Quality-of-Life for AD

Quality in healthcare has been on the decline for the past several decades in many nations across the globe.[156] In its 2001 report, *Crossing the Quality Chasm*, the IOM informed the public that the quality of America's system of healthcare was systematically flawed and in urgent need of improvements.[157] Along with declines in quality, there is has been a closely related loss of trust within healthcare. For Americans this may be attributed to various factors pertaining to the modern organization of our healthcare system including managed care's replacement of fee-for-service, the shared decision making model of the doctor-patient relationship, and the magnitude of medical errors and safety issues.[158] The Alzheimer's population may be more apt to experiencing poor quality outcomes in a primarily medicalized system that is not designed to meet the unique needs of this population.[159] Although specific breeches of trust and quality may be pinpointed to individuals, quality is a property of the organization and improvements in quality must be made on the systems level. The first step in promoting change aimed at quality improvement is in rebuilding and strengthening trust within organizational relationships.[160] The internal ethical climate of HCOs can be enhanced through considerations of relational autonomy. When considered, trust should be built between patients and professionals through patient-centered models of care. Similarly relational autonomy should be used within organizations to strengthen professional ethics to build trust and ultimately promote quality.

i.   Promoting Patient and Family-Centered Care

The role of the physician and the relationship between patient and physician has changed dramatically over time.[161] Paternalistic decisions made by physicians on behalf of their patients have for the most part been replaced by shared decision making.[162] Trust is built and

strengthened through shared decision making when communication is open and honest and when partnerships are developed between physicians and their patients.[163] A model of shared decision making that emerged in the 1980's and emphasizes a relational role between healthcare providers and patients is patient centered care.[164] Patient centered care requires that healthcare providers tailor their practice to incorporate each patients' individual needs and preferences allowing patient's values to guide the decision making process.[165] When practiced correctly, patient centered care has been shown to improve quality outcomes and patient wellbeing.[166] Quality tends to improve even more when patient and family-centered care is practiced.[167] Collaboration between all healthcare professionals, patients and their family members is reflective of care ethics in that it emphasizes the value of relational autonomy not only between the patient-family dyad but this dyad and their associated healthcare providers.[168] The resulting outcomes are positive for patient good as well as for rebuilding trust and improving quality within HCOs.

ii.   Strengthening Professional Ethics

In order for organizational missions and values to hold meaning they must be carried out efficiently by all employees. Carrying out missions and values through not only words but also actions is a central ethical obligation for the HCO.[169] Substantial emphasis has been placed on corporate compliance programs in the HCO, these mainly focus on legal and regulatory issues and have developed a negative perception by employees who view the programs as a way to police employee actions.[170] Legal issues may influence mission and value based decisions but compliance and ethics are different. Developing a positive method of promoting ethical actions among all employees so that mission and values are carried out can also be challenging. One reason is because each employee has their own individual set of morals and motives.[171] Another

reason is because of the many different types of professionals and their various roles within the organization.[172] There are methods to enhance professional ethics within HCOs.[173] One method which shows potential to improve disease specific ethical standards, especially pertaining to dementia, is the use of clinical practice guidelines (CPGs).[174] Fostering strong professional ethics in an unobstructed manner enhances the HCO's internal ethical climate by respecting the reciprocal relationship between employees and organizational leaders.[175] Uniformity may be especially beneficial to patient good when providing guidance on situations, like those associated with AD, that raise a multitude of ethical dilemmas for organizations.

B. Social Responsibility: Containing Costs and Improving Access Associated with AD for Public Good

Just as HCOs have expectations of their patients and employees, and they of the organization, communities also have expectations of HCO's. An HCO's accomplishments of meeting community expectation will determine the external ethical climate of the organization.[176] A positive external ethical climate is important to the success of the HCO and thus there is a distinct link between HCOs and social responsibility. In fact, although the role of HCOs have evolved significantly since their establishment within the country during the early 1800's, they have always assumed some degree of responsibility to society.[177] Stewardship continues to be an essential element in maintaining virtuous HCOs.[178] Today, access and cost are consistently being attributed as barriers to attaining adequate care within the current healthcare market.[179] These barriers, if not dealt with appropriately, jeopardize the external ethical climate of organizations. In the face of the growing burden of AD, the HCO ought to institute internal policies and standardize practices that are intended to promote public

good. Setting limits through medical policy and making palliative care and hospice standard practice for the treatment of AD may improve external ethical climates.

i.   Setting Limits through Medical Policy

The majority of emphasis on American medicine is placed on the market-based organization of healthcare but there is also a value based approach that gets less attention. This approach has been claimed to be necessary to ensuring the sustainability of our high cost healthcare system by focusing on values and limits of medicine that are in society's best interest.[180] The notion of futility, medical treatment that offers no benefit, has been a topic of debate in healthcare since the rise of medical technology and the evolution of complete patient autonomy.[181] Managed care companies have established general guidelines on limits of unnecessary medical care through medical necessity policies.[182] Professional organizations, such as the American Geriatric Society, have clarified their positions on appropriate end-of-life practices pertaining to advanced AD. [183] Most hospital and public policy thus far however has not established clear cut guidelines on the application of futility or establishing limits in the treatment of end-stage conditions.[184] Medical policy pertaining to such issues could be instrumental in not only cost control but value setting and ensuring transparency regarding what organizations view as best practices in caring for particular end-stage conditions.[185]

ii.   Standardizing the Use of Palliative Care and Hospice

The World Health Organization (WHO) recognizes palliative care as an appropriate form of care for anyone facing a chronic, ultimately fatal disease. The WHO emphasizes that proper palliative care is a priority for public health and encourages all nations to promote the service as appropriate for their county's particular needs.[186] In the US, hospice care is traditionally limited to patients with a life expectancy of six months or less wishing to forego curative measures. The

provision of palliative care does not have to be limited to those in the last six months of life and should be separated from hospice to encompass anyone who has a terminal or serious illness without regards to their wishes for treatment.[187] This broad-based model of palliative care, or supportive care, can be provided in conjunction with treatment efforts to improve quality-of-life through its multitude of personal benefits.[188] Both hospice and palliative care use are directly proven to decrease healthcare costs.[189] Unfortunately, there are barriers to accessing the benefits.[190] If the barriers are overcome and the use of palliative supportive and hospice care becomes standardized for use throughout the entire trajectory of AD, its course will likely be better managed resulting in public good associated with improved access to care, improved integration of a fragmented system, and cost control.

The ultimate goal of organizational ethics is to foster a virtuous organization by ensuring that stewardship and integrity are evident along with proper decision making processes and ethical behavior.[191] The multitude of dilemmas created by AD for individuals and society may jeopardize the goals of organizational ethics programs in the absence of a sound plan to best manage all aspects of the disease. An internal ethical climate may become unsound when individuals within the organization do not consistently display the organizational mission and values through their daily work.[192] Relational autonomy should be incorporated to promote a positive internal ethical climate by promoting patient and family-centered care and working to strengthen professional ethics. These aspects act to foster positive relationships between patients and providers as well as between employers and employees. An organization's ethical reputation can be threatened when society has unrealistic expectations of HCOs.[193] Social responsibility should be embraced to avoid this threat by setting limits pertaining to the treatment of AD and standardizing the use of palliative care and hospice throughout the entire disease course so that

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the organization's preferred approach to AD management is transparent to society. Together these initiatives will work together to rebuild trust by improving issues related to quality, access and cost.

In summary, an ethical approach to managing the burden of AD is essential because throughout the disease course various ethical issues are prominent. Such issues pertain to areas of clinical ethics, research ethics, neuroethics, end-of-life ethics, and organizational ethics. The ethics of care offers a unique framework to managing the burden of AD through its distinctive considerations of relational autonomy and social responsibility. Relational autonomy focuses on the interdependence of people and their susceptibility to vulnerability throughout the life span. When promoted during the mild stages of AD, focus is placed on psychosocial considerations and preserving quality-of-life which may ease burdens associated with caregiving and medical decision making common in the more advanced stages of AD. These efforts will all be reinforced when organizational ethics promote patient and family-centered care and strengthens professional ethics. Social responsibility is essential because the practice of care in today's society is no longer a private matter and the fruitful survival of society depends on care. During the mild stages of AD social responsibility promotes the expansion of research initiatives and the reduction of its associated stigma while in the advanced stages, social responsibility calls for a multidisciplinary approach to care and reducing unnecessary hospitalizations. Organizational ethics can support these efforts by establishing medical policy related to costly treatments and standardizing the use of palliative care and hospice beginning with the initial diagnosis of AD.

If new approaches to the management of AD are not constructed as our population continues to grow and age, its burden will continue to have expanding, negative impacts on individuals, organizations and society. This notion has raised enough concern that in 2011 the

US passed the National Alzheimer's Project Act and put into motion the National Plan to

Address Alzheimer's Disease, a plan especially devised to address the personal and public

burdens of the disease.[194] While the Plan does call for action associated with the discovery of

pharmaceutical treatments, it also acknowledges that other avenues of disease management are

an urgent necessity. The promotion of treatments focused on individual and community

resources rather than on medication may be the key to sustainable health systems and healthy

aging.[195] Constructing an ethics of care approach shows promise to meeting the Plan's goals and

managing the burden of AD in a sustainable manner.

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Chapter Two: The Burden of Alzheimer's Disease

To fully grasp the current burden created by Alzheimer's disease it is crucial to understand and appreciate the historical evolution of disease and the role of the doctor as well as the rise and necessity of ethics associated with modern day healthcare. The time period marked by the conclusion of World War II (WWII) in 1945 can be used as an approximate historical marker when what was once customary in medicine rapidly changed and started a new era that will hereafter be referred to as modern medicine.[1] Prior to the conclusion of WWII, most common illnesses were infectious in nature including conditions such as dysentery, influenza and small pox. These illness tended to have a rapid onset followed by either imminent death or a relatively quick and full recovery. Recovery, if it were to occur, likely happened within a few months at most and it was not common for people to experience lasting side effects or disability.[2] The same was true of those involved with accidents, because life-saving medical technology was either nonexistent or not as readily available as it is today. Life expectancy during this time period was significantly lower than it currently is and infant mortality rates much higher.[3] The average life span increased by 30 years from 1900 to 1999 and has plateaued since 2012 at 78.4 years.[4]

During earlier times doctors tended to the sick within the privacy of their patient's homes. The pioneers of medicine worked in a field that lacked formal training, had little technology, received low pay and existed without formalized medical organizations or healthcare systems for guidance or employment. Doctors were members of the community who helped their ill or injured neighbors not for financial reward but rather for the profit of a good reputation.[5] The age old Hippocratic Oath was the only existing universal standard guiding their work, its main focus was on the behavioral expectations of doctors, particularly how they ought

to serve their patients.[6] Most doctors of this time were credited with possessing the virtue of compassion, a professional virtue that consists of two important features; ability and willingness to share in the suffering of another person and a desire to alleviate that suffering or support it when alleviation is not a possibility.[7] Compassion is often associated with sympathy, a shared feeling, and empathy, the ability to understand the shared feeling, because these both contribute to the virtue.[8] Compassion uses the feeling of sympathy and the understanding of empathy to inspire action aimed at easing the suffering of another person or other non-human life forms such as an animal.[9] This professional virtue combined with an informal system of healthcare that offered very limited medical interventions enabled a paternalistic relationship between doctor and patient to be highly accepted for much of medicine's history. Paternalism at this time did not carry with it a negative connotation rather it implied a benign relationship in which doctors made decisions based on what they believed was in their patients' best interests. [10]

Chronic diseases were significantly less common, some even non-existent, during the time in history when accidents and illnesses claimed the lives of most people at a younger age. Developments in the areas of medical science and technology began occurring rapidly after WWII and since then the trajectory of infectious diseases and the course of recovery from accidents has significantly impacted life expectancy, changes to the tradition of medical ethics and the relationships between doctors, patients and healthcare systems. [11] Longer life spans have become prevalent since the rise of modern medicine. Once fatal diseases, such as dysentery and small pox, are no longer responsible for mass casualties of the young. Modern technologies have enabled for life to be sustained physiologically longer than nature alone once allowed.

The elimination, prevention and cure of traditional maladies have allowed for the rise of new diseases that are common enemies of good health and wellbeing today. [12] Diseases such as

cancer, diabetes, heart disease and dementias surfaced as people started living longer and changed many of the characteristics common in medicine prior to WWII. Today many diseases tend to be chronic, degenerative conditions which can be maintained over time. Although many have no known cures, treatments often allow people to live longer lifespans that consist of more years marked with illness and disability.[13] Because degenerative diseases tend to be chronic but not immediately terminal, other comorbidities can arise as symptoms are being treated. This has led to medically complex patients. Diseases such as Alzheimer's and conditions such as persistent vegetative state (PVS) have arisen and take away the capabilities of the mind while allowing the body to survive.[14] Other diseases such as amyotrophic lateral sclerosis (ALS) and multiple sclerosis (MS) take away the body's physical capabilities while leaving the mind to remain intact through the degenerative process.

Inevitably, the doctor's role also morphed with the evolution of modern medicine. Doctors are no longer primarily seen as compassionate neighbors working only within their local community and services are no longer predominantly provided in the privacy of patients' homes. Doctors moved their work into offices and hospitals which tend to be part of large healthcare systems. More often than not patients now come to see the doctor when care is needed. The doctor's role has become highly professionalized, technological and associated with higher social status and increased pay.[15] Claims are made that high interest in emerging technologies has replaced the virtue of compassion in many physicians today.[16] Although still bound to the Hippocratic Oath, doctors' degree of responsibility has expanded over time.[17] Doctors now specialize in specific areas of medicine, providing expertise in only one area and referring their patients to other specialists when needs in other areas arise. Practice parameters have expanded

beyond local neighborhoods and have become formalized through accrediting bodies and ethical oversight organizations such as the American Medical Association (AMA).[18]

Ethics in medicine today consists of more than the doctor's expected standards of behavior as it now entails how much and to what extent lifesaving and sustaining technologies ought to be utilized. Advancing medical technologies and the formalization of the entire medical system has impacted perspectives and practices associated with the general goals of medicine; treatment, cure and care.[19] These morally relevant and modern controversial dilemmas have taken traditional medical ethics to a new level which today is its own field of study referred to as bioethics.[20] Shared decision making between physicians and patients is currently the acceptable relationship in healthcare. Paternalism is no longer tolerable because with so many options people desire to have a voice in their medical care.[21] Doctors, patients and their family members now decide together what to do when confronted with any medical situation.[22]

Advancements in technologies that now allow people to live with conditions that less than a century ago would have undoubtedly caused imminent death have brought about a sundry of changes. The change in life expectancy has allowed for the rise of one chronic, degenerative condition in particular, Alzheimer's disease, which has created an enormous burden not only for Americans but for all people across the globe.[23] Quite simply, this is because the biggest risk factor to developing the disease is merely growing older and living longer. As more people live longer, more people face this disease which is anything but simple.[24] AD is a vast and growing burden on individuals and society for an array of reasons which will subsequently become clear. Concern related to AD has become critical enough that the federal government united in a dual party agreement in 2011 committing to effectively address the burden by 2025 in order to lessen the severity of its projected impact.[25] The specifics of this multilevel burden will be described

through an examination of the correlation between its mild and severe stages as well as by exploration of how organizational ethics should be developed to integrate personal care and public good related to the disease.

I.   The Correlation between the Mild and Severe Stages of Alzheimer's Disease

The symptom most commonly associated with AD is dementia. According to the *Diagnostic and Statistics Manual of Mental Disorders* (DSM-5) dementia consists of evidence of major decline in memory, language or learning that obstructs independence with daily activities resulting from an array of conditions including but not limited to AD.[26] Although AD is the leading cause of dementia, accounting for up to 80% of all dementias, other related conditions also cause people to experience the symptom of dementia. Less prevalent but related conditions include; vascular dementia, dementia with Lewy bodies (DLB), mixed dementia, Parkinson's disease (PD) and normal pressure hydrocephalus. These conditions have their own unique etiologies, symptoms, treatments and therefore are not the same as AD.[27] Often, the general public is unaware that there are symptoms other than dementia caused by AD. This may be because before the turn of the century a suspected diagnosis of AD was unable to be made until a person experienced a moderate to severe degree of dementia.[28]

Advances in neuroimaging technologies around the turn of the 21st century have enabled clinicians to make more affirmative diagnoses of AD as well as earlier diagnoses that can occur before the onset of dementia. The advances now allow the course of AD to be divided into various stages that cover a vast spectrum of cognitive and physical abilities and inabilities from complete independence with daily activities to the inability to perform any such task without complete assistance. These stages are; preclinical AD, mild cognitive impairment (MCI) due to

AD, and dementia due to AD.[29] The capability to identify AD during earlier stages of its

generally long, downward course and before the onset of moderate to severe dementia means the

difference between diagnosis when people possess the capacity for autonomy and diagnosis

when the capacity for autonomy has been compromised by the symptom of dementia.

Autonomy has become an increasingly treasured feature of the human condition in recent

times as well as a basic principle of biomedical ethics.[30] The concept of autonomy refers to the

individual freedom and ability to self-govern. Without scrutinizing the numerous individual

theories of autonomy, a common generalization can be made that autonomy is dependent on the

conditions of liberty and agency.[31] Liberty will not be debated in this work as it will be assumed

that liberty exists within the US healthcare system. Agency, however will become a point of

contention throughout this work as the course of Alzheimer's disease hampers people's

capability for deliberate action. The concept of human dignity, although more ambiguous than

the concept of autonomy, is also an essential consideration when examining the course of AD.[32]

During the mild stages of AD agency and dignity are not normally questioned but as the disease

progresses to its severe stages the ability for people to maintain agency is destroyed and the

extenuating cognitive impairments raise uncertainty about the extent to which human dignity

ought to be considered.[33]

A. The Mild Stages of Alzheimer's Disease

Scientifically and physiologically Alzheimer's has continued to puzzle researchers since

psychiatrist, Alois Alzheimer, discovered the condition over a century ago.[34] It is clear that

plaques, a collection of beta-amyloid proteins, and tangles, a breakdown of tau proteins, are

evident in the brains of those with the disease.[35] However over the century there has been a great

divide among scientists as to whether it is the plagues that actually cause the disease or the

tangles. Research has done little to clarify the plaques versus tangles debate and over time more theories and genetic links to the causation have been derived. Despite countless studies, no definitive evidence has yet supported one theory over another.[36] Some hypothesize that there may be various causes of AD, perhaps even more than one type and that the inability to identify its exact origins may be the main obstacle preventing the discovery of valuable pharmaceutical treatments and cures.[37] Another difficulty with AD is that unlike many other diseases there is not any type of diagnostic testing that identifies the disease with complete certainty.[38]

Most recently, advancing technologies have allowed researches to better identify the earlier, milder stages, of AD.[39] The earliest, prodromal, phase encompasses a span of two decades or more where dementia and other visible symptoms of Alzheimer's are not present. During the prodromal phase however, biomarkers of AD can be detected through neuroimaging techniques to indicate the physiological presence of the disease.[40] The biomarkers do not predict with certainty that one will eventually exhibit the symptom of dementia, they only indicate there is a potential to develop the symptoms of AD like dementia.[41] MCI is another phase in the mild stages of AD when one exhibits cognitive impairment and memory loss but not yet severe enough to impact overall daily functioning.[42] People with MCI are able to function autonomously and like the preclinical phase, MCI does not indicate with certainty that one will progress onto the later stages when dementia will be present.[43] The ability to identify Alzheimer's in its mild stage has raised numerous points of contention associated with whether or not diagnostic disclosure at this stage has any clinical relevance.[44] Knowing what may follow if progression onto the later stages were to occur allows for important concepts such as human dignity, autonomy and agency to be more fully explored in the mild stages before they are impacted by advancing dementia.

i. Human Dignity as an Intrinsic Value

Throughout the ages, the notion of human dignity seems to have been an elusive concept despite its common usage within both religious and secular capacities.[45] That its definition is mystifying has become remarkably clear during the human rights movement and recent origination of the field of bioethics, so much so that its worth as a normative concept has come into question.[46] Questioning the legitimacy of dignity is problematic because this concept has been widely utilized as a cornerstone for various national and international doctrines that delineate the appropriate treatment of all people.[47] In response to rising concerns about the concept and in particular its utilization by the President's Council on Bioethics, Edmund Pellegrino, Adam Schulman and Thomas Merrill edited a book titled *Human Dignity and Bioethics* to help the public better understand the complex yet essential meaning of the word dignity.[48] This 2009 anthology asserts in its preface that protecting human dignity is the fundamental motivation of bioethics which cannot and should not be ignored because of dispute over a universally acceptable definition for the word.[49] Acknowledging that the concept of dignity has true prominence within the field of bioethics is not itself sufficient for incorporating its meaning appropriately, its semantics must be more clearly defined based on the topic to which it is being directed.[50]

Daniel P. Sulmasy explores the concept of dignity as a value in his work titled, *Dignity and the Human as a Natural Kind*. Here he breaks down the different connotations of dignity and the ways in which different notions of human dignity may be applicable to the human condition.[51] This work sheds light on the ways in which these multiple notions may be most relevant to bioethics specifically the areas of aging and illness. The most fundamental notion of dignity is the intrinsic value which is bestowed upon something based solely on its type of

natural classification. Intrinsic human dignity then is the innate value that all members of the

human species possess solely based on their physiological composition, or their belonging to the

human race.[52] Human dignity of the intrinsic nature is always present and equal among all

human kind and it is this universal notion of dignity on which basic human rights are based.[53]

Dignity of the intrinsic type is static and may be better described as organic worth, a value that is

difficult to describe but one which people just tend to innately know exists.[54] Accepting that all

human beings have intrinsic human dignity insinuates that those who suffer through advancing

dementia remain equally dignified as members of the human race but perhaps could be

considered damaged or injured members of the dignified species.[55]

      ii.   The Attributes of Dignity, Autonomy and Agency

A different, but nonetheless widely utilized and definition-lacking, notion of dignity

refers to an attributed value, which is placed upon one entity by another. Dignity of this type is

no longer intrinsic and universally static among all members of one kind, or among all humans

when the topic is about people.[56] Attributed dignity is instrumental and requires there be

someone to place an extrinsic value upon oneself or upon another person or group of persons.[57]

It is attributed dignity then that is being referenced during discussion about dying with dignity or

dignified medical treatment and so on and so forth. This is because the discussion requires

someone to assert a value to dignity and from that value determine when life, or medical

treatments, no longer meet that particular value of dignity.[58] Differentiating between intrinsic

human dignity and the attributed dignity of persons is imperative in bioethical dialogue. Intrinsic

dignity, as it will be referred from here on out, is of set value. To argue this perception would

require in depth dialogue at a deep existential and philosophical level. Attributed dignity, as it

will be referred, is not a set value. Its value will vary from person to person and is closely tied to

individual values, morals and personal beliefs. Such qualities are what bioethics aims to consider in its quest for what ought to be done.[59]

Like attributed dignity, autonomy and agency are instrumental rights allotted to people possessing certain characteristics. These freedoms, although described as universal, are not intrinsic. While they are granted to the large majority of people, not all humans are yielded with autonomy and capable of agency just by their mere belonging to the human species. The ability to exercise capacity and autonomy are commonly questioned and often bequeathed to surrogates under certain circumstances, i.e. when working with prisoners, children, the severely mentally disabled and those with advanced dementia. Despite some exceptional populations, autonomy has become among the main principles of Western bioethics and an ideal that is emphasized by all heath care providers and their organizational policies. The capacity to carry out autonomy in healthcare is referred to as agency. The requirements for agency have been determined by people who have put standards in place thus making agency and autonomy attributed liberties just as dignity can be an attributed value. During earlier stages of AD dignity, autonomy and agency are hardly questioned, it is during the later stages when they become highly contemplated.

B. The Severe Stages of Alzheimer's Disease

Experts suppose that the prodromal phase of AD may be present for a decade or more, studies have indicated that once the later phases of the mild stage are reached an excess of two-thirds of people will progress to the severe stages within five years. Various factors influence the rate at which people with AD will decline but once the moderate stages are reached, decline towards the severe stages tends to accelerate abruptly.[60] Advanced dementia is the hallmark symptom of the severe stages. This end stage condition is characterized by severe physical and

cognitive disability requiring complete care dependence in all areas of daily living. [61] Typical features include incontinence, inability to speak more than a few words and inability to ambulate.[62] Common complications include; issues pertaining to nutrition and hydration, tendency for infections and increased prevalence for pneumonia.[63] Advanced dementia is a terminal condition and treatments for its complications have limited to no effect on prolonging life.[64] Advanced dementia is seen at the end stage of other neurodegenerative conditions such as; Lewy body dementia, normal pressure hydrocephalus, Pick's disease, Huntingdon's disease, Parkinson's disease and AIDS but advanced dementia of the Alzheimer's type is by far the most prevalent of conditions producing the symptom.[65] AD is the only neurodegenerative condition to be ranked among the top ten leading causes of death in the.[66] The severe stages of AD creates a burden to the individuals who have the disease, their families, those who assume caregiving roles as well as on society in general.

i.   Personal Burdens Associated with Advanced Dementia

The need for complete care dependence during the severe stages of AD creates physical, psychosocial and financial tolls on people with AD and their family members. Philosophical concerns arise also as cognitive and physical decline accelerates. Such concerns center around the notion of selfhood, whether it remains in-tact during advanced dementia and if so how to support it and preserve it as the disease continues to progress.[67] The physical decline resulting from advanced dementia makes people with Alzheimer's more prone to depression and other complex, comorbidities.[68] During this phase of AD primary caregivers are essential for around the clock care. Care associated with assistance in the areas of feeding, toileting and mobility are physically taxing on caregivers and the time requirements may by socially taxing as well.[69] Psychological burdens are also assumed by caregivers because people with advanced dementia

no longer possess agency and cannot make their own treatment decisions which tend to be more difficult in the severe stages of AD.[70]

Over 80% of older Americans are cared for by family members, or other persons who take on the caregiving role informally and voluntarily. Trends indicate that these caregivers frequently contribute their own moneys to offset the financial needs of the person for whom they provide care even when this results in the need to decrease their own personal spending.[71] Those who are not cared for at home or by a family member may be placed in a care facility, the costs of which in many cases impoverishes individuals and their immediate families.[72] These stressors put caregivers at increased risk of personal health problems and mortality as well as negative work related and financial issues.[73] Caregiver stress is a cyclical concern because there are not only risk factors associated with the caregiver but caregiver stress negatively impacts the quality of care received by their patients.[74]

ii.   Societal Burdens Associated with Advanced Dementia

Globally, it is estimated that beyond 35million people over the age of 70 have dementia. This number tends to be under reported and is expected to grow exponentially over the next several years if adequate methods of control are not developed. [75] Although trends are identified, dementia is an equal opportunity condition as it is prevalent in both developed and developing nations, across all ethics groups and social classes.[76] More women than men tend to show symptoms of dementia and theories suggest this may be associated with the tendency for women to live longer than men or because of the physiological differences between genders.[77] In America, over five million citizens are living with AD today.   The estimated cost of AD in the US currently lies somewhere between $150 billion to $215 billion annually and is projected to increase by about 80% by the year 2040.[78] The majority of these high costs are absorbed by

Medicare and Medicaid; Medicare as most affected by dementia are over the age of 65 and Medicaid because many people run out of their own personal assets during the long trajectory of the disease.[79] When personal funds are exhausted, Medicaid is often relied upon to cover the costs of long term care in nursing and assisted living facilities.[80] The high and rising costs associated with dementia are a part of a larger concern associated with the overall rise in the country's healthcare spending at rates which are becoming unsustainable.[81] This immense prevalence and cost makes AD in its severe stages a copious burden on society.[82]

Since the turn of the century, advances in neuroimaging and other related technologies have enabled the detection of AD in its earliest of stages. Many people do not realize that the prodromal phase of AD develops within the body decades prior to the onset of symptoms. During the mild stages of AD cognitive symptoms range from nothing to only mild impairments. During this stage there tends to be no major qualms about one's ability to act autonomously as their own agent and attributed dignity remains for the most part intact. It is not until the moderate to severe stages when the commonly associated and quite debilitating symptom of dementia occurs. The more advanced dementia becomes, the more the issues of attributed dignity, agency and autonomy become complicated. Likewise, as the disease progresses to its severe stages the personal and societal burdens escalate in complexity. The advances that have allowed for detection and diagnosis of AD during mild stages have also created unique opportunities. For although there is no guarantee all with mild stage AD will progress onto severe stages, knowing that the potential for advanced dementia looms in the future allows for important personal and societal considerations to be more thoroughly thought out before individual agency and capacity are no longer able to be exercised freely. After characterizing the

multifaceted burden of AD and the prospects offered during the early stages, organizational ethics should be developed to integrate advantageous facets of personal care and public good.

II.   Developing Organizational Ethics to Integrate Patient Care with Public Good

Providing high quality healthcare in a manner which is both affordable to patients and profitable to providers has been a dilemma for organizational ethics for the past several decades.[83] The growing prevalence and burdens of AD have contributed to this struggle. Although more is known about AD today than was known a century ago, this knowledge has not yet led to effective advances in medical or pharmaceutical treatments for the disease nor the symptom of dementia.[84] AD is the only condition in the top ten leading causes of death that has no standard method of prevention or treatment.[85] Some progress has been made in clarifying non-medical, non-pharmaceutical interventions that may effectively prolong the mild period of the disease process.[86] Exploring these avenues is essential because when people remain in the prodromal or MCI phases of the disease quality of life can be maintained and costs associated with AD can be reduced.[87] The current structure of the American healthcare system, however, creates barriers to incorporating these forms of prevention and treatment into the standard of care for AD. One barrier exists because the system is predominantly centered on a treatment and cure model of care in which providers are reimbursed for services geared toward issuing prescription medications or surgical interventions intended to treat and cure medical conditions.[88] With neither of these types of services especially helpful for the condition, AD brings about little financial return or at least less financial return overall than conditions associated with standard and effective interventions.[89]

Other barriers to providing standard care to the Alzheimer's population in the US are associated with a system which is often fragmented and lacking specific training and expertise on issues of aging. Great strides have been made in geriatric medicine since it was introduced as its own specialty in 1988 but there are still not enough physicians formally trained on the unique needs of the aging population.[90] As the baby boomer generation now begins to surpass the age of retirement it is estimated that millions of more healthcare workers will be needed over the next 15 years in order to provide them with care.[91] Healthcare providers who lack proper training in aging issues and specifically about AD tend to not make proper diagnoses, ensure proper care of Alzheimer's patients or provide proper support to their caregivers.[92] The limited number of geriatricians and primary care physicians who are aptly educated about AD still have to work within a system which is fragmented meaning organizational relationships between facilities, providers and insurers are not designed to ensure smooth functioning and transitions.[93]

The US was not alone when it prioritized collective action against AD with the passing of the National Alzheimer's Project Act.[94] Other nations, including the United Kingdom, Germany and Japan, have recognized the elusiveness of dementia, the growing at risk population and the urgency to take action.[95] Just last year, 89 member states of the WHO met for the first Conference on Global Action Against Dementia in order to bring worldwide attention to devastation of dementia, raise the priority given to the disease and establish a foundation to begin to develop a comprehensive and affordable plan to tackle the burden globally.[96] That the burden of AD is growing, is not limited to one geographic area, and has negative impacts on both personal and societal levels are common factors among the array of national and international plans. This collaborative consensus supports the imperative to look beyond traditional models of treatment and cure to overcome the burdens of AD. It is also important to realize that the goals

of medicine as established by the Hasting's Center in 1996, emphasize not only goals associated with treatment and cure but also goals related to prevention and care.[97] Organizational ethics then ought to be expanded to incorporate models of care to improve quality of life and enhance public wellbeing.

A. Improving Quality of Life

Past assumptions typically associated the symptoms of AD, specifically those of cognitive decline, with the natural aging process but today we know this is in fact not true.[98] AD and its symptoms are not a normal features of the aging process but aging is however the leading risk factor for developing AD.[99] The prevalence of AD is growing because more people are not only alive today but this larger group of people is also living longer than ever before.[100] Because people used to live shorter life spans traditional human development theorists had little inclination to differentiate periods of adulthood but now some theorists see the need to make a differentiation. This modern time in human development has been coined the "third age" by Peter Laslett. It is during this span where one's responsibilities to work and family have lessened but traditional old age associated with frailty and illness have not yet transpired. When anticipating the third age people hope to enjoy personally fulfilling activities and voluntarily engage in civic interests.[101] Growing old in the traditional sense may be adjourned for as long as adults remain healthy and active. Maintaining an outward appearance of youth has become desirable to some. The marketplace has assisted in efforts to avoid the traditional looks of old age by developing a bountiful array of anti-aging products designed to mask the outward appearance of age as well as supplements claiming to slow its inward process.[102] Maintaining an acceptable quality of life becomes of key importance during this time. While AD threatens and

eventually damages quality of life, it can still be improved and maintained to various degrees before declining in the face of the disease.

i.   The Personal Importance of Quality-of-Life

Quality of life is a value judgement about the perceived significance of one's life experience. This value, referring to a state of satisfaction, can be described in numerous ways and is dependent upon various factors that differ from person to person. Quality of life is subjective, meaning it is comprehended differently by different people thus making it difficult to measure.[103] Quality of life has become a focal point in most areas of healthcare today, maintaining and enhancing it are among the fundamental goals of medicine.[104] AD, specifically the circumstances brought about by dementia, threatens to disrupt the standards people commonly associate with a good quality of life.[105] The array of negative effects dementia has on people's lifestyles is one of the greatest fears associated with the condition. The time period prior to the onset of dementia offers an opportunity to incorporate activities which show the potential to delay the onset or slow the progression of AD.

While difficult to measure, quality of life is a value most accurately rated by the person living the particular life. Observers, whether they be family members or clinicians, tend to rate quality of life lower than the person actually experiencing the life.[106] Johnson, Siegler and Winslade refer to these assessments as personal evaluations verses observer evaluations.[107] The early stages of AD allow people to project their own personal evaluations about how the later stages may impact their quality of life. Such projections can help ensure that future observer evaluations will be more on track with what the personal evaluations may be despite an inability to communicate accurately in the face of advancing dementia. People with AD are not the only ones whose personal quality of life is jeopardized by the advancement of the disease. Caregivers

experience disruptions to what they consider a good quality of life when they face the responsibilities and burdens associated with caring for someone with AD.[108] Caregivers include both those who voluntarily provide care to a family member and those who are employed to provide care. Both groups, informal caregivers and professional caregivers, experience varying degrees of emotional stress which lead to burnout.[109]

ii.   Maintaining and Improving Quality-of-Life

Quality of life in the face of AD can be positively impacted when various measures are properly engaged. Foremost, the prevention of AD would be ideal but unlike other common chronic conditions, such as diabetes and heart disease, the impact of risk factor modification for AD has been underexplored.[110] Some clinicians are beginning to speculate about the risk factors associated with AD and methods of disease prevention. The expanding prevalence of dementia has also brought increased attention to the importance of cognitive health. Cognitive rehabilitation programs are standard care for people recovering from brain injuries and stroke. While not yet well supported through research, activities aimed at enhancing cognitive health are showing promise of preventing, or slowing, the onset of dementia.[111] Clinicians in California are piloting such activities through implementation of neighborhood cognitive shops which focus on preventing and slowing dementia by providing individualized programming for people with and without AD who want to enhance their cognitive health. Participants' cognitive needs and personal interests are assessed to provide unique regimens designed to improve or maintain cognitive health through diet, exercise and mental activities. The outcomes are showing positive impacts on personal quality of life.[112]

For people beyond the early stages of AD, maintaining quality of life continues to be a central concern. As individuals' customary lifestyles are threatened by advancing dementia

concerns rise associated with safety and activities of daily living. Those who will be cared for at home by an informal caregiver must consider safety and financial issues and the burdens which will be placed upon their family caregiver. Those who turn to residential facilities for care must confront concerns about finances as well as issues related to neglect and abuse as they have become closely associated with the culture of care facilities.[113] Various initiatives, such as the Eden Alternative's Greenhouse Projects, have emerged to address these concerns and to enhance the quality of life experienced by their residents.[114] People who have endured years of caring for people with AD, like author Joanne Koenig Coste, have used their experiences to design unique approaches that enable people to deal with the complexities of tending to someone with dementia more effectively.[115] Likewise, palliative care programs focus on enhancing quality of life for patients as well as supporting their caregivers. Palliative care programs are appropriate for patients regardless of where they select to be cared for, this by extension means that when palliative care is properly utilized both informal and professional caregivers are provided with support while enduring the caregiver burdens associated with AD.[116] These various methods address quality of life concerns for people impacted by all stages of AD.

B. Enhancing Public Wellbeing

The extension of the average human life span by a quarter of a century over the 1900's was made possible by public health efforts and the rapid advances of medical science and technology.[117] Mankind learned how to manipulate and circumvent death, an event once uncontrollable by human intervention, and how to decrease and sometimes altogether eradicate infectious disease through advances in treatment and prevention.[118] Longer human life spans have altered cultural norms and redefined wellbeing. Although the spike in longevity has leveled off since the early 2000's, increasing life expectancy beyond 78 years has allowed for new

threats to arise alongside the triumphs to population health.[119] AD is among these threats and

one which especially wreaks havoc on a considerable portion of the older population, ultimately

placing societal wellbeing in jeopardy today.[120] Some individuals may find solace in

consumerism related to anti-aging products however the marketplace nor science has yet to

achieve the overall elimination of the body's innate tendency to age. Emphasis on wellbeing and

healthy lifestyles, through activities of health promotion and prevention, seems to be the key to

slowing down our biological tendency toward aging, or at least a means to embrace aging more

gracefully.[121] Maintaining wellbeing in the face of AD has value to society and there are ways to

encourage this type of wellbeing at the population level.

      i.   **The Societal Value of Wellbeing**

Wellbeing is another concept that has been imprecisely defined and is difficult to

measure due to its subjectivity. Regardless, it is prevalently used in various fields of study

including psychology, economics, public policy and public health.[122] Analysis of its ambiguity

will be avoided and rather a streamlined definition of communal wellbeing will be presented for

subsequent application to the societal burdens of AD. Similar to quality of life, wellbeing is a

value indication referring to a state of satisfaction.[123] It can be used to describe a state of

individual satisfaction, it may also be used to describe a communal state of satisfaction.[124]

Referring to the vigor of society, wellbeing takes on a geographical approach to how needs are

satisfied in order to achieve an adequate level of welfare for all members of a particular society,

including its most vulnerable constituents.[125] This non-static, concept refers to the overall state

of contentment created within a population under certain circumstances.[126] Based on this

definition, wellbeing will be used as a societal, macro level, value reference whereas quality of

life will be used as a personal, micro level, value reference. Wellbeing encompasses, but is not

limited to, considerations related to economics, public health and public policy.   Correlations have been identified between enhanced wellbeing and positive societal attributes such as decreased violence, improved physical and mental health, and improved trust thus wellbeing is an essential element to thriving societies.[127]

Wellbeing can be threatened by various factors including stereotyping and discrimination. Ageism, the negative stereotyping and discrimination against the older population, has become prevalent in American culture for some time. It occurs casually and systematically, intentionally and unintentionally and is an issue that negatively impacts the growing number of older people in various areas of their daily life.[128] Elders were once viewed as members of society possessing a unique wisdom and held value as contributors to both families and communities. Aspects of modernization and the constant pursuit to banish death for as long as possible are blamed in part for the movement away from this view and towards ageism.[129] When old age is embraced as a natural part of life, not a stage that ought to be avoided because it indicates defeat, respect and appreciation for the elderly as valuable family and societal resources may again emerge and eliminate some aspects of ageism.[130]

ii.   **Encouraging Wellbeing in Society**

The predominance of AD in our society is massive, rising, costly and addressing it has become a governmental imperative, therefore wellbeing as it relates to AD must become a top priority. Preventing the onset of AD by five years within the population will decrease the prevalence and its debilitating aspect of dementia by half. [131] The overall cost savings associated with such delays are estimated to be huge and in particular will positively impact national concerns about healthcare spending.[132] Decreasing the prevalence of AD and lowering spending associated with the disease favors enhanced wellbeing.   Healthcare organizations become

obvious partners in the pursuit of wellbeing because they have contact with countless members

of our society annually. If all, or at least most, HCOs standardly encourage preventative

measures related to AD and the onset of dementia the beneficent delay is more likely to be

detected across society.[133] Although prevention measures associated with AD and dementia are

not yet well established or standard, expanding programs like the neighborhood cognitive shops

is considered by some to be a way to confront the societal problems associated with dementia in

a streamlined, less medically focused and more cost effective manner.[134] Non-biomedical

approaches to enhancing societal wellbeing become more essential with each passing day that

pharmaceutical advancements aimed at slowing or preventing AD do not successfully occur.

AD is a major health concern that the American healthcare system is not currently

designed to address efficiently. This is because unlike other common medical conditions which

have standard forms of treatments and cures at this time there are no forms of surgical or

pharmaceutical prevention, cure, of effective treatments for AD. Overcoming these

organizational barriers is essential to getting a proper handle on this disease. Organizational

ethics can be designed to address avenues outside of surgical and pharmaceutical interventions

that integrate personal care and public good to improve quality of life and enrich societal

wellbeing in the face of the Alzheimer's crisis. Focusing on maintaining a good quality of life

throughout the aging process is a primary aim of healthcare and there are unique methods that

show promise to prolonging personal satisfaction even when faced with AD. Furthermore,

ensuring society at large remains secure in the face of epidemics, such as AD, is a global focus

and helps to boost trust, reduce costs and augment personal security within our own country.

Wellbeing urges us to base considerations for life choices upon not only individual wants and

needs but also upon the wants and needs of the larger society. Such a focus then shifts

biomedical approaches of disease management towards more socially focused approaches to care.[135]

III.   Conclusion

Since the early 1900's when Alzheimer's was first identified our knowledge about the disease has expanded but we are still at a loss for any type of cure or treatments which are beyond minimally effective. The burden created by a lack of treatment and cure has compounded over the past century as a result of advancements in other areas of medicine which have enabled more people to survive infancy and go on to live lifespans averaging more than 75 years. Since the leading risk factor for AD is simply aging, this combination of more people living and living longer than ever before has enabled AD to grow from a sporadic phenomenon to a global epidemic. Many aspects of healthcare changed over this timespan as well. With the expansion of medicine and medical technology, the role of the physician has changed, doctors practices which were once very private are now often part of a large conglomerate healthcare system and because of these changes some claim that medicine's focus has shifted from one of compassion to one of technology. Today's healthcare system is designed to focus on and be heavily reimbursed by identifying an ailment and prescribing a technological, surgical, or pharmaceutical type of prevention, treatment and/or cure. This organizational design neglects to adequately address the array of issues that occur over the long, multi-year course of AD, a course that not only ridden with health related dilemmas but ethical type dilemmas as well.

When the course of AD is considered in its entirety it becomes clear that there is an association between the mild stages and the severe stages of the disease. Taking advantage of this association allows for individual autonomy to be maximized and the shared decision making

process to be as comprehensive as possible. This occurs when opportunity is taken of the time

when ability for individual autonomy and agency remains unaffected by the onset and

advancement of dementia since it is the symptom of dementia, not the mere diagnosis of AD that

eventually impedes upon one's capacity for autonomy and raises questions about agency and

dignity. When agency is not in question people may establish how they attribute dignity to

themselves, the aging process and the dying process. Exploring these issues will enable

surrogates to make appropriate decisions on behalf of the person with AD once dementia

eliminates that person's autonomy and potential for agency. This is vital because in the more

severe stages of AD decision making becomes increasingly complicated as numerous personal

and societal burdens arise. The ultimately culmination of personal and societal burdens at the

severe stages of AD make people with the disease, their caregivers and society susceptible to

vulnerability.   Bearing in mind the entire spectrum of this disease allows people to incorporate

their own ethics into an individually appropriate care plan. This consideration also allows HCOs

to incorporate ethics specifically designed to improve quality of life and enhance public

wellbeing from an organizational perspective. Devising a framework considerate of both

personal and societal morality is the key approach to managing this vast array of burdens created

by AD.

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<u>Chapter Three: Systematic Analysis of the Ethics of Care for Alzheimer's Disease</u>

Applied ethics is the area of moral philosophy which concerns itself with issues that are both controversial and morally relevant for the purpose of analyzing concepts of behavior related to these issues.[1] Bioethics is a specifically focused subset of applied ethics examining controversial and morally relevant issues brought about by recent advances in science and technology.[2] This unique field of study takes an interdisciplinary approach to systematizing, defending and recommending concepts of morally appropriate and inappropriate behaviors related to modern healthcare and clinical research by considering numerous aspects of issues including, but not limited to, those which are scientific, clinical, legal, theological, political and philosophical.[3] As bioethics was emerging as an established, professional field of study pioneer bioethicists worked tirelessly to validate the applicability of theories and methodologies to the various matters of the field. Several decades later there is still not a single, accepted method of bioethics but rather the field continues to utilize a compilation of methods and theories.[4] The lack of an agreed upon methodology and the continued inclusion of multiple disciplines into the field gives bioethics its distinctiveness and allows scholars to intermingle and redevelop theories as they continuously strive to analyze issues as they evolve with advancing science, technology and culture.

Western nations, the United States in particular, have significantly tended toward the use of principlism as its main approach to bioethics.[5] The use of four main principles; autonomy, beneficence, nonmaleficence and justice, as the basic pillars to address ethical situations ascended as recoil following public outrage over the misconduct of human subjects in medical experimentation. Global atrocities such as the Nazi Medical Experiments and nationally occurring cruelties such as the Tuskegee Syphilis Studies and the array of human misconduct

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disclosed by Henrey Beecher in his 1966 New England Journal of Medicine article reinforced the urgency for bioethical consideration in both clinical research and clinical care as well as urged for its incorporation into government and public policy.[6] Three of the principles were initially introduced in 1978 in the Belmont Report and all four principles became more intricately developed into a practical approach to moral decision making in Tom Beauchamp and James Childress's work *Principles of Biomedical Ethics*, the 7th edition of which was published in 2013.[7] While the four principles have become heavily incorporated into Western bioethics and act as a foundation for institutional and governmental policies, procedures and approaches to decision making in research and clinical care, this has not occurred without criticism.[8]

Clouser and Gert are among prominent critics of principlism having emphasized that the four principles, while applicable to most issues, do not act as a comprehensive moral theory or provide moral guidance amidst controversial and morally relevant issues.[9] This point is not to critique principlism or commend alternative approaches proposed by Clouser, Gert, or other opponents of principlism, as the principles are valid considerations for such stated dilemmas and each prompt important inquiry when such dilemmas are contemplated. This point is to acknowledge and agree with Clouser and Gert's opinion that moral guidance is necessary when confronting complex, modern issues involving human beings, human responses to advancing science and technology as well as the human needs arising from these advancements.[10] It is for this reason that this dissertation selects a moral theory, the ethics of care, on which to base the management of a major ethical dilemma, how to manage the personal and societal burdens of an ethical laden illness which is negatively impacting a vast and growing portion of the aging population, Alzheimer's disease. The principles of biomedical ethics as well as other

methodologies will be incorporated into this larger framework of care ethics specifically designed for issues of bioethics.

The ethics of care, or care ethics, is a moral theory that has been developed over recent decades to establish a unique approach to modern moral issues. This moral theory asserts that the value and practice of care is the basis for human nature and human flourishing based upon its perspective that human beings as a species are interconnected and dependent on one another and society for survival.[11] Based on this premise, the context of care ethics includes ideals about right and wrong behavior as well as guidance on what ought to be done when faced with ethical dilemmas.[12] The ethics of care offers unique approaches to issues such as domestic violence, childcare, education and the criminal justice system. It has been used to suggest better methods of caring for people with physical disabilities and also been suggested as an alternative framework to curative care for improved management of chronic illness.[13] The ethics of care should be applied to bioethics as it has the potential to act as a framework to ethically manage the unique needs of people living with progressive illnesses like Alzheimer's disease.

Historical analyses indicates there is significance between bioethics and the ethics of care. Unlike traditional moral theories and many professional fields of study, both care ethics and bioethics only began to evolve since the latter half of the 1900's. Similarly to other aspects of life and culture, their continued growth has been considerably impacted by industrialization. As World War II concluded, marking a pivotal time in the history of healthcare for most of the world, but especially industrialized nations, bioethics emerged during this era in reaction to the various cruelties in medical research and care that gained public attention and evoked outrage.[14] It was during this time in history that the imperative for more careful provisions to ensure for people's voluntary participation in clinical research emerged, that protection for all people from

acts of marginalization became essential, and that all areas of research and care became more closely scrutinized. These imperatives gave rise to the importance of ethics in the field of healthcare.[15] Over the next several decades as rapid developments in science and technology occurred (i.e.: advances such as more effective antibiotics, life-saving surgical techniques, organ transplantation and life-prolonging measures such as kidney dialysis and mechanical ventilators) hope and efforts became increasingly focused on extending the life span and avoiding premature death. Simultaneously, these onslaughts of care raised dilemmas about how much should be done to prolong life especially when quality-of-life was irreversibly hampered.[16] Events pertaining to issues of quality versus quantity-of-life were more closely speculated upon by professionals from an array of backgrounds, including medicine, government, philosophy and theology. It was from such dilemmas that the multidisciplinary field of bioethics evolved.[17]

Just as bioethics was conceived to counter the endangerment of vulnerable people for the advancement of the medical sciences, the ethics of care was conceived from the feminist movement aimed at countering gender oppression and recognizing the importance of caring relationships between people. This moral theory is based on a feminist philosophy which asserts that all people, not just men, have the capacity for morality and reason.[18] The initial motive for this assertion became evident in the 1960's when women began to challenge the traditional moral theories asserting that only men were rational beings capable of morality. This type of feminist movement has persevered in asserting that men, women and often children are capable of reason and can function as moral beings.[19] Furthermore, some feminist philosophers have justified the value in the work of caring, such care-related work often tends to be linked to the female gender. It is from these notions that the ethics of care has evolved.[20] As science and technology have changed the boundaries of life and death by expanding what is medically possible, the ethics of

care has recognized the importance of caring roles and their impact on civil society by proposing a moral theory asserting that all people and societies require some degree of caring relations for survival.

Enthusiasts of the ethics of care have argued that it is the only true ethic as it places no gender based restrictions thus leading to a fairer, more compassionate ethic.[21] Critics however, have questioned its capabilities to function as an independent moral theory through accusations related to care ethics simply being a theory of gender differences.[22] While the evolution of care ethics undoubtedly began from theories of gender differences and set out to overcome gender oppression, the ethics of care as a moral theory is not just about the lives of females but about the relationships between all people, both male and female, and their connection to society.[23] The roots of the ethics of care are most commonly associated with Carol Gilligan's 1982 work, *In a Different Voice*. This groundbreaking work was a rebuttal to psychologist, Lawrence Kohlberg's theory of stages of moral development which declared that males were more morally mature than females. Gilligan opposed his theory and recognized that traditional moral theories tended to focus on justice and duties while paying little regard to empathy and care. Empathy and care, from Gilligan's perspective, are the more essential, yet under recognized, elements necessary for human flourishing.[24]

This notion of care and the role it plays for individuals and societies became a point of contemplation for the evolving feminist movement. Like bioethics, feminism is comprised of a broad and diverse theoretical foundation from which its logicians can function.[25] Because the work of care was traditionally associated with women and assumed to have very little, to no moral value the concept of care-related work split feminist thinkers into two general cohorts. The first cohort, second-wave feminism, asserts the view that women ought to give up care work

and join the male dominated, moral realm of society. Second-wave feminism ignited tremendously when Betty Friedan's book *The Feminine Mystique* became a national bestseller in 1964 and was reignited again in 2013 with the publication of Sheryl Sandberg's bestseller *Lean In, Women, Work and the Will to Lead*.[26] The second cohort, care-focused feminism, although viewed less mainstream and more within academic circles, persevered to highlight the value of care, the morality that results from its work, and the necessity of care to all people regardless of gender.[27] It was Gilligan's concept of empathy and care that gave rise to this unique school of care-focused feminist philosophers, many of whom continued to further develop the ethics of care as a moral theory. First editions of books such as Nel Nodding's *Caring: A Feminine Approach to Ethics and Moral Education*, Joan Tronto's *Moral Boundaries: A Political Argument for an Ethic of Care*, and Sara Ruddick's *Maternal Thinking: Towards a Politics of Peace*, were published in the 80's and 90's to illustrate and promote the moral value of care-related roles.[28] This modern moral theory focuses not only on what standards are morally permissible but also on what actions are morally necessary in response to these standards.[29] The precise details of these two feminist cohorts and the care ethics evolution, when clearly understood, overcomes the criticisms related to the ethics of care being merely a theory of gender differences. This analysis of the ethics of care will not critique the two cohorts or scrutinize second-wave feminism, rather it will embrace the care-focused feminism school of though and the moral theory of care ethics.

More complex criticisms of the ethics of care question the theory's concept of human nature and the normative value of care. A well-defined concept of human nature is essential for a normative moral theory as it is from reflection upon human nature that the norms and values of human behavior evolve, ethically constructed social systems are created, and from which

judgments should be made about wellbeing.[30] Traditional perspectives of human nature were

developed based on the aspiration of humans for reasoning and justice placing the primary focus

on the role of autonomous, healthy males who are able bodied, contributing members of society.

These traditional concepts of human nature are not cohesive with the ethics of care because they

are not gender neutral, do not encompass the span of an entire human lifetime, or take into

consideration times of physical or mental latency, therefore care ethics opposes this perspective

of human nature and views it as unsustainable.[31] The ethics of care bases its focus of human

nature on the inclusion of care and both the female and male genders. The inclusion of care as a

component of human nature establishes as a norm that human beings are not spontaneously

autonomous. Humans begin their lives dependent on care for survival and likely will again need

to receive or provide care at times throughout their lifespan. This need for care implies that

people are social beings concerned not only about their own well-being but about the well-being

of others.[32]

This care ethics' concept of human nature should be fortified when ideals are borrowed

from a contemporary philosophical school of thought known as personalism. Unlike traditional

philosophies which focus on human consciousness, personalism views human actions as being

influenced by more than just physical characteristics alone as its focus is on the uniqueness of

each individual and the potential of each individual's capabilities.[33] While personalism views

people as unique subjects, it is not strictly focused on individualism as each subject is considered

as part of the larger world thus having responsibilities to others and society.[34] One major

contribution from personalism is the development of the concept of person, known as, "the

human person adequately considered," here the uniqueness of human beings is elaborated

through eight main points which take into consideration humans as part of society. Among eight

main points personalism establishes that humans are relational and embodied subjects who were created in the image of God thus sharing a fundamental level of equality and dignity.[35] This all-encompassing reality of what makes humans unique offers a perspective on right and wrong, sets a stage for an ethics of responsibility, and further develops a strong concept of human nature.[36]

When adequately considered, people are moral subjects capable of acting not only freely but also consciously and this leads to a sense of responsibility. People do not just have a body but they are a body and humanness comes from the needs for other worldly effects, from relationships with others and from society at large. Although each person is unique, all people are fundamentally equal as they share the same foundational conditions for survival and it is from these similarities that dignity arises, not from the characteristics and accomplishments that contribute to uniqueness.[37] Despite such a well-developed and all-encompassing definition of human nature a downfall of personalism is that it does not offer a broad enough framework to consider what ought to be done when faced moral dilemmas and thus cannot function as its own moral theory. Another downfall is that there is a theological association with Christianity which may deter non-Christians from its utilization in ethical theory. Despite frequent association with Catholicism, the personalist school of thought emerged a few decades before the change in the Vatican and is therefore not a philosophy developed and utilized strictly by Catholic thinkers.[38] Like the ethics of care, personalism is a more modern approach to ethics and is not strictly individualistic because it views each subject as part of the larger world thus having responsibilities to others and society.[39] The ethics of care therefore ought to emulate the ideals of personalism to enhance its concept of human nature.

The concept of care has been another point of contention for care ethics as arguments have been made that care is subjective, voluntary, and describes only a particular relationship

thus having no normative value.[40] The normative value of care becomes heightened when its norms and values are defined and when the obligation to provide care is clarified.[41] Defining care is a difficult task, the word is deeply rooted in the everyday language of people and is used in many realms with various respects. Prominent care-based feminists Joan Tronto and Berenice Fisher define care as, "activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, ourselves, and the environment, all of which we seek to interweave in a complex, life sustaining web".[42] This definition is reflective of some of the components of the human person adequately considered relating the activity of care to the interconnection of human nature. From this definition care is explained to be a four phase process that includes; caring about, taking care of, care-giving, and care-receiving.[43] The ethical elements of care then include; attentiveness, responsibility, competence and responsiveness.[44] This definition of care, which is reflective upon a concept of human nature based on the interconnectedness of people and the ethical elements of care, establish norms and values of care and removes the possibility of care being only subjective.

Again a personalist approach to care ethics should be used to validate the normativity of care. Linus Vanlaere does this by using the concept of the human person adequately considered to debunk the notion that care is only a voluntary act between those in particular relationships. [45] He argues that because people are corporeal, rationality is not essential for dignity neither is the presence or maintenance of our physical or mental health. It is the capacity to lose, or to never have developed, rationality, physical or mental wellbeing that makes all people equally vulnerable.[46] These elements of corporeality and vulnerability make care essential to human flourishing. This concept of dignity establishes that all people possess an inherent dignity.[47] It is

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because of this dignity and the interrelatedness of people that care is more than a voluntary act. Care can be focused to ensure its qualitative elements are based on the needs of the particular recipient, but the obligation to provide care is not only directed particularly because it is a universal element of morality.[48] Dignity and care are thus universal parts of human nature. The ethics of care claims that the universal need for care is the basis for morality because all people will need care at various points throughout their lifespans to ensure individual and societal survival.[49] This claim in conjunction with a comprehensive concept of human nature and a normative concept of care allows the ethics of care to function as a contemporary moral theory, one which is especially applicable to the contemporary field of bioethics.

A systematic analysis of the ethics of care and its usefulness for Alzheimer's disease will be launched and endorsed in this chapter. Bearing in mind that exclusivity of bioethics lies in its openness to interdisciplinary inclusion and its willingness to incorporate multiple methodologies, the ethics of care framework created here for use in bioethics will evolve as a moral framework by utilizing and incorporating other established philosophical schools of thought and approaches to moral decision making. These inclusions will ultimately strengthen the ethics of care as a moral theory and this framework will become clearly applicable for general use in bioethics and specific use in managing the burdens of AD. This framework will be grounded through the two main components of care ethics; relational autonomy and social responsibility.

I.   Relational autonomy

The notion of autonomy is a prominent feature of bioethics. As a principle of bioethics, autonomy affirms that each competent person is entitled to make decisions pertaining to their healthcare based on their own individual determination and such decisions need to be respected

even when clinicians, and others, may not be in agreement with particular decisions.[50] When

persons are not competent, an appropriate surrogate decision maker needs to make decision on

their behalf while extending the same respects.[51] Autonomy is deeply rooted in American

bioethics as respect for autonomy is one of the four principles of biomedical ethics instituted by

principlism. Although expressions of autonomy vary based on national origin, religious, or our

cultural considerations, autonomy is also valued worldwide as it became a global principle of

bioethics in 2005 when UNESCO's Universal Declaration on Bioethics and Human Rights was

adopted.[52]

 As the use of and dependency on principlism expanded, there has become a tendency for

autonomy to be viewed as the central principle of American bioethics despite statements by

Beauchamp and Childress that they never intended for there be a hierarchal order to their

principles.[53] The principles, autonomy in particular, were derived primarily from right-based

theories which emphasize individuals and societies as completely independent agents detached

from one another, giving little attention to emotions or the unique situations of individuals.[54]

The principles, as aforementioned, act merely as a method of guidance to ethical decision

making and therefore are not an isolated moral theory. The ethics of care, in contrast is an

objective moral theory which unlike traditional moral theories is not right-based but rather based

upon the universal need for care.[55] When care becomes the more encompassing moral value

relationships between people and communities are respected and accounted for, therefore

shifting the view of autonomy from one of independence to one which is more relational.[56]

 The focus on a rights based notion of autonomy since the expansion of modern medicine

following WWII should come as no surprise, nor be perceived as having elite intentions. The

traditional paternalistic model of decision making between clinicians and patients became

notoriously associated with negligence towards patients and mistrust associated with the expansion of healthcare systems and movement away from doctors in private practice.[57] Attempts were made to overcome these hindrances by placing increased emphasis on the role of individual patients and their rights within the doctor-patient relationship through measures such as informed consent and patient bills of rights.[58] The pendulum of individual, patient orientated focus however may have shifted from one extreme to another; from the clinician having all say in medical matters to the patient being so in control of decisions that clinician's professional position in the therapeutic relationship becomes jeopardized. Such a shift has put beneficence in conflict with autonomy at times.[59]

Rights based theories of autonomy, perchance inadvertently, have led to an oversight on how to sufficiently consider the proper features of autonomous persons specific to persons who are facing modern medical issues such as life ridden with chronic degenerative diseases. As people are living longer in the face of more curable and treatable conditions, many people lose, or become at jeopardy of losing, the complete individualistic type of autonomy brought about by rights based theories.[60] Ruud ter Meulen examines the distinctions of the caring role between people who face acute illness and those who face chronic illnesses. Care for those facing acute maladies where cure is a feasible and short term goal involve only brief encounters of interdependency, ones which can be acceptably superficial. To the contrary for those facing chronic maladies where cure is not the main goal, or not achievable in the short term, care through interdependency becomes more fundamental, less superficial and essential to ensuring people retain their self-worth.[61] Such a relational model of autonomy focuses on the interconnectedness of people and the moral reciprocity that evolves from such relationships. A rights based model of autonomy is incompatible with the needs of people facing AD. Although

individuality may be retained during early stages, as the disease progresses eventually all capacity for independence will be obstructed. The relational model of autonomy constructed by the ethics of care is more cohesive for considerations related to the burden of AD as people are viewed in a more relational manner and within a context that considers and values emotions like compassion and empathy.[62] Autonomy within the care ethics framework focuses on the interdependence of people, rather than their independence, and takes on a unique view of vulnerability which is universal in nature, rather than trait based.

A.   Interdependence

The premise that the human species would not survive without care is among the core foundational philosophies of the ethics of care. Most fundamentally, infants would not survive infancy without the care of another human being. When care is provided, most infants are able to develop into autonomous people. Care however, is still needed by most people at times throughout their lifecycle either permanently or temporarily depending upon various life circumstances.[63] The unexpected need for care is exemplified in the classic bioethics case of Dax Cowart whose life was challenged and forever changed as the result of a gas explosion that occurred when he was in his twenties, when he was independent and worked as an Air Force pilot. Following the explosion Dax suffered numerous injuries resulting in permanent disfigurement and disability. Despite Dax's autonomous desire to forego treatments and be allowed to die as a result of his injuries, his overridden pleas for these wishes is what has made his case a classic to bioethics, he faced several years of medical treatment and rehab and today, over 40 years later, lives a productive life as a patient right's attorney with the assistance of care.[64]

People may become independent after infancy but still need brief periods of care throughout childhood and adulthood thus fluctuating between periods of independence and dependency. Some people however, are care dependent from time of birth until time of death. The need for care whether fluid or static, does not undermine persons' intrinsic dignity nor their potential for attributed dignity. Eva Fider Kittay, prominent philosopher and care ethicist, proclaims the essential role care plays in morality for people who live with profound intellectual disabilities from birth throughout adulthood. As she has witnessed firsthand, having an adult daughter with such a disability, care when properly provided and reciprocated allows people challenged with significant disabilities to lead meaningful and dignified lives.[65] It is vital to acknowledge that care is a cyclical process, it is given and received, and the process has moral implications for those who receive care and also for those who provide care.[66]

The perception of care as a universal need has persuaded care ethicists to employ a concept of autonomy which is related to the interdependence of people, as opposed to traditional concepts which views people as completely individualistic and removed from one another. This contemporary conception of autonomy clarifies that when relationships are essential to survival they are not always entered into voluntarily thus this concept is contrary to the traditional model of autonomy which is not considerate of involuntary interdependence.[67] The ethics of care perceives people as more than egotistic individuals in constant pursuit of their own self-interests and because of this relational autonomy allows value and focus to be placed on particular relationships rather than solely on universal rules. Particular relationships are natural and moral decision making within such relationships occur just as frequently, if not more often, than they do individualistically or universally.[68] Value of particular relationships also indicates there is significance in personal narratives. Personal narratives are simply the details of each particular

person's life situation for example who they identify as their family, their social characteristics and their perception of their own quality of life. These narratives fluctuate and change with time and experience.[69] When the interdependence of people and their personal narratives are embraced, emotions are respected and relationships of trust are formed.[70]

i.   Respect for Emotions

Impartiality and universal norms are essential features of traditional moral theories. These theories tend to ignore the role of human emotions because emotions create interference with the ability to exercise impartiality and adhere to universal norms, the central components of the traditional rights based moral frameworks.[71] This becomes problematic when the psychological role of emotions is considered. The consciousness of cognitively intact human beings, from a psychological standpoint, involves a constant flow of emotions which prompt behavioral responses. The inclusion of emotion within a moral theory thus is merely natural and the exclusion of emotions threatens to inhibit human flourishing.[72] The ethics of care acknowledges the cohesion between consciousness and emotion and accepts that emotions are natural occurrences resulting from relationships of interdependence.[73] As a result the framework created by the ethics of care values moral emotions like empathy, compassion, and sensitivity. Moral emotions can build off one another and work together to promote mutual responsiveness and consideration for others. Some people have a more inherent inclination toward the expression and acknowledgment of such emotions, but these emotions can also be cultivated through time and experience.[74]

Ties to emotions have created an association between the ethics of care and virtue ethics, some philosophers have even suggested that care ethics is simply a form of virtue ethics.[75] Virtue ethics is an ethical approach that explores morality through virtues, positive character

traits, and what motivates and results from virtuous actions.[76] While similarities exist between

the ethics of care and virtue ethics, the ethics of care is more sophisticated than virtue ethics as it

embodies more than descriptions of personal characteristics and their relevance to morality.

Valuable emotions from an ethics of care perspective do not only consist of personal emotions

but emotions that are shared between people who find themselves in mutual relationships of

care.[77] When properly understood care ethics embraces virtuous emotions not because emotions

alone make the person who possess them a moral individual, but because these emotions result

from the value and practice of caring relationships between people. It is the caring relationships

between people and their communities which are essential to morality according to the theory of

care ethics.[78] Furthermore, the ethics of care does more than label vices as negative attributes

that keep those who hold them from achieving their full moral potential. By focusing on the

importance of moral emotions and relationships between people, the ethics of care denigrates

negative emotions, such as anger and hatred, and deters their associated hostile behaviors.[79]

The mutual reciprocation of moral emotions can be exemplified in the early stages of

Alzheimer's disease while those diagnosed still maintain capacity. Those diagnosed show

sensitivity to their impending need to receive care while those with whom they have close

relationships show sensitivity to their impending need to ensure necessary care is in some way

provided. Empathy results when diagnosed individuals reflect upon the forthcoming burden of

their care partners and when care partners reflects upon the helplessness felt by those diagnosed

with AD. Mutual responsiveness results when both parties accept and react to the need for

caregiving and care receiving. Mutual responsiveness will occur in each interdependent

relationship but the personal narrative will differ within each particular relationship. It is the

particular personal narrative that guides what ought to be done in response to the situation.

ii.   Formation of Trust

When moral emotions are considered significant bonds of trust are easily formed. Because of the emphasis that the ethics of care places on relationships of interdependence, trust is central to the ethics of care.[80] If interdependency is fostered but trust is not, there are no boundaries to ensure that interdependent relationships are healthy and beneficial, and do not become harmful. As care based feminism originated, its focus was on ensuring that relationships occurring in the private realm of family and home were caring and not abusive thus the ethics of care ethics was initially developed to address private issues such as domestic violence and child abuse. From its onset, the ethics of care emphasized that relationships of interdependency should never be constructed to suggest that submission to unfair treatment or violence is indicated or acceptable. Interdependent relationships of care are appropriately fostered within a morality based on care and therefore harmful relationships are not fostered.[81] Right's based moral frameworks have been criticized for enabling harmful relationships to be fostered and neglecting the value of trust. This partly occurs within rights based approaches to morality because universal norms are assumed and particular narratives and neglected.[82] The moral responsibility to avoid harm within interdependent relationships contributes to the normative value found within the ethics of care as does the acceptance that not all people retain the same set of basic capabilities.[83] The context of trust developed within the ethics of care provides an easement to ensure mutual respect and responsiveness occur amicably.

Returning to the example of those in the early stages of Alzheimer's disease, trust is important to enhancing relational autonomy and in reinforcing to those diagnosed with AD that their dignity will be maintained as the disease progresses. Relational autonomy and trust are not just ideal and important for relations between family and friends, but also essential between

patients, physicians and other professional care providers. As will be subsequently detailed in the section about social responsibility, the focus on care work and caring relationships have expanded beyond the private confines of households and families since the initial development of care ethics. The understanding that care is no longer only a private occurrence primarily taking place within individual family units is key to appreciating why those impacted by AD ought to be considered within a framework that respects and promotes trust within interdependent relationships.

B.   Vulnerability

The concept of human vulnerability has significantly impacted the field of bioethics and the development of its multiple methodologies. As modern medicine materialized, an awareness developed that some advances resulted only because of various harms intentionally or unintentionally inflicted upon people who were not in a position to defend themselves.[84]   The awareness of, and consideration for, human vulnerability resulted in the development of ethical principles and codes which emphasize the need for consideration of those who may be at risk of marginalization.[85] In doing so, bioethics has traditionally tended to categorize groups of people as vulnerable based on intrinsic or extrinsic qualities which place them into a particular group (i.e. racial minorities, the poor, the homeless).[86] Categorization criteria for vulnerability are limiting, as they may exclude people who are vulnerable despite certain characteristics, and they can be inappropriately inclusive, as they may label people as vulnerable who may not actually be. This categorization method was primarily developed for use in research as it aimed to protect human subjects in research and heighten researchers' awareness of the potential for marginalization when selecting participants.

Vulnerability in medical research can be compared and contrasted to vulnerability in clinical care but not all people are at risk of becoming human subjects. It is more likely however, that at some point in their lifetimes all people will find themselves in some way vulnerable to conditions of health. Despite this overall risk to health related vulnerability, vulnerability as it applies to clinical care has been considered less than has vulnerability in clinical research.[87] Without debate, intrinsic and extrinsic factors can, and often do, heighten potential for vulnerability in areas related to health conditions and clinical care. The bigger picture however is that all human beings are susceptible to vulnerability related to health and illness therefore such a concept of human vulnerability must be all encompassing and universal.[88] Health related vulnerability typically tends to be linked to autonomy and the ability to provide informed consent but this focus is narrow and exclusive at times.[89] People can still be vulnerable and susceptible to marginalization when potential for autonomy is still intact. The case of Dax Cowart clearly illustrates these points. At the time of the explosion, Dax a young, able bodied, white, American, working, male did not possess any categorical factors of vulnerability. Yet following the accident, even though his cognitive capacity for autonomy remained intact, his extreme injuries and the lack of consideration regarding his personal desires for care made him a considerably marginalized patient.[90] For situations such as Cowart's, and situations where capacity for autonomy have been lost, vulnerability may be more precisely determined on an individual basis.[91]

Deborah Stienestra and Harvey Chochinov have explained vulnerability as a universal yet dynamic and particular concept that fluctuates throughout one's life.[92] Their definition is reflective of human states of health today as all people will likely be receivers of clinical care but how this care is influenced by individual life circumstances; including physical, psychosocial

and spiritual factors, and by the particular healthcare system within which they receive care, will vary. Particular considerations are essential features for an ethical approach to clinical care today.[93] Thus, making the incorporation of particular considerations within a universal definition of vulnerability ethically sound and in accordance with the ethics of care. Degenerative illnesses, like AD which cannot be cured or slowed and will continue throughout one's remaining lifespan, tend to increase universal vulnerability because the physical and psychological integrity of self becomes threatened.[94] Enduring all that the burden of AD entails, including the erosion of cognition while facing a wide array of sensitive decisions pertaining to life and death, have created a vulnerability that captures all people facing the situation, not only those with the diagnosis but also their family members and other support systems. The ethics of care recognizes that all people are at risk for vulnerability and awareness of this promotes fairness among unequals and emphasizes the value of care related work.

i.   **Fairness among Unequals**

The ethics of care is unique in that when imbalances of equality are present it does not attempt redistribution but rather accepts the imbalances and accommodates for them within relationships. Contrary to rights based frameworks that become one-sided when impartiality is fostered and personal values are not taken into account, care based frameworks promote fairness among unequal relationships by acknowledging personal values, and promoting partiality and solidarity.[95] Traditional frameworks may have been more feasible and less problematic historically when paternalism was the acceptable clinician-patient relationship, options for medical interventions were more limited and life spans were shorter.[96] Today however, as treatment options continue to expand, life expectancy has reached an all-time high and patients must take on a greater role in medical decision making, the role of power and equality within

moral frameworks ought to be reconsidered. The ethics of care responds accordingly as it works to redistribute power.[97] Within this unique mindset, the concept of dependency also becomes seen through a unique vantage point. Those who are able to engage in daily activities independently are no longer seen as more powerful than those who are dependent in various regards. Relations between the independent and the dependent are no longer hierarchical but rather interdependent. Dependency, like vulnerability, is an intrinsic feature of the human condition which for many is present to different degrees and occur intermittently over time.[98]

Establishing that there ought to be fairness among unequals is beneficial to bioethics, and markedly so in areas of aging and health, because here relationships are often not equal, and creating an equal playing field may not be a realistic option. For example; relationships of power and knowledge are often unequal between clinicians and patients, as are relationships of physical and cognitive abilities between the person in need of care and the person providing care. Care, within the ethics of care, is a process involving various phases each entailing moral implications.[99] Joan Tronto explains the phases as fourfold. The first which she calls caring about is the simple acknowledgement of care as a basic necessity of humanity. The second phase, taking care of, occurs when one takes on some degree of participation in responding to the need for care. The third and fourth phases she identifies as care-giving and care-receiving; the direct action of meeting another person's need for care and the other's response to the care provided.[100] Although the phases may seem cyclical and straight forward, they often play out in a complex fashion. Not everyone will recognize care as the basic human need which it is, and still others who make this recognition may never consider responding to the care needs of others. People do not tend to move swiftly between the roles of care provider and care receiver, just as the level to which human vulnerability impacts each individual's degree of dependency on others

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is not either all or nothing.[101] The flux of vulnerability and dependency is profoundly associated

with AD, this will become clearly apparent in the following chapters. When the continuous,

malleable sequence of providing and receiving care is regarded as a normal part of human nature

and less like a burdensome disruption to the normal flow of life, power and dependency become

less relevant, vulnerability becomes morally motivating and the infliction of harm is avoided.[102]

ii.   **The Value of Care Related Work**

Care work once primarily took place within the privacy of home but today it is taking

place both at home and in the market place and being provided by both informal, unpaid,

caregivers and formal, professional, caregivers.[103] Historically, when most care work took place

at home, the value of care work went under recognized, marked by little to no pay in return for

the hard work and dedication necessary to carry out the efforts required for quality care.[104]

Today the value of care work is increasing but its recognition still tends to fall below the value

attributed to non-care related work thus theorists are now beginning to more scrupulously

contemplate value as it relates to care work.[105] Gender and race claims have been made for the

lack of value associated with caregiving roles as care work was traditionally seen as work carried

out by women, and especially by women of color.[106] Regardless of the validity of these claims

stereotypes must be overcome because today men take on informal caregiving roles at

statistically significant rates as do people of different races.[107] Men are not only taking on

informal caring roles more prominently today but the presence of men in care related careers

such as nursing is also escalating.[108]

Today our population is such that there are more people on the higher side of the aging

trajectory than ever before. Resultantly, the need for and rates of caregiving at later stages of

adulthood to care for an aging population, as opposed to the needs during younger adulthood to

care for infants and children, is increasing.[109] An estimated 15 million Americans are providing informal care for persons with AD today.[110] Feminist perspectives have been helpful in bringing light to the value of both informal and formal care work. The ethics of care reinforces the value and the necessity of care work as care becomes understood as an inescapable dimension of morality, the need for which all people are susceptible to just through their humanness. The interrelatedness and vulnerability of all people emphasizes the value of care and thus care work ought to be seen as a natural and inescapable proponent of humanity.

The first component of the ethics of care is relational autonomy which focuses on the interrelatedness between people. When understood appropriately, relational autonomy fosters relationships of mutual responsiveness through a process of caring about, taking care of, care giving and care receiving.[111] The ethics of care does not reject the capacity for individual autonomy but recognizes that there is a more prominent tendency for interrelatedness throughout life than tendency for complete independency. Acknowledging interrelatedness results in the respect of emotions and the building of trust. Furthermore, it suggests that care work ought to be more highly valued because care is an essential factor to the human condition and vulnerability is universal and inescapable as it pertains to health and wellness. Consequently, this main component of the ethics of care creates a moral framework that operates to reduce the vulnerability that arises when the capacity for individual autonomy is overcome by frailty. People who are faced with AD, and related dementias, are vulnerable due to the impending loss of individual autonomy and the need for complete care dependence that accompanies the condition's moderate to severe stages. The model of relational autonomy offered by care ethics works to reduce and respect universal vulnerability by fostering unequal but partial relationships between persons with advanced dementia and their care partners. The second component of care

ethics, social responsibility, compliments relational autonomy as it focuses on the interrelatedness between people and their communities.

II.   Social Responsibility

Social responsibility is not a new concept but its meaning and application to modernity has reemerged in philosophy and ethics. It has been most prevalently used recently in regards to corporations and the obligations businesses have to the communities in which they operate. While this is an important aspect of the notion, a less developed but equally important aspect of social responsibility pertains to the moral responsibilities that individuals have to the groups and communities in which they are involved.[112] This particular type of responsibility has a distinctive focus that lies between the narrow view of individual moral responsibility and the wider view of collective social responsibility. The uniqueness of being caught between these two ends of responsibility perhaps contributes to its theoretical and normative underdevelopment. Collective responsibility is the broadest application of moral responsibility. It looks at concepts of power and the influence of power on the collective actions of large groups. There are differing positions on the notion of collective moral responsibility that can be applied to ethical issues associated with the actions of large groups. Some situations where the notion of collective moral responsibility may come into play include world hunger, wars, gang related violence, and public policy issues.[113]

Individual moral responsibility is more narrowly focused than collective responsibility. As a normative concept moral responsibility has typically been used to judge how well individuals function from a perspective of responsibility. The process of justification in most situations has occurred through the evaluation of categorizing individuals as moral agents and

thus judging them based on their actions. Moral responsibility can also encompass another area, the responsibilities associated with a particular role. [114] This less explored area of moral responsibility is the main focus of social responsibility. A role can be loosely focused when applied to responsibility, such as the role of human beings. Roles can also be specialized as in for example, the role of a parent, the role of a spouse or the role of a clinician. Depending on the priority of the role and the closeness between the person in the role and the recipient of the role's actions, how special the role is may be judged and subsequently treated in a hierarchical fashion. The less intimate the role has typically indicated a lesser associated priority of responsibility thus particular roles have often been treated as a priority over general roles.[115]

Judgements about moral responsibility are inevitably tied to judgements about moral duties and obligations. In his book, *Protecting the Vulnerable A Reanalysis of Our Social Responsibilities*, Robert Goodin assumes a philosophical approach to social responsibility by disputing the common assumption that the duties and obligations assumed by most people ought to only be particularly focused. He argues that while duties and obligations to particular others will most often take priority, they should not blind people to their duties and obligations to the larger social interests of society because such general interests have validity and importance essential for morality.[116] Such duties and obligations are not only philosophically supported but also supported through psychological actions. This becomes clear through Tom Kitwood's work titled *Concern for Others, A New Psychology of Conscious and Morality*.[117] These two perspectives suggests that morality encompasses great depths covering not only each individual's own needs and the needs of those to whom they are immediately related but each individuals' contribution to the collective needs which must be fulfilled to achieve and sustain a good and just society. Both works have created a foundation for social responsibility as a normative concept.

The imperative to consider social responsibility within the realm of bioethics became globally recognized in UNESCO's Universal Declaration on Bioethics and Human Rights. Social responsibility and health is incorporated into the declaration as one of the guiding principles of global bioethics.[118] Although the concept of social responsibility was new to the area of healthcare and bioethics, the International Bioethics Committee (IBC), the advising body who oversaw the formulation of the declaration, viewed social responsibility as an essential moral duty. This acknowledgment recognizes that practical concerns regarding healthcare and its associated scientific progress are worthy of being considered from a social and political perspective because many related issues are not able to be appropriately controlled on just an individual and private level.[119] The scope of this principle is broad and within it falls the obligation to promote health and social development. These obligations should be carried out not just at the global level but also on more locally focused levels of society. Specific focuses are necessary because different societies have different cultures and priorities to consider.[120]

As complex in nature as it may be, the general, ethical concept of social responsibility should be defined as the obligation of an individual to contribute through regular actions to the wellbeing of society at large. [121] The concept of social responsibility is so heavily incorporated into the ethics of care that it plays a principle role as one of its two main components.[122] While relational autonomy focuses on particular relationships and their essential relevance to morality, social responsibility focuses on the moral relevance of general relationships with distant others and the larger society. As an overall moral framework the ethics of care emphasizes the importance of our moral duties and responsibilities to both particular and general others by viewing the value and practice of care as essentially relevant to the survival of both individuals and societies.[123]

Just as the personal implications of Alzheimer's disease indicate vulnerability for patients, the far reaching societal implications of the disease indicate risks of vulnerability for society. The notion of social responsibility in care ethics works to overcome societal vulnerabilities by promoting responsibility.[124] Responsibility for people with Alzheimer's disease is not able to be contained only within the confines of privacy. People who are effected by the disease either as patients, caregivers or family members need the support of public goods, services and financial assistance. Medical care is needed, long term care is needed and supportive services are necessary to get through the extended period of time this terminal condition tends to last.[125] Social responsibility is a main component of care ethics because care is no longer just a private matter and for this reason care and justice need to be incorporated together rather than existing in opposition.

A.   The Expanding Practice of Care

The social responsibility to ensuring care occurs within society is reinforced because a main goal of the collective field of medicine is care. The main goals of contemporary medicine as established by the Hasting's Center are; "the prevention of disease and injury and promotion and maintenance of health, the relief of pain and suffering caused by maladies, the care and cure of those with a malady and the care of those who cannot be cured, and the avoidance of premature death and the pursuit of a peaceful death". An order of priority for these goals was not set because significant differences occur between one health related situation and another.[126] Claims can be made that aspects of the contemporary goals of medicine have been successfully achieved because the population is living longer than ever before, many disease can be prevented, treated and cured. Contrary claims can also be made that as a result of meeting some goals, such as the prevention of an untimely death, many people will go on to face more years

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marked with illness and disability.[127] Although the goals clearly focus on the aspects of both

cure and care, not separating one from the other, physicians and patients alike tend to place more

emphasis on efforts to cure and prevent mortality for as long as possible. Unfortunately cure is

not always possible and eventually becomes an unachievable goal of medicine. Care however is

always possible and can occur while cure is being sought and when cure is no longer a realistic

goal and when treatments become futile.[128]

The ethics of care supports the ever present role of care and the responsibility society has

to ensuring it occurs. Parallel to its paramount claim that people cannot survive without the care

of other people, the ethics of care avows that societies cannot flourish or survive with the care of

people either.[129] This notion becomes especially evident in present-day societies where the

practice of care is no longer predominately occurring between family members and within the

private home setting. Care continues to take place at home but a large portion of people seek

care from the larger community. In some situations care at home is provided by family members

and in other situations professional caregivers are hired to work within private homes. In various

situations people in need of care are moved into community based facilities where all care is

provided by paid professionals.[130] This shift has disseminated care related work into businesses,

big and small, and has resulted in care contributing to the market economy in various ways.[131]

A unique feature of modern-day care is that care providers are not always family

members with a vested interest in the wellbeing of those for whom they care. Complete

strangers are regularly employed to provide care, provisions which often require the navigation

of intimate, personal boundaries.[132] Even when there is a lack of personal connection between

caregivers and the care receivers, the provision of good care remains essential due to the

interconnectedness of people and society. In places, like the US, where healthcare is a prominent

part of the economy people enter the marketplace not just to address acute care needs but also in search of long-term care to manage the day to day needs of the frail and elderly. In these regards, much of the care work associated with health and aging that used to take place privately at home has now become placed in the public domain. With the expansion of long-term healthcare to the economic market, solidarity will help ensure quality care is provided while reinforcing why improvement is necessary.

      i.   **Solidarity and Quality Care**

Solidarity, a common sense of interdependency and unity between members of a community, is a value fostered by the ethics of care. Solidarity is traceable among small groups of individuals throughout history but the concept of solidarity as applied to the larger population was slow to develop throughout history. The increasing value of solidarity can be traced through the emergence of the human rights discourse and the development of global bioethics.[133] As the human race evolved and collective intelligence increased, the value of solidarity to the survival and advancement of our species became more evident. The concept of solidarity created the notion that all people deserve some degree of common moral treatment. From this notion changes evolved in how criminals were punished and solidarity became a driving force behind the abolishment of slavery.[134] Solidarity calls for equality among members of the larger society even when there are imbalances of resources and power. With solidarity as a leading value the common good of all members of the larger society becomes the focal point of individual and joint efforts ultimately producing strength in times of despair and crisis.[135]

The Universal Declaration on Bioethics and Human Rights includes solidarity as a global principle of bioethics.[136] Formally referred to as Solidarity and Cooperation, the concept of solidarity was important from the conception of the Declaration because it establishes that all

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people are unified as members of a larger community and while individuals are free to do as they chose, they also have a cooperative obligation to their community. The purpose of both individual freedom and obligation to cooperate is to maintain the wellbeing of humanity.[137] The Declaration alleges that individual countries should incorporate these global principles into their healthcare systems as they see fit. America has tended to place more focus on autonomy and individual freedom in healthcare. In contrast other countries, like the United Kingdom, have tended to place more focus on solidarity basing individual decisions on their likely impact on the greater community.[138]

Solidarity becomes a significant and constructive concept when people still desire and expect quality care even when care is provided beyond the confines of home, or by people whom may be otherwise strangers. Since the expansion of care into the pubic quality, access to, and cost of healthcare has become a concern that greatly impacts the public and has become an issue for bioethics. From a quality perspective, people want and deserve beneficial care. People who have to leave their loved ones to be cared for expect them to receive the same quality of care they would receive at home if being cared for by family. Unfortunately in America there are major flaws in the quality of the care that is being provided.[139] The ethics of care establishes a societal imperative to improve quality of care based on its affirmation that people are interrelated and dependent on care.[140] The IOM has suggested that higher quality of care will more likely occur when healthcare delivery systems customize disease management approaches for a small number of prevalent conditions, such as AD, rather than assuming the customary individualized patient approach to care.[141]

The moderate to advanced stages of AD inevitably require an all-encompassing level of care and their survival throughout the course of the disease ultimately becomes dependent on the

care of others.[142] The physical and cognitive limitations put people with advancing dementia in a vulnerable position. Their caregivers may also become vulnerable as they address how to best meet the needs of those with the condition. The prevalence of the disease and its impacts on society makes the challenge of providing adequate long-term care more than a particular concern. High quality care when confronted with situations such as AD is often associated with care that, above all other considerations, maintains patient safety.[143] People desire more than just safety when seeking care and such a unilateral focus hampers quality. Atual Gawande illustrates the shortcomings of the prevalent long-term care options in this country in his bestselling book, *Being Mortal* and explains that when patient safety is the predominant focus the result is often increased use of physical and chemical restraints which hamper patients' freewill and ability to remain in an environment which adequately portrays their typical home-like setting throughout end-of-life.[144] While patient safety is a key element to quality care it is not the only element. Solidarity motivates that those effected by AD be afforded quality care beyond the maintenance of patient safety.

ii.   Potential for Improvement

Overall healthcare in the US ranks poorly in comparison to other developed nations.[145] Inefficiencies are prevalent in overall personal health status, quality of care, and fairness.[146] Long-term care facilities, including both assisted living facilities and nursing homes, tend to be institutionalized, retaining an institutional feel despite offerings of resort-style entry ways and dining area designs. Many facilities host large numbers of residents but employ low numbers of staff. Such resident/staff ratios are justified as necessary because of costs and budget constraints but with such ratios residents are often not able to receive the individualized attention necessary to maintain their capacity for independence and dignity.[147] The business and regulatory aspects

of healthcare have placed a strong focus on meeting health and safety guidelines above providing a desirable home-like setting. The lack of focus placed on personal joy and sustenance of life have motivated some long-term care innovators to make remarkable efforts to incorporate simple pleasures into publically provided long-term care.[148] The Eden Alternative and the Greenhouse Project exist as examples of how long-term care can be successfully designed to fulfill personal desires of care while still meeting the publicly required regulatory mandates. Their design features smaller family-style neighborhoods rather than large institutional like facilities where residents remain as active as possible in their own care and daily life, for as long as possible.[149] Such approaches work to maintain resident dignity despite the necessity for continuous care.

The preservation of intrinsic human dignity has societal significance and is essential even when confronted with issues related to injury, illness, aging. This idea has been founded in part by the human rights movement and the nature of bioethics. Throughout time, human rights have evolved to promote human dignity as well as to recognize and prevent the individual and societal destruction that results when human dignity is disrespected.[150] These efforts were solidified in 1948 when the Universal Declaration of Human Rights declared through its 30 articles that there are basic dignities bestowed to all people, across the globe regardless of color, creed, national origins and actions.[151] This declaration makes a unique statement consistent with social responsibility, that there is, and should be, solidarity among the human race by asserting that no one group of people has superiority over another and all groups are to be respected and valued as human beings.[152] Through this declaration, the United Nations emphasizes the interconnectedness of all people. Similarly, bioethics emerged, not just to study individual ethical issues related to advancements in science and technology, but to reinforce the importance of human dignity possessed by all people. This is especially evident based on a study of

bioethics and its historical reactions to the global atrocities occurring over the past several decades.[153] The ethics of care encapsulates both bioethical and human rights type considerations for human dignity on the social level through its component of social responsibility. When applied to issues of aging, social responsibility asserts that the intrinsic dignity of all people ought to be maintained even when injuries and illnesses, like AD, are present. Therefore, because there is potential to improve care in manners that maintain dignity for those with AD there is also a social responsibility to do so.

B.   Care and Justice

Throughout this analysis, the ethics of care has been contrasted to traditional, rights based moral theories. In such theories the focus on human nature hinges on the concept of independent, autonomous and rational males ultimately making justice and rights the foundation of their frameworks.[154] As the ethics of care has emerged, care ethicists have debated about the appropriate role of justice within a theory of care because the ethics of care disputes that the independent, rational, male model of human nature is an accurate representation of humanity's majority.[155] Some early care ethicists made arguments that justice does not fit, in any way, within the framework of care, while others suggested that justice be contained into some realms of society, such as those pertaining to law and order, and care be contained in other more private sectors.[156] Both of these perspectives have been rejected by noteworthy care ethicists whose work have enhanced the development of the ethics of care.   Joan Tronto and Virginia Held convincingly assert that justice has an important and valid place within the ethics of care. Tronto urges that separating the two devalues care to the private realm of society, something that must be avoided after so much effort has been focused on recognizing the value of care in society's public realm.[157] Similarly, Held asserts that justice is a necessary component of care, just as are

other virtues and principles, but care must remain the larger framework within which justice, and other factors, should be considered. Her rationalization for this is that care is always necessary for the advancement of society while justice maintains order and equity but is not always needed by all people.[158]

The inclusion of justice within the ethics of care allows for a more palpable application to bioethics as bioethics has established that a duty to justice is among its main contributions. Justice in bioethics is typically applied to issues affecting social systems by applying traditional norms and theories that guide the fair and equitable distribution of benefits and burdens and in healthcare ethics, theories of justice are commonly used in relation to issues pertaining to access to care, costs or rationing resources. Principlism affirms justice as one of its four guiding principles.[159] Although the ethics of care does not name justice as a main component of its moral framework it can still account for the relevance of justice to morality.[160]   When justice falls within the larger framework of care, it becomes clear the care should not primarily be a commodity and that power ought to be refocused based on social responsibility.

i.   **Care as a Commodity**

While care once had little societal value and was often taken for granted as work naturally assigned to women and slaves, today care has become a more highly regarded need and service often carried out by trained professionals.[161] The perception of health related care has particularly evolved and has come to be viewed and distributed differently across the globe.[162] In the US care has become predominately a marketable service which can be bought and sold. The commodification of care has prevailed in the US because privatized healthcare has remained the norm unlike in nearly all other countries where healthcare is accepted as a societal good, a basic provision which is generally provided for to a defined extent by some type of governmental

allocation.[163] In 2015, 65.6% of Americans under age 65 had privatized insurance while only

25.3% of people in the same age group had publicly provided coverage.[164] When there is more

emphasis on care as a commodity than on care as a basic human need to which people have a

right, ethical issues pertaining to access and quality arise. Through its affiliation with social

responsibility, the ethics of care offers a unique approach to these ethical challenges which

should work in cooperation of democracy. By establishing that care is a basic need for people

and societies, the ethics of care identifies that care should not be limited to only those who can

afford its costs.[165] Furthermore, within such a perspective equal access to affordable, quality

care is a necessity for morality. The ethics of care thus illuminates the moral dangers of largely

commodifying care and results in the challenge of determining how to ensure the basic features

of care are offered within healthcare systems to result in morally responsible societies.

This challenge is especially applicable to the burden of AD in the US. Navigating the

healthcare system over the course of the diseases is claimed to be highly frustrating and

disjointed. Such features are evident from initial attempts to get an honest and proper diagnosis

when mild symptoms arise, to getting connected with community resources and services as the

symptoms of dementia surface, and to exploring appropriate and affordable long-term care

options as they becomes necessary.[166] The National Plan to Address Alzheimer's Disease

identifies the shortcoming of the fragmented system and proposes plans to progress towards

overcoming the hurdles and improving the system of care for people with AD.[167] Arguments are

made that in order for the ethics of care to make an impact large enough to be noticed on a

societal level the political boundaries need to be expanded to value care and accept it as an all-

encompassing framework from which political actions are based.[168] Based on its initial bi-

partisan support, the Plan initially seems to have recognized the value of care on the societal

level and since it is legally bound to be carried out until at least the year 2025, time remains for further political differentiation between care as a basic good and care as a commodity.

ii.   **Refocusing Power**

When care is the foremost foundation of a moral framework traditional power structures are refocused resulting in the reduction of power hierarchies in such a way that all people within society are regarded as equal, although not the same. When this occurs the results are that trust is built and mutual consideration transpires between all people.[169] When structures of society are looked at from a position of care it becomes evident that power influences how care is provided and to whom it is more readily available. When care is given increased value, these hierarchies of power become more evident.[170] Within political systems, the ethics of care does not eliminate the political role of power but rather eliminates the coercive capacity of political power.[171] When used in a political context care forges unique considerations for equality based on the mutual interconnection of all people within a system.[172] Social responsibility persuades that power hierarchies ought to be refocused in order to adequately provide a basic level of care to all members of the social system. Once established configurations of power may be difficult to restructure, but changes to existing power structures are often necessary for the greater good and the concept of care has the capacity to evoke change.[173]

When care ethics is applied to healthcare systems, power structures between patients, providers and administrators stand to be reduced or eliminated. This may potentially lead to improved trust and consideration between care providers, care receivers and those overseeing the larger healthcare system. From an organizational perspective, healthcare agencies can afford to improve the trust of the people within their communities.[174] From a political perspective a greater focus on the need for care may eliminate some of the partisan power struggles that tend

to occur when attempts are made to expand public healthcare coverage. Such power struggles were evident in the design of the Patient Protection and Affordable Care Act of 2010 and continue to surface as efforts are made to repeal and replace it.[175]   The restructuring of power will promote the design of less fragmented healthcare systems, ones that resultantly become more focused on providing high quality care to populations which specifically seek and need a stronger emphasis on care rather than cure. Care after all, may be more valuable than cure throughout the endurance of progressive illnesses like AD.

By placing care as its core consideration, the ethics of care recognizes that individuals have responsibilities to the larger societies to which they belong. Thus the concept of social responsibility maintains that general relationships are equally as important as particular relationships. These notions are significant in today's world because care is no longer contained within the privacy of home and family units. As our population ages and faces increased years marked with the need for daily care, care has become a product of the public marketplace. As a result ethical issued have arisen pertaining to quality of care, the commodification of care and the roles of power in society. From an ethics of care perspective, issues of justice do not need to be considered separate from issues of care but care must be the larger framework within which justice is considered otherwise societies face increased threats of vulnerability. Social responsibility encourages the reduction of societal vulnerability by refocusing power and recognizing the potential for changes in the provisions of care aimed at maintaining intrinsic human dignity.

III.   Conclusion

In 1968 Garrett Hardin published an article titled, "The Tragedy of the Commons" to provoke thought on how to respond to arising issues associated with rapid population growth.[176] Since then, the article became highly acclaimed, republished, analyzed, critiqued and conveyed onto fields of study beyond ecology. The overarching moral dilemma portrayed by Hardin's description was at what point does individualism becomes perilous; how long one does rightfully chose self-interest over the interest of close by others.[177] In 2013 Joshua Greene authored a book; *Moral Tribes Emotions, Reason and the Gap between Us and Them*, extending the moral dilemma to the choice between us and them in what he refers to as, "the tragedy of the commonsense morality."[178] Greene explains Hardin's dilemma as more simplistic in nature, one human morality is capable of solving, while his dilemma is a more complex moral problem for people to decipher. Greene suggests that complex moral dilemmas which volley obligations of particular relations and general relations would be easier to navigate if there were a universal morality which all people were familiar.[179] Robert Veatch acknowledges a similar dilemma specific to healthcare that has surfaced in the rise of shared decision making and patient rights. The dilemma he illustrates is that although patients and clinicians are expected to share responsibilities in the decision making process, clinicians will almost never share the same morals, values and belief systems as their patients making a truly shared decision making process nearly impossible.[180] Likewise the burden of AD creates a dilemma of how to accommodate for a growing population that is at risk of losing their cognitive capacities and capabilities of caring for themselves. At times the burden may hit close to home but regardless it is threatening mass amounts of others within our communities, nations and across the globe.

An overarching theme in these morally challenging scenarios is cooperation. Cooperation is a simple process at times but complex and oppressing at other times. Moral predicaments commonly arise surrounding cooperation especially when individuals are pivoted against one another. The morality of cooperation perhaps becomes even more complicated when intimate groups are faced with how to cooperate with others to whom they are less personally connected.[181] When thoroughly analyzed, the ethics of care makes the complexities of cooperation more translucent. The ethics of care is a modern moral theory that offers a unique framework of ethical guidance.[182] The theory intends to provide an alternative to aged, traditional theories as it has evolved only in the past quarter century.[183] A modern field, such as bioethics, that continues to change and expand, cannot thrive on ancient moral frameworks. A modern framework that values the care necessary for human and societal survival offers greater opportunity for the moral stability of this unique field of applied ethics. This is especially true when applied to the burden of Alzheimer's disease which creates a multifaceted predicament concerning individuals specifically and society generally. Although the ethics of care has feminist roots it is vital to note that the application of the ethics of care to issues in bioethics is not the same as taking a feminist approach to bioethics.[184] This remains true even though some of the facts and figures of AD tend to impact women more prevalently than men.[185] Care is not gender specific and furthermore as a moral theory the ethics of care has been developed beyond the gender divide and works to consider all people equally.[186]

Care is the main essential element of human nature from this perspective of morality. While the ethics of care does not shun the human potential for independency it recognizes that people are not spontaneously autonomous, but all people have a natural need for care upon birth and most people will have an intermittent need for care throughout the lifecycle. Based on this

foundational need for care, people are more interconnected than isolated from one another. While individual uniqueness is appreciated and fostered, individuality does not overcompensate for the mere humanness which gives all people basic intrinsic dignity. Because human flourishing results from care, care becomes a normative concept. Thus it is from a perspective of care, above all other perspectives, that moral decisions must be made.

When the ethics of care is systematically analyzed, its two main components, relational autonomy and social responsibility, create a framework that address ethical issues and guide action from both particular and general perspectives. When pondering the moral impasses illustrated in Greene's work, the concept of relational autonomy coincides with the me-versus-us predicament and the concept of social responsibility coincides with the us-versus-them predicament. Relational autonomy views people as interrelated rather than independent, respects emotions and forms trust.[187] These factors allow vulnerability to be viewed from a universal perspective based on the need all people have for care at some points throughout their lifetimes thus creating a sense of fairness among unequals and placing value on care work. Social responsibility for care is essential because care has expanded from private realms of society to public realms.[188] Despite the need for publically provided care, quality is still desired and potential for improvements exist. Care and justice are not separate issues but within the framework of care ethics, care is the wider issue within which justice must be considered.[189] From this perspective care should not be considered a commodity and power should be refocused. These main concepts work in conjunction to support human flourishing and prosperous societies. This framework offered by the ethics of care offers great potential to guide the long term management of Alzheimer's disease. The next three chapters will illustrate how

this may occur by applying this framework to the specific burden of AD experienced during the

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<u>Chapter Four: The Ethics of Care during the Mild Stages of Alzheimer's Disease</u>

I.   Introduction to the Mild Stages

In 2007 Lisa Genova, a neuroscientist and author, brought to life the fictitious character she called Alice Howard to depict what life may be like for someone living with early onset AD. Throughout the pages of her bestselling novel, *Still Alice*, readers are captivated by the impact AD has on this 50 year old, esteemed Harvard linguistics professor, wife and mother of three adult children. From her first symptomatic experiences to the wide array of challenges brought on throughout the disease's progression to full blown dementia readers are brought to laughter and tears in a very true to life fabricated version of AD.[1] What's interesting about Alice's story, and perhaps why the character appeals to such a large audience, is that she is faced with AD when she is in the prime of her life and career at only 50 years old. AD is traditionally associated with older people, people who are retired or considered frail and elderly so this may leave readers curious as to why then Alice Howard at 50 years old begins forgetting how to get home from work or finds herself tearing through kitchen cabinets looking for her car keys only to realize they cannot be found there because she was in her neighbor's house not her own. Alice's character portrays early onset AD, as opposed to sporadic AD which strikes people after the age of 65. Early onset AD is known to occur when people are in their 40's and 50's but is far less common than sporadic AD, making up less than 5% of all Alzheimer's cases.[2] In sporadic AD, dementia symptoms tend to onset after the age of 65. So while many of the struggles Alice Howard and her family face in the book are common to all people with AD regardless of whether it is early onset or sporadic, Alice experiences the disease at a younger age than 95% of all people with AD.

The prevalence of sporadic AD has climbed to an all-time high and will continue to grow and devastate those whom if effects if changes are not soon made.[3] The large majority of the people who will get AD will be those who have survived long enough to enter into late adulthood. Today this cohort of people reaching later adulthood is far larger than it was just about 70 years ago. The advances brought about by public health, science, and technology have allowed for an increase in life expectancy and a decrease in infant mortality.[4] As of lately the population of older adults across the globe has grown rapidly and continued, significant growth is expected into the foreseeable future.[5] In the US, life expectancy for men born in the year 1900 was 46.3 years and for women 48.3 years, by 1997 life expectancy climbed to 73.6 years for men and 79.2 years for women.[6] This significant achievement was made possible by the rapid advances in science and technology following WWII, as well as by the expansion of US public health initiatives during the 1900's.[7] Various public health developments and enforcement efforts that occurred during the 1900-1999 time period have enabled our population to survive to an older age. Examples of such achievements include; the development of vaccines for polio, small pox and other communicable diseases, sanitary advances in water treatment and sewage removal, improved food safety and refrigeration, animal control laws, advances in family planning and prenatal care, and education about tobacco risks.[8]

Since the turn of the century, the spike in longevity has leveled off and average combined life expectancy today is estimated at just over 78 years of age.[9] As more people are living and living longer than ever before society is faced with a demographic transition unlike any it has ever experienced.[10] Extending the average life expectancy has created changes in cultural norms and redefined concepts of wellbeing as they apply to health and aging. Despite efforts to avoid mortality for as long as possible, old age in the US is still highly stigmatized.[11] Trends in the

American marketplace have influenced the ideal that aging ought to be avoided by creating a vast array of products and services marketed to slow the aging process. Consumerism has not yet achieved the elimination of the human body's innate tendency to age, emphasis on wellbeing and healthy lifestyles however may slow aging, or at least promote a means to embrace the process more gracefully.[12] Concerns pertaining to a large aging population raise ethical imperatives on multiple levels. Points of contention include how will this population be cared for, what are the financial implications for this population and what ought to be done regarding resource allocation.[13] These concerns are present solely based on a growing population but concerns do become further problematic as health complications arise.

Contemporary ethos about health status likely stemmed from The World Health Organization's constitution which was written in the late 1940's. Within its charter a high set of global standards were established when health was defined as, "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmary." Additionally, it was declared that every person has a right to the highest possible standard of health.[14] Founded in 1948, the WHO was conceived in the midst of a century that would witness the average life expectancy of Americans increase by over 25 years and its standards have impacted all health related discourses. Although it has been over 60 years since this declaration was written the WHO has not made any changes to its initial definition of health, or to the standard to which all people are entitled to health. The Organization has held tight to its original ideals on health despite criticism of the definition, and the undeniable changes that have since occurred in factors that negatively affect health. Criticism of this definition of health have been prominent in scholarly literature where the definition and its standards have often described as unrealistic and too lofty to actually be achieved.[15] Bioethicist and co-founder of the Hastings Center, Daniel

Callahan is among the list of critics of the WHO's interpretation of health. Callahan credits the WHO as a major source of contribution to the unsustainable factors present in today's healthcare systems. He highlights unsustainable factors such as an endless search for medical cures and unwillingness to accept aging and death as a natural and inevitable part of the lifecycle. These factors, according to Callahan, have stemmed from this all-inclusive definition of health which has, perhaps unintentionally, made it the norm for human beings sense of self and morality to be completely dependent on their embodied abilities and state of health.[16]

As the population with high health standards ages it is necessary to explore existential, theoretical, empirical and other aspects related to advancing age because as positive as living longer may seem, there are also associated consequences. As members of the US baby boom generation are beginning to reach traditional retirement age, some are faced with the task of deciding how to fill their days as their careers come to an end yet their bodies and minds remain vital and engaged. The time between this fondly awaited third age and the lurking, dreaded fourth age, when frailty sets in, is undetermined. Some critique whether there is plausibility to the theory of the third age or if it is just a life stage that some happen to stumble upon if good health and prosperity allow. Others have theories about the meaning of old age and to which limit the human life span ought to be enhanced.[17] Harry Moody describes four scenarios regarding how the life span ought to potentially evolve into the future. The first, prolongation of morbidity contemplates putting off death for as long as possible even when quality is compromised. The second scenario, compression of morbidity, envisions working to promote optimal health within the current fixed life span. Thirdly, prolongevity imagines extending the life span beyond what is currently feasible by approaching aging as a curable illness. The forth scenario referred to as recovery of the life-world, takes a socially considerate approach to

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considering the life span based on what is best for the collective society.[18] Unique issues will be

raised depending on which direction the future of aging heads.

It is essential to consider that as people are living longer lifespans, a statistically

significant portion of people are spending many of these years navigating complex health

statuses brought about in part by chronic conditions. Chronic diseases are the leading causes of

death across the globe today, often yield in a slower dying process with more years marked with

chronic health issues and disability, and are associated with high healthcare costs.[19] Chronic

diseases, encompass an array of conditions that require continuing medical attention and endure

for at least one year, most often longer or indefinitely. In most cases one's ability to perform

activities of daily living are impaired by these conditions and not uncommonly they limit

independence and can be associated with chronic pains, all factors which can hamper quality of

life.[20] Over one quarter of Americans are currently living with more than two chronic diseases

making multiple chronic conditions (MCC) a new focus for the Department of Health and

Human Services and other agencies involved in the care and treatment of chronic illness. Having

MCC complicates health status and physical functioning even more so than having one chronic

condition alone.[21] The CDC estimates that approximately 75% of all annual healthcare spending

in the US is related to chronic diseases. In 2010, 86% of the healthcare budget was used to treat

people with MCC. Additionally, high costs not directly related to healthcare are also associated

with chronic diseases. These indirect costs include lost productivity, specifically wages lost due

illness, disability or early death.[22]

Slight variations are found in rates of occurrence among ethnic groups and between

genders but chronic diseases significantly affect people of all ethnic and socioeconomic groups.

While chronic conditions are known to occur during all ages of the life cycle, they are most

commonly found in people over the age of 65. In the 65 and over age group 85% of people are found to have at least one chronic disease.[23] AD is among the list of prominent chronic diseases that occur during later adulthood, others include heart diseases, diabetes, hypertension, chronic respiratory conditions, arthritis, stroke, and cancers.[24] The prevalence of AD today is to some degree directly related to the increased population of older people. AD is now the sixth leading cause of death and the most expensive disease in the country.[25] It progresses slowly as the disease process begins years before the onset of dementia symptoms and in some cases symptoms of dementia never occur despite the physiological evidence of AD. The mild stages of AD consist of the time before the onset of dementia. The ability to identify the mild stage offers a unique and potentially vital time period because if, and when, dementia symptoms onset they are irreversible.[26] The mild stages impact areas of clinical care, research and public health and the issues associated with the mild stages are related to both bioethics and neuroethics.

A. Bioethics and the Mild Stages

The mild stages of AD have only become evident to the human eye in recent decades. Although these stages are the first to occur biologically, they are not marked by prominent outward symptomology as most indicators of this stage occur only internally or do not disrupt people's capacity for daily functioning.[27] Knowledge that the pathology of AD occurs internally years prior to the onset of dementia has opened up new doors of possibilities offered by this unique time period to the people who have AD, their companions, clinicians, researchers and perhaps the future trajectory of the disease.[28] This may sound optimistic about a disease which there is traditionally not much to be optimistic about but as will become clear, the earliest stages of AD may be an important key to various positive advancements in managing the condition. Embracing the possibilities of the preclinical stages, rather than focusing on the possibilities of a

future with dementia may promote various improvements to individual quality of life and societal wellbeing. Three general health related disciplines that all have distinct purposes, goals, and ethical approaches come into play during the mild stages of Alzheimer's disease; clinical care, clinical research, and public health. While these three distinct areas of healthcare often operate in isolation from one another, here they collide and ought to be considered in collaboration to efficiently utilize the opportunities offered by this stage.

Clinical care is the healthcare discipline perhaps most commonly thought of by the general public, it is the care that occurs within a therapeutic relationship between patients and their physicians, or other clinicians, with the purpose of providing direct benefit to the patient and avoiding harm regarding a particular malady.[29] Clinical research refers to scientific investigation performed as per a protocol intending to advance knowledge rather than directly benefiting the human subjects involved.[30] Clinical care and research have withstood a long and complicated history associated with human harm, public outrage, and moral inquiry over what to do as a result and in light of how to move forward. A long compilation of issues have made clinical care and research a major focus of bioethics today.[31] Clinical ethics emphasizes trust, veracity, transparency and fairness among its multiple approaches to ethical practice. Research ethics holds a high regard for morals and the fair treatment of human subjects but its ethical codes and guidelines promote fairness between researchers and human subjects in a different fashion than is standard in therapeutic relationship in clinical care. Although both areas have come to hold autonomy as an ethical focal point, full disclosure and confidentiality are not the prime tenants of research as they are clinical care. Public health is a separate branch of healthcare whose primary focus is on population health.[32] Like clinical care and research, public health has a long and complex history dating back to Ancient Greek times. Despite this, public

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health has become a well-established field whose professionals provide valuable, cost effective services related to the prevention of disability and disease, and the promotion of health among population groups.[33] Ethics is a concern for public health but there remains debate about what ought to be the primary focus of public health ethics and how to appropriately navigate individual autonomy when the public good is at risk.[34] These three discourses have contributed greatly to the state of the world's health today and despite often operating independently it is not unusual for issues pertaining to public health and research to find their way into the clinical care environment. Throughout this chapter it will become evident that the mild stages of AD have prompted convergence among these three distinct disciplines as well.

Scientific advances have taught us a lot about the aging process. Particular to AD we have come to realize that the human brain can maintain healthy function as it ages and severe cognitive deficits do not result naturally from the aging process but as a result of illness and injury. Dementia, of any type, is not a direct result of aging and is always associated with some type of pathology. Aging does however remain the biggest risk factor for developing AD and Alzheimer's related dementia.[35] This became clear as people began living longer and the prevalence of AD became increasingly predominant and more widespread. These trends prompted more clinical interest in the condition and raised much curiosity among researchers about its causation and potential for treatment and cure.[36] For many decades diagnostic standards were not well established and were limited to a probable diagnosis when common symptoms were exhibited and other attributable diagnoses were ruled out.[37] Until only recently, a definitive diagnosis of AD could only be made through post mortem exams.[38] For these reasons, the lack of effective treatment options and reasons associated with stigma, disclosing a

probable diagnosis of AD directly to the person experiencing dementia was not standard practice despite the high priority of patient autonomy in healthcare.[39]

Autopsy is no longer the only means to confirm the physiological indication of AD. Specific biomarkers indicative of AD can be identified in vivo through positron emission tomography (PET) and magnetic resonance imaging (MRI), and in the laboratory through the analysis of cerebrospinal fluid (CSF). These types of biomarker identification and interpretation are relatively new as they have only became evident to researchers in 2007. Thus, their analysis and utilization is not yet standardized and used most commonly in clinical research at this time.[40] Genetics have also come to play a part in identifying a biological predisposition to Alzheimer's disease yet a general discussion about genes related to AD tends to cause some confusion if the difference between familial AD and sporadic AD is not clearly understood.[41] The only situation in which genetic mutations determine with certainty AD will develop is related to familial AD, a form of early-onset AD making up only 5% of cases. Researchers have linked genetic mutations, such as apolipoprotein E-e (APOE-e4), to sporadic AD but these genetic indicators only identify an increased risk to potentially developing AD, they do not predict with certainty the condition and its symptoms will develop.[42] The ability to identify Alzheimer's pathology without brain autopsy has also created the realization that this pathology can be present years prior to the onset of symptoms and in some cases the pathology is present yet symptoms never onset. This preclinical stage of AD is an asymptomatic time when there is said to be a biological susceptibility to dementia that can only be identified through testing and imaging.[43]

Beyond asymptomatic AD, the mild stages of Alzheimer's also includes situations in which people experience early, and only relatively mild symptoms of the disease. This early symptomatic period, also called predementia, consists of MCI, a condition which could progress

onto full dementia or could remain as MCI throughout the remainder of one's lifetime. MCI can be as perplexing to comprehend as preclinical AD because a slight degree of cognitive decline is expected with age.[44] Clinicians must determine if such slight cognitive declines are consistent with normal aging or if they are beyond the normal expectation and related to AD. Furthermore, cognitive impairment can manifest as a result of other medical conditions and factors such as head traumas and substance use, therefore when cognitive impairment is not in line with normal, age related cognitive decline other causes must be ruled out before a diagnosis of MCI due to AD can be appropriately made.[45] MCI causes issues related to memory which are so slight in nature that the deficits are typically only noticed by the person experiencing them or those with whom they live. MCI does not interfere with one's ability to perform activities of daily living or ability to navigate themselves within public. There are currently no pharmaceutical treatments to reverse MCI or prevent it from progressing onto dementia, and likewise no pharmaceutical means of preventing preclinical AD from progressing to MCI. Studies do indicate that biomarker results can be used in conjunction with a diagnosis of MCI to predict the rate at which symptoms might progress to dementia. At this time such projections can only be most accurately made by very skilled clinicians and are not yet standard practice in traditional clinical care.[46]

The mild stages of AD, particularly the mild stages of sporadic AD, have caused concern related to uncertainty. While uncertainty is always present in all aspects of life, uncertainty in healthcare raises vast unease.[47] The concept of uncertainty is expected and accommodated for to some degree in clinical research but uncertainty in clinical care tends to become more unsettling. This perhaps explains why diagnosis of AD in the mild stages has been most commonly utilized in research despite having the potential to positively impact patient lifestyle changes which may have clinical indications. Benjamin Djulbegovic finds that when clinicians clarify uncertainties

better care is provided individually and across organizations.[48] Uncertainties related to the mild

stages of AD can be related to genetics, biomarkers, lack of effective treatments, and unproven

methods of prevention. Frustration also likely surrounds the lack of effective treatments despite

numerous attempts in drug development. Researchers continue to seek pharmacological

advances in the area of AD. Some hypotheses in the area of dementia prevention are beginning

to show promise but the precise ability to understand and relay uncertainty surrounding genetic

and biomarker prediction would require education to all clinicians followed by the time and

patience clinicians would have to exert in order to relay this information onto their patients

efficiently.

Generally, the full disclosure of diagnoses has been standard protocol in clinical care

based on patient rights to autonomy and the ethics of truth telling in medicine. Traditionally, a

diagnosis of probable AD was considered a common exception to this standard by many

healthcare providers based on the fact that patient competency was usually diminished by the

time dementia was prominent enough to warrant the probable diagnosis.[49] The early detection of

biomarkers has opened up the possibility of disclosure prior to impaired capacity but disclosing

such a diagnosis remains an area of contention. Currently, the diagnosis of preclinical AD is

only used for research purposes and it is often part of the research protocol that patients are not

informed whether or not they test positive.[50] Full disclosure at the early stages of AD is not

standard even when there are some clinical applications as is the case with MCI.[51] There are

significant ethical concerns associated with disclosing a biological susceptibility to dementia

when there is no therapy available to modify either AD or dementia.[52] The concerns include

philosophical considerations pertaining to selfhood, particularly questioning if the self in the

early, pre-dementia stages of AD will be the same self as the one existing in a state of

dementia.[53] These philosophical concerns turn concrete when an early diagnosis may lead to preemptive suicide and drastic reconsiderations of advanced planning.[54] Other concerns include issues associated with stigma and how society may limit those who have the potential to develop dementia.[55]

B. Neuroethics and the Mild Stages

The significant technological advancements that occurred as the calendar turned to the 2000's not only gave people more insight into the human brain but also prompted people to ponder about their meaning and insinuations. For up until this time the brain and nervous system remained among the most mysterious aspects of the human body and while this perhaps remains true today more has become known in the past two decades than was ever known before.[56] The advancements which opened up the potential for an early Alzheimer's diagnosis also contributed to the development of a new and unique field of ethical inquiry, neuroethics. This is especially interesting because while AD in general raises unique neurological issues, the mild stages remarkably expanded the realm of neuroethical contemplation.[57] Scholarly interest heightened surrounding the advances being made in neuroscience and their associated ethical implications not just pertaining to AD but also relating to brain injury and other neurological illnesses, neuropharmacology, neurosurgery, and neuroenhancements to name a few. As neuroscience advanced and technologies now allow for new found insight into the brain and nervous system multidisciplinary interest groups regularly inquire about their associated ethical implications.[58] As a result neuroethics, a two pronged, pluralistic field of inquiry that seeks to examine ethical concerns related to the effects of neuroscience on the brain from an array of perspectives in order to consider the impact neuroscience has on matters of personal care and public good, emerged.[59]

Neuroethics is seemingly similar to bioethics, it is a multidisciplinary field that uses multiple methodologies to explore moral concepts related to the impact of advancing technologies on human nature. While some consider neuroethics a specific branch of bioethics, others however feel strongly that neuroethics is its own unique and independent field.[60] Adina Roskies, the philosopher credited as a forefront pioneer in defining neuroethics in 2002, argues that the unique connection between brain, behavior and sense of self makes the field one of its own despite the similarities to bioethics.[61] The origins and appropriate associations of neuroethics will not be debated here, rather it will be recognized that based on the inherent nature of the two fields bioethics and neuroethics will overlap as they apply to the overarching burden of AD. For example, the mild stages of AD have become fascinating to neuroethics especially as the potential for early disclosure has become possible but when consideration goes beyond just ethics related to the neurocognitive aspects of AD the focus can no longer be specific to only neuroethics. Similar to a dualist perspective on mind and body, neuroethics and bioethics may be two distinct fields but often one cannot, or does not, exist in isolation of the other. This dissertation will touch upon concepts which are certainly neuroethical in nature but the overarching thesis is to consider ethical issues related to AD. Some issues will be specific to bioethics, others to neuroethics but the issues when considered as a whole impact individuals and society to such a degree that movement beyond the labels in a necessity. The ethics of care provides a collaborative framework in which this can occur.

This chapter will consider AD in its earliest, mildest form. This will mean considering factors specifically associated with aging and how aging relates to clinical ethics, neuroethics, research ethics, and public health ethics. For some people, the mild stages of AD holds no meaning, the presence of biomarkers are unbeknownst to them, no symptoms are present and

there is the potential that this remains the case indefinitely. For others, the mild stages maybe be marked with mild cognitive impairments that produce anxiety about the possibility of a future with dementia. Knowing biomarkers or MCI are present may motivate people to adopt lifestyle changes that promote cognitive health and the identification on early pathophysiology may provide researches with new avenues to explore treatments for a disease that has become devastating on both personal and societal levels. Within the ethics of care framework the mild stages of AD can be incorporated into a larger plan to promote positive influences on personal and public good despite the potential for progressing to advanced dementia. The impact of early diagnosis for patient care will be considered through the lens of relational autonomy and the benefits of early diagnosis for the public good will be considered through the lens of social responsibility.

II.   Relational Autonomy: The Impact of Early Diagnosis for Patient Care

The awareness that all humanity is interrelated can be traced throughout history. From a physical perspective, the notion of the common heritage of humankind resulted from attempts to legally sort the common physical, material world in which all humans live.[62] It was eventually agreed upon that the depths of the ocean floor and the heights of the moon and stars as well as various ancient phenomena, such as the Egyptian temples belonged not to one geographic local but to all of humanity. The common heritage of humankind became more pertinent as the people of the world became more interrelated as a result of modern globalization. With advancing globalization it has been established that the global population not only shares an interest in the physical world but it also shares a common moral foundation as well.[63] The common morality is a general and basic set of moral tenants shared by virtually all people and societies who seek to

maintain human flourishing.[64] The common morality has influenced the field of bioethics in its pursuit to examine issues of science and technology and their influence on humanity. That there is a common morality shared between most people reinforces the extent of human interrelatedness.

Beyond the common morality, moral norms tend to less generalized and vary from culture to culture, country to country and even person to person.[65] A multitude of factors can influence how morality is defined and for some time philosophical input tended to be limited to intellectual and academic discourse. Advancing healthcare and technology, according to some, revived the field of moral philosophy by creating concrete issues that needed philosophical contemplation to steer their appropriate utilization.[66] At the basis of moral scrutiny lies issues such as moral status, personhood, self, identity, and agency. All are notions that have influenced and guided concepts of autonomy. Moral status is at the underpinnings of morality looking at who, or what, is worthy of moral regard. Typically, moral status is granted to all human beings but different theories suggest when an organism that possesses human potential actually attains moral status. On one end of the spectrum, some theories assert that moral status begins from the moment of conception while theories on the other extreme of the spectrum assert that full moral status is not achieved until full adult development is reached.[67]   Potentiality is a theory that argues a newly formed embryo has a right to moral status merely based on its having the potential to become human. Graduality in contrast theorizes that moral status is attained gradually and full moral status is not attained until adulthood when full mental capacity is developed.[68] Moral status debates are especially relevant to beginning of life issues, associated arguments are commonly made in ethical debates about abortion and more recently have been raised about the use of embryonic stem cells.[69]

Moral status is different than personhood but related in such a way that it gives rise to the potential for personhood. From personhood, or the condition of being a person, arises the concepts of agency and identity, concepts that have impacted the development of autonomy as a main consideration in bioethics. Theories of personhood are numerous and have been debated on theological and philosophical levels for much of time. Defining the concept has lied at the heart of ethical deliberations and a universal definition has not been reached. Some theorists base personhood on biological components, some base personhood on cognitive capacities, or on various other notions.[70] Tom Beauchamp has claimed that defining theories of personhood have failed to be helpful in normative analysis because so much time is spent on debating theories that focus on what ought to be done about specific issues becomes less relevant.[71] Moral status and personhood can be applied to concepts related to dignity. In regards to AD, some may argue that moral status, and/or personhood, and thus, dignity decline or are all together lost with advanced dementia.[72] Such notions will be addressed in the next chapter but as applied to the mild stages of AD it can be assumed, regardless of theory preference, moral status, personhood and dignity remain unaffected by the mild stages of AD. Some may argue that this is untrue for certain persons based on profound mental or cognitive impairments that may have jeopardized these elements prior to the onset of advanced dementia. Such claims will be ignored in this work and it will be maintained that all adult age persons have attained moral status and personhood and possess dignity.

Personhood within the field of bioethics, like autonomy, has traditionally tended to be based upon the traditional Kantian concept of persons being free agents. Thus personhood and autonomy become focused on agency and an individual's ability to exercise choices, freedoms, and rights independently.[73] Personhood, when more liberally considered, becomes more focused

on self-identity than on agency.[74] Ruud ter Meulen argues for the adequacy of this socially

constructed concept of persons within the domain of bioethics. Identification, identity, and sense

of meaning, he believes, are especially important in a model of autonomy for people with

chronic conditions.[75] Relational autonomy is reflective of this socially constructed model of

autonomy which is applicable to AD. In the mild stages of AD agency will remain in-tact but at

some point if the disease progresses towards the severe stages personhood related to agency will

deteriorate. Personhood related to self, however may not have to deteriorate even when

dementia becomes advanced. Hilde Lindemann considers the claim that personhood becomes

lost with advancing dementia but refutes that such claims allow for these people to be neglected

or cared for less well than those whose personhood cannot be questioned.[76] She makes the claim

that based on our shared human condition it is morally correct to assist in holding these people in

personhood and justifies this claim by describing how each person develops personhood initially

based on the narratives that occur between each of us and the individuals and societies by whom

we are surrounded.[77] Lindemann reflects upon a socially constructed concept of personhood and

infers that personhood, like autonomy within care ethics, is relational and to some degree

dependent on our surroundings. Shifting gears from traditional perspectives of complete

independence towards perspectives of interdependence, will positively impact and promote the

early diagnosis of AD when factors beyond the medical diagnosis are considered and efforts are

made to preserve quality-of-life.

A. Refocusing Medicalization to Include Psycho-Social Considerations

An interesting sociological trend began to emerge along with the shift towards modern

medicine in the late part of the twentieth century in which issues that were not necessarily

medical issues began being treated as such. Medicalization, as it is referred to, was first noted in

the areas of psychiatry where once only socially linked issues such as deviance and hyperactivity started to be treated as medical conditions.[78] Over the years other conditions that were historically not considered medical, for example menopause, or issues never even heard of before, for example post-traumatic stress disorder (PTSD), have made their way into medical jurisdiction. Some conditions have become completely medicalized while others are medicalized only to a certain degree but regardless concerns have been raised about the implications of medicalization.[79] Included among these concerns are the expansion of and focus on pathology, increased medical authority, excessive promotion of pharmacology, and social control.[80]

Interestingly, the contemporary goals of medicine were devised by the Hastings Center over twenty five years after the arrival of the medicalization phenomena. These goals include aspects of cure, treatment, and care. They are not established in a hierarchy and can be pursued in tandem as each goal does not have to be focused on separately from the others. Despite the elaborate focus of these goals, cure does tend to be the most emphasized contemporary goal of medicine for both physicians and patients alike as both parties tend to place more emphasis on efforts to cure, or at least prevent, mortality for as long as possible.[81] For this reason approaches to many conditions are heavily focused on the biomedical model of disease management which primarily seeks pharmaceutical and medical interventions to treat disease. For some diseases and conditions medicalization is beneficial because it provides effective treatments and cures. When effective treatments and cures are not evident, this approach can be negatively focused because it places primary emphasis on the dysfunction and limited abilities created by the medically unmanageable condition. Aging has become highly medicalized meaning the aging process has become primarily viewed from the perspective of health and illness.[82] Cognitive and physical decline in older people are addressed as a medical indication and attempts are made to remedy

the declines rather than embrace them as a natural occurrence as was done in the past. Naturally then, because of its association with aging, AD has become medicalized.[83] While some Alzheimer's associated issues cannot be separated from medicine other associated issues may not be best addressed through a medical model for as of yet medical type interventions have failed to effectively impact AD. Such failings have produced frustration with AD.

Biomedical approaches have come to be viewed as negative in that they focus on dysfunction and what has been lost.[84] Medicalization can be expanded when psycho-social considerations supplement the biomedical approach. Bio-psychosocial approaches to medicalization are increasing in popularity because they more positively focus on people's abilities. These models consider not only the evident disease processes but also considers individual psychological and social factors, factors which are crucial because they significantly impact people's lives. The bio-psychosocial model is especially applicable to AD because the condition is closely associated with cognition. Care can be improved when emphasis is placed on existing abilities rather than on what has been lost to the disease, or what may potentially be lost if it progresses.[85] The mild stages of AD can be utilized to further explore first hand, personal accounts of the ways in which the condition impacts those who are experiencing it. Such insight could revolutionize thinking related to AD because most of what is already known about the lived experiences of AD has primarily been based on second hand accounts after the onset of dementia.[86] More precise understanding of the lived experience of AD in its mildest stages offers insight about how quality of life and wellbeing is best preserved. [87] Furthermore, the mild stages provide an opportunity to gather details about individual personhood and identity that will become helpful to ensure that each person's unique personhood and identity can be maintained by others if and dementia occurs. Psycho-social assessment during the mild stages of

AD will enable better patient care throughout disease progression. [88] Focus on psychosocial assessment during the mild stages of AD will expand upon the benefits of personal narratives and care planning.

i. Benefits of Personal Narratives

When AD is considered a strong association tends to link impending cognitive decline with loss of agency and identity. While cognitive decline does eventually damage agency, it does not have to destroy identity. Attention to psycho-social factors helps ensure identity and personhood are maintained throughout the disease process.[89] Psycho-social factors are most accurately described when provided by the actual individual being considered. Because the mild stages of AD are not marked by dementia, the symptom which extinguishes cognition, this time period can be utilize to collect the most accurate individual accounts of personal identity. Personal narratives are simply the story of one's life, how an individual has made sense of the occurrences of their lives, and the precise details of what makes each person a unique individual. Narratives have been used in the area of human services for some time now but only recently have clinicians realized their usefulness in patient care.[90] Narratives arise based on memory, what is remembered and how past events are recalled. In Western culture today memory is highly regarded and closely associated with self and identity.[91]

Memory inhibiting illnesses, like AD, threaten the integrity of personal narratives. Many of the narratives that have thus far allowed for insight into life with AD have occurred as second hand accounts, most of which are provided by caregivers. Perspectives from close observers of the disease are valuable but firsthand accounts of the Alzheimer's experience offers unique benefits leading to better comprehension about positive coping strategies which can lead to improved patient care and quality of life.[92] Understanding how one perceives their own quality

of life is best determined through first-hand accounts meaning that it is best to have quality of life discussions with the person living the life being probed. Studies have shown that second hand accounts, asking someone other to the person living the life being probed, consistently rate the quality of life experience lower than the actual person does.[93] Based on a similar notion, that the best way to understand the lived experience of the mild stages of AD is to seek understanding from persons actually in the mild stages. A unique study concluded in 2004, it examined the subjective experience of 13 people living with early AD and observed that resiliency exists within people diagnosed with impending memory issues and that upon diagnosis they practice efforts to preserve their identity. This is the opposite of the typically assumed reaction to an early diagnosis of AD which assumes that those diagnosed will react with devastation and despair.[94] Although this study was small it indicates the significance that personal narratives offer to better understand aging and furthermore indicates the marginalization that occurs to this population when personal narratives are overlooked.[95]

Resiliency when faced with an Alzheimer's diagnosis is evident through the pages of the book, *Losing My Mind An Intimate Look at Life with Alzheimer's Disease*. In this autobiography, Thomas DeBaggio attempted to overcome the silence typically associated with AD as he wrote this book very soon after being diagnosed at age 57 with early onset AD. His work is an original, first-hand account of the experience of someone in the milder stages of the disease. When DeBaggio got the diagnosis of AD after complaints about subtle yet steady memory issues, initially only obvious to himself, he elected to write his narrative intertwined with factual information about AD. This unique narrative recalls events of his past, and explains his perception of present events related to life with early onset AD as they unfolded.[96] First-hand narratives provide an enormous amount of insight into the lived experience of AD. Appreciating

lived experiences are consistent with psycho-social approaches to disease and would not be possible without the disclosure of a mild stage diagnosis. Medicalized aspects of disease management may also stand to benefit from these narratives when pharmacology advancements are made in the treatment of AD in determining the efficacy of such pharmaceutical products on quality-of-life.

ii.   Benefits of Advance Planning

The idea of advance planning began making its way into personal and professional conversations about healthcare in the 1980's. As life saving measures became more sophisticated and readily available it became clearly evident that despite their ability to save and extend life these measures also intervened at times when death may be the preferable option to a longer life dependent on machines to provide basic bodily functions for an indefinite amount of time. Cases of people, young and old, involved in tragic situations made their ways into courtrooms and media outlets to determine what to do in these tragic situations where once competent adults were suddenly brain injured, lacked cognitive capacity and their bodies were dependent on machines for the basic functions of breathing and eating. The most famous of these early cases were Karen Ann Quinlan and Nancy Cruzan, woman in their 20's.[97] Years of legal battles between these women's families, and families of other people in similar situations, eventually led to the urgency to promote advance planning, an idea that became backed by law when the Patient Self Determination Act of 1990 (PSDA) was passed by congress.[98]

Advance planning is simply guidelines people provide about their future wishes for healthcare for if and when they may be in a situation where they have lost cognitive capacity to make medical decisions for themselves. Informal advance planning occurs when discussions about future care wishes occur between a person and their medical providers or a person and

their families. Formal advance planning involves the completion of advance directives, legal documents that typically consist of proxy directives, a durable power of attorney for healthcare, and treatment directives, a living will.[99] The PSDA expanded awareness about advance directives by requiring all healthcare facilities receiving federal funds to ask patients upon admission whether or not they have advance directives and ensure each patient is aware they have the right to complete the directives.[100] Both informal and formal forms of advance planning have become legally and ethically acceptable standards in healthcare. These are practical methods of expressing the importance of autonomy in healthcare as individuals are able to capture their beliefs whether they be of cultural, religious or personal preference when they are in a competent state so that they may be utilized later when cognitive capacity may become compromised for whatever reason.[101] While advance planning primarily developed in the mindset of individual autonomy, relational influences are clearly visible as planning gives one person the opportunity to have their views expressed and understood by the people with whom they will rely on for care. Furthermore, advance planning will help maintain dignity when individual desires are respected.[102]

Despite the legal attention given to advance planning and the media attention to cases that have supported their necessity and value, estimates indicate that formal advance planning only occurs in 18-30% of all adults with only 1 in 3 chronically ill people having completed them.[103] Clinicians tend to claim time constraints when asked why more effort is not given to discussing their completion and patients tend to have a larger variety of excusing that include simply putting it off or deferring to family. The urgency to complete advance directives or at least have informal advance planning discussions with clinicians become heightened with AD. Most sources urge that people in the mild to moderate phases of dementia still retain the capacity to

state their wishes regarding care planning yet when AD is evident efforts to participate in care planning activities are often avoided.[104] This becomes unfortunate when people endure the severe stages of AD and their surrogates are faced with making an onslaught of sensitive medical decisions.   The mild stages of AD ought to be embraced as a time with heightened urgency to address both formal and informal types of advance planning. With no cognitive decline or only mild cognitive impairments and the more pronounced possibility that sensitive medical decisions may have to be made in the future when cognitive decline actually prevents one from self-determination, the mild stages offer a time span in which an individual's particular views on their own personhood and identity can become clearly understood so they may be best preserved and carried out into the future.

B. Preserving Quality of Life

Through the previous exploration of medicalization it is evident that the medical model of care primarily focuses on disease and disability. Health then from the perspective of the medical model becomes defined as, "the absence of disease or disability."[105] A similarity occurs between this definition of health and that of the WHO ought definition, as both consider that there to be a complete absence of all maladies in order for one to fit the image of health.[106] This becomes problematic when compiled with the knowledge that so many people today live with chronic illness for much of their lifetime. Simply considered, only 15% of the country's population over age 65 may be considered healthy as it is known that at least 85% of this population has at least one chronic condition.[107] This 15% does not account for people in this age group with disability or ailments not failing into the chronic illness category therefore it is likely a safe assumption to conclude that from the perspectives of the medical model or the WHO that most of the country's population is not healthy. Such generalizations are harmful to

individuals and society. Many older Americans tend to consider themselves healthy even when disease is present, just as many people who live with a disability do not consider themselves unhealthy.[108] Fortunately there are alternatives to these all or nothing approaches to health in which health is more loosely defined and emphasis is placed on functional status and comfort.[109]

Ideals about health are closely related to culture and their most popularly accepted definitions establish a cultural norm. Cultural norms, once established are not easily changed but shifts have definitely occurred throughout history.[110] In the times of antiquity health referred primarily to harmony and balance but as humans became more knowledgeable about biological processes the concept of health shifted. The idea of fighting illness was introduced by Francis Bacon during Renaissance times and remained associated with notions of health for centuries.[111] Today health as a cultural norm has become very closely associated with the absence of disease and this is attributed to the advancements that followed WWII.[112] As each day passes further and further from this time period, and as people and society now face the challenges of how to respond to what has resulted from the rapid advances in modern medicine, cultural norms stand to change. Increasing emphasis is being placed on the wellness model, rather than the medical model. Health through the wellness model if defined as, "health promotion and progress toward higher functioning, energy, comfort, and integration of mind, body, and spirit," a definition significantly unlike the other models discussed herein.[113]

The wellness model is positively focused as it does not focus on what is lacking but rather on building up resiliency to facing existing or impending disease and disability. Wellness approaches to aging are imperative to ensure the population remains healthy for as long as possible and learns how to adapt to the currently unavoidable bio-psycho-social declines that will inevitably occur with age. A study in New Zealand by Christine Stephens, Mary Breheny, and

Juliana Mansvelt indicates that people do not solely focus on physical abilities, or lack thereof, as they age but rather base individual notions of wellness on a variety of capabilities in which they find value.[114] Capabilities vary from person to person and without directly associating with people on an individual basis it must be difficult to assume what each person views as a valuable capability. This in turn makes capabilities difficult to empirically measure. Another factor that dramatically impacts wellbeing, and is difficult to measure empirically as it cannot be determined without direct discussions with individuals is quality of life. Quality of life is a value judgement that people have about the state of satisfaction with their current life situations. From an ethical perspective assessing quality of life is a vital part of clinical care and must be attained directly from the person experiencing the particular life to be most accurate.[115]

Mainting quality of life and wellness are promoted by the contemporary goal of medicine referred to as, "the prevention of disease and injury and the promotion and maintenance of health."[116] This goal realistically recognizes human finitude but maintains that medicine does not have to be completely focused on rescue in times of crisis by emphasizing that there is value in disease prevention and health promotion. Prevention can take place through public health efforts but also occur through individual efforts.[117] Successful examples of disease prevention and health promotion are evident in efforts to cease smoking to reduce respiratory illnesses and lung cancers. While it took public health efforts to educate the population to the risks of smoking and benefits of caseation, it took individual effort to actually yield positive results. Advocates of Alzheimer's research feel hopeful that sometime soon there will be a way to prevent the disease. Additionally, various studies are preliminarily indicating there may be methods of stalling the onset of dementia. If efforts to delay the onset of dementia can be successful it will first mean that people in the mild stages must partake in the recommended

measures of preventing the onset of dementia. Such efforts will promote wellness and preserve quality of life in the face of potentially looming dementia and can impact cognitive health as well as emotional health.

i. Cognitive Health

In 2006, a committee made up of representatives from the National Institute of Health, the National Institute on Aging, the National Institute of Mental Health, and the National Institute of Neurological Disorders and Stroke, defined cognitive health related to aging as, "not just as the absence of disease, but rather as the development and preservation of the multidimensional cognitive structure that allows the older adult to maintain social connectedness, an ongoing sense of purpose, and the abilities to function independently, to permit functional recovery from illness or injury, and to cope with residual functional deficits".[118] Prior there was not a universally acceptable definition of cognitive health despite the heightened focus on the issue due to the upwelling incidence of dementia. The definition established by this committee, known as the Critical Evaluation Study Committee, is in line with the wellness model of care's definition of health in general as it does not focus on disease or disability and acknowledges the value of focusing on capabilities despite deficits. This is encouraging for people in the mild stages of AD as despite having physiological indications of disease and/or experiencing mild cognitive deficits people can still be considered cognitively healthy.

Cognitive health can become threatened by risk factors for dementia and the presence of mild stage AD is certainly the greatest risk factor for dementia, it is also a risk factor that cannot be modified. There are other suspected risk factors for dementia, some of which are modifiable, but in addition to raising curiosity identified risk factors have also caused speculation because they have not yet been thoroughly investigated.[119] Hope lurks on the horizon about the potential

offered by formalized cognitive rehabilitation programs and less formalized activities that may enhance cognitive health by preventing the onset of dementia in people with mild stage AD.[120] Regimens can be designed to maintain cognitive health through diet and exercises that includes both physical and cognitive activities.[121] Such modifications are viewed by some as wellness focused, rather than medically focused, methods of preserving or improving quality of life for aging adults.[122]

Though there has been major advances in neuroscience since the turn of the century, the brain remains a mysterious organ and various functions of the brain as well as pathologies associated with the brain are not yet entirely understood by doctors and scientists. Different theories have been raised as to why the brain responds the way in which it does, or does not in unique instances. The cognitive reserve theory is credited for attempting to explain age related brain response as the theory alleges that the brains of those with higher education, career attainment, and/or more involvement with leisure activities in later adulthood respond more proactively to brain pathology than do the brains of people with less exposure to such factors. The idea that this type of cognitive reserve exists is of interest to some researchers because it could help clarify why some people with advanced Alzheimer's brain pathology never show signs of dementia, or why some live much longer than others before the onset of dementia.[123] Earlier diagnosis of AD will potentially enable more research to be done clarifying the validity of the cognitive reserve phenomena. If the cognitive reserve proves to be true, lifestyle choices would in fact have a beneficial impact on prolonging the onset of dementia even when AD pathology is evident in the body. Such a confirmation could change, or even set, the standards for patient care of early AD.[124]

ii.   Emotional Health

Emotional health, like cognitive health, is an important factor in successful aging.[125] A definition of emotional health that is reflective of the wellness model goes beyond merely identifying that there is an absence of psychiatric illness and more broadly incorporates a person's ability to regulate and identify their own emotions and adapt them appropriately.[126] The deterioration of emotional health is a concern for the entire aging population not just those with AD. As already accounted for, it can be statistically assumed that most people over age 65 will face some type of physical condition. These physical conditions whether they be chronic conditions or disabilities, may or may not be able to be medically managed well enough to avoid negatively impacting individual quality of life. Emotional health may better be addressed and maintained in order to continuously promote positive quality of life even in the face of physical decline.[127] Numerous lifestyle changes have been identified which can positively impact emotional health throughout the aging process. Some changes are consistent with those suspected to improve cognitive health, like diet and exercise and others may include meditation or social interventions. More research is essential to better understand the impact of lifestyle modifications on emotional health but it is clear that better emotional health positively impacts quality of life during later life stages.[128]

Disclosing that someone has the biomarker indications of AD or confirming that someone has MCI rather than cognitive decline consistent with normal aging is associated with the concern that such knowledge will disrupt emotional health causing anxiety, depression, or even suicidal ideation. Concerns about the impact of diagnosis disclosure on emotional health have contributed to the logic some clinicians and researchers provide for not disclosing the diagnosis.[129] Superficially, the thought of suicide by an older person in reaction to a medical

diagnosis may sound extreme but suicide attempts and rates are more prevalent worldwide among older people than any other age group. Trends and behaviors related to suicide in older people tend to be different than that of people in younger age groups and less publicized as well.[130] General studies have found a correlation between diagnosis of physical illness and suicide in the elderly, rates are higher among people with multiple physical diagnoses, and there was no indication that these studies considered AD among the conditions.[131] Studies specific to AD found a significantly low risk of suicidal ideation following an Alzheimer's diagnosis after the onset of dementia. From these studies it has been reasoned that a preclinical diagnosis of AD may slightly increase the risk of suicidal ideation but this still remains unlikely.[132]

Not disclosing a preclinical diagnosis of Alzheimer's diagnosis may actually adversely impact emotional health as there are indications that some people find solace in knowing their genetic risk. This has been especially true for some people with a history of familial AD and people experiencing symptoms consistent with MCI who report that the unknown causes more emotional distress than does either a confirmation or ruling out of AD.[133] Additionally the REVEAL study indicated that adverse psychological reactions are not typically found after the disclosure of AD in its mild stages.[134] Disclosing the results of biomarker testing, regardless of their indications, may in actuality enhance people's emotional health by providing relief to fear and anxiety. Furthermore, knowing that studies that have linked illness with increased suicidal ideation should indicate to clinicians the importance of incorporating risk assessment into their practices and directing patients towards lifestyle changes that will strengthen their emotional health despite the presence of mild stage AD.

Definitions of health, cognitive health, and emotional health that focus only on freedom from disease are negative, harmful to quality of life, and inconsiderate of psychosocial factors.[135]

The mild stages of AD are also not currently consistent with the medical model of disease management because there are not effective treatments and no cure exits. Medicalizing AD is harmful to patient care because the focus becomes fixated on what has been lost or may become lost as the disease progresses. Wellness approaches to disease incorporate psychosocial considerations by focusing on what individuals find important to their lives as a whole. This is especially important to people in the mild stages of AD because when psychosocial factors are considered in conjunction with medical factors the emphasis of care becomes focused on each patient as an individual rather than on the potential to develop a symptom that will strip people of their identity or sense of self. Personal narratives become valuable in learning how each patient identifies themselves and the ideals upon which their sense of self is based. Care planning becomes more important because it intends to help ensure people can maintain their identity when cognition may erode. Although the idea of having preclinical or early AD may seem dreadful measures can be taken to preserve quality of life. Lifestyles that focus on improving or maintaining cognitive and emotional health show benefit to quality of life. Disclosure of an early diagnosis of AD is essential to ensure all of these factors that positively enhance patient care are adequately carried out.

III.   Social Responsibility: Benefits of Early Diagnosis for the Public Good

Ever since chronic diseases replaced infectious diseases as the leading causes of death in the US, disputes occur pertaining to the degree to which each individual ought to be responsible for determinants of their own health.[136] In the past poor health status in much of the world was due to infectious disease. Industrialized nations, like the US, have overcome the enduring devastation associated with infectious diseases and a good deal of this success is associated with

environmental changes made by public authorities; for example the provision of clean drinking water and improved sanitation.[137] Chronic diseases are different from infectious diseases as there are more factors that may be controlled on a personal level to control their onset and intensity. Lifestyle factors that are found to contribute to chronic disease and may be controlled on a personal level include, smoking, excessive drinking, overeating and lack of regular exercise.[138] Consideration of these, and other, controllable lifestyle factors have prompted the debate about to what degree, if any, people ought to be held accountable for their own health.

From a mindset of individualistic, traditional autonomy it may seem that personal responsibility for health ought to outweigh society's responsibility to health, especially when chronic diseases are considered. The ethics of care asserts otherwise as does the Universal Declaration on Bioethics and Human Rights. Through its focus on the interconnectedness of all people and the importance placed on societal wellbeing, the ethics of care insinuates the importance that individual health has on society and the resultant obligation society has in promoting for the health of its members.[139] The Universal Declaration on Bioethics and Human Rights promotes the vital role society plays in health through Article 14, Social Responsibility and Health, which states that there is more than just an individual responsibility to health and that health is the responsibility of all sectors of society.[140] UNESCO justified societal obligation to improve the health status of its members by explaining that there are multiple determinants of health status, many of which cannot be directly controlled by individuals, and although some factors can be controlled through lifestyle choices not all people have the aptitude or abilities to control their lifestyle choices adequately.[141] Solidarity works in conjunction with social responsibility and health to promote health, access to healthcare, and reduction of factors that negatively impact health.[142] Each individual social system then must work to identify what

unique needs face its population and how best to achieve improved health status based on these needs.

Social responsibility differs from public health as the concern is not just with population groups but also includes concerns for individuals.[143] Even as nations fulfill their social responsibilities to the environmental factors that have been shown to improve health, their obligation does not cease. Rather it continues to promote the moral obligation to ensure every person achieves quality of life and dignity to the highest degree possible.[144] Some claim that the response to this ethical charge has been a primary focus on access to healthcare above most all measures. While access is an important ethical consideration in the carrying out social responsibility, other methods of health promotion, such as prevention, may be more cost effective.[145] Clearly AD has become an issue of great enough concern on the individual and societal level that nations ought to be socially responsible for alleviating the burden by ensuring dignity and quality of life are maintained. The US has recognized and is carrying this out through the National Alzheimer's Project Act. This law specifically appreciates the potential offered by the mild stages of AD and acknowledges the potential role early diagnosis may play in identifying methods of inhibiting disease progression.[146] When the mild stages are utilized to expand research initiatives and reduce stigma associated with an Alzheimer's diagnosis, health promotion will occur, social responsibility will be embraced and public good will be stimulated with the ultimate goal of lessening the burden caused by AD.

A. Expanding Research Initiatives

Biomedical research with human subjects has been a sensitive area for ethical inquiry for more than the past half century. Unscrupulous medical experimentation occurred before this time but it was only since the realization of the scandalous activity occurring through the Nazi Medical Experiments that public efforts were made to ensure medical experimental was conducted in a more morally acceptable manner. In response to public outcry prompted by this and other experiments conducted with questionable regard to human subject protection international oversight organizations and national agencies established ethical standards for research with human subjects.[147] Since 1981, in the United States it is the Common Rule that acts as the basic criterion for maintaining ethical standards and research integrity when human subjects and federal funds are involved.[148] The basis of the Common Rule and other standards for ethical research is the promotion of a comprehensive ethical approach to research with human subjects that above all ensures the voluntary consent of subjects and their protection from exploitation.[149]

The aim of clinical research is to improve health conditions through generalized knowledge that is gained through trials with human subjects. Unlike patients in clinical care who are looking for help with their medical condition in the here and now, the human subjects involved in clinical research may stand to gain little from the particular research trial and the knowledge created through their participation is usually focused on helping others in the future. This set up often leads to instances of human exploitation, treating a person unfairly in order to gain benefit.[150] Among the key ethical standards to prevent exploitation is the ensuring unprejudiced participant recruitment and obtaining proper informed consent to ensure participation is completely voluntary. Ensuring that human subject participation in clinical

research was clearly voluntary initially met moral objectives but it was not long before contemplation occurred regarding research with populations that were unable to provide autonomous consent due to questionable capacity for decision making. Populations in question included children, people with mental disabilities, and adults with cognitive impairments, like AD.[151] The ethical standards of past research with people with AD and other related dementias will not be explored here it will rather be suggested that when clinical research pertaining to AD is conducted with people in the mild stages of the disease, the voluntariness of the informed consent process will not be an issue.

The mild stages of the disease may also open up unique opportunities for research. Unfortunately, the past 30 years of Alzheimer's research have been ridden with one disappointment after another. The trials have been unsuccessful in concluding the deliberation between tau versus amyloid as the culprit and/or cure to the disease and furthermore have failed to identify any types of prevention or treatments that offer substantial impact on disease trajectory.[152] Traditionally research focused on Alzheimer's disease has involved subjects that were in more advanced disease stages, after the onset of dementia.[153] Researchers now suspect that the key to curtailing Alzheimer's may be found in the mild stages, particularly during the prodromal phase. Even if cure continues to elude scientists, there is hope that prevention and treatment during the earliest phase may shift AD from a progressive, degenerative disease to a manageable chronic condition.[154] This type of disease shift has occurred with HIV/AIDS. Although HIV/AIDS is significantly different than AD, HIV/AIDS was a major health epidemic in the 1980's. Today through advocacy and research the US, and many other nations, have changed HIV into a manageable, chronic condition where people who have the virus can remain asymptomatic and in many cases avoid progression onto end stage AIDS. As a result, prevention

and treatment have made it less devastating today than it was just two to three decades ago.[155] If AD could remain in its prodromal phase indefinitely, or if the dementia stages become delayed by at least 5 years, the associated personal and societal burdens would be significantly less damaging. Unique approaches to research during the mild stages, including non-pharmacologic research and research that is patient centered may lead to these ideals becoming a true reality in the fight against AD.

i.   Beyond Pharmaceuticals

There are currently five pharmaceutical agents approved by the FDA to treat the symptoms of AD. While these drugs can be helpful in concealing the symptoms of AD during various stages, they are not disease modifying, meaning that do not slow the progression of the disease or treat its underlying cause.[156] The pharmaceutical industry has been successful in developing not only drugs for the symptom management of many conditions but also disease modifying drugs for various medical conditions such as cancers, cardiac disease and some mental health conditions. The industry has become well known for its high costs and high profits. For example, the US pharmaceutical industry spent over 67 billion dollars on research and development in 2010.[157] In recent years, the industry has faced waning productivity due to various factors including high costs, increased trial failures and a disconnect between the industry's business model and research goals.[158] The number of clinical trials aimed at AD are relatively few compared to the overall number of trials being conducted and since 2007 Alzheimer's related clinical trials have had a failure rate of over 99%.[159] Pharmaceutical research and clinical trials focused on the discovery of disease modifying agents are certainly important to the future of AD and public policy is pushing for more Alzheimer's related drug research. As a result ten Big Pharma companies are now working in uncharacteristic

collaboration, rather than competition, on efforts related to Alzheimer's research and development.[160]

There is also an imperative for non-pharmaceutical research to help identify ways to prevent and modify AD.[161] A comprehensive analysis of clinical trials for non-pharmacological therapies with people with Alzheimer's and other related dementias indicates that numerous studies have shown promise in improving quality of life for people with dementia and their caregivers. The analysis concluded that these research efforts thus far have been small or of low quality but that there is good potential for value to come out of larger, higher quality trials focused on non-pharmacological research.[162] Most of this research was performed in people who had already been experiencing some degree of dementia. Because dementia is not reversible, non-pharmacological therapies found to be beneficial at the dementia stage result in symptom management not disease modification. Some researchers are now hopeful that therapies aimed at diet and lifestyle modification incorporated prior to dementia will reduce risk factors to ultimately prevent or prolong the onset of dementia due to AD.[163] Dietary changes and exercise successfully impact conditions like cardiovascular disease and there is evolving indications that they may also positively impact the effects of AD, but more randomized controlled trials are necessary to confirm. Other lifestyle modifications suspected of positively modifying the course of AD are related to reducing chronic stress, increasing personal happiness and maintaining strong social networks.[164] While the general population may benefit in various ways from such modifications those who are aware they have prodromal AD or MCI may be more motivated to incorporate the changes into their lives consistently.

ii. Patient Centered Research

Ethical concerns are prominent in all clinical research with human subjects. The concerns become more complex when research involves AD, even AD in its mildest stages when cognition is not impaired. Anytime research involves human subjects the particulars of participant recruitment should always be carefully considered.[165] Recruiting participants in the mild stages of AD can be difficult because there are no overt symptoms present to indicate one does in fact have prodromal disease. While primary care providers are often valuable at referring potential participants to clinical trials, diagnosing preclinical AD is not standard care so referring people with preclinical AD is difficult. Furthermore, studies suggest that primary care settings tend to overlook symptoms of MCI so even when mild symptoms are reported the process of appropriately directing potential candidates toward mild stage trials is still problematical.[166] Once cognitively intact participants are successfully recruited for mild stage trials, the informed consent process needs to be done meticulously and the potential for therapeutic misconception needs to be thoroughly addressed.[167] Ethical standards suggest that healthy participants should not be subjected to harm in order to advance scientific knowledge.[168] The process of otherwise healthy participants undergoing MRI, CT scans, and spinal taps to identify biomarkers for AD may contradict this standard.[169] Trials targeting the mild stages must carefully consider whether or not biomarker results are kept confidential or disclosed to participants. The emotional health concerns aforementioned arise when contemplating disclosure during research as do concerns about the impacts of stigma when increased philological risk for cognitive decline is confirmed.[170] Concerns pertaining to stigma will be explored in the next section but while stigma associated with AD impacts individuals it is a societal concern as well. Even though participants may be in the mildest stages of AD vulnerability ought to remain an overarching

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concern because the participants are at risk for progression onto more advanced stages of Alzheimer's. These and other concerns must be carefully contemplated when designing clinical trials.

Clinical care settings have begun to identify that when models of patient centered care are adopted quality outcomes and patient wellbeing are improved.[171] As mentioned in chapter one, and will be further detailed in chapter six, patient centered care is a model of shared decision making that puts patients' unique preferences at the center of the patient-clinician relationship.[172] Similar thinking has started to be incorporated into clinical research as a way of bolstering the research establishment from business and ethical perspectives.[173] There is reason to believe that involving the patient more closely in what and how information is disclosed during trials may beneficially address the ethical concerns associated with Alzheimer's related research.[174] The Patient-Centered Outcomes Research Institute (PCORI) was created under the Patient Protection and Affordable Care Act of 2010 to promote research that focuses on not only improving health conditions in the future but also addresses patients and clinicians current needs.[175] Since its formation in late 2012, PCORI has been working to incorporate the dynamic complexities of 21st century healthcare with the needs of patients, clinicians and the research community in a manner which is most ethical and productive to meeting the particular needs of all involved while also attempting to positively impact the future health status.[176] The complexities PCORI seeks to address are the same complexities that have fueled the burden of AD; multiple chronic illnesses, an abundance of treatment options, and a complex healthcare delivery system.[177] Thus, when patient centered tenants are incorporated into Alzheimer's related research ethical design and conduct stand to be enhanced.

B. Reducing Stigmatization

The civil rights movement and the emergence of various civil rights organizations have worked to eliminate prejudice and discrimination as socially acceptable behaviors. Categories such as race, religion, gender, sexual orientation, and age are categories where prejudice and discrimination have occurred and thus been protected for through various non-discrimination policies. Without addressing the effectiveness of the policies on the other categories mentioned, a generalization can be made that ageism, prejudice or discrimination based on a person's age, not only continues to occur but is widespread and acceptable.[178] Age related prejudice has become socially condoned through widespread humor about aging, products and procedures mass produced and marketed to counteract the aging process while few efforts are being made to overcome the negativity surrounding a process which is constantly occurring to every single living person with each passing day.[179] The WHO recognizes ageism as a global issue that negatively impacts the health status of older people, a population that is now at an all-time high and expected to continue growing.[180] Ageism is a relatively new phenomenon that has only become a trending issue since the time when science and technology advanced the possibilities of modern medicine, prior elders were a valued and respected cohort. Within the US today ageism has prompted an unfortunate tendency for older people to be deprived of respect and dignity.[181]

Ageism has provoked age related stigma. Stigma occurs when a negative attribute is associated with certain conditions leading people with that certain condition to be categorized as less valuable than those without the condition. Hence age related stigma occurs when older people are considered less valuable than younger people. Peter Laslett explores what he calls "hostile and demeaning descriptions of the elderly," and the social changes occurring over time

that have given rise to the negative connotation of aging as he considers the essential personal and societal obligations necessary to promote a better third and fourth age for all.[182] Frederick de Lange contemplates why there is not more appreciation for elders in his book, *Loving Later Life An Ethics of Aging*. Among other factors he finds, that society tends to have a great deal of anxiety about aging, even more so than anxiety about death.[183] de Lang asserts that the ethics of love theologically and ethically supports improved care and respect for the older population.[184] These and other scholars have identified the stigma that is associated with aging and acknowledged that the stigma ought to be overcome because the aging population is not at risk of dwindling in the near future. Furthermore, people living to advanced ages has become a common occurrence because of the advancements welcomed by people and society. Social organizations are also concerned about age related stigma and are working to promote a more positive perspective on aging and implement public health and policy initiatives that encourage healthy aging.[185]

Aging anxiety and stigma become more compounded when the idea of cognitive decline and AD enter the picture. For some time now people, famous and ordinary alike, have publically shared their personal stories about the tragic effects of AD. Public disclosure tends not to be motivated by the welcoming of pity or sympathy but rather by the desire to extend awareness and gain public support for the disease in hopes of changing the future for others. On November 5, 1994, former President Ronald Regan joined this alliance when he addressed the public to announce his diagnosis of AD. This intimate and poignant address marked the conclusion of his time spent as a figure constantly captured by the public eye. Before taking to a more private lifestyle he took the opportunity to publically proclaim his position on the importance of the early detection. President Regan's choice to disclose his diagnosis of AD was impacted by

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earlier experiences with cancer. He found that the public's awareness of his bouts with cancer and his wife's battle with breast cancer raised public awareness which helped to encourage early cancer detection and treatment for many other people.[186] While early detection of AD may not have yet been a scientific capability for President Regan in the 1990's, he experienced the potential offered by the early diagnosis of other illness and perhaps saw hope for the future of AD. The former president could have chosen to keep his diagnosis private to avoid the stigma but his bravery in opening up to the American people, and people across the globe, undoubtedly got people thinking more critically about AD. The stigma attached to AD has implications that may negatively impact people with an early diagnosis but because there are benefits to early diagnosis the stigma needs to be overcome, or considerably lessened for public good.

i. Implications of Alzheimer's Related Stigma

Stigmas are negative and can have detrimental impacts on those they effect. When someone is stigmatized their identity is jeopardized because the stigmatized person or group is viewed by others as less valuable to society.[187] The general public tends to lack understanding about the mild stages of AD, when autonomy is still possessed by people with preclinical AD or MCI. Therefore, AD in general is typically associated with the moderate to severe disease stages when dementia is present and people's abilities to act autonomously are compromised.[188] While surveys indicate that most people know of AD and are familiar with its classic symptoms, there are still widespread misconceptions about the disease. Some misconceptions are about diagnosis and often result in delayed diagnosis. The misconceptions heighten the stigma felt by many people impacted by the disease often causing isolation.[189] In a large phone survey conducted across 54 countries it was found that stigma has caused one in four people to conceal their diagnosis from relatives and friends. The same survey concluded that stigma prevents people

with AD from utilizing services. Stigma then also likely acts as a barrier to finding solutions to the disease because these avoidances prevent people from participating in studies that may be beneficial in validating effective methods of dementia prevention.[190] Family members, including caregivers and non-caregivers, of those with AD are also at risk of being stigmatized based on their relationship to a person with the disease. "Courtesy stigma," as it is referred, has also contributed to the decision for people to conceal their Alzheimer's diagnosis from others.[191]

As early identification of AD becomes increasingly common, the lack of public understanding about the mild disease stages can negatively impact those diagnosed and their family members in other ways as well.[192] If public perception about mild stage AD does not change, the stigma could lead to discrimination. Discrimination is the differential treatment of certain groups of people and can be employed on the individual and institutional levels.[193] Concerns have been raised that if privacy regarding a preclinical diagnosis of AD is not properly protected for, people with positive biomarker results may be refused to enroll in, or eliminated from health insurance, life insurance and/or long-term care insurance plans. Because there is grey area in the Americans with Disabilities Act (ADA) the potential for employment discrimination for people with asymptomatic AD has caused concerns.[194] For people with MCI, institutional discrimination may threaten personal agency if policies are devised to impact at what point the ability to drive and control finances and other personal matters ceases.[195] Discrimination is found to negatively impact people across the psychosocial spectrum resulting in a decreased quality of life and has been linked to increasing the likelihood of other medical issues such as depression and high blood pressure.[196]

    ii.   **Moving Past the Stigma**

If suspicions are correct and the mild stages of AD hold the key to reducing burdens associated with AD then efforts to decrease Alzheimer's related stigma and therefore discrimination must be employed to make preclinical findings less concerning. Doctors Jalayne Arias and Jason Karlawish have identified that legal and regulatory efforts unique to biomarkers for Alzheimer's are lacking but necessary to ensure protection from insurance and employment discrimination. Although such biomarkers are currently only detected through clinical research, the electronic clinical record may disrupt confidentiality because it often contains not only information about clinical care but also about clinical research involvement.[197] As genetic testing became more common it raised similar concerns, how to prevent discrimination and stigma based on predictive information, and non-discrimination policies were put into place. Unfortunately the genetic protections do not extend to biomarkers as biomarkers and genetic materials are technically different.[198] There could be discrepancies in how people with MCI are protected by the ADA because MCI has not yet been medicalized to the point when it is considered a clinical condition.[199] Careful considerations of how biomarker results can be contained confidentially or how discrimination based upon them can be prevented is necessary to promote beneficence to those participating in mild stage research and to enhance the good of the public who stand to benefit from their participation.

A public health initiative was launched in 2007 by the Centers for Disease Control and Prevention and the Alzheimer's Association and expanded in 2013 when other aging organizations joined. This initiative, The Healthy Brain Initiative, is working to address the issues and implications that arise, or have the potential to arise, regarding stigma and discrimination about AD.[200] The value of public health efforts has been displayed in other conditions since the latter half of the twentieth century and the hope is that similar results will

help change the future course of AD by promoting cognitive health among the entire aging population.[201] The Healthy Brain Initiative is focused on five main items of action to meet this goal; monitoring and evaluating, educating and empowering, developing policy and training a competent workforce.[202] Putting the importance of cognitive health into the public health arena offers hope to overcoming the stigma attached to cognitive issues and aging by expanding public education about mild stage AD and the potential that it may not ever progress onto dementia. Just like having high cholesterol does not indicate the certainty of future heart disease or stroke, Alzheimer biomarkers and MCI do not indicate the certainty of progressive dementia.

Over the decades various public health efforts have been successful in reducing the strains created by some health conditions. While there is growing hope that a public health focus on AD will see similar success, such efforts alone do not satisfy social responsibility as framed by the ethics of care to morally address its burden. Social responsibility demands that social systems must also identify the unique needs of the Alzheimer's population and determine how to meet these needs, while promoting dignity and the highest quality of life possible. Many professional organizations have begun to agree that the platform to successfully change the burden of AD my likely lie within the mild stages thus it is socially responsible to embrace this stage.[203] This should be done by expanding research efforts prior to the onset of dementia and to include more than pharmaceuticals which may lead to a disease modifying treatment that could constructively alter the course of AD. Patient centered research design may further impact the benefit of Alzheimer's related research. Public fear and misconceptions about AD, especially misconceptions about asymptomatic Alzheimer's, that have created stigma and the potential for discrimination need to be overcome because both threaten the wellbeing of those with AD as well as their family members.

IV.   Conclusion

Today it is a possibility to detect AD in its mildest forms, prior to the onset of any

symptoms or when only mild cognitive symptoms are present.[204] At this stage, unless it is the

less common form of familial AD that has been detected, there is no way to guarantee whether or

not the disease will advance onto its moderate and severe stages when dementia hampers agency,

identity, and autonomy. Following many decades where the burden of AD has grown

exponentially without witnessing successful interventions that sufficiently modify the disease,

experts now anticipate that the appropriate interventions to gain control of it will be found in the

mild stages.[205] Disease modifying interventions, whether they be pharmaceutical or non-

pharmaceutical in nature, could drastically reduce the personal and societal burden of AD by

intervening before the onset of the devastating and irreversible symptoms and shifting the course

of the disease to either be prevented or maintained in its mildest form. Despite this promising

potential and the fact that when in its mild stages AD does not detrimentally impact people's

abilities for self-care and autonomous action there is still great fear surrounding the detection and

disclosure of mild stage AD. Concerns have been raised that early diagnosis and disclosure

could compromise personal wellbeing without certainty that the disease will advance.[206]

Such a fearful approach to early diagnosis is negatively focused and overlooks the

personal and public benefits offered by the mild stages of AD. This fear is likely linked to the

negative stigma that has become closely associated with aging and AD and the stigma needs to

be addressed to prevent personal hardships and discrimination from occurring unnecessarily.

The benefits and burdens of the mild stages must be carefully considered but careful

consideration does not indicate that we should allow fear alone to stand in the way of

advancement. Dr. Jason Karlawish of the University of Pennsylvania concludes his article titled,

Addressing the ethical, policy, and social challenges of preclinical Alzheimer disease, with a pertinent statement, "the discovery of preclinical AD may be how we prevent the tsunami of AD dementia, but we must not drown in the challenges created by our own discovery."[207]

The ethics of care framework promotes a positive focus on the mild stages of AD that expands opportunities to promote quality patient care and societal wellbeing. Relational autonomy during the mild stages incorporates psychosocial considerations into the medical aspects of AD by focusing on the benefits offered by personal narratives and advance planning. Relational autonomy also promotes preserving individual quality of life by focusing on cognitive and emotional health and wellbeing. Social responsibility identifies that the public stands to benefit when research initiatives are expanded into the mild stages, and that this can happen while still accounting for individual needs when research is patient centered. Social responsibility recognizes the problems associated with stigma and works to move past this by helping the general public better understand the mild stages of AD and how they differ considerably from the more severe stages. Relational autonomy and social responsibility work in tandem to guide that early diagnosis and disclosure of mild stage AD ought to be done in an ethical manner that is considerate of the risks but also embraces the benefits that may greatly benefit individuals with AD, their family members as well as society at large.

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Chapter Five: The Ethics of Care during the Severe Stages of Alzheimer's Disease

I.   **Introduction to the Severe Stages**

The progression of AD can be categorized into three stages, mild, moderate and severe. While the general public has tendency to associate the diagnosis of AD with dementia, dementia is not present until the moderate and severe stages of AD. Dementia is not a disease but rather a term used to describe a set of symptoms, according to the Mayo Clinic, "dementia describes a group of symptoms affecting memory, thinking and social abilities severely enough to interfere with daily functioning".[1] Dementia can be present with a wide range of medical conditions, some reversible and others not reversible. AD is the most common cause of dementia and dementia of the Alzheimer's type is not reversible. Dementia involves declines in the areas of memory, thinking, emotion, social behavior and awareness of time and place to the extent that activities of daily living become difficult and eventually impossible to complete independently.[2]

In 1982, Dr. Barry Reisberg developed the Global Deterioration Scale to describe seven stages of dementia and it has since been used as a clinical instrument to assess the degree of decline to which a person is experiencing dementia. An overview of the seven stages of clinical characteristics begins to provide an understanding of the personal burden that dementia inflicts upon those with the condition. During mild decline forgetfulness of the familiar is evident and begins to raise concern, progressing to a point where it begins to interfere with work and cause anxiety. The stages of moderate decline are characterized by advanced confusion and inability to recall recent personal or world events. Managing one's personal finances and traveling to unfamiliar locations becomes difficult and eventually daily assistance in many areas is essential. In its severest stages, dementia causes people to forget the names of those closest to them as well as recent life experiences. People experience personality changes, become unaware of their

surroundings and need significant assistance in most areas of daily living. Ultimately dementia

will cause one to lose all verbal abilities, mobility, continence and the ability to eat.[3] After a

progressive downward decline, dementia in its most advanced stage leads to death if death was

not caused be another condition in the long period of time over which dementia tends to

progress.

Dementia is present during the moderate stage of AD. This stage tends to consist of

several years of cognitive decline which impacts people's personalities in different ways. The

moderate stage is marked with increased forgetfulness and hampered abilities to recall basic

personal information. During the moderate stages people may become more withdrawn, begin

wondering, and eventually lose control of bowel and bladder functions.[4] During the moderate

stage supervision becomes increasingly necessary as does assistance to fulfill tasks of daily

living. Although the moderate stage of AD will not be detailed in this dissertation, the stage

does raise multiple ethical concerns for patients, their family members and caregivers, as well as

society. Eventually the moderate stage of AD will progress onto the severe stages of AD, also

known as the late or final stages of the disease. During this stage cognitive decline worsens to

the extent that people with AD become unable to participate in conversations, lose abilities to

control movement and swallowing, and lose awareness of their surroundings. People with severe

AD not only need supervision but become completely dependent in all areas of personal care

because dementia becomes severe.[5] According to the GDS severe dementia consists of two

stages, severe cognitive decline and very severe cognitive decline. These stages are

characterized first by loss of awareness of recent events, necessity for assistance in bathing and

toileting, progressing next to an inability to speak more than a few words, inability to ambulate

and complete incontinence.[6] During the latter stage, also referred to as advanced dementia, there

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is an unavoidable need for complete care dependence. Advanced dementia is a terminal

condition although an exact prognosis often proves difficult to make.[7] Advanced dementia

occurs as the end stage condition of various neurodegenerative diseases but again AD is the most

common and currently the sixth leading cause of death for Americans.[8]

The clinical manifestations of the severe stages of AD also bring about moral concerns

pertaining to the person with advancing dementia. During the severe stages those with AD no

longer possess agency and are not capable of autonomous action. This in turn has led some to

question concepts of dignity as it applies to people with advanced dementia.[9] Dignity is

questioned because it is often tied to concepts of self and personhood which become

compromised as dementia progresses. Recall from chapter two that there are two categories of

human dignity; intrinsic which is static and present merely by being human, and attributed

dignity which is dynamic and associated with one's sense of self. Intrinsic dignity ought to be

enough to warrant proper care for those with severe AD.[10] Theories have been proposed that

based on intrinsic dignity those caring for the people with advanced AD are responsible for

ensuring dignity is maintained when these individuals can no longer maintain their own

dignity.[11] For those who will look past intrinsic dignity and focus on attributed dignity lost as

dementia takes over self and personhood, counter arguments have been made to support the

maintenance of attributed dignity to those with severe AD.[12] In the book, *The Enduring Self in

People with* Alzheimer's, Sam Fazio writes about the importance of maintaining dignity of those

with Alzheimer's by focusing on aspects of self which remain evident despite progressive

cognitive decline.[13] Fazio highlighted studies done during severe stages of AD that indicate a

sense of self still prevails during advanced stages. Once study found that personal pronouns

remain in the limited vocabulary of people with severe cognitive impairment and another study

focused on nonverbal forms of communication that are retained after verbal language is completely lost.[14]

The overall span of AD can endure for a decade, some cases have lasted beyond two decades which means that the severe stages of the disease do not tend to occur quickly with advanced dementia, the very final phase of the severe stage, often enduring for more than a year. Initially diagnosed with early onset AD at 57, Thomas DeBaggio, the author of autobiography, *Losing My Mind An Intimate Look at Life with Alzheimer's Disease,* lived with AD until he was 64 years old.[15] Former President Ronald Regan was diagnosed with sporadic AD in 1994 at the age of 83 and died ten years later at the age of 93. A second hand account of President Regan's years with AD was depicted through his daughter's, Patti Davis, book *The Long Goodbye*. This book, which reads as a journal, tells about the grief faced by family when watching a loved one progress through AD. The majority of the book references days when President Regan was likely in the moderate stages of AD then jumps to his final days when advanced dementia was indeed present.[16] What's clear throughout the progression of the story is that Davis is aware her father is dying from a disease that no one, not even a former leader of the US can do anything to slow, hasten or escape. Before applying the ethics of care to the severe stages of AD it will first be helpful to understand death and dying in today's context as well as contemplate the notion of human finitude in an era focused on treatment and cure.

A. Death and Dying Today

Previous chapters have appraised the changes brought about with time related to; advancements of science and technology, the professional role and ethical expectations of doctors, and the evolution of chronic diseases. Historical analysis of death and dying also indicates that remarkable changes have occurred over time regarding end of life. Historically,

the death and dying process was an uncontrollable event that tended to occur peacefully and privately. This is contrary to today's typical experience in which the dying process tends to be more controlled, yet less peaceful and less private.[17] Prior to the nineteenth century there was little anyone could offer to remedy, disrupt, or slow the dying process. Even doctors during this time period could be of little service to avoid the call of death. Death often occurred on a battlefield, or as the result of traumatic injury in the midst of daily activities. Natural death resulting from age or illness tended to occur within the home and often in the very bed of the dying person. Typically, family, friends, clergy and the neighborhood doctor were present during the dying process and at time of death. Unlike today however, this was not a process marked with much emotion. Death was considered a natural and unpreventable event accepted and not challenged by the dying person, their family members, or medical professionals. Funerals were not formal events and the remains of the dead were left to be taken care of by the local church as they were of little concern to survivors of the deceased.[18] This type of death is referred to by Phillip Ariès as a "tamed death".[19] Ariès in his famous work, *Western Attitudes toward Death: From the Middle Ages to the Present,* goes onto to illustrate that death has moved from a tame event to one that is "wild," avoided, and almost "forbidden," despite human inability to ultimately overcome death.[20]

Beginning around the time of the 18th century, death and dying became a more emotionally tied occurrence. It was early in this time period that dying persons began to plan and manipulate what would occur in the future following their deaths. Last will and testaments began to be used by the dying as formal methods to pass on property, possessions and power rather than merely a way for the dying to reflect upon their life as it had previously been.[21] For survivors of the dead, this time marked a change when grief and mourning became a more

socially accepted and expected reaction to death.[22] Burial methodologies and funeral practices

became more formalized and elaborate, especially in the US. Survivors developed stronger

emotional ties to the deceased thus cemeteries moved from the outskirts of town into city limits.

The cemetery became a place to visit and continue to be connected to those who have died rather

than just a place to dispose of bodily remains.[23] Since the later part of the twentieth century

people no longer tend to die at home but do so more often in hospitals while holding onto the

hope that death can be prevented by skilled clinicians and advancing technologies.[24] Here the

dying are surrounded by strangers and medical equipment which offers the possibility of hope to

extend life or, at the least, manipulate the timing of death.

Prior to modern times, ethics surrounding end-of-life primarily focused on acts whose

intentions were to directly end life through suicide and direct euthanasia, suicide being the more

common issue then. These acts tended to be discouraged against based on the religiously tied

sanctity of life argument. Sanctity of life is a term that refers to the special value given to human

life and the corresponding obligation to respect and preserve it. The word sanctity is associated

with sacredness or holiness and the overall concept of sanctity of life is a paramount principle to

various popular world religions. The term therefore is widely used by ethicists seeking to justify

or refute issues from religious perspectives. [25] Despite its common association with religion, the

linguistic roots of the term sanctity of life cannot be explicitly traced back to a religious

foundation.[26] The phrase, respect for life, is an ethical perspective which offers similar meaning

without carrying the implication of religion.[27] Both terms, sanctity of life, and respect for life,

were developed centuries ago when society and particularly medical capabilities were much

different, less intense and less capable of prolonging biological life therefore today ethicists

should exercise caution when using the terms as they no longer explicitly clarify what ought to be done but rather provide guidance for avoiding the implicit violation of life.[28]

During the nineteenth century, respect for life was incorporated into Thomas Percival's famous code of ethics, which eventually became the foundation for the code of ethics of the American Medical Association. This code indicated that death was an enemy to be avoided and veracity was overlooked as a standard when treating the ill and dying as the acceptable professional behavior was to encourage the patient to live.[29] This ethos of medicine was acceptable during this time period because little was able to be done for the ill and dying. As time progressed into the 20th century medical technology advanced and life sustaining interventions became more numerous but still doctors tended not to discuss death with their patients or even admit to other medical professionals that particular patients were nearing death. The work of two doctors in two different countries brought light to the notion that even when illness was no longer medically manageable and life's end was nearing that care was still necessary to control not only physical pain but also emotional and psychological pain.[30] In the United States it was Elisabeth Kubler-Ross's work with the dying and publication of her groundbreaking book, *On Death and Dying* in 1969 that raised the public's awareness about the needs of the dying and the ways in which these needs have been neglected for many years by the medical system.[31] Around the same time, in the United Kingdom Dame Cecily Saunders devised a similar concept about the pain control needs of the dying and consequently opened the first hospice.[32]

Through their work which involved interacting directly with people with terminal illnesses, Kubler-Ross and Saunders found that even when not told by medical personal that their condition was terminal, the majority of patients knew their end was near and longed for human

interaction to share that time with.[33] Kubler-Ross identified five emotional stages that people

experience prior to their death; denial, anger, bargaining, depression and acceptance and noted

the important role healthcare providers and family members play in assisting the terminally ill

through the stages.[34] Saunders coined the idea of total pain which identified that dying people

experience not only physical pain but also psychological and emotional pain and that in addition

to proper pain medication people need a holistic approach to pain which includes interaction with

other people during end stage illnesses.[35] The concepts devised by Saunders and Kubler-Ross

several decades ago are still utilized in end of life care today. What these women determined is

that when care providers turn their backs on the terminally ill and allow them to die in isolation,

as had been done prior to their work, the dying process does not happen well. Their work

identified that a good and proper dying process occurs as a relational experience between the

terminally ill and their care providers, and family members.

Eventually the importance of truth telling regarding all aspects of healthcare, not just

those pertaining to end of life, became a standard expectation. One study found that in 1961

90% of physicians reported they would not tell a patient about a cancer diagnosis but by 1981

over 90% of physicians reported they would tell a patient about a cancer diagnosis.[36] This

complete turnabout may be associated with the inception of biomedical ethics standards into

clinical care. The principle of respect for autonomy was first established to promote respect for

persons, disclosure, veracity and the shared decision making relationship which could not

properly occur without patients having proper knowledge of their health situation.[37]

Furthermore, it became clear that withholding the truth from patients caused more harm than

benefit to the patient. This reversed traditional thinking that withholding truths from patients

was done for their benefit and put the principles of beneficence and nonmaleficence at odds.

Truth telling in healthcare is not limited to only instances where informed consent must be obtained but is expected in all aspects of communication between clinicians and patients. Some clinicians report the problems associated with uncertainty as reasons they avoid, or are uncomfortable with, truth telling at times but truth telling is legally supported despite uncertainty and has been attributed to increasing trust and patient satisfaction, improving health outcomes and reducing morbidity.[38]

Truth telling standards, and realizations about the dying process such as those promoted by Saunders, Kubler-Ross and others like them have enhanced care at the end of life since the 1950's but it is not yet completely satisfactory.[39] Despite telling patients the truth about diagnoses, many physicians still report discomfort with discussing death and the dying process.[40] Death occurs in all populations; pediatrics, adult, and geriatrics, with each population raising both unique and similar concerns about the process and best practices. One might assume that conversations between clinicians and patients about death and dying would be easiest when working with people who live with serious illnesses but this is untrue.[41] Conversations are necessary to ensure people receive care at the end of life that will be in line with a good death because there is no universally accepted standard of what constitutes a good death, nor is there a lot about this in academic literature.[42] One small study conducted in 2002 found that ideals about a good death varied from person to person thus reaffirming the need for individual conversations about end of life options and desires.[43] In their 2014 report, the IOM highlighted the current shortcomings of American medicine at addressing end of life issues properly today and concluded that strides need to be made at providing end of life services to older adults and adults with serious illnesses which are in line with each individuals' values and preferences while also being of high quality and cost effectiveness.[44]

B. Human Finitude in an Era of Treatment and Cure

Some scientists foresee a future with a vast expansion of human capabilities, extenuating human lifespans or perhaps immortality made possible through various enhancement capabilities. Critics of the speculated potential of transhumanism question how individuals and society could potentially withstand such changes and whether movements towards such enhancement modalities ought to even be contemplated.[45] Until these conjectures emerge into reality humanity remains mortal because despite the most recent medical advances humans continue to exist within the constraints of a limited lifespan. Mortality, an aspect of life which all people have in common, contributes to the universal vulnerability related to health and wellbeing and makes death a natural, inevitable part of the human life span. Within the constraints of finitude a desirable health state becomes the means by which a fulfilling lifespan can be accomplished. A desirable health state cannot be viewed as an end within itself. But according to popular thought within western cultures today health is often viewed as an ends rather than a means and death is often viewed as the ultimate enemy of human life rather than a natural occurrence that is in fact a certainty to all.[46]

The constraints of human finitude have been increasingly challenged over time. Some challenges have brought about beneficence while others have brought about little or no benefit and from some perspectives even inflicted harm. The field of medical research is a major contributor to the notion that human life can be continuously prolonged and death ultimately avoided. In his book titled, *What Price Better Health*?, Daniel Callahan identifies the various moral harms that have arisen throughout the evolution of medical research and what he calls the research imperative, the continual urgency to overcome human suffering and death related to disease.[47] An ultimate hazard as he points out is the paradoxical cycle created by the imperative

that the more we advance our medical capabilities the more we want to continue the expansion to ultimately postpone death for as long as possible without enough regard for the associated consequences. The demand then leads to an infinite array of medical possibilities made available for use within clinical care.[48] Although there are not yet an infinite number of healthcare options, we currently live in a society that has what may seem to be an almost endless number of techniques to perpetuate biological existence.

Accepting human finitude does not mean that death must be embraced prematurely or that medical interventions ought not to be pursued, it is simply accepting that each life has a limit. Such an acceptance still allows for reasonable expectations within the lifespan such as the expectation to utilize medical options to avoid dying prematurely and/or avoiding a painful death.[49] Individual values and societal values, when their consideration is ethical, can be used to determine and define reasonable lifespan expectations. Values can also be used to determine what to do with the seemingly endless possibilities of modern medicine. There are three possibilities; what can be done, what is actually done and what should be done. The unlimited extent of all medical possibilities is what can be done. What is actually done is determined by healthcare providers and patients and impacted by issues such as access, affordability and availability of resources. What should be done is determined by evaluating the values of patients and providers in conjunction with what is possible and what may actually be done.[50] In actual healthcare practice there has tended to be less investment in determining what should be done and more on what can be done versus what is actually done. Achieving a successful healthcare system in an increasingly aging population with fewer and fewer limits on what can be done will require emphasis to be placed on aligning what is actually done with what should be done.[51]

Contemplating what should be done and accepting that the human life span has a finite biological ending requires that people face inherent vulnerability. The word vulnerable has two applicable definitions according to the Oxford English Dictionary; "exposed to the possibility of being attacked or harmed, either physically or emotionally," and "in need of special care, support, or protection because of age, disability, or risk of abuse or neglect."[52] As long as death remains an inescapable part of the human condition and as long as illnesses and injuries continue to exist and evolve all people are vulnerable to harm in such a respect. For even those who escape a life marked with illness or injury and live a life marked with independence are still prone to death at some point. This inevitable fact is in accordance with the ethics of care's universal view of vulnerability. According to the ethics of care, all people are vulnerable to some degree regardless of their level of, or capacity for, independence based on human mortality.[53]

The ability to face universal human vulnerability and better decipher what should be done may be improved when old age is appreciated and the prosperity of society is promoted. As previously explained, negative stereotyping and discrimination against the older population has been prevalent in the American culture for some time now.[54] Ageism may be provoked by the continuous search for cure and efforts to prevent death.[55] If time constraints on the human life span are accepted as normal, reasonable limits on medical intervention were established, and death under proper circumstances embraced, many aspects of ageism may be eliminated. This would redirect society to once again view old age and frailty as a natural part of life rather than a stage to be avoided because it marks defeat ultimately leading to respect and appreciation for the older population as valuable members of family and society as was once the case decades ago.[56] While the possibilities of immortality or excessively longer lifespans may be intriguing, when

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thoroughly considered they may yield in negative repercussions. Death plays an important role

for communities as it allows for room for new members as resources are limited and there are

great social consequences associated with an ever enduring population.[57] The consequences may

concretely include a job market that cannot adequately serve all those in need of work.

Rationing of resources that become scare with larger societies would likely be necessary.

Currently relied upon programs such as Medicare, may no longer be financially feasible. The

overall impacts of these and other consequences on society would be vast and dramatic. Radical

changes in public policy would likely be morally necessary.[58] Without limits as well as fair

consideration and implementation of values into the possibilities of medical advancements

society may not be able to prosper for the benefit of future generations.

       The norms of death have changed dramatically with the rise of modern medicine.[59] Prior

to modern medicine end of life ethics was merely concerned with the intentional ending of life

through suicide or euthanasia. Determining terminal prognoses or when a person actually enters

the dying process has always been difficult but today it is even more so. In many cases it seems

that there are other medical interventions to try in hopes of defeating death if even for a few

more minutes, days or weeks.[60] As a result, end of life ethics today encompasses not only those

issues but also what measures must or ought to be utilized to preserve life and for how long.

Although anything but simple, simply put end of life ethics focuses very much on issues of

quantity of life versus quality of life. When referring to quantity of life, the term vitalism can be

applied. Vitalism is the theory that even when all other human functions are destroyed basic

organic life must be preserved if the capabilities to do so are available. Its objective purpose

focuses solely on quantity of life measured by the length of time one lives. Vitalism is the

opposite of quality of life which is defined as the state of satisfaction associated with the

experience of living. Quality of life is a value that is subjective and therefore perceived differently by different people.[61] Although the two can exist in tandem, quantity of life and quality of life are often put at odds because of the capabilities of modern medicine. The contemporary goals of medicine were established to enhance both quantity and quality despite that there come times when one has to be chosen over the other.[62] Ethically and legally the contemporary healthcare system is structured in such a way that when the two become adversarial, quality of life considerations can override quantity of life considerations when it is the autonomous intention of patients, or their surrogates, to favor quality of life.[63] Many religious teachings also support quality of life considerations despite their high respect for sanctity of life.[64]

The severe stages of dementia infringe upon self-determination and following a path focused on personal preferences whether it be focused on quantity of life over quality of life, or quality of life over quantity of life. The conditions brought about by dementia's progression commonly disrupt popularly held quality of life standards.[65] The array of negative effects dementia has on people's lifestyles is perhaps one of the greatest fears associated with the condition and it is in the severe stages when these issues are most pronounced and when death and dying must be contemplated. A statistically significant proportion of Alzheimer's related deaths occur in hospital settings with aggressive treatments being administered despite family members' desire for comfort care. [66] Quantity of life will in-deed be limited during the severe stages because advanced dementia is a terminal condition.[67] This chapter will explore end of life ethics associated with the severe stages of AD according to the ethics of care framework. First, relational autonomy will be used to consider vulnerability during a time when complete care dependence is necessary for people with AD and therefore must be provided by others. Then,

social responsibility will be used to consider the societal benefits of hospice and palliative care in a population where the prevalence of AD is growing and at risk of becoming overbearing.

II.   **Relational Autonomy: Vulnerability during Complete Care Dependence**

Reflecting on traditional concepts of autonomy in western bioethics compared with relational autonomy as constructed by the ethics of care will indicate the two were constructed from much different platforms therefore, in moving forward there may be a potential for the two to exist in cohesion rather than opposition. The traditional principle of autonomy was initially devised to counter two issues; one, unethical research intentionally deceiving human subjects, and two, paternalistic actions of physicians as clinical care advanced to a point where patients had multiple options for care and treatment.[68] This idea of autonomy as a principle of biomedical ethics only entered into this context when the Belmont Report was written in 1979 and in the same year when Beauchamp and Childress published the original edition of *Principles of Biomedical Ethics*. The principle of autonomy was derived from the principle of respect for persons and the notion of the common morality as the primary, and relatively narrow, focus of the emerging field of biomedical ethics at this time was on protecting the individual liberty and free will of human beings in clinical research and clinical care through proper informed consent.[69] Over the next decade the ethics of care began materializing from a more broad focus attempting to contemplate morality as it applied to gender and role differences. Autonomy through this lens was not individualistic but relational as the nature and scope of care ethics was focused on a bigger picture of morality and how proper human interaction between one another and society has meaning and leads to flourishing. Ultimately, the principle of respect for autonomy became one of four main principles in a methodology devised to contemplate ethical

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issues in clinical care and research while relational autonomy became one of the two main components of an entire modern moral theory.

In their most recent, seventh edition of *Principles of Biomedical Ethics*, Beauchamp and Childress conclude their chapter on respect for autonomy by stating, "we should be mindful that the history of informed consent and the place of autonomy in biomedical ethics are still under development."[70] While the freedom of competent individuals to make their own healthcare decisions and the need for human subject protection in clinical research will always lie at the heart of biomedical ethics, the evolution of the human life span, emerging technologies, and the progression of certain diseases have pushed for a notion of autonomy that encompasses more. Future editions of the book may expand the principle of respect for autonomy to incorporate relational considerations, until then the principle will have to be compared and contrasted to the relational model of autonomy. Although not designed specifically for dilemmas of clinical care or research, the ethics of care has established a more encompassing concept of autonomy that offers great potential for the field of bioethics especially in circumstances where vulnerability is high and care dependency is essential. The severe stages of AD precisely exemplifies these circumstances. Traditionally, the principle of respect for autonomy focused its concerns on protecting patients, or those receiving clinical care or participants in clinical research. Relational autonomy, as a component of a moral theory, is more encompassing when applied to issues in bioethics because it is concerned with considering all parties affected by the issue at hand, not just patients or research participants. As has been illustrated, when applied to AD, relational autonomy is concerned for the person with the disease as well as how it impacts their family members, caregivers, and the community at large.

Relational considerations become essential in the advanced stages of AD. In a poignant article titled, Still Gloria: Personal Identity and Dementia, Francoise Baylis explores the importance of relationality in maintaining her mother's personal identity, belonging and recognition as dementia destroys her personality and ability for appropriate social interaction.[71] Although dementia will and does change one's personality, personal identity and individual personhood remain despite the person's inability to outwardly express these personal characteristics any longer. The person with advancing dementia may not be able to express or recall their own values, experiences, emotions and beliefs yet they can be recalled and maintained by those who surround the person. Baylis clarifies that there is a difference between dementia's ability to destroy personality and its ability to destroy one's personal narrative which will continue to exist on and be reinforced by those who care enough to stay close as dementia progresses.[72] What Baylis found through experiencing her mother's decline with dementia is consistent with Hilde Lindemann's work referenced in chapter four, which suggests that those whose cognition remains in-tact have a moral obligation to assist in maintaining the personhood of those whose cognition is compromised by advancing dementia. This moral obligation, as she justifies, is based upon the shared human condition. [73] The conclusions drawn by both authors exemplify the relationality of autonomy, the innate need human beings have for one another, not just the need of the ill for the assistance of the healthy, but also the need of healthy to carry out the humanness of the ill. Furthermore, because their conclusions are based upon the shared human condition their conclusions are also grounded in the common morality.

The severe stages of AD is the point in the long stage of the disease's trajectory when the people with the disease will have lost capability for deliberate actions. From a legal and ethical perspective this means the severe stages of AD will take away people's agency. Autonomy at

this point must become relational or the entire concept of autonomy would have to be disregarded completely. At times when an individual's capacity to maintain agency is lost because of dementia's destruction of cognitive abilities there may be some question about how this diminished, or completely deteriorated, cognitive status impacts concepts of personhood and human dignity.[74] Dementia will destroy agency and personality but recall that when liberally considered personhood is not based on agency but on self-identity which ought to be properly maintained by others when dementia is present.[75] Similarly, the attributed dignity of persons with dementia can be maintained by others. The intrinsic dignity of persons with dementia remains despite cognitive impairment because intrinsic dignity is an innate value granted to all human beings.[76] While relationality is not necessary to uphold the intrinsic dignity of people in the severe stages of AD, relational autonomy is morally motivating and should be used by others to ensure the proper care of people in the severe stages of AD when the innate dignity shared by all people is recalled and acted upon. Complete care is needed by people in the severe stages, heightening vulnerability for both care receivers and caregivers and during times when sensitive medical decisions need to be made.

A. Caregiving

The world's largest prevalence of familial AD has been identified in Antioquia, a small state in the northwest part of Columbia, South America. In general familial AD is rare, but in Antioquia this genetic condition has been wreaking havoc at high rates on families in the region for many years, often affecting multiple family members at the same time.[77] Recent lineage studies have traced the genetic condition back several generations and theories suggest that this inherited form of AD has become so rampant in this region due to a combination of its rurality, a tradition of families having a large number of children, and a historical tendency for marriage

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and reproduction to occur between people of close relations.[78] Neurologist, Dr. Francisco Lopera, and his team at the University of Antioquia have spent over two decades treating and researching the unique presence of AD in the area. Citizens' whose family have been dealing with early on-set AD for generations have willingly become cooperative with genetic research conducted by Lopera and his colleagues, as well as other genetic researchers from across the globe. To date these lineage studies have greatly advanced knowledge about familial AD. This is beneficial not just to the people of Antioquia and other people around the world whose family carries the genetic mutations for familial AD but it also offers potential benefit to unlocking mysteries related to sporadic AD as well. This is because although the age of on-set and genetic composition differs between the two forms of AD, its symptomology, progression and other clinical aspects are quite similar.[79] There are currently pre-symptomatic trials taking place with the people in Columbia and the hope is that results will advance preventative and treatment options for all forms of AD.[80]

In addition to the valuable genetic discoveries, what has also been revealed by studies with the people of Antioquia offers insight into various other aspects of AD, including those of ethical concern.[81] A neurologist based out of the University of California, Santa Barbara, Dr. Kenneth Kosik, has also been intimately involved in working with Dr. Lopera and his patients in Columbia. In the preface and first chapter of a book he co-authored with Ellen Clegg, *The Alzheimer's Solution; How Today's Care is Failing Millions and How We Can Do Better*, his travels to and time spent in Columbia are detailed.[82] Particular attention is given to the way in which the families provide care to their loved ones afflicted with AD and how it differs from the way in which care is typically provided in the US, and other developed nations. In this region where there are no care institutions such as nursing homes, hospices or assisted living facilities,

the burden of care is adopted by other family members. One of the women whose stories are detailed named Consuela, cared for her husband as he declined from AD while she was raising several children. Less than two decades after her husband's death Consuela became the carer for two sons and a daughter all with familial AD. Her young adult grandchildren live with the concern and curiosity of whether the will endure the same fate as either a caregiver or care receiver.[83] Through his work with Consuela and others in the region who live with the impacts of AD, Kosik remains impressed and intrigued by the way in which quality care is provided by family members in their homes, in a manner which incorporates love and attention from all generations young and old. Older age and debility he notes are not hidden away but remain within the scope of daily life for all family members, as a result the people who decline remain valued by family members and the community. Observations are also made about differences in the healthcare system for in the Columbian region there are less care providers and smaller, less fragmented systems but the time providers spend with their patients and the attention given to patients' families seems less focused on time restrictions and more focused on understanding unique individual needs.[84]

At some point as AD progresses from the mild to moderate stages some degree of caregiving becomes necessary. It is during the severe stages that the needs of those with AD becomes highly intense and demanding as complete care dependence is required and caregiving becomes a twenty four hour a day necessity throughout the end of life.[85] Unpaid caregivers, also referred to as informal caregivers, are people who provide care free of charge and often without formal training. Typically informal caregiving is provided by family and/or friends in one's home. Paid caregivers, also referred to as formal caregivers, are professionals who are employed to provide care. Formal caregiving can occur also occur in one's home through home healthcare

or hospice services, or it can occur within long term care facilities. The provision of care to one person can be shared between formal and informal caregivers. These types of caregiving are not exclusive to the Alzheimer's population but providing care to people with AD, regardless of whether it is formal or informal, raises various unique issues that are cause for concern, including exorbitant costs and risk for burnout and caregiver fatigue.[86] Some of the issues associated with caregiving for people with dementia are type specific while some issues span both types. Regardless, dementia related caregiving issues are worthy of concern and contemplation, and should be beneficially considered from the perspective relational autonomy.

i.   Matters Related to Informal Caregiving

The National Alliance for Caregiving (NAC) and The AARP Public Policy Institute conducted a study throughout 2014 to gather information about informal, unpaid caregiving in the US, specifically informal caregiving that was provided to another adult who is age 50 or older. The report, Caregiving in the US 2015, created a comprehensive rendering of the current trend of informal caregiving occurring within the nation. Approximately 34.2 million people provided this type of caregiving either at the time the study was conducted or within the past year of the study, many of whom reported to have been a caregiver for at least the past four years and/or expect to be caregivers for the next 4 years or more. Eighty-five percent of these people provide care to a relative. This study concluded that caregivers in the US are a diverse group spanning all ages and ethnic groups, genders, and socioeconomic classes. On average caregivers were 49 years old, ten percent were age 75 years or older, and 60% of all caregivers were female.[87] This report examined people providing caregiving to people with any type of condition including long and short term physical problems, memory impairments, emotional and behavioral problems, and developmental and intellectual disabilities.[88] The Alzheimer's

Association found that in 2015, 15 million people provided over 18 billion hours of informal caregiving services to people with AD. Although unpaid, the estimated value of informal caregiving to people with AD that year was over 222 billion dollars.[89] There are similarities in trends found in general caregiving and in caregiving specifically for people with Alzheimer's but the nature of AD makes matters related to caregiving for people with AD unique and complex especially during the latter moderate stages and severe stages when decline drastically impacts cognition, behavior, and physical abilities.[90]

The burden faced by informal caregivers is multifaceted. Role confusion tends to occur between actual relationships and the relationship of caregiver and care receiver. For example, the importance of the husband wife relationship can be neglected when one spouse becomes the caregiver for the other spouse. Whether the neglected relationship occurs between spouses, between children and their parents, or between other co-dependent relationships, overemphasis on the caregiver role and less emphasis on the more intimate relationship can create frustration.[91] As the disease and disability progress the caregiver burden can become isolating as well as more physically and emotionally demanding. Caregivers have reported that as the needs of the person requiring care increases, there are less people willing to assist in providing unpaid assistance to the person to whom they are providing care. Likewise as the needs of the person receiving care become more intense, caregivers report increased issues related to their own health.[92] Many caregivers find themselves amidst what has been referred as the, "sandwich generation" where they are faced with taking care of their own children as well as their aging parents, or other relations, who endure the decline of AD or other conditions.[93] Caregivers of the sandwich generation report a lower quality of life than other caregivers.[94] Employment status often becomes compromised when caregivers take on the caregiving role leading to leaves of absence,

or leaving the workplace all together. Thus financial difficulties can threaten informal caregivers. The overall health and wellbeing of informal caregivers is jeopardized while they put forth the efforts necessary to meet the multiple array of needs facing those with AD.[95]

The decision to provide informal caregiving to a person with AD is typically promoted by love and altruism.[96] There are different types of love and the philosophy of love can be complex, even across familial ties as well as ties between people with close relationships.[97] Compassionate love is a type of love associated with altruistic motivations to assist family members and close others.[98] Compassionate love has been defined as, "an attitude toward other(s), either close others or strangers or all of humanity; containing feelings, cognitions, and behaviors that are focused on caring, concern, tenderness, and an orientation toward supporting, helping, and understanding the other(s), particularly when the other(s) is (are) perceived to be suffering or in need."[99] Although no formal studies have been done on the impact of compassionate love on Alzheimer's caregivers, hypotheses have been made that such love reduces the psychological caregiver burden when spouses provide care to their partner with Alzheimer's.[100] By extension it may also be postulated that compassionate love reduces informal caregiver burden and thus services geared to support informal caregivers ought to focus on identifying or bolstering the ideals and feelings of compassionate love held by caregivers towards those to whom they provide care. Reducing the burden of the millions of people assuming the role of informal caregiver to people with Alzheimer's disease has become an issue of national concern.[101] This is because the burden of informal caregivers, as outlined here and further detailed in other formal reports, makes informal Alzheimer's caregivers vulnerable based on the array of physical, emotional, psychological, and social factors that they face. Any one of these factors or a combination of factors puts caregivers at risk for burnout and caregiver fatigue.

The relationship between caregiver and care-receiver is relational. Caregivers for people with AD report the desire to keep their family member at home and perceived obligation as the leading reasons that they took on the caregiving role.[102] Care-receivers in later stages of AD are dependent on their caregivers for all activities of daily living, for the maintenance of their dignity, and for the continuation of their personhood. The dependence on another for the fulfillment of these humanistic wants and needs puts those with AD in a position of vulnerability as well.[103] Despite the relationality of providing care to closely related others, caregivers do not always provide quality care and care-receivers can become oppressed and at risk of being harmed. This can happen when there is a lack of love, but even when non-harmful types of love, including compassionate love are present, harm by the caregiver to the care-receiver can occur. The burden of caregiving can erode away the focus of love, or can cause caregivers to resent those they care for and furthermore caregiver stress and fatigue can lead to harm of the person with AD.[104] Even when people with AD are placed in long term care facilities, where formal caregiving is provided, informal caregivers may retain some aspects of their roles by acting as an advocate for their loved one, ensuring their personal narrative is understood by the formal caregivers and even by remaining involved with ADL assistance.[105] Informal caregivers ought to be provided with the supports necessary to appropriately carry out their duties as a caregiver based on the fact that they are vulnerable while also providing care to a vulnerable group, informal caregivers give of their own time and money to provide necessary care to a cohort of people who are among a public health crisis, and without the services of informal caregivers the already large financial burden associated with AD on the formal healthcare system would be even larger.

ii.   Matters Related to Formal Caregiving

Formal caregivers can be considered any type of professional paid for their caregiving services. Because of this broad definition there is a wide range of professions that are grouped into this category including physicians, nurses and social workers. Though these types of professionals are involved in the general care of adults with dementia the types of care they provide tend to be skilled rather than custodial. The majority of paid, formal caregiving for people with dementia is provided by aides, such as nurse aides, personal care aides or home health aides. Aides assist with custodial types of care like activities of daily living (ADLs), such as bathing, dressing and feeding, as well as instrumental activities of daily living (IADLs), such as meal preparation, shopping, and housekeeping.[106] Like informal caregivers in general, and informal caregivers specifically caring for people with AD, formal caregivers also tend to be women more prevalently than men.[107] Although most adults requiring care receive care at home from informal caregivers, formal caregiving often supplements the care provided by informal caregivers at home.[108] People living at home with dementia can have formal care through various home health care services, home hospice and palliative programs, or by community based programs such as adult day care programs. People with dementia may also receive formal care outside of the home in other residential facilities such as assisted living facilities and long term care nursing facilities. Estimates indicate that over 40% of all people living in assisted living facilities have a diagnosis of AD as do over 60% of all people living in nursing facilities. It is not unusual for people with AD to move between home, hospital, and other residential setting throughout the course of the disease.[109] The cost of formal caregiving is high, most individuals cannot afford to pay out of pocket for the amount of care necessary to meet the needs required by Alzheimer's related dementia. Federal and state dollars fund a large portion of this

type of care through Medicare and Medicaid.[110] New York, California and Pennsylvania have reported the highest Medicaid costs associated with Alzheimer's care in the US.[111]

Despite the need for formal caregiving among older adults care related concerns remain prevalent. In addition to the expense associated with formal caregiving, issues related to lack of adequate training of formal caregivers, and issues related to the quality of care being provided are among the major concerns.[112] All states require certain amounts of training for formal caregivers, including training specific to dementia. Regulations do not always specify the amount and types of training specific to dementia provided to formal caregivers and therefore the quality of training varies from facility to facility. Regulations have not yet become more stringent or standardized despite a growing knowledge that quality of care improves when more proper and thorough dementia training is provided to formal caregivers.[113] A study published in 2010 that reviewed all publications over the prior 14 years addressing dementia training for staff of assisted living and long term nursing facilities concluded that training styles and durations varied greatly from facility to facility and that effective training does improve quality of care and quality of life. It also concluded that a major challenge occurs between providing training and actually incorporating what is taught into practice, thus organizational changes need to occur to ensure the skills being taught to caregivers are effectively relayed to the actual care they provide to others.[114] Incorporating caregiver training into practice enhances the reciprocal relationship between formal caregivers and people with dementia by improving the way in which care is provided and received.

Some may wonder why anyone would chose to be a formal caregiver to people in the severe stages of AD being that the condition is complicated physically, psychologically and socially. Some may imagine it is just a job and a means to earning an income but many who

devote their careers to caring for others, formal caregiving is more than just a means to financial security. Despite work which may be stigmatized because of the often "dirty work" involved when others are completely care dependent (assisting people who are incontinent of bowel and bladder, unable to bathe themselves, etc.) many formal caregivers find their work rewarding as it makes them feel good about themselves because they are able to make a difference in the lives of people who can no longer care for themselves.[115] Formal caregiving often requires caregivers to provide care to strangers but this does not mean there cannot be emotional ties between the interdependent relationships of strangers. Appropriate types of love can be felt towards unknown others and towards humanity in general. Susan Sprecher and Beverly Fehr explain this in an article titled, "Compassionate love for close others and humanity".[116] Although compassionate love has not been extensively studied, compassionate love does not only occur between people who know each other personally as it can occur between strangers. Sprecher and Fehr found that compassionate love is a selfless type of love that can improve the wellbeing of those who feel it and provide it to others.[117] While people in the severe stages of AD are dependent on others for all ADLs and to ensure their intrinsic dignity is maintained, some formal caregivers are also dependent on those who need care for their own enhanced wellbeing and the maintenance or development of their attributed dignity as attributed dignity can be acquired through vocation.

B. Medical Decision Making

At times throughout history changes occur more hastily than the public anticipates and therefore individuals and societies are sometimes ill equipped to appropriately process and handle the implications that follow. This was the situation that occurred with the rapid advances of science and medical technologies following WWII. The convergence between the modern,

extenuating capabilities of medicine and the unique and differing values of individuals created

situations for which society's precedents, policies, and laws had not yet considered or

prepared.[118] This was the situation in various areas of medicine but especially evident in the

areas of healthcare that handled situations that involved end of life issues. The lack of standards

surrounding a new end of life culture that now included technological measure that could save

and extend life beyond what was traditionally possible lead to confusion on how to proceed

when personal values conflicted with professional and administrative concerns. The then

standard paternalistic approach to what occurred in patient care was challenged by an array of

life sustaining measures that did not always improve life in a way in which may be valued by

patients. People desired a new approach to determine what occurred in patient care that was

more considerate of mutual respect and reciprocity between clinicians and patients. This resulted

in a number of clinical cases entering court rooms for resolution and promoted the incorporation

of ethical consideration into healthcare at end of life.[119]

Two of the most well-known and regularly referenced cases in area of modern medical

care at end of life which prompted new ways of approaching end of life care in the era of modern

medicine involved Karen Quinlan and Nancy Cruzan. Karen Quinlan was one of the first

prominent cases to task the courts with setting parameters for medical decision making that

involved allowing death to occur despite the availability of life supportive technologies. She was

a 21 year old female who suffered irreversible brain damage after a suspected overdose of

barbiturates in 1975 and as a result was put on mechanical ventilation. As her condition

continually deteriorated over the next several months her parents desired the withdrawal of

ventilator support but Quinlan's physicians and administrators of the hospital refused due to

concern that the withdrawal of life sustaining measures would make the professionals liable for

murder.[120] After a year of court battles, this case, *In the Matter of Quinlan*, was settled by the Supreme Court of New Jersey who ruled in favor of Quinlan's parents, concluding that they were appropriate surrogate decision makers and able remove the ventilator, allowing for natural death, without criminal liability.[121] This case set one of the first precedents for decisions about forgoing extraordinary life sustaining treatment and began to establish that these decisions are best made in hospitals by appropriate surrogates rather than in court rooms.[122] Media outlets across the nation informed the public about the case, bringing national attention to these types of end of life issues and prompted people to start having informal discussion about their end of life wishes and began to establish the importance of formal and informal forms of advanced planning.[123]

A few years later a similar case entered into the national spotlight this time involving a 25 year old woman named Nancy Cruzan who was in a persistent vegetative state following a car accident which occurred in 1983. Mechanical ventilation was removed at the request of Cruzan's parents shortly after the accident when the extent of her injuries became apparent, but in 1987 her parents requested that artificial nutrition and hydration be stopped to allow for a peaceful death, a request to which her care facility and the local judge were uncomfortable. This case, *Cruzan v. Director, Missouri Department of Health*, proceeded all the way to the level of the US Supreme Court where it was determined that her parents request to remove the feeding tube could be obliged only if there was clear and convincing evidence that Cruzan would have wanted it removed. Six months later Cruzan's parents presented such evidence to their local county probate judge who approved their request and Nancy Cruzan passed away in December of 1990.[124] This case reconfirmed the precedent that when people cannot make decisions for themselves an appropriate surrogate decision maker can refuse medical treatment, and it set the

precedent that artificial means of nutrition and hydration can be considered extraordinary measures. The case also encouraged Congress to pass the Patient Self-Determination Act (PSDA), a law establishing that patients have the right to make their own healthcare decisions, including the right to refuse medical treatment and the right to complete advance directives.[125] Clinical cases such as those presented by Quinlan, Cruzan and others have altered the end of life culture in the country. The obligation for healthcare providers to have conversations about death and dying and involve patients in medical decision making is now part of the legal standards. Although people can still chose to avoid these issues, healthcare providers are legally and ethically obligated to address these issues with all patients.

Medical decision making can be very complex for patients or their surrogates especially those who lack healthcare knowledge, but involving patients in medical decision making is imperative because people face a multitude of options about how to treat, or not treat, certain medical conditions.[126] Issues pertaining to quality of life are intertwined with issues pertaining to quantity of life. How to proceed when faced with sensitive end of life, healthcare decisions is often a process that requires exploration of personal values.[127] Traditional notions of autonomy seemed to be a reasonable and practical means by which to consider medical decision making as it became evident that an ethical framework was necessary to guide such decisions. The principle of respect for autonomy ensured voluntariness an understanding and was considerate of personal values from an array of secular and religious aspects.[128] Prioritizing the moral importance of autonomy validated the consent process and advance directives as vital components of medical decision making.[129] As traditionally constructed autonomy and its practical applications in healthcare touched upon the concept that at certain times interdependence is necessary but the focus of medical decision making remained dedicated on

traditional ideals of strict individualism. Perhaps this is because these processes evolved from cases similar to Quinlan and Cruzan when the capacity for autonomy was lost within an instant, at a younger age when chronic conditions and degenerative disease where not fully considered. When chronic and degenerative disease like Alzheimer's occur the concept of autonomy being strictly individualistic in nature becomes invalid.

The severe stages of AD and advanced dementia undermine traditional notions of autonomy and muddy the already complex process of medical decision making at life's end as decisions must be made by a surrogate decision maker. In order for the process to occur while upholding the values of the person with AD there needs to be interrelational communication and consideration between patients, their surrogate decision makers and clinicians. Unfortunately there tends to be a breakdown in this area as patients' wishes are often not properly adhered to even when advance directives had been properly executed prior to the onset of illness and disability.[130] Moral dilemmas often surface around medical decision making during the severe stages of AD resulting in heightened vulnerabilities for all involved.[131] Because AD persists over many years and several stages, the earlier stages should act as a time when the values and opinions about an end of life with AD can be more precisely considered. Such preemptive consideration will lessen the burden during later stages. End of life decision making for people with advanced AD will also alleviate vulnerabilities when the distinction between ordinary and extraordinary care are well recognized and when decision makers are able to distinguish between natural death and aid in dying.

i.   Ordinary versus Extraordinary Care in Advanced Dementia

The vast array of treatment options brings into conflict the issue of ordinary versus extraordinary care. In order for the medical decision making process to proceed appropriately,

meaning that the decisions made are in the best interest of the patient, this ethical dilemma must be worked out so that those acting as decision makers understand the choices they are facing. Because of the nature of advanced dementia, decision makers for those in the severe stages of AD are usually surrogates. The person with AD however could guide their surrogate's decision making process through advance planning and advance directives prior to the onset of dementia and in this case it is the person who will eventually have advanced dementia that needs to understand and be able to differentiate between ordinary and extraordinary care. In the simplest terms, ordinary measures are medical interventions which in all probability will yield in the patient's return to a normal state of being while extraordinary measures are medical interventions that will not in all probability result in the patient's ability to return to a previously normal state of being, or a reasonably acceptable state of being.[132] Differentiating between ordinary and extraordinary can be morally problematic because it is not specifically the intervention that is deemed ordinary or extraordinary but the circumstances in which the intervention is utilized. This hypothetical case can be used to better clarify. Suppose a 60 year old female who is known to have pre-symptomatic AD, has no outward signs or symptoms of the disease and is otherwise healthy is in a car accident resulting in immediately evident lung contusions. Mechanical ventilation is used as ordinary measures as it is intended to be temporary, once the lung contusions heal the woman will in all likelihood be able to return to her previous state of being. After closer examination and testing it is found that the women has suffered extensive brain injury and she will more than likely advance to a persistent vegetative state. In this situation, mechanical ventilation becomes extraordinary as the woman will not likely ever return to her normal activities of daily life due to the brain injury.

According to state issued advance directive documents several interventions become optional when one is permanently unconscious or has and end-stage medical condition. These interventions include; CPR, mechanical ventilation, surgery, dialysis, antibiotics, chemotherapy, radiation and mechanically administered nutrition and hydration.[133] There are scenarios when any of these interventions may fall into the category of ordinary measures and scenarios when they may all be considered extraordinary. Often times there is a great deal of gray space when the category to which they fall is unclear. Individual values and opinions regarding vitalism and quality of life influence how these measures apply in different scenarios. When decisions involving ordinary versus extraordinary care come into play people may question whether a decision to avoid extraordinary care is consistent with suicide, considered a form of direct killing, or holds the decision maker liable for death that results. Decision makers, whether patients themselves or surrogates, should be assured that such concerns are invalid in situations where the burdens of interventions outweigh the benefits because allowing one to die from an underlying medical condition is distinguishable from acts of direct killing. Decisions to withdraw care, discontinue an intervention once it has been started, or withhold care, choosing not to initiate an intervention, in extraordinary situations are referred to as forgoing care. The legal system as well as secular and various denominations of religious ethics have affirmed that there is no distinction between acts of withdrawing and withholding care and both may be done legally and morally when the burdens of electing or continuing care surpass the benefits.[134] Forgoing care is an act that facilitates allowing to die when treatment is futile or illnesses have reached their end stages. When advanced dementia is present the severe stages of AD are known to be an end-stage condition.[135] Because the healthcare system is designed in such a way that the ultimate decision on forgoing care must be made by a patient or surrogate, and must be based on

the patient's personal morals and values, regardless of the underlying condition or the degree to which it has advanced, relational autonomy becomes an absolute necessity in the severe stages of AD.

ii.   Allowing to Die and the Limits of Aid in Dying

The Uniform Definition of Death Act, drafted in 1981, defines that death is officially determined in one of two ways; cardiac death, the cessation of cardiac functioning, or brain death, the cessation of brain functioning.[136] The ways by which people reach the point of death however are countless. Because cure is often the primary focus of modern medicine and life prolonging treatments and technologies can offer the potential to put off death through their use, medicalized deaths have become common. While curative and preventable measures are quite often welcomed and valuable throughout the lifespan, eventually a time comes when such measures no longer offer benefit and can actually result in harm. The pursuit of cure and treatment may offer relief from pain and suffering caused by disease and injury but they can also cause pain and suffering. The line between measures that are helpful and measures that are hurtful is not habitually clear. Daniel Callahan, describes the tug-of-war between the push to use technology to save life and the desire to preserve a decent quality of life as "technological brinkmanship".[137] Being in a position to determine exactly where this line lies between life and death can create a state of vulnerability. Medicalized deaths can be avoided when people elect to forgo life sustaining measures before the onset of a medical crisis, or by electing no further treatment at an appropriate time and proceeding with comfort measures only. Hospice and palliative care programs help people avoid a medicalized death and potentially reduce vulnerability associated with end of life decision making. The goals of these programs are to foster a peaceful and natural dying process. Regardless of whether choices are made to engage

in life sustaining measures for as long as possible or avoid them all together, forgoing interventions during the end-stage of illnesses like AD are not considered direct killing but rather such decisions are considered to be allowing death to occur from the underlying condition.

For some people neither a medicalized death nor a natural death are desirable options. Resultantly, over the past several decades there has been a rise in the controversial movement referred to as, "aid in dying". This movement has expanded in an effort to support the freedoms of terminally ill people to end their life through euthanasia or more precisely physician assisted suicide.[138] The word euthanasia as interpreted from its Greek origins means good death. In the context of modern healthcare, euthanasia has come to be known as intentionally causing the death of an ill person through direct actions.[139] The intent of this action is to relieve pain and suffering. The controversial practice of euthanasia can be viewed as alternative to a medicalized death because some see it as a compassionate way to end suffering and avoid medical power under appropriate circumstances, yet some believe it is murder and should be condoned.[140] Euthanasia is considered the intentional act of causing the death of someone who is terminally ill and/or suffering. The action of euthanasia can be inflicted by suffering people themselves or by others, it is considered voluntary when patients ask for the infliction of death and involuntary when they do not. Assisted suicide is similar to euthanasia, the difference lies in who takes the action of administering the life ending measures. Assisted suicide occurs when ill people request the assistance of another person to provide the means to end their life, such as by requesting a lethal dose of medication, but the ill people themselves administer the means with the intent of taking their own lives.[141] When such requests are made to physicians it is referred to as physician assisted suicide. Physician assisted suicide, or physician aid in dying as it has most recently become termed, is the form of euthanasia occurring when physician are involved in

providing the means by which their patients can inflict their own death at a time of their choosing.[142] Some countries have legalized or decriminalized physician assisted suicide, including the Netherlands, Switzerland and most recently Canada.[143] Since 1997, six states in American; California, Colorado, Montana, Oregon, Vermont and Washington, have legalized aid in dying through physician assisted suicide when it follows specific guidelines and processes. The guidelines vary from state to state but all include safeguards requiring a terminal prognosis of six months or less, evidence of mental competency, and that the life ending medication is self-administered.[144]

Before any state in the US had legalized physician assisted suicide, Jack Kevorkian notoriously brought the issues of euthanasia and assisted suicide into the limelight of the public attention. Described as "unpolished and confrontational", Kevorkian notoriously made it his life's work to assist over 100 terminally ill people in their death through assisted suicide, which he insisted was always requested and consented to by those he assisted. He was able to outsmart legal regulations and avoid prosecution for his role in assisted suicide for nearly a decade. In 1999 however he crossed the line from assisted suicide to active euthanasia when he administered the lethal injection to a man with ALS who wanted to die but was physically unable to self-administer the medication. As a result Kevorkian was put in prison.[145] Kevorkian was no stranger to AD as he did receive requests from people suffering with the condition, in fact one of the first of Kevorkian's assisted deaths to be made public involved a woman named Janet Adkins who was a 54 year old female diagnosed with early on-set Alzheimer's disease. According to reports by Kevorkian and Adkin's family she wanted to end her life while she still maintained mental capacity to make the decision rather than face a future with dementia. Kevorkian provided a legal dose of potassium chloride to Adkins, but it was Adkins who intentionally, self-

administered the lethal dose of medication in June of 1990.[146] Adkins story, like Kevorkian's

other stories, were not publicly well supported, highly questioned and criticized.

Today physician assisted suicide remains a morally controversial issue. While some

people find aid in dying justified based on the right to autonomy, others continue to voice

various moral concerns some of which pertain to; the physicians' oath to nonmaleficence, the

devaluing of human life, and concerns about fair access.[147] Despite its provocative nature, the

aid in dying movement has gained in support, according to a 2014 Harris Pole, physician assisted

suicide is supported by 72% of Americans, an all-time high. Growth in popularity is credited to

natural evolution and a reemergence of the issue brought about by the highly publicized Brittany

Maynard story, a case involving a 29 year old female with brain cancer who ended her life

through physician assisted suicide which was highly publicized and gained a good deal of public

support.[148]

Regardless of where one stands on the moral permissibility of physician aid in dying, and

even for those who reside in states where the practice is legalized, people afflicted with AD do

not meet the criteria to consider aid in dying as an end of life option. [149] As it currently stands

where physician aid in dying is practiced, the person requesting this options must be terminal,

meaning based on disease phase they will likely die in six months or less and they must be

mentally competent at the time the request for assisted death is made. When AD is the disease at

hand, people are not mentally competent when they reach the terminal stage. Furthermore, they

most likely cannot self-administer the medication. Thus far there is not a preemptive option for

aid in dying, meaning it has not become an option that can be planned in advance and carried out

under the direction of healthcare proxies. Even for measures which are currently a standard part

of advanced planning like the refusal of antibiotics, surgeries, or artificial nutrition and

hydration, some question the appropriateness of the limits and freedoms of precedent autonomy.[150] Precedent autonomy considers the validity of advance planning that occurred by competent people years before the onset of dementia who may not have presumed they may actually be in a happy or content state as dementia progressed through the moderate to earlier severe stages, prior to its terminal phase.[151] Concerns about the validity, importance and interpretations of precedent autonomy reinforces the need for relational consideration in autonomy especially during life's end stages in the face of dementia related to AD.

During the severe stages of AD care dependency is high and vulnerabilities become heightened for the millions of people with AD and the millions of people who care for them. When relational autonomy, as a component of care ethics, is embraced vulnerabilities are alleviated making the duration of end stages of AD more manageable for all involved. Relational autonomy emphasizes the important role of compassionate love in providing care to those with dementia, the fallout of which is reduced harms to patients, reduced burden to caregivers, and the enhancement of attributed dignity in both populations. Relational autonomy becomes essential for the medical decision making process in the severe stages of AD as dementia completely contests the characterization of traditional autonomy. Without allowing autonomy to become relational the decision making process would return once again to physician paternalism, a practice which bioethics has worked diligently to overcome. Honoring relational autonomy during the severe stages of AD would positively impact the way by which people with AD reach their death by better ensuring the distinction between ordinary and extraordinary care is understood and by better ensuring that end of life wishes, to either die a medicalized death or a death free from medical interventions, occur when futility becomes

evident. The other component of care ethics, social responsibility, highlights the utility of hospice and palliative care for the public good during the severe stages of AD.

III.   Social Responsibility: Benefits of Hospice and Palliative Care for Public Good

Palliative care is a multidisciplinary approach to enhancing quality of life for people with serious or chronic illnesses. Since the 1960's, palliative care programs have been adopted by many countries throughout the world and efforts are continually made to expand the services to areas where palliative care is not offered or underdeveloped. The exact definition and methods of providing palliative care varies geographically, but palliative care has been recognized by the WHO as an appropriate form of care for anyone facing a chronic or ultimately fatal disease. The WHO emphasizes that proper palliative care is a priority for public health and encourages all nations to promote the service as appropriate for their county's particular healthcare system and cultural needs.[152] In the US, palliative care has traditionally been thought to be limited to only patients with a life expectancy of six months or less, wishing to forego curative and treatment measures but palliative care can be offered to any person facing a chronic condition regardless of disease prognosis or whether or not patients are seeking curative or non-curative care. Within the US healthcare system there is a distinction made between palliative care and hospice. Hospice is a more specific service falling under the palliative care umbrella that offers palliative care services to people as they are nearing death. This hospice model of palliative care has become dominant in the US because of the healthcare's system of reimbursement.[153]

To be considered appropriate for hospice services Medicare guidelines requires that two specific criteria must be met regardless of payer type. The first criteria requires that people receiving hospice services have a terminal prognosis of six months or less, assuming the disease

follows its naturally expected course, the terminal prognosis must be certified by a physician.

The second criteria requires that those receiving hospice services no longer wish to pursue

curative treatment.[154]   The National Hospice and Palliative Care Organization (NHPCO) states

that the mission of hospice is to enhance quality of life through the use of palliative care at life's

end.[155] The outcomes of improving quality at end of life through hospice services has both

proven and suspected outcomes. Hospice and palliative care use is directly proven to increase,

wellbeing and quality of care as well as decrease healthcare costs. More research is necessary to

confirm but claims have been made that with efficient hospice use, people may live longer than

expected.[156] Morality affirms that adequate care ought to be provided at life's end. Recently

however, the quality of end of life care provided in America has been criticized and propositions

for change have been made.[157] The large portion of people currently living in the severe stages

of AD as well as the larger proportion estimated to enter these stages in the future make up a

significant portion of society who will be benefited by the appropriate use and provision of

hospice and palliative care as the severe stages are part of a chronic condition that will eventually

become terminal. This far reaching burden has implications not just for individuals but for

society as well. While the severe stages of AD increases the risk of societal vulnerability, social

responsibility when properly promoted reduce this risk.[158] Hospice and palliative care programs

promote social responsibility in the face of advancing dementia through their multidisciplinary

approach to care and by reducing avoidable hospitalizations.

A. A Multidisciplinary Approach to Care

Interdisciplinary approaches to patient care have increased in popularity over the past

several decades leading to the development of multidisciplinary treatment teams. The

multidisciplinary approach to care is currently the primary approach used in most sectors of the

US healthcare system today.[159] Multidisciplinary treatment teams consists of physicians, nurses, social workers, chaplains, therapists and representatives from other disciplines who are involved with the treatment of patients. Multidisciplinary teams may meet regularly to collaborate on patient cases or teams may be structured in a case management fashion in which one professional leader coordinates the input of all disciplines.[160] A collaborative team approach to care improves communication, outcomes and ensures more consistent ethical considerations because focus is not only on the medical factors but on all factors, including psychosocial factors that impact the person as a whole.[161] Hospice and palliative care programs use a multidisciplinary approach to enhance quality of life during life's final stages by providing physical, social, spiritual and emotional supports to patients, their caregivers, and their family members. This approach prepares patients, caregivers and family members for the impending death as well as providing bereavement services to survivors following the death of their loved one.[162] These programs provide services to their patients in various settings including acute care settings and residential setting such as private residences assisted living facilities and nursing homes.[163] The multidisciplinary care teams functions to enhance quality of life though various tasks such as; proper disease management, ensuring smooth transitions and communication between care settings, providing caregiver support, and alleviating pain and suffering.

The mystery of human suffering has existed for as long as history can be traced. The notion of suffering varies from person to person and may be influenced by religious and cultural beliefs.[164] When a person appears to have died comfortably it is commonly remarked that he or she did not suffer, while in contrast when a person was seen in pain it may be remarked that he or she was suffering. While the words pain and suffering are at times used synonymously, and while the two words are closely related, it is imperative to recognize and appreciate that they are

not always synonymous. The extent to which pain is related to suffering however has been debated.[165] The assumption tends to be made that suffering is associated with physical pain hence making it specific to ailments of the body.   While this is true, it is not the complete extent of suffering. Suffering is not only physical but can be emotional and psychological in nature as well. Such suffering can occur in conjunction with physical pain and also despite physical pain thus making pain specific not just to the body but to the mind as well. Pain does not always result in suffering just as suffering is not always the result from pain. The concept of suffering is not static, it is difficult to define and its source and degree vary from person to person. One element of suffering that is inevitably consistent is that suffering is almost always the result of threats to one's sense of self. It is because of this that quality healthcare cannot be achieved when the mind and body are not considered separately.[166] The multidisciplinary treatment teams of hospice and palliative programs strive to address the intricacies of pain and suffering by addressing both the physical issues and psychosocial issues of those they serve.

   i.   **Addressing Physical Pain and Suffering**

Palliative care services strive to reduce pain associated with enduring illnesses and other types of conditions. Hospice services by extension strive to reduce pain at end of life in an effort to allow for death to be as comfortable as possible. One of the methods for accomplishing these goals when physical pain is present in patients is through the use of pain medications. Administering pain medications at the end of life raises concerns for some people. One of the main concerns is that the use of pain medications, especially morphine, may hasten death. For many faith based people, there is a common concern that use of pain medications may interfere with suffering that is caused by, or necessary for religious purposes.[167] Hospice and palliative care programs are designed to be considerate of the religious and non-religious dilemmas their

patients, and patients' family members, anticipate or experience while enduring life threatening illnesses or when they reach life's end. The hospice philosophy indicates each patients' personal belief system and their choices regarding care are embraced in hospice's efforts to relive symptoms of distress and ease pain.[168]

Although they cannot verbalize pain and discomfort, people with advanced dementia do experience physical discomfort as end of life nears and despite the lack of ability to intentionally communicate other indicators can be used to assess pain in this population.[169] A study published in 2004 found that a significant number of patients in the terminal phase of AD residing in nursing homes who were not involved with palliative care experienced uncomfortable interventions such as; regular intravenous therapies and lab draws, the use of restraints, and the placement of feeding tubes. These people also commonly experienced other distressing symptoms such as pressure ulcers, shortness of breath, fever, and constipation.[170] A similar study by some of the same researchers found that when family members were properly informed about the terminal nature of advanced dementia, the potential discomfort associated with interventions, and the potential for complications, the surrogate decision makers were more likely to make decisions to limit care in hopes of allowing their loved one to pass away as comfortably as possible.[171] Hospice and palliative care professionals are experienced at having these conversations with family members regarding the physical pain associated with burdensome interventions in a time sensitive and compassionate manner to ensure that decision makers for people with advanced dementia fully understand the risk-benefit ratio and can properly determine what constitutes ordinary versus extraordinary care in each particular situation thus limiting unnecessary physical pain at end of life.

ii. Addressing Psychosocial Pain and Suffering

In addition to physical symptoms, hospice and palliative care programs focus on providing psychosocial support to their patients, family members, and caregivers throughout the disease process. This is an essential focus because the dying process can be psychologically agonizing to not only patients but their family members and caregivers who also endure the burdens of AD. The hospice and palliative care approach incorporates caregiver education and the use of counseling techniques into their work. The multidisciplinary teams work to ensure smooth transitions and communications between care settings when they occur, and helps patients to comfortably remain in their home setting through physical decline by using patient-centered approaches to realistic goal setting, regular follow up, and adequate caregiver support.[172] Family members involved in the medical decision making process are at risk for suffering due to the stressful nature of this process. Hospice and palliative care programs are especially helpful in alleviating psychosocial distress because they strive to take into consideration not just physical factors but also cultural and religious factors as they relate to the dying process. Ultimately, quality of life tends to be enhanced through the use of hospice and palliative care because of the efforts aimed at providing psychological support and maximizing wellbeing for their patients, family members, and caregivers.

Like physical distress, people with AD also experience psychological distress. Depression and anxiety are common in people throughout the stages of AD. Antipsychotic medications are prevalently administered to people in the severe stages of AD.[173] People providing care to those with AD also experience psychological distress as a result of their caregiving responsibilities. The level of caregiver distress has been found to be drastic enough to be considered a concern worthy of public health attention.[174] Compared to non-caregivers,

people providing informal care to another person with AD are more likely to take prescription medications for anxiety and depression. Caregivers are also more likely to see their primary care physician, visit an emergency room, and are at increased risk for mortality.[175] It is reasonable to assume that through the use of hospice and palliative care, caregiver burden associated with AD will be reduced through the focus on caregiver support, in essence reducing the identified risks associated with this burden.

B.   Reducing Unnecessary Hospitalizations

People with dementia have higher rates of hospitalization than people of the same age groups, with similar comorbidities who do not have dementia.[176] Many of these hospitalizations are unnecessary and could be prevented with proper disease management.[177] Hospitalization, including trips to the emergency department, can further complicate dementia by putting these patients in the stressful hospital environment which commonly promotes and increases delirium and functional decline, as well as puts people at risk for sentinel events, events unrelated to the reason for hospital admission that cause additional and unexpected physical or psychological harm.[178] Potentially avoidable hospitalizations for people with dementia may be due to the expected complications of advancing dementia such as difficulties with eating and drinking or pneumonia, or they may be due to complications in identifying other health complications, such as UTI, early because people with dementia cannot communicate signs and symptoms efficiently, or the hospitalizations may be more social in nature rather than medical related to caregiver fatigue or unpreparedness for the expected course of dementia.[179]

It has been found that unnecessary hospitalizations of people with dementia can be prevented through various measures such as improvements to how the severe stages of AD are addressed and managed by primary care physicians but unfortunately the unique needs of the

Alzheimer's population are not efficiently addressed in the current model of care for chronic diseases.[180] In addition to the aforementioned issues, hospitalization of patients with advanced dementia increases the potential for poor end of life experiences. Negative experiences at end of life in hospitals tend to occur because hospital staff are unfamiliar with patients, hospital staff tend to spend less time with the medical decision making process, and services are often fragmented which can lead to the administration of care that contradicts patient or surrogate end of life wishes.[181] As opposed to acute care, hospice care more regularly promotes end of life care that is in line with patient and family wishes. Hospice has been shown to reduce hospitalizations in the last few months of life for people with advanced dementia, its services also incorporate education and counseling surrounding whether to utilize of forego non-beneficial medical interventions.[182] Reducing unnecessary hospitalizations for people with advanced dementia is socially responsible as the outcomes are improved quality of life and reduced healthcare costs for those who have irreversibly reached life's end. Hospice and palliative care services contribute to these efforts by understanding futility as it pertains to advanced dementia and by fostering a dignified death.

    i.   **Futility in Advanced Dementia**

As the options for care at end of life expanded, the line between living and dying became more blurred. This grey space motivated some professionals to attempt to establish a point when aggressive treatment no longer offered any potential good for patients and thus should no longer be utilized. This concept became known as futility.[183] Futility is a state when none of the available medical treatment will bring about benefit to the patient and treatment is useless because the underlying condition is too advanced to be helped.[184] While the definition of futility can be simply stated as medical treatment that offers no usefulness, its application has been

anything but simple. The need for a concept of futility emerged from the combination of expanding capabilities of medical technology, and the rights of patients to make their own medical decisions because life sustaining technologies became more commonly used to keep people alive even when it was clear that without the technologies people were most likely to die imminently because there was no hope of alleviating the underlying medical condition. Patients' right to autonomy requires that physicians involve patients, or their surrogates, in all medical decisions but this right can poses issues for clinicians whose patients/surrogates demanded continued treatments that are known to be futile.[185] How and when medical futility is applicable has not yet been clarified or well established in healthcare as it has not been widely addressed by organizational or public policy.[186] Patients and their surrogates are prone to vulnerability when they find themselves in medical situations where the point of futility is near or has been reached. Professionals and organizations are also prone to vulnerability when futility has been reached but policy allows for care to continue regardless when that is the decision made by, or for, patients. Thus futility is a societal concern.

In general it may be difficult to define exactly when end of life begins.[187] This complicates knowing when ordinary care may become extraordinary and when treatments, interventions, and certain types of conditions become futile.   Various measures create troublesome situations surrounding the concept of futility. The use of artificial nutrition and hydration (ANH) is one such measure that often creates sensitive, ethical end of life dilemmas. For about sixty years the use of ANH at end of life has been an ongoing point of ethical contention among healthcare professionals, patients and their family members.[188] Debates about its use, non-use or discontinuation have sparked personal and public controversy. In its position statement on ANH, the NHPCO explains that the issue of AHN at end of life is very sensitive but

the organization does not take a position for or against the use of AHN, rather, it recommends that decisions regarding AHN should be made, just as other medical decisions, by a competent, well informed person who is able to weigh its benefits and burdens.[189] Hospice and palliative care services can be offered to patients who elect the use of AHN in most instances, the only reason AHN may interfere with the provision of hospice services is when its use is directly linked to the patient's terminal diagnosis, as issues in this situation may be raised because of Medicare regulations.

The use of ANH in people in the severe stages of AD remains prevalent and controversial. When the severe stages of AD are evident, particularly the final stage of advanced dementia, the condition is irreversible, has reached its final stages thus it has become futile. When this stage is properly understood from a medical perspective decision makers may be more willing to accept its futility and make medical decisions that are in the best interest of those with severe AD. Despite a lack of policy surrounding futility, the American Geriatrics Society has taken a public stand on the use of ANH when advanced dementia is present. Their stand asserts the extraordinary component of the measure and its futility when advanced dementia is evident. They publicized their position in their journal in 2014, stating that, "Feeding tubes are not recommended for older adults with advanced dementia. Careful hand feeding should be offered; for persons with advanced dementia, hand feeding is at least as good as tube feeding for the outcomes of death, aspiration pneumonia, functional status, and comfort. Tube feeding is associated with agitation, greater use of physical and chemical restraints, greater healthcare use due to tube-related complications, and development of new pressure ulcers."[190] Despite their firm position, the American Geriatrics Society still asserts that patients and the surrogates have the right to make their own choices based upon the patient's wishes and values when the use

ANH is raised but also asserts that professional care providers and caregivers are obligated to properly ensure decision makers understand the associated risks and benefits in perspective with the condition of advanced dementia.[191]

ii.   Fostering a Peaceful Death

When the severe stages of AD are reached, the condition is terminal and death is inevitably approaching. Death from advanced AD can be jousted with through medicalization or it can be embraced peacefully as the natural, unavoidable occurrence that remains a genuine part of the human condition. The pursuit of a peaceful death is a goal of medicine that conjoins with the avoidance of premature death. The prevention of early death is encouraged through this goal but the acceptance of death as an ultimate part of life remains an obligation intricately associated with the human condition. The goals of medicine acknowledge the barriers to a peaceful death that have been created by the emphasis on cure in modern medicine but still define a peaceful death as, "one in which pain and suffering are minimized by adequate palliation, in which patients are never abandoned or neglected, and in which the care of those who will not survive is counted as important as the care of those who will survive".[192] A peaceful death can occur in any setting but it has been found that death in the acute care hospital setting tends to be less peaceful in nature than does death that occurs elsewhere. By its very definition hospice is an end of life program that aims to promote a peaceful death. Hospice works to provide a peaceful death and therefore when treatments are deemed futile and demise is imminent hospice care ought to be utilized to ensure the goal of a peaceful death is achieved in all possible cases. Through its efforts to provide physical, psychosocial and spiritual support to the dying, their family members, and caregivers vulnerability may stand to be less of a threat. For patients with dementia this may be because through the various types of support provided by hospice their

sense of self remains more intricately intact throughout cognitive decline. For family members this may be due to the psychosocial support that is provided as their loved ones decline over an extended period of time, and for caregivers this may also be related to the psychosocial support which can ease compassion fatigue and burnout. As will be more detailed in the next chapter, society stands to benefit when a peaceful death is promoted as quality of life at life's end is improved and end of life costs are reduced.

Social responsibility pertaining to end of life care was emphasized in the introduction to the 2015, IOM report titled, *Dying in America*. The report claims that all Americans are responsible to ensure and expect that adequate care is properly provided as life comes to an end.[193] As it currently stands over 5 million American lives will come to an end as the result of AD as it is a terminal condition that becomes most complex and life threatening when it progresses to its severe stages. Social responsibility becomes advantageous during the severe stages because it encourages that the various burdens of this prevalent condition be managed as competently as possible. Social responsibility is promoted when hospice and palliative care is used to manage the severe stages of AD. This is especially evident when it is understood how these programs use multidisciplinary approaches to care, and how their use can reduce unnecessary hospitalizations. The use of multidisciplinary care teams lead to improved disease management with more ethically focused tactics which address the needs of patients, their family members and their caregivers. Avoidable hospitalizations are circumvented more regularly when advanced dementia is understood in terms of its futility and when patients are enabled to experience a peaceful death.

IV.   Conclusion

Adequate care at the end of life is a crucial component of human morality. Despite its innate relationship with the human condition, the provision of end of life care in American has recently been identified as in need of improvements that can enhance quality and sustainability.[194] Because it is a terminal and complex condition, end of life care specific to AD needs addressed as improvements are made to end of life care. During the severe stages of AD personal vulnerabilities become heightened. For those with the disease this is due to their complete dependency on the others for care, those who care for people with AD are also vulnerable due to the multiple complexities associated with providing care to someone with dementia. High levels of vulnerability impact the caring relationship and endanger relational autonomy.[195] Both people with AD and their caregivers depend on a variety of support, medical support is needed, long term supports are essential, and other supportive services are necessary throughout the duration of this terminal condition.[196] Relational autonomy as constructed by the ethics of care reduces vulnerabilities common to the severe stages of AD. When relational autonomy is embraced concerns pertaining to both paid and unpaid caregivers will be better comprehended and addressed. Relational autonomy also helps identify the complexities related to medical decision making. It will guide that better clarification be provided between ordinary and extraordinary measures in the face of advancing AD and also identify what it means to allow for death to occur as a result of advanced dementia.

Social responsibility as constructed by the ethics of care also becomes important during the severe stages of AD. This is because the disease has immense prevalence and creates far reaching societal implications. The notion of social responsibility in care ethics works to overcome societal vulnerabilities by promoting community accountability.[197] Palliative care and

hospice services will positively impact societal responsibility to those affected by advancing

dementia. Hospice and palliative care professionals understand the intricate nature of pain and

suffering and are able to comprehensively address issues related to pain and suffering as they

effect patients with AD, their family members and caregivers. Hospice and palliative care does

this by approaching care from a multidisciplinary perspective addressing issues pertaining not

only physical in nature but also psychosocial and spiritual issues, all of which are worthy of care

and concern at end of life. Hospitalizations are more common for older people with dementia

than older people without dementia. When unnecessary, hospitalizations not only increase

healthcare spending but also negatively impact the end of life experience. Use of hospice and

palliative care has been shown to reduce these unnecessary hospitalizations, improve the end of

life experience and foster a more peaceful death despite the presence of AD. Ultimately by

incorporating the ethics of care framework into end of life care for people with AD

vulnerabilities will be reduced, patient care and public good will be increased, and the ethos

surrounding end stage AD will be improved.

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Chapter Six: Integrating Ethics of Care with Organization Ethics to Manage Alzheimer's Disease

I.   Introduction

Organizational ethics is a newer component of healthcare organizations (HCOs). First introduced by the Joint Commission for Accreditation of Healthcare Organizations (JCAHO) in 1995 and soon thereafter supported by the American Hospital Association (AHA), organizational ethics aims to promote performance improvements by incorporating ethics into all aspects of the organization to ultimately foster a positive ethical climate.[1] American HCOs function within the market economy but are dynamically different than other types of businesses corporations. There are a vast array of stakeholders in the business of healthcare and the relationship between consumers, providers and payer sources is more often than not incongruent as there is no universal system for care in the county.[2] Such circumstances make the proper combination of business ethics, clinical ethics and professional ethics essential to the success of the HCO. When aligned properly ethical decision making occurs and moral behavior is displayed by all members of the organization, ultimately yielding a virtuous organization.[3]

The urgency to promote virtuous organizations whose missions and values portray high ethical standards is the result of various scandals that have occurred within the business of healthcare over the past several decades.[4] For example, the Veterans Administration (VA) has been identified for various scandalous organizational activities over the past century. In 2014 the Phoenix VA was found to have deliberately neglected the needs of over one thousand patients to manipulate reported wait times.[5]   These, and other organizational scandals, have resulted in a declining sense of trust for HCOs by the public. Trust is an essential element in quality care and must be rebuilt and maintained on the systems level.[6] In 1990, the Institute of Medicine (IOM)

first defined quality in healthcare as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."[7] Over ten years later, in its groundbreaking report, *Crossing the Quality Chasm*, the IOM depicted the quality of America's system of healthcare delivery as dynamically flawed and in need of dire improvements. The main areas where quality was claimed to be deficient were patient safety, patient-centeredness, effectiveness, efficiency, timeliness and equity. Subsequently these six areas were recognized by the IOM as the framework for quality improvement in healthcare delivery.[8] Beginning in 2012 Medicare began to reinforce the importance of quality in healthcare to its providers and HCO's by basing 30% of its reimbursement on patient satisfaction surveys.[9]

Among recommendations for improving quality of healthcare delivery is the recognition that certain common conditions effecting large portions of the population require customized disease management approaches in order to adequately achieve high-quality care. AD and other related dementias are among this short list of common conditions.[10] While the challenges presented by AD are well known and well documented, there has not yet been great advances in the quality of care received by those affected by the disease.[11] The current system is fragmented, which can only aggravate cognitive difficulties. It is also primarily medicalized, focused on treatment and cure, resulting in the unique needs of the Alzheimer's population often being overlooked or poorly managed due to the absence of treatments and cure for the condition.[12] Furthermore, the approach to care in the current system is most often based on the traditional notion of autonomy which is not an appropriate model for the millions of people facing AD. Before exploring how the ethics of care should be integrated into organizational ethics to manage the burden of AD, it is first necessary to understand why the concept of sustainability is

important to healthcare systems and why it is unlikely that the current healthcare system in the US will be sustainable if changes are not soon adopted.

A. The Importance of Sustainability in Healthcare Systems

The word sustainable has become a popular buzzword across the globe. The word itself means to endure or remain capable of being maintained.[13] Its increased use, and that of its derivatives, may be associated with the rising array of concerns related to climate change. The importance of sustainability is being explored in many aspects of business practice commonplace in the world today. As emphasis on concern surrounding the health of the planet and the potential of depleting its resources becomes more standard in many aspects of modern civilization various systems are exploring how to have a more positive impact on environmental sustainability.[14] Healthcare systems are not exempt from the areas that contribute to the rising concern for the sustainability of the environment. Across the globe healthcare systems use vast amounts of energy and other natural resources and produce high amounts of harmful emissions. Fortunately, clear measures aimed at positively improving these factors are available to healthcare organizations who so desire to promote sustainability.[15]

Special consideration for the responsibility that healthcare systems, and the health sciences in general, have to sustainability have been internationally illustrated by UNESCO's Universal Declaration on Bioethics and Human Rights. UNESCO, in its mission and quest for international peace and security, took a leading role in guiding bioethics on a global level when it developed this declaration and released it to the public just over a decade ago.[16] Articles 16 and 17 of the declaration declare the protection of the environment as well as the protection of future generations as leading principles of global bioethics.[17] UNESCO recognizes the great benefits of emerging healthcare technologies and also their potential to cause great harms to not only the

human race but also other species and the environment.[18] Additionally, UNESCO recognizes

these benefits and burdens must not only be weighed in consideration of the present but also

must be weighed in consideration of future humanity for the generations to come.[19] Through

these unique efforts UNESCO has emphasized the significant role the health sciences play on the

capacity for both our environment and our species to endure indefinitely.

At the same time that healthcare systems contribute to the sustainability of the

environment, healthcare systems must be concerned about their own sustainability. Medical

capabilities continuously expand in today's rapid pursuit of curative treatments. The distinct

goals of modern medicine include aspects of both cure and care as well as the pursuit of a

peaceful death.[20] Death, however continues to popularly be viewed as an enemy that should be

avoided at all costs. This emphasis on prolonging the lifespan and avoiding death have perhaps

blurred the significance of other goals and made the notion of avoiding an untimely death a top

priority. The outcomes of this trend include rising costs, limited resources and concerns about

allocation and access to care.[21] How the outcomes are handled by the healthcare systems of each

individual nation impacts the sustainability of each healthcare system. In order for a system to

be successful it must also be sustainable.

B. The Current Unsustainability of the United States Healthcare System

Recent trends in the United States show increasing concern that the current system is

unlikely to be sustainable. In a special article published in the New England Journal of Medicine

in 2012, accomplished physician Harvey Fineberg illustrated multiple areas of inefficiency

commonly found throughout the US healthcare system. These inefficiencies, he affirms, have

contributed to a system that is both unsuccessful and unsustainable.[22] The failure of the

country's success was clearly indicated in 2000 when the World Health Report gave the US a

ranking of 37th among the other developed nations of the world. This occurred despite its top notch ranking for high healthcare spending in comparison to the same countries. This ranking should not have come as a huge surprise as the US's mortality rate in boys and men had continuously fallen behind that of other countries as well as having had made slower improvements to the rate since 1974.[23] According to Fineberg, successful healthcare requires heathy people, superior care and fairness, most of which the US healthcare system has proven to lack overall. The factors necessary for sustainable systems; affordability, acceptability and adaptability are also not evident in the country's overall system.[24] With all the complexities involved with healthcare it would likely be difficult to separate factors influencing success from factors influencing sustainability. Closer examination of one the biggest complaints about the sustainability of US healthcare, affordability, and various success factors will reinforce why it is unlikely America will achieve success or sustainability if changes to its system are not made.

Some will argue that the US healthcare system cannot be compared to the systems of other nations because unlike other developed nations healthcare in the US is market regulated rather than government regulated.[25] Historically healthcare was a slowly developing enterprise contributing to the US's market economy but since the conclusion of the Second World War it has increasingly become a major contributor yielding not only great profit but also increasingly high associated costs.[26] According to the Center for Disease Control (CDC) the US witnessed a 14% increase in its healthcare spending over just seven years when in 2007, 16% of its gross domestic product, or 2.2 trillion dollars, was spent on healthcare related expenses.[27] These costs far exceed any other nations healthcare spending, are perhaps the greatest threat to the US's fiscal budget, have ruined our global competiveness, and bankrupted many families, even those with health insurance.[28] This was illustrated in a 2008 episode of the PBS show Frontline

entitled, *Sick around the World*. This episode investigated how other capitalistic, democratic nations provide healthcare in ways which are more affordable and marked with higher quality than the care provided in the US. While all of these nations have unique healthcare systems, they all set limits to the free market, ensure all citizens have health insurance, and none of them reported problems with individuals becoming bankrupt as a result of their medical expenses.[29]

The issue of healthcare costs can be endlessly dissected and reviewed. The top overall factors contributing to the high costs in the US can be categorized into various groupings including high and rising prices, administrative expenses, fraud, and unnecessary services. Unnecessary services account for more of the expenses than do any of the other categories. Although the issue of using unnecessary services, or providing what is sometimes referred to as low-value care or no-value care, is a huge issue it is one that has the potential to be targeted and controlled.[30] Managed care organizations became prevalent beginning in the 1970's as a means of reducing costs by controlling and managing the provision of care and services. Although highly unpopular, managed care was somewhat successful in controlling healthcare costs for a few decades until legislation and politics as well as opposition from physicians and patients intervened and disrupted their success.[31] Following the height of managed care's success many providers have returned to models of care where they are financially rewarded for overtreatment, even when it can best be described as unnecessary.[32] The reality of a very complex healthcare system that impacts individuals, businesses, the government and society at large is that costs are rising and are not sustainable at any level of impact.[33]

A successful healthcare system is not an easy task to achieve. Many factors contribute to the overall measures of healthy people, superior care and fairness. Citizens must have the highest level of health possible, care must be safe, effective, timely, patient centered, equitable

and efficient, and access to care must be without any type of discrimination.[34] In research supported by the Commonwealth Fund, it has been concluded that in several recent years, including 2014, the US has ranked behind 10 other nations, including Canada, the UK, France, Germany and Australia, in almost all of these areas. While achieving a good score in a few areas such as preventative medicine, the US ranks far below the other nations in most other areas, such as safety and access, ultimately placing the country at the bottom of the list of performers. Canada ranks just slightly better than the US on these success factors while the UK and Switzerland rank far ahead.[35] The lack of universal healthcare coverage is often blamed for the US's shortcomings in such rankings. The push for universal health coverage has been a resurfacing debate in the US for at least a century but has consistently failed to gain governmental approval.[36] With the latest attempts at healthcare reform through the Affordable Care Act and a growing emphasis on incorporating quality measures into healthcare reimbursement rates, there is rising hope that the US will be able to improve in some areas.[37] Much work will need to be done on a nationwide level to ensure success is improved, even greater work will be necessary to surpass other nations on the list.

The ethics of care offers a relation-based approach to organizational ethics that embraces the complexities and particularities of relationships.[38] Such an approach respects and acknowledges the unique composition of the relationships within HCOs, and as previously established respects and acknowledges the unique needs of the Alzheimer's population. Incorporating the ethics of care into organizational ethics enhances quality of patient care and promotes public good by tailoring patient/provider relationships and professional/organization relationships to better understand and embrace the unique needs of the Alzheimer's population. This chapter will explain how the integration of relational autonomy and social responsibility

into organizational ethics should occur to ultimately foster a more sustainable healthcare system in the face of AD.

II.   Relational Autonomy: Improving Quality-of-Care for Alzheimer's Disease

As has been detailed, the evolution of healthcare has witnessed a histrionic changing relationship between providers and patients. The doctor-patient relationship throughout much of medicine's history was commonly based on benign paternalism because doctors were rather limited in options for medical intervention.[39] As such options expanded following WWII, patients were no longer satisfied with paternalistic approaches to care and desired to have a voice in treatment decisions through a shared decision making relationship.[40] Shared decision making replaced paternalism and became the foundation for ethical decision making in healthcare.[41] The flux in this relationship was impacted by various factors and undoubtedly contributed to the decline in trust for the healthcare system. The days when people would go to their doctor with an issue, receive advice or treatment, and then pay for the service, or have the service paid for by insurance without question, was no longer. People now have to navigate large healthcare systems, with doctors and other various allied healthcare professionals of many specialties. Advancements in information technology now makes it possible, and common, for people to research their possible ailments and prospective treatment options prior to seeing their physicians. This has eliminated the traditional notion of doctor knows best and often shifted the thinking to patients knowing and informing the physicians what they believe to be best.[42]

Since the rise of managed care, treatments are subject to scrutiny from insurance companies and may not always be fully covered. While managed care has made improvements to cost and quality of care, it has also created great frustrations within the system. Patients do

not always have access to physicians of their choice and physicians no longer have the option of ordering treatments or services without consideration for their patient's insurance benefits and their limitations.[43] HCOs must ensure their employees provide services which will be both reimbursed and cost effective. These factors present barriers to trust within the shared decision making relationship. Studies have suggested that despite these, and other barriers, the shared decision making model is well accepted but not well implemented. The poor implementation has prevented patients from getting the highest quality of what they expect out of patient-provider relationships. Complaints include not receiving the desired information, or enough details about the information, and confusion about appropriate self-care and follow up.[44] These grievances are indicative of one sidedness on part of healthcare providers in ensuring patients' needs are well met and this ultimately impacts patient care. Placing more emphasis on relational aspects of this relationship will accommodate the short comings of the shared decision making relationship. Relational approaches emphasize the individual qualities that make each person unique rather than emphasizing a universalistic, one size fits all approach. Care and its related decision making process will occur in a truly moral nature when individual identities are more precisely understood within the relationships of patients and care providers.[45] Quality-of-care should improve when patient and-family centered care is promoted and when professional ethics are strengthened.

A. Promoting Patient and Family-Centered Care

The urgency of a relational approach to shared decision making began to emerge on national and global levels in the 1980's when two unrelated people, Harvey Picker and Angelica Thieriot, were so unsettled by their own personal medical experiences that they pioneered efforts to improve the experience of care for other patients.[46] In the late 70's, after a battle with serious

illness and a two week hospital stay that left her in severe emotional distress despite clinical success, Angelica Thieriot established an organization known as Planetree. Planetree focuses on promoting patient centered care through complete culture change. Since its development, over 100 hospitals in the US have adopted the Planetree model of care.[47] Renowned physician Harvey Picker experienced similar frustrations firsthand throughout his wife's battle with chronic illness. Subsequently, Picker pioneered the concept of patient centered care and started the Picker Institute, a foundation focused on improving healthcare through its implementation.[48] Both organizations emphasize the importance of the patient's experience as the foundation to caring relationships and the key to ultimately improving quality-of-care.[49]

Initially seven dimensions to patient centered care were identified; (1.) respect for patient's value, preferences and expressed needs, (2.) coordination and integration of clinical care, (3.) information, communication and education, (4.) physical comfort, (5.) emotional support and alleviation of fear and anxiety, (6.) involvement of family and friends, and (7.) transition and continuity.[50] An eighth dimension, access to care, was added shortly thereafter.[51] The IOM recognized patient centeredness as one of the six recommended aims to improving quality-of- care, six of the Picker principles are identified in this recommendation. By promoting that healing relationships are always achievable in healthcare, whether through pursuing cure or relieving suffering, the IOM emphasizes the importance for healthcare providers and organizations to welcome the variability of all patients and customize their care accordingly.[52]

Patient centered care has been shown to improve quality outcomes and patient wellbeing when performed accurately and consistently.[53] By putting the patient and family, rather than the disease, at the center of care this model of care opens up lines of communication between patients/families and healthcare providers to ensure there is an equal exchange between all

parties. Consideration for what is medically indicated and feasible from provider perspectives as well as what is valued and desired from patient perspectives are equally exchanged and contemplated to devise individualized treatment plans.[54] The necessity to promote a higher quality of care and enhance patient wellbeing on behalf of the Alzheimer's population has already been established. The potential of patient centered care in making these goals achievable for the Alzheimer's population are evident through the qualities of patient centered care and through its benefits to healthcare systems.

i. Qualities of Patient Centeredness

The patient and patient's family lie at the very basis of patient centered care. Family in patient centered care is a term that is defined particularly by each individual patient as family is not always descriptive of blood relatives but can more broadly include whomever patients indicate as being trusted partners in their healthcare.[55] Similarly to relational autonomy, patient centered care recognizes that from an ethical perspective family is essential to each individual's wellbeing, this is especially so to those who are older and facing chronic conditions. People falling into these categories are often more dependent on family to ensure they receive quality care. Family is therefore recognized as more than just a surrogate to step in when cognition is hampered but an essential component to ensure continual high quality care throughout the patient's lifespan.[56] Because of this patient centered care welcomes appropriate family members into the care relationship, accepts their contributions, and provides them support just as patients are welcomed and supported.[57] The inclusion of both patients and their families tends to further improve quality and thus some models of care have advanced the title of patient centered care to patient and family-centered care.[58] Regardless of what the model is titled, true patient centered

care values family and includes family as an essential quality of proper patient care since involvement of family and friends is among the 8 Picker Principles of patient centered care.

The incorporation of family into care is essential to ensuring other qualities of patient centered care are met, especially when patients present with limited ability to communicate as is often the case with AD. Communication that is clear and understood by patients is a leading characteristic of patient centered care. Methods of ensuring communication is understandable have been established through the model.[59] Family acts as either the receiver of communicated information when patients no longer possess the capacity to understand, or family can act as someone to assist patients in processing information when mild to moderate cognitive impairments hamper patients' ability to do so on their own.

Patient centered care prioritizes individuality because it views each patient as a unique individual with different values, preferences and needs. Respect for individuality and acceptance that what is desirable by some patients is not desirable by all patients with the same illness is an essential trait of patient centered care and is exemplified through the principle of respect for patients' values, preferences, and expressed needs. Acknowledging diversity and paying special attention to individual cultures is made essential through this aspect of the patient-provider relationship.[60] Similar to the ethics of care, patient centered care accentuates qualities of empathy and compassion.[61] Empathy is the ability to share and understand the feelings of another person. Although it is often associated with sympathy, sympathy is simply a shared feeling and does not require the ability to understand.[62] The ability to feel empathetic does not insinuate that one agrees with the decisions or actions of another but that the feelings of another are recognized and understood. Compassion is the professional virtue that consists of two important features; ability and willingness to share in the suffering of another person and a desire

to alleviate that suffering or support it when alleviation is not a possibility.[63] Compassion stems

from the feelings and understanding of empathy, inspiring actions to ease the suffering of

another person.[64]

In addition to individual values and family inclusion, patient centered care prioritizes the

importance of virtuous professional actions. The quality of responsiveness, readily responding to

the needs of others, may seem like a basic quality for all healthcare providers. Unfortunately,

lack of responsiveness has contributed to decreased quality of care and lack of trust in the

healthcare industry. Blame can be placed on the multiple number of specialists involved in each

patient's care, the enormity of today's healthcare organizations, and the fragmentation within the

system.[65] The principles of patient centered care work toward improving the responsiveness of

healthcare providers in order to deliver better care and ultimately improving quality as perceived

by patients. The principle of information, communication and education requires providers to be

responsive to patients in ensuring these elements are not just conveyed but conveyed in a manner

that is understandable and effective for patients.[66] Responsiveness is also accentuated through

the principle of coordination and integration of care which requires providers to be responsible

for the coordination of services and ensuring smooth transitions for patients as they navigate the

healthcare system.[67]

The principles of physical comfort, and emotional support and alleviation of fear and

anxiety promote the quality of responsiveness in reference to the duty of healthcare providers to

relieve suffering. Despite the ease in which some people can ignore the suffering of others,

efforts to relieve human suffering is a duty to which all people are bound.[68] Suffering is often

associated with physical pain hence making it specific to ailments of the body.   While this is

true, recall that this is not the complete extent of suffering. Suffering can be emotional and

psychological in nature as well. Such suffering can occur in conjunction with physical pain and also despite physical pain thus making pain specific not just to the body but to the mind as well. Pain and suffering do not always coexist and their source and degree vary from person to person.[69] Patient centered care acknowledges these aspects of suffering by incorporating principles aimed at prompting providers to adequately address both the physical and emotional issues of patients and their families.[70]

ii.   System Benefits of Patient Centeredness

In a 2007 report commissioned by the Picker Institute, Shaller Consulting explained that there are seven key attributes necessary to achieve patient centered care on the organizational level; committed and engaged leadership at the CEO and board of directors level, a strategic vision which is clearly and constantly communicated to all members of the organization, involvement of patients and families, a supportive work environment for all employees, systematic measurement and feedback, a quality built environment, and supportive technology that engages patients and families in the care process.[71] Implementing a culture of patient centered care is not an easy task and does not occur instantaneously. It does however have multiple system benefits that offer the potential to assist organizations in meeting the stringent demands of today's healthcare reform.[72] These demands include the necessity to improve quality-of-care with careful consideration of patients' desires for care, resource allocation and cost containment.

Tracing back hundreds of years, and commonly linked with the maxim, "do no harm," the Hippocratic Oath is the oldest testament to the inclusion of ethical standards in medicine.[73] Although these age old ideals as well as various other modern ethical standards for healthcare professionals promote doing good and avoiding harm, errors in medicine continue to occur at

alarming rates. For the majority of time throughout the history of HCOs errors and safety issues involving patients were thought to be just an expected result of medical practice. It was only at the turn of the most recent century when medical errors and patient safety issues began to be recognized as a major issue for concern.[74] Dr. Lucian Leape brought this issue to the forefront of modern medicine in his famous article, *Error in Medicine*, which was published in a 1994 issue of the Journal of American Medicine. Leape identified incidence and causes of errors and recognized the need for a systems approach to reduce errors.[75] Studies estimate that between 1 in 8, to 1 in 3 hospital admissions result in some type of error costing somewhere between 17 and 29 billion dollars annually, while some errors are minor causing little harm, other errors result in death.[76]

Patient safety, "freedom from accidental injury", is among the six aims of improving the quality of healthcare systems as outlined by the IOM. The aim reinforces the imperative to promote the standard that patients enter HCOs to get help, not to be harmed and thus they should be assured that all processes and procedures are done correctly and safely at all times of the day and night, all days of the year.[77] Patient centered care is associated with reduced medical error and increased patient safety, a vital organizational benefit of the model. The Dana-Farber Cancer Institute (DFCI) realized the crucial role attention to patient and family experiences plays in promoting a safe organization after such views were ignored leading to tragic medication errors. As a result DFCI enacted major culture changes promoting patient centeredness and has experienced positive results in their incidence of errors.[78] In addition to DFCI there is considerable support for the use of patient centered care to improve patient safety.[79] Improved patient safety across systems will undoubtedly improve quality-of-care, improve patient satisfaction and reduce costs for organizations.

Improved patient compliance with self-care and follow-up care results from the qualities of patient centered care. This will yield enhanced patient wellbeing, ultimately impacting the betterment of quality and trust for HCOs.[80] High costs associated with healthcare negatively impacts quality and hampers the sustainability of HCOs. Critics of patient centered care may fear putting patients and families at the center of care because the results could be that healthcare providers will have to do everything the patients and families want therefore raising costs without regard for effectiveness or efficiency. This has not been the case. Through successful incorporations of the model it has become evident that the majority of patients and families want to hear providers' professional recommendations and the true risks and benefits before making care decisions.[81] Some methods of developing a culture of patient centered care can be easily spearheaded by an organization. Some methods require little costly technology to incorporate and get results that can lower overall healthcare costs.[82] Costs are lowered through outcomes associated with reducing hospital length of stay, reducing readmissions and reducing emergency department use.[83]

Patient centered care is linked to emphasizing and improving transparency in HCOs. This occurs when HCOs partner with patients and families during clinical consultation and during organizational aspects of planning and decision making. Patient and family involvement on the organizational level can occur when patients and family volunteers are incorporated into board and organizational meetings.[84] Transparency is the act of making information pertaining to HCOs publically available so that consumers can make truly informed decisions when selecting providers, services and organizations. Such information includes statistics pertaining to outcomes, patient safety and patient satisfaction.[85] Transparency in clinical consultation is becoming increasingly important in healthcare and will continue to prevail as an essential

element to sustainable organizations. Healthcare reform is beginning to call for patient feedback as a determinant for provider financial reimbursement through the Hospital Consumers Assessment of Healthcare Providers and Systems (HCAHPS) scoring method.[86]

B. Strengthening Professional Ethics

An important aspect of organizational ethics is ensuring professional performance reflects the HCOs mission and values.[87] A positive ethical climate cannot be achieved without the cooperation of those who work within the organization.[88] In HCOs today, there are a multitude of employees performing different roles related to patient care as well as other tasks necessary for organizational function. Many of these employees are bound to a set of professional ethical standards specific to their vocation. Integrating each unique set of standards into the overall standards of employee expectations is one of the great challenges facing HCOs.[89]   The respectful cohesion between all employees is vital to achieving success in improving quality-of-care and can best be achieved and maintained when harmony exists from the highest level of leadership to all employees in the organization.[90] Relational autonomy is useful in achieving this task as it identifies each employee as a unique individual but also acknowledges that each individual contributes to the overall success or failure of the organization.

The meaning of the word profession can take on numerous connotations.[91] Literary works have established and interpreted its definition in different ways throughout time. These distinctions will not be explored in detail but rather some overall definitions will be briefly explained. Sociological perspectives generally view a profession as an occupational group that has high educational standards and high social status. The general philosophical perspective views a profession as a group of people who share an occupation with an established set of standards.[92] Both schools of thought refer to a profession as an occupation. Because

occupations are a way of life and usually reflective of the contemporary culture, some notions of what is meant by profession have even argued that moral values are connected to its meaning. While all professions have faced great changes over the past several decades because of rapid industrialization, medical professions have witnessed the most drastic of changes as science and technological advances have transformed the medical industry entirely.[93]

Medical professionalism most commonly examines the profession of being a physician.[94] While physicians may be among the most commonly thought of medical professionals, today's healthcare industry is highly composed of employees belonging to various other professions, for example nurses, pharmacists, therapists, social workers and administrators. The healthcare industry is also reliant on various occupations that are essential but may arguably be referred to as a profession because they lack their own individual code of ethics or membership organizations.[95] For example housekeeping staff, maintenance workers or dietary aides may fall into this category of non-professional vocations but each are essential to the overall function of an HCO. It has been established that the aim of organizational ethics is to promote quality performance and foster a positive ethical climate on all levels of the organization.[96] Based on this, the philosophical perspective of profession is best suited to encompass all of the different groups of employees necessary to ensure HCOs function properly. This perspective qualifies all essential vocations as professions without bias to their associated education level and social status.[97] Under such a definition all employees may feel equally valued for the essential role they play in organizational function. Furthermore, if a profession is only defined as such when professional codes of ethics define their role, each individual carrying out a vocation joins a profession when they agree, based on terms of employment, to abide by the HCO's code of

ethics and do their part in carrying out the specified organizational mission and values.[98] Each

employee is an agent of the HCO and thus personifies what the organization represents.[99]

While establishing professional ethics on an organizational level which encompass all the

unique professional codes of ethics as well as establishes standards for all employees whether or

not they have to follow other professional standards is challenging, doing so is essential to

promoting a virtuous organization.[100] Each individual vocation performed by employees of

HCOs does not exist in isolation. Rather they all work in tandem or intersect to carry out the

organization's mission. In their book about perfecting patient care, Karen Wolk Feinstein, Susan

Elster, Colleen Vribin and Steven Spear describe how such a systems approach encompassing all

employees within a health system will improve quality in healthcare.[101] Rather than placing the

responsibility of carrying out high quality care in different organizational silos, these authors

uniquely emphasize the role of the entire system at improving quality.[102] In its plan to address

the needs of the Alzheimer's population, the National Plan to Address Alzheimer's Disease lists

enhancing quality care as its second goal and delegates numerous methods in which healthcare

professionals should work towards its successful achievement. While the plan has tailored its

guidelines to direct care professions, it does not disregard the need for system consideration as

the plan is intended to guide quality improvements pertaining to the burden of AD for the overall

US healthcare system. [103] Although organizational ethics ought to focus on enhancing

professional ethics for all its employees some ethical issues are more pertinent to certain groups

of professionals. Matters that are more specific to direct care workers, the organizational agents

such as physicians and nurses who have the most intimate contact with patients, include issues

pertaining to individual professional concerns and issues pertaining to concerns pertinent to

groups of professionals.

i. Concerns Pertaining to Individual Professionals Involved in Direct Care

Just as the word profession has an ambiguous meaning so does the word professional. Some common agreement is that healthcare professionals in direct contact with patients exhibit characteristics that separate them from other types of professionals. Such characteristics include extensive training and commitment to continuing education, commitment to the wellbeing of others and, the possession of humanistic ideals, virtues and morals. Because healthcare professionals in direct practice must possess these and other unique characteristics the relationship between provider and patients is often unequal.[104] In addition to the frequent dissimilar knowledge base between providers and patients, the relationship can be further unequal when the patient is experiencing vulnerability due to their malady. The ethics of care acknowledges that relationships are often based on unequal terms and that imbalance is unavoidable in certain circumstances. Despite these issues, care ethics works to eliminate and avoid the formation of power hierarchies. This occurs through its commitment to relational autonomy in which fairness among unequal relationships is fostered based on the theory's unique definition of vulnerability and respect for the universal need for care.[105]

The experience of AD can place stress on the patient-provider relationship. While strain is often thought of from the perspective of the person with AD, strain can occur from the professional's perspective. The complicated burden of AD is reaching an apex during a point in time when unique societal trends are occurring. Science and technology have allowed for various medical interventions that can prolong life without concern for life's quality. Desires to continuously expand the life span with concern for quality of life are leading to new types of research with human subjects.[106] New political movements, specifically right-to-die movements, are occurring to counter the quest for emphasis on quantity of life over quality of life by giving

individual's ultimate control over their end of life choices.[107] All of these various trends are ridden with moral and ethical controversy often causing dilemma for all involved. Emphasis in today's healthcare system is predominantly on patient choice and patient autonomy. Many times this focus leaves physicians and other direct care professionals in the lurch without recognizing how their individual morals may be effected. It is important for organizational ethics programs to recognize that moral dilemmas occur and impact healthcare professionals on an individual level.[108] Professionals can be hindered from providing the best quality of care possible when these dilemmas are not properly recognized and dealt with resulting in moral distress. Moral distress can negatively impact ethical climate thus making such issues a prime concern for HCOs.[109] Two aspects of moral concern that threaten the moral integrity of direct practice professionals on an individual level are clinical conflicts of interest and conscientious objections.

The concept of conflict of interest tends to be thought of as a compliance issue for organizations. While this is certainly true, conflicts of interest are of ethical concern as well. Conflicts of interest can occur within all organizational levels including those associated with boards of directors, within midlevel management, and within patient care.[110] Professional conflicts of interest exists when a provider has motive to make decisions, or persuade decisions to be made, that are not in the patient's best interest.[111] Conflicts of interest are unavoidable in today's healthcare market where a multitude of demands are placed on professionals related to cost, cost control, financial rewards, quality, and best interest. The existence of conflicts of interest do not pose ethical issues but ethical issues may arise when the conflict is acted upon with disregard to professional and organizational codes of ethics or patients' best interests.[112] For physicians and other direct care professionals, conflicts of interest pose ethical issues based

on the codes of ethics instituted by their licensing body which guide such professionals to put the interest of their patients first.[113]

Historically, conflicts of interest tended to occur in areas of medical research but in the recent past conflicts of interest are becoming more prevalent in clinical care.[114] Examples of potential conflicts of interest that can occur within clinical care are; providers receiving incentives from pharmaceutical companies to utilize their medications, providers practicing in or being financially affiliated with multiple HCOs and moving their patients between the organizations, or when incentives from managed care organizations might influence treatment decisions.[115] As a result most organizations have implemented disclosure policies to ensure potential conflicts are revealed to prevent negative repercussions. In similar efforts, two federal regulations, the Federal Anti-Kickback and Anti-Referral Statutes, have become law.[116] Disclosure policies alone have not been enough to prevent ethical dilemmas from surfacing. In order to ensure professionals are better protected more effective policies and safeguards ought to be implemented.[117] Such efforts recognize and appreciate the reciprocal relationships between providers and the organizations to which they are employed and affiliated. Furthermore, safeguarding against patients accusations of unethical provider conduct relating to conflicts of interest will likely enhance quality and trust for providers and organizations. [118]

When direct care professionals become agents of HCOs through employment, they do not disregard their own moral compass for that of the organization. Professionals are still protected by the common moral norm of respect for persons and thus have the digression to maintain their own personal morals.[119] At times the morals of direct care professionals may conflict with types of information and interventions their patients request even when such requests are offered by the affiliated organization. When this occurs professionals may refuse to provide the

information, provide the intervention, or assist with the intervention based on conscientious objection. Although there are various reasons professionals may refuse to provide services supported by the HCO, only refusals based on personal morals are considered to be conscientious refusals.[120] Conscientious objections first became an issue for organizations in the 1970's when the Supreme Court first ruled on *Roe v. Wade. S*ince then, as medical sciences have continuously expanded medical options, issues associated with maternal and reproductive health as well as end of life issues and various other aspects of healthcare throughout the lifecycle have found their way into the consciousness of healthcare providers. For this reason conscience clauses and other organizational polices have been established to address such objections when they arise in practice.[121]

Organizational approaches to dealing with and preventing ethical repercussions associated with conscientious objections are both simple and challenging. HCOs have an obligation to adequately achieve effective methods to deal with conscientious objections in order to maintain an acceptable balance between their providers' integrity and their patients' demands and the autonomy associated with each group. [122] The importance of maintaining professional integrity is emphasized through various professional codes of ethics including those of the American Medical Association and the American Nursing Association but codes also stipulate that conscientious objection must be distinguishable from discrimination towards patients.[123] Respecting and keeping professional integrity in tact has multiple benefits including enhancing and fostering professional compassion, and allowing professionals to remain loyal to their profession without compromising their own personal values. These and other benefits lead to improved quality in healthcare.[124] Because of the prevalence of AD most physicians, nurses and other direct care professionals will come into contact with people affected by the disease.

Situations that may prompt conscientious objections in working with the Alzheimer's population include disclosure of preclinical diagnoses, advance directives that facilitate voluntary stop eating and drinking directives, the use of artificial nutrition and hydration in severe stages, and perhaps eventually issues associated with preemptive suicide if right-to-die movements are successful throughout the country and their stipulations advance to include consideration for the cognitively impaired.[125]

ii. Group Concerns for Professionals Involved in Direct Care

In their efforts to prompt significant quality improvements in the American healthcare system during the 21st century, the IOM suggests that common chronic conditions should be identified and focused on as the first step in making system wide quality improvements. The rationale behind this proposition is that focus on specific conditions will, among other benefits, reduce fragmentation and be more satisfying to patients.[126] Alzheimer's disease and other related dementias were listed as one of these top 15 priority conditions.[127] If AD is to be a priority condition for any HCO, organizational leaders must determine how to make the condition and the primary area of specialty into which most Alzheimer's patients fall, geriatrics, more valued and better understood by direct care providers. Estimates indicate that although the older American population will double over the next two decades, the number of direct care providers, including physicians, nurses and social workers, specially trained in geriatrics is not increasing. This may be partially due to undervalue of care providers in aging related professions in the country.[128] In efforts to improve quality of patient care for this growing population of consumers, HCOs ought to be concerned with the lack of professional education related to AD as well as the lack of ethically focused clinical practice guidelines for dementia care.

The healthcare system is ever changing as are the roles and responsibilities of direct care professionals.[129] Despite the continuous evolution a traditional obligation of professional ethics remains a core focus, advocating for patients.[130] Advocating for the patient can occur in many ways but perhaps the best way to publicly support patients is to ensure the providers entrusted with their care have the proper tools necessary to provide them with the best care possible. Education is among a direct practice professional's best tools. Professionals come to organizations with their formalized education already obtained. Education does not stop there, continuing education is essential to healthcare providers.[131] Unfortunately there is a lack of education among providers specific to the needs of the Alzheimer's population and this discrepancy is often overlooked by organizational leaders.[132] The National Plan to Address Alzheimer's disease indicates that building a workforce of direct care professionals with the skills necessary to provide high-quality care to those with AD is an essential strategy to enhancing care. For success these skills need to be developed and fostered through the education of all direct care professionals involved with people in all stages of AD.[133] One of the worldliest renowned experts in AD, Peter Whitehouse, M.D. considers education to be the most vital tool necessary to overcoming the burden of AD. In moving forward effective, new directions in professional education will embrace interdisciplinary, rather than discipline specific, learning.[134] Remarkable achievements can occur that impact patient good, in areas such improving care delivery and addressing ethical issues, when organizations focus on and implement interdisciplinary teams in geriatric care.[135] When organizational leaders provide valuable, disease specific education to its direct care professionals, the relationships between providers and patients as well as those between providers and their organizations are shown value and given the tools necessary to improve patient care.

Among the strategies identified by the National plan geared at enhancing quality-of-care is the identification of high-quality dementia care guidelines. Such guidelines will be stage specific and applicable across all care settings as well as take into consideration various other patient particularities.[136] Clinical practice guidelines (CPGs) evolved as an effort to increase quality in healthcare by providing disease specific guidance on complex medical decision making. CPGs incorporate scientific evidence, clinical knowledge and patient values into each recommendation. Over the years thousands of CPGs have been developed and are housed in national and international clearing houses. Unfortunately the overwhelming development has caused some question into the validity and efficacy of many of the guidelines.[137] Weighing the benefits and burdens of the incorporation of CPGs into practice and selecting which guidelines to utilize is quite a task for organizational leaders. The overall use of these guidelines is claimed to be an ethical practice. Unfortunately, there are no specific requirements pertaining to how well or how consistently ethical issues specific to particular diseases should been incorporated into CPGs.[138] The ability for direct care professionals to be familiar with ethical issues that are common in clinical care and, the development of techniques to identify and properly handle such issues are goals of organizational ethics today.[139] One study suggests that ethical issues are inconsistently incorporated into CPGs specific to dementia.[140] Identifying and utilizing CPG's that include ethical issues specific to AD and dementia fosters professionalism among direct care professionals by making the identification of ethical issues standard practice when working with people with AD. Awareness of specific ethical issues cultivates awareness and empathy thus enhancing the relationships between providers, patient and organizations.

The qualities of patient centered care; family inclusion, clear communication, empathy, compassion, and responsiveness in combination with its organizational benefits; improved

patient safety, promotion of transparency, enhanced patient compliance and reduced healthcare costs work together to improve quality in healthcare. This is because patient centered care is a model of care that focuses on properly carrying out the provider-patient relationship of shared decision making. While all patients stand to benefit from HCOs that promote patient centered care, those with AD will have improved quality-of-care when patient centered care is properly carried out because those with AD are more dependent on relationships of care rather than their own individual autonomy to achieve and sustain wellbeing.[141] Systems will also benefit when the large population of consumers effected by AD receive care that ultimately improves quality while reducing costs. HCOs are composed of employees and individual affiliates that work together to carry out the organization's specific mission and values. Among the tasks of leaders focused on organizational ethics is ensuring professional ethics are intact and in line with that of the organization's expectations.[142] This is not a small or simple task as there are numerous occupations essential to the successful overall operation of HCOs today.[143] When organizational ethics considers and incorporates relational autonomy into professional ethics these programs become strengthened and the ultimate results improve quality-of-care. While the complexities in dealing with the Alzheimer's population can further complicate professional ethics and negatively impact patient care, organizational safeguards pertaining to conflicts of interest and conscientious objections as well as attention to countering the typical lack of education and ethically focused CPGs surrounding AD will positively impact quality of patient care. Social responsibility should also be incorporated into organizational ethics to further reduce costs and improve access related to AD.

IV. Social Responsibility: Containing Costs and Improving Access Associated with AD for Public Good

The concept of social responsibility has become common in corporate America and across the global market place. Corporate social responsibility grew in popularity as a result of public outrage regarding various business scandals and debates surrounding whether businesses are responsible only to drive a profit or if they have a more encompassing responsibility to a vested interest in the communities from whom they profit.[144] Numerous corporate scandals, such as the Enron Scandal, and scandals involving other well-known companies such as Xerox, Bristol-Meyers-Squibb, and Rite Aid, occurred between 1998 and 2002 and are detailed in the book by Jerry Markham titled, *A Financial History of Modern U.S. Corporate Scandals: From Enron to Reform*.[145] The results of these, and other, corporate scandals were a lack of public trust for corporations by individuals and communities. Many corporations responded by enhancing their ethics and proving their contribution to social responsibility in order to regain public trust and ultimately sustain economic gains and competitiveness within the market. HCOs are among the types of American corporations faced with the aftermath of corporate scandals. As a result, organizational ethics programs within HCOs are increasing in value and implementation.[146] While efforts driven by organizations as a whole have undisputed value, healthcare providers ought to display socially responsible behavior on an individual level as well.

Practitioners in the field of public health may display a greater regard for social responsibility as the area of public health is distinct from the area of clinical care. Because public health is population focused rather than focused on individuals, the emphasis on individual autonomy is less prominent in public health decision making and application. Such an increased focus on society may have increased social responsibility but it has also tended to characterize the field of public health as coercive and controlling since the field has had a great

impact on public policy and mandatory health related measures.[147] Providers in the field of public health are not the only professionals obligated to social responsibility just as providers in clinical care can not only be obligated to some degree of socially responsible practice when issues concerning public health arise in their work. Most healthcare professionals are obliged to social responsibility through their individual codes of ethics. Professional codes of ethics are devised for specific occupations regardless of the general field in which the professional will practice. The AMA in the preamble to its Code of Ethics calls for all physicians to recognize an obligation to society.[148] Likewise, the American Nurses Association recognizes the duty of social responsibility for all nurses.[149] This is also true of other professions who find themselves working within the field of healthcare, particularly in clinical care. Like other branches of healthcare, such as public health and clinical research, clinical care providers are held to a degree of social responsibility. Social responsibility adds conceptual and concrete benefit when applied to clinical care.

Bioethics, in its quest to consider and positively shape the field of healthcare, has established that a duty to justice is among its main contributions. In its traditional sense, based on norms and theories that guide the fair and equitable distribution of benefits and burdens, justice is usually applied to issues affecting social systems. In healthcare, theories of justice are commonly used in relation to issues pertaining to access to care, costs, or rationing resources.[150] While the ethics of care does not identify justice as one of the main components of its framework, it still accounts for the relevance of justice to morality.[151] Justice considerations in bioethics are often viewed in opposition to other obligatory professional duties such as beneficence and autonomy. Justice commonly becomes regarded as the responsibility of policy

makers and not a primary concern for providers chiefly focused on clinical care.[152] It may be within this realm of justice that social responsibility is conceptually situated.

The duty of stewardship, the responsible use of resources, is one which is commonly associated with justice. The meaning and application of stewardship in healthcare is unclear.[153] Stewardship has been applied to persuade responsibility and influence policy at society's broadest levels. Like justice, stewardship is often used to determine how society will justly allocate healthcare resources and ensure access to healthcare while considering costs from a systems perspective with the goal of influencing political ideals and policy.[154] This type of stewardship, exercised and beneficial at the organizational level, should be considered socially responsible. Social responsibility also occurs through stewardship exercised at the individual level making social responsibility equally beneficial at the clinical level.[155] From a conceptual perspective, this may be another realm of justice where social responsibility ought to be considered. Social responsibility through stewardship and justice can indeed be achieved in the clinical relationship without compromising providers' obligation to patient advocacy for the greater good of society.[156]

The high costs of healthcare have resulted, in part, from decisions made within individual provider-patient relationships. The movement to shared decision making is directly associated with rising health care costs. Despite these truths, some contend that individual providers cannot be expected to be stewards and bear the responsibility of uniquely adapting their practices to accommodate cost containment. Such contenders recognize the area of opportunity for role related social responsibility but promote the necessity of stewardship at the organizational level where system wide policies are believed to be requirements to trigger improvement.[157] Another view emphasizes the potential for the healthcare system to save billions of dollars if individual

providers incorporate social responsibility when stewardship is applicable and does not overshadow the provider's obligation to beneficence or justice. This type of situation occurs in over one hundred areas of clinical care where the best standard of care has not yet been determined. In these instances multiple treatment options exist with differing costs but the same expected outcome. In such clinical situations provider discretion for cost can be made without compromising discretion for the degree of benefit the patient can expect.[158] Beyond these primary situations lie other clinical situations where costs can be remarkably contained with only a small variance in possibility of benefit to the patient when a less costly treatment option is chosen over a more expensive option.[159] Therefore, opting for cost containment when best practices are not standardized is a concrete basis for applying social responsibility into clinical care at the provider level.

Healthcare professionals have moral duties not only to the individuals they care for but also the societies in which they practice. The professional obligation to the wellbeing of the larger society constitutes social responsibility. Social responsibility has become a globally recognized ethical principle that ought to be carried out in a manner appropriate to each nation's unique culture. The US has a healthcare system unlike most others which may benefit from the proper implementation of social responsibility. When this concept of social responsibility and its potential applications to the existing healthcare system are properly considered, organizations will become more mindful of the benefits that result from incorporating limits and standardizing the use of palliative care and hospice under precise yet appropriate circumstances.

A. Setting Limits through Medical Policy

The boundlessness of medical progress is among the qualities of modern medicine that contribute to the likelihood of an unsustainable healthcare system. As health sciences and

technology expand, death is often postponed leading people to face worse health problems in the future or continue on in a lifestyle of lower quality. In each instance where death is postponed, new circumstances arise where people will again face death. This "ragged edge", as Daniel Callahan has referred to it, of medical progress is continuously being confronted and the popular focus is often on how to push the edge further away, although it will always remain.[160] When confronted with this edge, a place where medical decisions inevitably need to be made, there are various perspectives healthcare providers can reflect upon to guide the patient-provider relationship. The most common of these perspectives, evidence based medicine, has tended to lead the way since the culmination of modern medicine.[161] Evidence based medicine relies on scientific evidence, rather than clinical expertise and anecdotal information, to guide medical management. The purpose is to ensure decisions are supported by the most accurate, valid and up to date scientific information.[162] Evidence based medicine has led to a noteworthy degree of improved quality and cost savings for the healthcare system. This significance however, evolves from research and can lack some degree of relevance in clinical care. Furthermore, evidence based medicine alone has not allowed for the incorporation of value as perceived by the patient to be considered in medical management, therefore providing little guidance on when medical interventions ought to be limited despite their scientific support.[163]

Healthcare's emphasis on scientific validity and constant strive for advancements has become a point of contention from a humanities perspective. It has been suggested that in the current state of medicine there is no longer an adequate amount of concern for the humanities and this has led to several negative implications for our overall wellbeing.[164] Other suggestions assert that science and technology have replaced the necessity for compassion in medicine thus making compassion beyond the usual duties of the modern day physician.[165] Despite such

speculation, the AMA supports the continued incorporation of compassion into medical practice by requiring compassionate care in its code of ethics.[166] The inclusion of virtues like compassion and other humanistic qualities such as caring and kindness are unlimited resources associated with little cost.[167] Their inclusion into a decision making framework may well lead to the increased value and quality of healthcare, factors which are essential to enhancing healthcare's sustainability.[168] While medical decision making occurs between patients and providers it is guided by medical policy. Although the tendency of medical policy in US HCOs has not been on limitations, policy ought to be better focused on promoting limits when morally appropriate. Two ways limit setting in clinical care should occur is through organizational policy focused on value based medicine and through organizational policies that emphasize quality of life as it relates to health state.

i. **Value Based Medicine**

Value based medicine is an alternate to evidence based medicine that is be used to guide medical management within the patient-provider relationship. Value based medicine is not a replacement to evidence based medicine but is rather an extension of evidence based medicine. This type of extension is often overlooked or fails to be properly incorporated into the dynamics of medical decision making.[169] Value based medicine is the incorporation of patient perceived value, cost considerations and scientific evidence into the practice of medical decision making.[170] A value based perspective allows for patient's to weigh in on the degree to which they perceive the worth of medical interventions they are facing. This ultimately allows for a higher quality-of- care and better utilization of healthcare expenditures.[171] The incorporation of value into the medical decision making process pays respect to the importance of humanistic influences, such as the meaning of life, death and suffering, by making values and not scientific evidence alone

important considerations.[172] Pushing clinical considerations beyond just scientific evidence may be challenging within the ethos of today's medicine but the worth and need to do so becomes relevant when the elusiveness of value is overcome.

Value in healthcare is said to be based on two factors, length of life and quality of life.[173] These factors are often considered rivals although they do not have to be played against one another. Length of life, like scientific evidence, is objective and factual, it is also simply measured by number of years lived. Quality of life on the other hand is subjective, varies from person to person and is rather difficult to measure empirically. Quality of life describes a degree of satisfaction associated with the experience of living and therefore is subjective because its true value is specifically dependent on the person who is having the experience. [174] Two people with the same life factors may perceive their satisfaction with the lived experience completely differently. Furthermore, observers to this experience tend to judge the degree of quality of life lower than does the person actually living the experience.[175] Because of its complexities, quality of life may be the factor that promotes hesitation towards the tendency to use value based medicine but value based medicine tends to be patient centered to ensure each patient's interpretation of quality is uniquely considered.[176] The opinion of patients about their quality of life, while objective, is essential to the provision of high quality care. The particular value of healthcare interventions must be adequately considered to truly ensure healthcare is of the highest quality and also cost effective.[177]

ii.   Health Related Quality of Life

Many factors contribute to one's perceived quality of life so where to start in its evaluation may be unclear. From a healthcare perspective quality of life is often focused on the extent to which diseases impact patients, but even when isolating for disease incongruities can

arise. Because chronic, progressive diseases, like AD, typically endure over longer periods of time, they tend to impact people to different degrees throughout their course. A way in which to reduce incongruencies about quality of life is to focus on health state rather than solely on the disease. Health state refers to health at a particular point in time thus theoretically accounting for the overall impact of multiple conditions and the varying degrees of disease severity.[178] Numerous empirical methods have been designed to measure quality of life. While none of these instruments have been especially designed to focus on health related quality of life (HRQOL), some can be useful in achieving a reliable measurement of cost-utility analysis.[179] A standardized tool for the measurement of HRQOL would likely help increase the consideration for this important value within the healthcare system. Considerations for the value of HRQOL are important to individuals and also to society at large.

Defining health and describing what good health is has proven to be a difficult task. What may be more universally agreed upon is that the pursuit of a good quality of life related to individual health is necessary to achieve personal fulfillment in life through psychological and social development.[180] To what degree quality is necessary to achieve satisfaction with the experience of life differs from person to person and may also differ during various stages of the life span. It is important to recognize this because what one person sees as a value or benefit another may see as a burden. From a healthcare perspective individual values must be taken into account to ensure quality considerations are individualized rather than generalized through a one size fits all approach.[181] Consideration for individual values in health related decision making helps ensure that each person has the opportunity to understand the potential implications medical interventions may have on their ability to achieve self-actualization and fulfillment.

Ultimately people ought to decide for themselves whether or not utilizing what science and technology has made possible is in their own best interest.[182]

Just as health is an individual good that aims to enable one to live a good quality of life, health is also a common societal good that aims to enable society to flourish with an acceptable degree of quality.[183] The potential that healthcare may offer to an individual does not necessarily remove it from its proper place within social constructs therefore just because a healthcare option is physically possible does not mean it must be provided to all members of society. Health is only one of many beneficial goods necessary for a just society. Others include clean water, education and proper infrastructure. Resources must be adequately distributed so that all essential societal goods may be sought and maintained.[184] Incorporating value into determining the importance and relevance of various medical decisions ensures resources are not being utilized merely to maintain life without consideration for the quality which they may or may not bring about.[185] Value based medicine does not promote the rationing of healthcare but rather it focuses on ensuring that what resources are selected for utilization in fact have a perceived value by those they are going to directly impact. Ultimately, many members of society may opt to pass on utilizing healthcare resources when they do not promote what is considered a beneficial amount of health related quality.[186]

B.   **Standardizing the Use of Palliative Care and Hospice**

AD is a chronic condition to which there is currently no cure and once symptoms onset they will continually progress and be present throughout the rest of one's life span. Because AD will advance and endure throughout the end of life, this condition tends to increase universal vulnerability because its symptoms threaten the physical and psychological integrity of self.[187] The early stages of AD may not exactly indicate that end of life is near but it does indicate that

the disease will be present, to some degree, throughout the remaining life span. Enduring AD and facing sensitive decisions that pertain to a life with cognitive and eventual physical decline and death have created a vulnerability that captures all people who face the situation. It is not limited to only those with the diagnosis but also includes their family members, other support systems, and the HCOs that must provide care. This vulnerability is compounded by the heavy focus on cure in modern medicine when one has a condition that cannot be cured. As explained in chapter five, hospice provide beneficial care for Americans affected by the severe stages of AD but only when the disease reaches its final end of life stage, when death is likely to occur within six months of less. This criteria creates barriers to getting people with advanced AD hospice services as it difficult to determine exactly when this end-of-life period begins.[188] It is also unfortunate that the benefits of hospice services are not tapped into until the final stages of AD because it is clearly evident that the entire spectrum of the disease creates a burden that stands to gain from such services.

Recall however, that the provision of palliative care does not have to be limited to those in the last six months of life because palliative care programs can be separated from hospice programs to encompass anyone who has been diagnosed with a serious illness regardless of prognosis and their desires regarding treatment measures.[189] This broad-based model of palliative care, also referred to as supportive care, should be provided in conjunction with treatment efforts and during early disease stages to improve quality of life by addressing medical issues as well as psychosocial and spiritual issues that arise as a result of chronic illness. Like hospice, broad-based palliative care has been shown to have multiple benefits including improving clinical outcomes, quality outcomes and improving the decision making process, therefore making it beneficial to all stages of AD.[190]

Daniel Callahan has suggested that better approaches to end of life issues could have a dramatic impact on quality of care and cost control because they consider cure and care in unison while embracing the challenging notion that death remains inevitable despite the advancements of medicine.[191] Some comprehensive programs have been designed and implemented to provide comprehensive patient centered, dementia care. Preliminary data from one such program designed by the University of California at Los Angeles Alzheimer's and Dementia Care program (UCLA ADC) indicates that these programs are well received and may very well achieve the goals of better individual care, better population health, and lower costs.[192] This program provides measures and has goals similar to those of palliative care programs. Despite indications of success these types of programs are not widely available and lack funding because they are not supported by HCOs or government healthcare services.[193] According to the WHO a public health approach to broad based palliative care ought to be incorporated into healthcare systems. While some broad based palliative care approaches have been rolled out in different countries specific to diseases such as cancer and HIV/AIDS, other disease would benefit from a disease specific public health approach to palliative care that is both effective and accessible to all people with the condition.[194] Due to the prevalence of AD and its capacious burden it is sensible that a public health approach to palliative care for the Alzheimer's population be meticulously designed and implemented immediately. Such an approach to all stages of AD would help organizations in multiple regards and ensure the government meets several objectives of the National Plan to Address Alzheimer's Disease. Standardly incorporating broad based palliative care earlier in the course of AD, particularly from the time of initial diagnosis, reincorporates compassion into medical practice and improve quality and reduce costs specific to AD.

i.   A Return to Compassionate Care

Despite there being an array of goals in contemporary medicine, they are not prioritized because not all medical situations are the same.[195] Both clinicians and patients tend to place significant emphasis on efforts focused on cure and preventing mortality for as long as possible.[196] While the contemporary goals of medicine clearly focus on aspects of both cure and care, not separating one from the other and not prioritizing one from the other, cure tends to also be the more common focus of today's HCOs. This is problematic in the face of AD because there is currently no cure or effective treatments yet people with AD still present to physician offices and emergency departments seeking assistance in addressing and dealing with the multiple problems that are rampant throughout the lengthy course of the disease. The results to HCOS are decreased quality of care, increased costs, and lower patient satisfaction. When the intricacies of AD are not well understood and addressed by healthcare providers it can lead to medical decisions that use advanced life prolonging technologies that do not provide benefit in relieving the malady of AD ultimately leading to the prolongation of life without the relief of Alzheimer's symptoms or the potential to return people to a reasonable level of functioning or wellbeing.[197] The advances of medicine and healthcare often result in confusion about when limits should be placed on their use. What conditions should be treated to allow for other, perhaps worse conditions to arise in the future becomes an ethical debate in healthcare.[198] AD complicates this debate not only for individual patients and providers but also for HCOs.

The American Medical Association's code of ethics proclaims in its first principle that all physicians shall provide their services compassionately.[199] This proclamation emphasizes that compassion is an essential element for all physicians practicing within the US healthcare system and the presumption can be made that compassion is an organizational expectation as well.

Despite its inclusion in the AMA code of ethics, the virtue of compassion is not always assumed to be a mandatory requirement for all clinicians today. Arguments are made that incorporating compassion into modern medical practice is above and beyond the usual call of duty for physicians.[200] To some, compassion may no longer be viewed as a necessary clinical duty because the education and focus of modern medicine is heavily influenced by science.[201] This belief separates compassion from treatment and cure but the goals of medicine however do not show a divide between the goals of treatment and cure, and the goal of care which is more commonly associated with compassion. By exercising compassion throughout all phases of medicine, clinicians will be more likely to alleviate vulnerability while still remaining in tune with advances in medical technology. Compassion is thus necessary to achieving goals associated with treatment and cure, just as it is for achieving goals of care. While AD cannot be effectively treated or cured, other conditions are commonly addressed throughout the course of AD therefore when compassion is integrated with advancements in medical science and technology, clinicians better assist people with AD in determining how other conditions ought to be addressed as they occur during the various stages of AD.

When HCOs emphasize the importance of reincorporating professional compassion into all medical situations, especially those when AD is present, both individual and organizational benefits will occur. Palliative care is designed to enhance professional compassion thus standardizing its broad based use throughout the entire course of AD promotes a resurgence of professional compassion. When those with AD reach the advanced disease stages palliative care can transition to hospice and compassion will be incorporated throughout the remaining life span to ensure death occurs naturally and as painlessly as possible for both patients and their family members. The entire course of AD, from early diagnosis in the mild stages to futility in the

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severe stages, causes duress not only for those with the condition but for our current healthcare system whose organizations do not have standardized practices to commendably confront the burden of the disease. The definition of palliative care as set forth by the WHO reflects that these compassionate goals specific to AD are within the spectrum of palliative care.[202]

ii.   Improved Quality and Reduced Costs Specific to AD

The majority of healthcare spending results from the portion of the population that have serious illnesses and chronic conditions. While the costs associated with this population are high the quality of care provided is not, a combination that results in low value healthcare. Low value healthcare is the result of care that is found to be costly and of inadequate quality because of such factors as fragmentation, overuse, high rates of medical error, reports of poor quality of life as well as other factors.[203] Such low value healthcare has been experienced by those with AD as these factors have contributed to the burden associated with the disease. As explained, HCOs who have promoted the incorporation of patient centered care have seen improvements in the value of healthcare provided. Palliative care is designed to stimulate patient and family-centered care thus when provided to people with AD the value of care provided and received will increase.[204] Unfortunately, there are barriers to palliative care in the US the biggest of which is a lack of palliative care services provided outside of the hospice realm. Other barriers include issues related to access and a workforce with insufficient training and expertise as well as a lack of public knowledge and understanding of palliative care.[205]

Despite barriers there are well established benefits that result from palliative care services. Some of the benefits, including symptom management, psychosocial support and grief support, impact patients and family members directly. Other benefits have not only individual but also organizational benefits. Studies have indicated that proper palliative care reduces

unnecessary hospitalizations, reduces costs and results in better patient and family satisfaction.[206] It has also been found that when palliative care is introduced early in the course of disease that clinical care and quality outcomes are improved. These benefits have been evident even when patients continue to seek disease modifying treatments while utilizing palliative care.[207] There is currently a pilot program being run through Medicare to test the outcomes of offering patients access to both hospice services and treatments simultaneously through a randomized controlled study. When the study concludes in 2020 the results may impact the way in which Medicare policy addresses palliative care and hospice.[208] If the results indicate what is expected, that the provision of palliative services improves quality of care and reduces healthcare spending throughout the courses of diseases not just at their end stages, changes may begin to occur within the current model of healthcare and its approach to disease management.

In 2004 Ruth Purtilio and Henk ten Have edited a book titled, *Ethical Foundations of Palliative Care for Alzheimer's Disease,* to begin addressing the unique issues of AD, how they impact people and communities across the globe and to create a foundation illustrating the impact that palliative approaches offer to the management of the multifaceted burden of AD. Specific organizational issues created by AD are remarked upon in numerous chapters as are the ways in which palliative care can, or does, address them.[209] It is recognized that often people with AD are sent to hospitals not for acute medical issues but as the result of breakdowns in their social networks. [210] This creates issues, especially in the US, because acute care practitioners here are not trained to handle social issues, nor is the reimbursement system set up to cover the cost of addressing social issues in an acute care setting. If palliative care services are standardly offered to all people diagnosed with AD, social issues will be addressed through palliative care teams within patients' homes and these unnecessary hospital admissions for social circumstances

will be reduced or all together avoided. Palliative care teams also begin addressing sensitive medical issues associated with advanced AD before they occur thus allowing the decision making process to occur more smoothly as it unfolds saving time and dollars for the acute care setting and enhancing patient and family satisfaction despite a difficult disease process. As the benefits of palliative become more evident there is a growing notion that it ought to be more broadly recognized by government and public health policy. In order to urge progress in this direction some are even beginning to promote palliative care as a human right.[211] If considered a human right, a reexamination of how organizations provide the services will need to occur. Even if palliative care is not considered a human right, its philosophy and application offers potential to improve the way in which care is provided across the spectrum of AD.

Social responsibility has recently become an important aspect of HCOs in order for them to regain and maintain public trust and to remain economically competitive among other providers. Through social responsibility HCOs should achieve these tasks by utilizing their resources responsibly while containing costs and improving access to quality care. These tasks are difficult for organizations but become more challenging in the face of AD. HCOs should address the challenges specific to AD by promoting policies that limit the extent of care provided. HCOs do not have to specifically set policies that state what exactly will or will not be offered to people with AD but they ought to use policy to promote the use of value based medicine and develop tools to measure and determine adequate health related quality of life. Through such policies patients and family members facing AD may be better able to navigate the kinds of care they really want and desire throughout the disease course. Standardizing the use of palliative care from the time of initial diagnosis would also be a socially responsible way of containing costs and increasing access to care in the face of AD. This is because palliative care

emphasizes the importance of compassionate care combined with scientific knowledge and improves quality and reduces costs to the populations it serves.

IV.   Conclusion

As the 20th century drew to a close and organizational ethics became a new trend endorsed by healthcare oversight organizations, initial thoughts were that this trend would be a passing fad. Today, almost two decades later, organizational ethics continues to be a focal point for organizations such as the JCAHO and AMA.[212] Although healthcare functions as part of the market economy in our nation, healthcare services are unique from other types of consumer goods and the provision of healthcare services is held in a higher regard than those of other types of marketable services. This is because healthcare is of special moral value and its provision is expected to be done with more moral consideration than other types of business.[213] Organizational ethics programs within HCOs must strive to uphold these moral convictions by incorporating measures focused on ethics not only related to business aspects of healthcare but also ethics related to clinical care and professional relations.[214] The successful organizational ethics program ultimately aims to foster a virtuous organization.[215]

An HCO will develop an ethical climate, internally the climate will reflect the ethical perception of the organization from within the system, and externally the ethical climate will reflect the perception of the organization by the community.[216] Each aspect will significantly contribute to the virtuousness of the organization. Internal aspects of HCOs will benefit from the concept of relational autonomy because the organizations are composed of many stakeholders who will benefit from this concept including its patients and providers. By incorporating relational autonomy into organizational ethics, quality-of-care should be improved. Quality has

been an area of criticism for healthcare throughout the past several decades. Quality related to care for people with AD has especially been a recent focus and an imperative for improvement.[217] Quality-of-care for the Alzheimer's population may very well be enhanced when patient centered care is promoted and efforts are made to strengthen professional ethics. Relational autonomy is reflected in the qualities of patient centered care and such models have benefits that improve the quality-of-care when provided by healthcare systems. An understanding of the importance of the interdependent relationship between healthcare providers and the organizations to which they are affiliated will emphasize the need to strengthen and maintain professional ethics. Professional ethics become strengthened and quality-of-care is improved when concerns pertaining to individual issues and group matters are addressed.

Social responsibility will strengthen both the internal and external aspects of HCOs as it will promote the containment of costs and increase in access. These aspects are in need of special consideration as they pertain to AD since the disease is specially correlated to higher costs and lower quality than many other conditions. Positive changes in these factors will occur when value based medicine and heath related quality of life considerations are reflected through medical policy. It would be a socially responsible measure to make palliative care a standard of care for all people diagnosed with AD because it emphasizes the importance of compassion in medical care and also improves quality while reducing costs through its multidisciplinary approach to care. Overall, organizational ethics programs improve the overall quality-of-care for the Alzheimer's population by integrating relational autonomy and social responsibility into its focus which will ultimately impact the burden of the disease by reducing costs and improving access.

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<u>Chapter Seven: Conclusion</u>

There is a place in Weesp, a city in North Holland that has spent the past 20 years pioneering a unique way of caring for people with dementia. Hogeweyk Village, or dementia village as it is often referred, is a one of a kind facility that provides care for 152 residents, all of whom are in the more severe stages of dementia, in a place designed unlike any other. Just as its name insinuates, Hogeweyk is a village, a gated community more precisely, where residents live in one of 23 houses within a neighborhood that has a grocery store, restaurants, a hair salon and other community places within its multi-acre property. The concept is designed upon the premise that the traditional nursing home is not a place many people look forward to having to live because it often is a place where people sit around waiting to die. Hogeweyk differs in that its residents do not sit around, they live in a place where they feel at home, rather than nursing wards residents live in smaller homes designed in a number of styles to which each resident is appropriately matched. Residents spend their days participating in activities they enjoy, for some this includes cooking and cleaning, for others going to the grocery store or pub within the village. Reminiscent therapy takes place in this design all day, every day. Care workers wear plain clothes as opposed to hospital scrubs and provide patient care while participating with their patients in their preferred activities. Because the village is gated, residents can roam freely and also safely despite their advancing dementia.[1]

All staff at Hogeweyk, from physicians to the people who work in the community stores to volunteers, are specially trained in dementia care, and staff to patient ratios are 2:1. Through this novel design and approach to dementia care administrators are finding their residents tend to use less medications, less restrains, and experience lower rates of behavioral issues than do residents in traditional style dementia care facilities. Additionally, resident's families report

higher rates of satisfaction and their quality of life appears superior. One of Hogeweyk's founders explain that they have created a place for people with dementia where caring lifestyles take place within a safe society. This remarkable concept is catching on and similarly designed facilities are beginning to be built in other countries. What is further notable about Hogeweyk is that it is a state-run care facility meaning it runs on the same budget as other Dutch care facilities and the cost to live there is the same as the cost to live in traditional care facilities.[2] This is because the Netherlands have publically funded, statutory healthcare coverage.[3] So while the design and services may be able to be replicated, issues related to costs and accessibility may play out differently in other nations.

Alzheimer's disease is intricately related to the concept of autonomy, or more specifically the erosion of autonomy. The slow yet progressive wearing a way of cognitive functions has resulted in millions of American adults who can no longer pay bills, take a walk alone, remember their own names or the names of those who they love, recall their past, reflect upon memories good or bad, and so much more. Ultimately physical decline joins alongside cognitive decline precluding these people from completing their own ADLs, mobility becomes lost along with the potential to swallow, eventually leading to death. The slow erosion of autonomy often causes people who witness AD to grieve twice for the person they love; once when their personality and sense of selfhood changes and again when their actual death occurs. The modern American culture highly values independence and rationality so the physical and cognitive deficits brought about by the disease are even further complicated by this ethos. The generalization that most adults have the capacity for independence and rationality is the foundation of modern medical ethics as well as legal precedent about medical decision making.[4] But as AD and other related

dementias expand to afflict more and more of the adult population the generalized ideals about rationality, independence, and autonomy will need to be reconsidered.

Much of what has been ethically and legally supported as related to autonomy in healthcare is specifically associated with autonomy which is precedent in nature. Precedent autonomy supports that choices made by a competent person prior to an injury or illness should be respected after competency is lost.[5] While well relied on over the past several decades, the concept of precedent autonomy raises various concerns when it is paired with Alzheimer's related issues, particularly those related to advanced directives.[6] One such moral issue being contemplated by scholars relates to the use of food and water and whether or not it is morally permissible for people to indicate in advance directives that they wish to stop being offered food and water when their dementia reaches a certain stage so that death will occur as a result of starvation and dehydration. Refusal for sustenance via voluntary stop eating and drinking (VSED) initiatives, or hunger strikes, are controversial when rationality is still intact, such has been the case with prisoners held at Guantanamo Bay and in the epic case of Elizabeth Bouvia. For over a decade military policy has supported the force feeding of hunger striking detainees in US military prisons.[7] In a legal and ethical battle that occurred in the 1980's a final determination was made that Elizabeth Bouvia, a competent women completely care dependent due to cerebral palsy, had the right to refuse food and water by mouth and could not be force fed even if her body weight decreased to a fatal point.[8] The right to autonomy for an adult with capacity is extended in general to law abiding citizens but in some situations, like the one illustrated by military policy on force feeding, not to prisoners. How precedent autonomy should be considered in situations where hunger strikes are desired by people who no longer maintain

capacity however is a more morally and legally complex issue but one that some in the mild stages of Alzheimer's want carried out when they enter later stages.[9]

Precedent autonomy is not only a concern when it comes to VSED. The concept of advance planning, particularly the treatment directives found within living wills, have some people questioning their applicability to people with dementia. Concerns are raised about the abilities of a person without dementia to truly foresee how their life will be lived and experienced when dementia on sets. Although AD and dementia are among the most feared conditions, many people in various stages of dementia appear to be living contently despite the personality changes brought about by the symptom. A brief, yet poignant example of such a situation was published in the journal of American Medicine in 1991, by Andrew Firlik, a medical student at the time, who met Margo, a woman with AD, during a summer gerontology elective. Firlik describes the experiences of his daily visits with the 55 year old woman who was in the midst of moderate to severe dementia. Despite the many questions Margo's dementia related tendencies and behaviors raised for the young doctor, his overall thoughts were that despite the oddness created by dementia Margo was the happiest person he had ever met. He summarizes that, "there is something graceful about the degeneration her mind is undergoing, leaving her carefree, always cheerful."[10] The article gives us no insight to who Margo was before she had AD, whether the life she was currently living was radically different, from a quality perspective, than the life she lived before dementia confined her to an apartment with a caretaker and multiple locks on the door to prevent her from wandering off alone and getting lost in the city. What the article portrays however is the story of a younger adult who seemed to be living happily and contently in the moment despite advancing dementia.

Ronald Dworkin reflects upon Firlik's story of Margo in his 1993 book, *Life's Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom,* in a chapter he titled Life Past Reason.[11] Dworkin poses what if types of questions about care directives Margo could have hypothetically issued before she was overcome with dementia. For example, he questions what if Margo wished that no types of treatments be administered for any serious of life-threatening conditions that she may develop. Dworkin then poses ethically ridden dilemmas like what do you do when a seemingly happy and content Margo who currently appears to enjoy her life gets an infection that may be adequately treated with antibiotics, treat it, or respect her precedent autonomy and forego treatment. He conceives how some people may wish to override precedent autonomy in Margo's case, or in similar cases where current evidence indicates that perhaps precedent autonomy is no longer applicable because the current situation indicates otherwise.[12] Dworkin concludes however, that the integrity view of autonomy, one which is consistent with respecting precedent decisions, overrides this evidentiary view of autonomy, one that neglects precedent autonomy when there is evidence to suggest current circumstances may contradict previous perspectives. He justifies this by explaining how the evidentiary view is morally paternalistic and violates the concept of autonomy.[13]

Some support Dworkin's view on fully supporting precedent autonomy even when advancing dementia may not as negatively impact a person's present state to the degree to which it was foreseen, while others refute his support of precedent autonomy under such circumstances.[14] Rebecca Dresser has spoken out against Dworkin's views in her 1995 Hastings Center Report article, Dworkin on Dementia: Elegant Theory Questionable Policy.[15] While Dresser explains that certain people do fully understand the course of AD and advancing dementia, the majority of people either express their wishes about future care without being

fulling educated and gaining full understanding about the disease course, have no idea under what circumstances their current autonomous wishes may be later reflected upon, or do not even take advantage of the opportunities for advanced planning. For these reason Dresser finds precedent autonomy less morally obligatory especially from a policy perspective and is supportive of moral paternalism when quality of life is still intact to an acceptable degree.[16]

The degree to which precedent autonomy ought to be respected when cognitive deterioration occurs slowly and steadily in the face of AD can be debated from a multitude of legal and moral perspectives. Each case of AD will differ from patient to patient yielding in thousands, if not more, circumstances under which advanced planning initiatives may or may not have occurred. When the individualist focus of autonomy subsides and a more relational focus of autonomy emerges each unique set of circumstances will be adequately considered in order to determine what is in each person's best interest. Just as Dresser begins to insinuate the importance of relational considerations in autonomous preferences of those with dementia she has also suggested the importance that societal considerations play in how those with advanced dementia are treated. She states, "We need rules setting forth the acceptable boundaries of precedent autonomy and proxy decision-making. Just as there are legal limits on the range of treatment choices parents may make for their children, so should there be limits on the range of choices competent persons have concerning their future treatment and the choices available to proxy decision-makers. In short, we as a society must take a moral and legal stand on which categories of incompetent patients must be treated and which may have treatment foregone."[17] Without directly stating it, Dresser has set up and justified the link between the ethics of care and AD. There is the necessity for autonomy despite the loss of personal rationality, but a more capable type of autonomy is one that is interpersonal rather than individualistic. Because the

disease has expanded to epidemic proportions there is also a need for more than personal responsibility for its consequences, a responsibility carried out by society as a whole is also necessary. Relational autonomy and social responsibility not only make up the framework for the ethics of care but also offer benefit to navigating the burden of AD.

The majority of scholarly works, general publications and news stories about AD begin in the same manner, describing a disease that is uniquely burdensome in that it is incurable, unpreventable, untreatable, personally and publically expensive and impacting a large and growing portion of society. Once the burden is clarified these works proceed on in their own direction. Like others, Dr. Dale Bredesen begins his recently published book, *The End of Alzheimer's; The First Program to Prevent and Reverse Cognitive Decline,* in this fashion. Dr. Bredesen explains that AD is feared in a way that no other disease is feared for two main reasons; the first is that it is the only disease in the top ten causes of death that has no effective method of treatment, the second is that it only becomes fatal after years of eroding people of their cognitive abilities and independence.[18] Unlike other authors, Dr. Bredesen goes onto explain the process he calls "ReCODE" a process for preventing and reversing cognitive decline related to AD.[19] His revolutionary theory is that there are three subtypes of Alzheimer's and the identification of the subtype is crucial for the reversal of the disease's impact.[20] His process begins by identifying each individual's biochemical, genetic, and other various factors that are causing the cognitive decline to determine which subtype of AD to address.[21] The particular subtype is then counteracted by appropriately manipulating five key factors; insulin resistance, inflammation and infections, hormone, nutrient and trophic factor optimization, toxins, and restoration and protection of lost or dysfunctional synapses.[22] Through brief description ReCODE may sound simple but following this process requires major daily commitments and

significant lifestyle changes.[23] Dr. Bredesen's has taken the first steps to a personalized

therapeutic approach to AD, one that the majority of people may find too difficult to follow due

to its intricate requirements yet this is a step that is unique to any other attempt to control AD

thus far. Thinking outside of the traditional pharmacological approaches to prevent, treat, or

cure Alzheimer's may be the key to getting the burden it creates under control in a manner which

respects relational autonomy and is socially responsible.

Maria Shriver is among a cohort of public figures who are currently using their platform

to research and advocate for AD in manners which reflect relational autonomy and social

responsibility. Shriver's work focuses on the impact AD has on women in particular because

nearly two thirds of people with AD are women, and 60% of the country's unpaid caregivers are

women.[24] Her foundation, The Women's Alzheimer's Movement, is dedicated to raising

awareness about the way in which Alzheimer's effects women and to doing gender specific

research as a means to find an overall solution to AD.[25] Despite her focus on women and

Alzheimer's, it was Shriver's father who endured the disease over the course of eight years and

prompted her passion in becoming a global advocate for the cause. She highlights many

individual stories about people with AD and their caregivers and also works diligently to

emphasize the necessity for change and support at the public policy level.[26] She works closely

with the Alzheimer's Association where the traits of relational autonomy and social

responsibility are also present to promote the importance of research, advocacy, and awareness

in the fight against AD in hopes of achieving their vision of, "a world without Alzheimer's."

The Alzheimer's Association is the world's largest voluntary organization focused on ending AD

and other related dementias through their mission, "to eliminate Alzheimer's disease through the

advancement of research; to provide and enhance care and support for all affected; and to reduce

the risk of dementia through the promotion of brain health."[27] The Alzheimer's Association was assiduous in developing and encouraging the passing of the National Alzheimer's Project Act, and the association remains conscientious in ensuring the goals of NAPA remain a priority for Congress.

When NAPA was signed into law in 2011 it reflected the importance of autonomy beyond just a notion of strict individualism by identifying the toll AD takes on the individuals it inflicts, as well as the toll absorbed by their family members, caregivers, and society at large.[28] Although NAPA may not have been designed with the ethics of care in mind, its premise and plans reflect the ideology promoted by this moral theory; that individuals are not singularly impacted by the disease and thus efficiently addressing the disease must take into consideration the problems it causes to those surrounding these individuals, and the society in which they exist. Because it is a burden so much beyond individual control, society must take responsibility in addressing its far reaching, multifaceted burden.[29] Since 2011, there has been indication that efforts to achieve the five goals of NAPA are being addressed but efforts among the five goals are inconsistent.[30] A 2016 report found that initiatives have been put into place to reach the Plan's goal related to research but that initiatives to reach the goals related to care and support are still lacking yet can be achieved through proper efforts.[31] The Alzheimer's Association carries out congressional activism efforts to help ensure policy related to both research and care are developed and appropriately supported by members of congress. Many of these efforts are completed or carried out through its advocacy program.[32] Volunteer advocates and congressional ambassadors have recently rallied in numerous public policy triumphs that reinforce efforts related to the association's mission. One such recent victory was getting the HOPE for Alzheimer's Act passed in 2016. As a result Medicare now provides coverage for

care planning for those living with cognitive impairments like AD.[33] The advocacy program also rallied to propagandize the importance of an additional $414 million in funds for NIH Alzheimer's research in 2018 and is currently working to get the bipartisan, Palliative Care and Hospice Education and Training Act (PCHETA) passed. PCHETA is focused on workforce training specific to palliative care, aiming to ensure this workface is both sufficient and well-trained so all people, including those with AD, will benefit from appropriate palliative care.[34]

Reflections of the role that both autonomy and social responsibility have in pursuing control over the burden of AD are present in various arenas of society. Outside of the academic literature not much specifically relates the role that morality may play in considering ways to address this burden. Morality is however evident throughout the facades of modern society and remains evident in the work of governmental policy. Due to the expansive burden of AD one consistent moral framework addressing the nature and burden of it ought to be used consistently by everyone involved in managing this created burden, for if the various aspects of AD continue to be circumvented and addressed based on situationally conceived approaches AD will continue to exist in a fragmented system. As previously indicated, the fragmented system of care is among the main factors negatively impacting quality of Alzheimer's care within the US healthcare system. Fragmentation should be reduced by utilizing one framework of care to address the burden of AD on personal and societal levels. The ethics of care offers an impressive framework that proficiently focuses on clinical and organizational ethics to integrate personal care and public good as it relates to the burden of AD in a sustainable and effective manner. Some fear that care cannot be a major concern for nations built and run on democracy, or a factor that guides a democratic nation forward successfully. Such fears have led people to fight the incorporation of care into government fearing that this would mean a complete change from

majority rule-type politics to socialized types of politics. Political scientist and care ethicist, Joan Tronto, disagrees completely and has scrupulously explained how care ought to be incorporated into modern democracy in a way which does not disrupt the role of the market, promotes better equality, and continues to respect the role of justice in her 2013 book, *Caring Democracy Markets, Equality, and Justice*.[35] Once it is agreed that care is essential to personal, societal, and modern democratic flourishing, especially as it pertains to the burden of AD, then the ethics of care become the larger framework from which the burden of AD is best addressed individually, communally, and democratically.

As a framework designed with two components; one that focuses on patient care through relational autonomy, and another that focuses on public good through social responsibility, the ethics of care address concerns during the mild stages of AD as well as concerns during the severe stages. When this framework is utilized the mild stages are embraced to lessen the difficulties associated with the severe stages. This framework also guides organizational ethics to improve quality of care and access to care while being considerate of costs and the importance of healthcare cost reduction. The ethics of care framework guides the management of AD in a way in which moral concerns are respected at the same time clinical and organizational concerns are addressed. Standardizing the way in which AD is approached from its earliest point until its final moments respects intrinsic and attributed human dignity and respects the universal vulnerability all people face as an innate quality of their humanness and potential for sickness and disability. Furthermore, this approach is respectful of the possibilities and limits of modern medicine, is considerate of medical statuses in conjunction with individual personal values, and is attentive to the greater needs of society without disrespecting individual choices. Overall, the moral framework provided by the ethics of care will facilitate the management of AD in a unique

and effective way which will decrease despair, and positively promote personal and societal

flourishing with or without future advances in medical and pharmacological technology related

to Alzheimer's.

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