Distribution Agreement

Jennifer Jin April 5, 2021

A Case Study of Opinions on Medical Agency in Alzheimer’s Disease and Alzheimer's Disease Related Dementias (AD/ADRD)

by
Jennifer Jin

Gillian Hue, PhD
Adviser

Neuroscience and Behavioral Biology

Gillian Hue, PhD
Adviser

Jennifer Sarrett, PhD
Committee Member

Whitney Wharton, PhD
Committee Member

2021

A Case Study of Opinions on Medical Agency in Alzheimer’s Disease and Alzheimer's Disease Related Dementias (AD/ADRD)

by
Jennifer Jin

Gillian Hue, PhD
Adviser

An abstract of
a thesis submitted to the Faculty of Emory College of Arts and Sciences
of Emory University in partial fulfillment
of the requirements of the degree of
Bachelor of Science with Honors

Neuroscience and Behavioral Biology

2021

Abstract

A Case Study of Opinions on Medical Agency in Alzheimer's Disease and Alzheimer's Disease Related Dementias (AD/ADRD)

by Jennifer Jin

The current study aims to identify themes regarding medical agency in Alzheimer's Disease and Alzheimer's Disease Related Dementias (AD/ADRD) and compare the perspectives of various stakeholders. A neuroethical analysis was done by conducting qualitative interviews, which revealed recurrent themes and knowledge gaps across four broad themes: 1. examination and evaluation of medical agency, 2. assignment of surrogacy, 3. current cognitive exams, 4. communication with various stakeholders about medical agency. The study results underscored the importance of developing a deeper understanding of a diversity of stakeholder perspectives, while also providing an opportunity for affected persons and their caregivers to learn about the importance of medical agency in their lives and introduce their viewpoint in the broader conversation.

A Case Study of Opinions on Medical Agency in Alzheimer’s Disease and Alzheimer's Disease Related Dementias (AD/ADRD)

by
Jennifer Jin

Gillian Hue, PhD
Adviser

A thesis submitted to the Faculty of Emory College of Arts and Sciences
of Emory University in partial fulfillment
of the requirements of the degree of
Bachelor of Science with Honors

Neuroscience and Behavioral Biology

2021

Acknowledgements

I would first like to thank Dr. Gillian Hue for her constant support and encouragement during this process. Her input and guidance were invaluable in turning my budding interest in neuroethics into a fully-formed neuroethics thesis.

I would also like to thank my two thesis committee members, Dr. Jennifer Sarrett and Dr. Whitney Wharton for their time, insight, and feedback.

I would finally like to thank my labmate, Meghan Hurley for her support and camaraderie in developing our neuroethics theses together.

Table of Contents

Introduction **1**

The Concept of Autonomy and Medical Agency 1

Determinants of decision-making capacity and the four aptitudes necessary for decision making 1

Figure 1: Four aptitudes for decision-making capacity 2

Current and Projected Prevalence of Alzheimer’s Disease and Alzheimer’s Disease-Related Dementia (AD/ADRD) 2

A diagnosis of AD/ADRD leads to loss of decision-making capacity 3

Individuals with AD/ADRD are a vulnerable population 4

Current tools for measuring medical agency 5

Assigning surrogacy 7

The key ethical principles in play 7

Capacity vs. competency 9

Significance of project 9

Research Goals **10**

Methods **11**

Basic Methodology 11

Reasoning for a Case Study Approach 11

Obtaining Consent 12

Data Collection 13

Concept Map/Interview Guideline and Structure 13

Figure 2: Preliminary concept map 14

Data Analysis 14

Results **15**

Table 1: Overview of participants 15

Table 2: Themes and Subthemes 16

Theme 1: Examination and evaluation of medical agency 16

Subtheme #1: Case-by-case evaluation 16

Subtheme #2: The “point” of compromise 17

Subtheme #3: Trust between physician and patient 19

Subtheme #4: The individual rights at stake 20

Theme 2: Assignment of surrogacy 21
  Subtheme #1: Framing 21
  Subtheme #2: Trust between husband and wife 22
  Subtheme #3: Partnership within relationships 23
  Subtheme #4: Legal planning and advanced directives 24
Theme 3: Current cognitive exams 25
  Subtheme #1: The utility and veracity of cognitive assessments 25
  Subtheme #2: Looking beyond cognition and cognitive assessments 27
Theme 4: Communication about medical agency 29
  Subtheme #1: Imposition of authority (paternalism) 29
  Subtheme #2: Empathy and respect for others 30
  Subtheme #3: Assumptions and generalizations 30
  Subtheme #4: Clarity in communication 31
  Subtheme #5: Importance of information 33
  Subtheme #6: Being heard 34
Discussion 36
Addressing study goals 36
  Figure 3: Updated concept map 37
Other major research findings 40
  Personalized medicine 40
  Differences in relationship dynamics between spouses vs. parents and adult children 41
  Amplifying voices 43
Limitations and future research 44
Conclusion 45
References 46
Appendix 51
Appendix A: Oral Consent Script (Traditional Authority) 52
Appendix B: Oral Consent Script (Dyad) 54
Appendix C: Interview Guideline (Traditional Authority) 57
Appendix D: Interview Guideline (Dyad) 58

Introduction

The Concept of Autonomy and Medical Agency

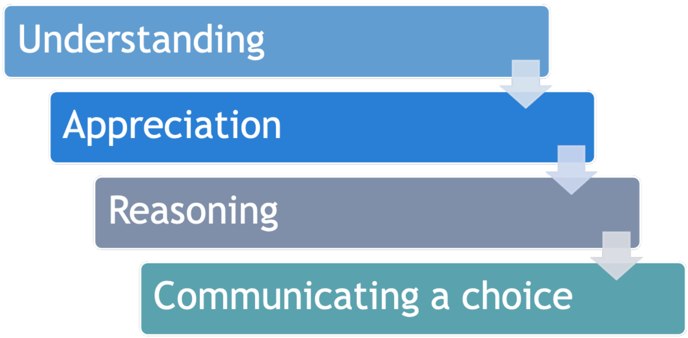
The right to individual autonomy is a central tenet of Western, particularly American, values (Kara, 2007). Autonomy refers to an individual's capacity for self-determination and self-governance, to live one's life according to their own choices and reasoning (Vaughn, 2017, p. 11). According to Beauchamp and Childress, the two elements necessary for true autonomy are liberty, freedom from external influences, and agency, the capacity to act and make independent decisions (Beauchamp & Childress, 2009, p. 100). In a medical context, the right to autonomy can best be seen through the element of agency and when individuals are able to make informed decisions concerning their own medical care and needs. Of course, there are populations that are generally not granted agency, including children and even individuals born with intellectual and developmental disabilities, whose parents usually make decisions on their behalf as designated guardians. There are also other populations in which medical agency is rescinded when individuals are no longer able to understand the meaning and consequences of their actions. This approach to medical agency can be perilous. Exercising agency implies intentionality and individuality in decision making, which contributes to defining one's sense of self and living autonomously. Because we often assign identity, value, and worth to our right to autonomy; taking medical agency away from someone can potentially interfere with their identity and diminish their own worth.

Determinants of decision-making capacity and the four aptitudes necessary for decision making

To protect patient autonomy, a fundamental right even for an impaired individual (Murgic et al., 2015), we must first understand what key capabilities are exercised in decision making. In most circumstances and with most individuals, especially if there are no obvious impairments, one's ability to make decisions is assumed.

In recent years, experts from various fields have come together to develop a cognitive model outlining four aptitudes necessary for decision making in the context of patient authorization and informed consent: comprehension, appreciation, reasoning, and communication of choice (Grisso & Appelbaum, 1998). Comprehension is the ability to understand the meaning of relevant information concerning the medical decision. Appreciation occurs when individuals incorporate the comprehended information to their personal values and beliefs to make a decision that they understand applies to them. Reasoning describes the ability to evaluate various alternative options and their unique risks, benefits, and consequences. Finally, communication of a choice refers to one's ability to clearly communicate the final chosen decision. When these four aptitudes appear to be intact, one's decision-making capacity is assumed to be intact as well.

Figure 1: Four aptitudes for decision-making capacity



Current and Projected Prevalence of Alzheimer's Disease and Alzheimer's Disease-Related Dementia (AD/ADRD)

According to the National Institute of Aging, America's 65-and-over population is projected to nearly double by 2050, increasing from 48 to 88 million, and life expectancy is also projected to increase by nearly eight years from roughly 68 to 76 years (He et al., 2016). As a result of an aging world population, neurodegenerative dementias are reaching epidemic proportions. Alzheimer's disease and Alzheimer's disease-related dementias (AD/ADRD) are two such disorders. In 2019, an estimated 5.8 million Americans were living with AD/ADRD. Since the older American population is only projected to grow, the prevalence of AD/ADRD will also inevitably follow this trend. AD/ADRD is the sixth-leading cause of death in America and between 2000 and 2017, the number of deaths from AD/ADRD increased by 145% (Alzheimer's Association, 2019). Taken together, this demonstrates how paramount it is to study this disease from various aspects.

A diagnosis of AD/ADRD leads to loss of decision-making capacity

As the brain ages, it begins to atrophy, leading to decreases in brain weight and tissue volume, expansion of cerebral ventricles and sulci (Skullerud, 1985), and reductions in synaptic density and neuronal integrity (Morrison & Hof, 2007). AD/ADRD also develops from these same contexts but bears more extensive damage due to the development of amyloid plaques and neurofibrillary tangles (NFT) (Moya-Alvarado et al., 2016). Cognitive impairments characteristic of AD/ADRD primarily arise from the degeneration of neuronal components, including synapses, axons, perikaya, and dendrites, in the limbic system, neocortex, and basal forebrain (Moya-Alvarado et al., 2016). The limbic system, consisting of the structures like the hippocampus, amygdala, and hypothalamus, is responsible for facilitating emotions, behavior, and memory (RajMohan & Mohandas, 2007). The neocortex is involved in higher level cognition and processing of sensory, language, motor, emotional, and associative information (He & Shi, 2017). The basal forebrain helps regulate the release of acetylcholine, the chief neurotransmitter in the parasympathetic nervous system, and consequently, the body's autonomic functions (Villano et al., 2017). Memory loss, which is the most prominent impairment in AD/ADRD, develops from deterioration to the circuitry connecting the hippocampus and neocortex (Moya-Alvarado et al., 2016). The degeneration of neuronal structures and pathways within these key areas can have widespread effects, and cognitive impairments and decline can inhibit the brain's executive functions, including disruptions in language, memory, attention, cognition, recognition, and more (Traykov et al., 2007).

The onset of these impairments can interfere with a person's ability to complete activities of daily living, grasp their bearings relative to time and space, and communicate their true will. Because of this, people with such impairments may eventually need assistance from a caregiver. These symptoms can also diminish one or more of the four components of capacity. For instance, impairments to short-term and semantic memory, or general world knowledge accumulated over time, can affect understanding and reasoning. Deterioration of attention, planning, organization, and cognitive flexibility can all impact understanding, appreciation and reasoning. Expression of a choice can be affected by difficulty with language and communication as well. Thus, the decision-making capacity for individuals with AD/ADRD can come under question until further investigation into each aptitude can be done.

Individuals with AD/ADRD are a vulnerable population

Progression of AD/ADRD can lead to deficits in independent decision-making capacity, which calls into question any impaired individual's ability to make sound medical decisions. Studies have shown that actual neural degeneration begins 20 years or more before symptoms arise (Reiman et al., 2012), making it extremely difficult to ascertain when decisional capacity becomes compromised. However, decisional capacity is critical in obtaining informed consent and patient authorization for any medical intervention since the patient must possess the capacity to comprehend relevant medical information and potential implications from the treatment before making an independent, voluntary decision (Fields & Calvert, 2015). Thus, in both medical and research contexts, individuals with AD/ADRD are considered a vulnerable population. Once cognitive impairments begin to affect executive functions, their capacity to provide consent are diminished and called into question. They also become increasingly vulnerable to coercion and influence from external perspectives. Because of this, it is all the more important to be able to assess decision-making capacity and safeguard the three principles of informed consent and patient authorization: autonomy, beneficence, and justice (Oruche, 2009). Again, autonomy is an individual's capacity for self-determination and self-governance (Vaughn, 2017, p. 11). Beneficence is defined as doing good to others (Kinsinger, 2009). Medical and research professionals should consider themselves under moral obligation to ensure that when interacting with patients or participants, they are removing any potential harm, which can apply to coercion. Finally, the principle of justice essentially equates to fair and equal treatment of people and as Aristotle once said, "[to give] to each which is his due" (McCormick, 2018). The principle of justice would be involved in advocating for equitable treatment of everyone, especially vulnerable populations such as individuals with AD/ADRD. It could also apply to appropriate access to medical treatments or ample opportunity to voice their perspectives.

Current tools for measuring medical agency

In the past few decades, there have been incredible strides in the development of capacity assessments. However, the consensus in the field is that there is still no one measurement or assessment tool that allows a physician or researcher to directly and completely measure an individual's capacity to consent (Howe, 2012). Cognitive screening measures, such as the Mini Mental Status Exam (MMSE) or the Montreal Cognitive Assessment (MoCA), were designed to quickly evaluate an individual’s neuropsychological and cognitive abilities (Gilbert et al., 2017). However, these global tests are indirect and insufficient, found to be most suitable for distinguishing between those who need further examination and those who do not and not as effective in helping make actual judgements about diagnoses (Dautzenberg et al., 2019; Mitchell, 2009). In addition, one particular study indicated that individuals who were deemed capable of decision-making were more likely to demonstrate awareness and understanding of their medical status (Karlawish, 2007). Furthermore, this association was found to be independent of the individuals’ overall cognitive function. Thus, exams that purely measure cognitive function and ability, such as the MMSE and MoCA, may be even more inaccurate in helping determine capacity.

The current “gold standard” for measuring capacity in the clinical research setting is the MacArthur Competency Assessment Tool for Clinical Research (MacCAT-CR) (Howe, 2012). The MacCAT-CR is a semi-structured interview designed to evaluate the four capacity aptitudes and can be modified to fit the specific needs and information for any particular study. It is quite comprehensive and has been validated through numerous studies. However, the MacCAT-CR still has substantial limitations. It requires extensive training to administer, depends on reliable documentation, and takes time to conduct (Howe, 2012). Because it relies so heavily on the administrator, on its own, the MacCAT-CR is inadequate in assessing one’s decision-making capacity as well.

Generally, the results from these exams could help physicians and researchers better understand the cognitive state of impaired individuals, which can then aid in determining their decision-making capacity. However, it is important to note that these tests are tools used to assess cognitive capacity and screen for the presence of cognitive impairments. They cannot directly measure capacity. Thus, quantitatively evaluating decision-making capacity and its pertinent factors in a comprehensive, yet simple way has proved to be a near impossible task. Not only this, but the wide spectrum of AD/ADRD presentations also makes it difficult to establish a blanket guideline regarding medical agency.

Because of this, most physicians and researchers tend to take a more conservative approach, often concluding that cognitive decline and diminished capacity render most individuals with AD/ADRD ineligible to possess medical agency (Alzheimer's Association, 2018).

Assigning surrogacy

According to current legal standards, medical agency is usually taken away once individuals are no longer able understand the meaning and consequences of their actions (Ellajosyula & Hegde, 2016). Thus, a “surrogate” authority is usually appointed to make decisions on the individual’s behalf. The most direct means of surrogacy is through a next of kin. These are legally established and apply to any conditions of incapacitation. For example, if a college student was in a car accident and was incapacitated, her next of kin would be called to make medical decisions on her behalf. This is a more relational designation and does not come with any legal rights or responsibilities, which means that even designated next of kin are under no legal obligation to make such medical decisions. However, there are more formal ways to assign surrogacy through legal means, including appointing a legally authorized representative or durable power of attorney for health care (Oruche, 2009). Implementation of surrogacy involves long and complicated legal processes.

The key ethical principles in play

Autonomy is an ethical principle that refers to one’s capacity for self-determination and exercise of personal choice (Vaughn, 2017, p. 11). Despite their diminished cognitive capacities, individuals with AD/ADRD still desire to preserve their autonomy. They still have personal desires and wishes that they would like to express and enact. However, once their medical agency is compromised, their autonomy and ability to live life as they want is inevitably compromised (Oruche, 2009). Surrogate authorities are then appointed, which raises the issues of authority and paternalism. Who then gets the right to make decisions on behalf of this impaired individual?

Paternalism occurs when someone, usually in a position of authority, overrides the actions or decisions of another for their own good (Vaughn, 2017, p. 10). This interference is done with the purpose of protecting them from harm. However, paternalistic actions effectively take away autonomy and individual authority to exercise decision-making capacity for self-determination. When surrogate authorities take over decision making for individuals with AD/ADRD, they are acting as weak paternalists. They may believe it is legitimate to interfere because they are acting under the justification of safety (Vaughn, 2017, p. 10). Not only this, but because individuals with AD/ADRD are also perceived to be incapable of making their own, logical decisions, this pattern of paternalism does not seem like a violation of individual rights and is permissible to many people.

Authenticity is another critical ethical principle to examine when considering medical agency in individuals with AD/ADRD. An action is authentic if it is made of one's own volition and stems from one's true self (Vollmann, 2001). This can certainly be complicated in individuals with AD/ADRD because of many factors. One that is especially important is their continuously declining memories. As the disease progresses, there may be disparities between an impaired individual's present and past, pre-AD/ADRD desires. The dilemma is this: how can we determine which desires best reflect the individual's real personality and true self? This is further complicated by the disease’s tendency to cause fluctuations in mental or lucid states (Holm, 2001). Thus, because the right to individual choice and agency is so nuanced and complex, we must not be quick to disenfranchise those affected by cognitive impairments from AD/ADRD.

Capacity vs. competency

When discussing medical agency in regard to individuals with AD/ADRD, it is important to distinguish capacity from competency. Capacity is defined as an individual's psychological ability to make informed, rational decisions by understanding, appreciating, and manipulating any relevant information (Leo, 1999). It is a medical term and is determined by a physician, usually a psychiatrist. Competency, on the other hand, is a legal term and refers to individuals “having sufficient [mental and cognitive] ability… [and] possessing the requisite natural or legal qualifications” (Black, 1979, p. 257) to participate in legal proceedings or make legally relevant decisions or actions (Darby & Dickerson, 2017).

Competency is a broad concept and encompasses a wide range of legal actions, including preparing a will, managing finances, and making medical decisions. Though competency is presumed to be intact unless proved otherwise, once an individual is adjudicated as incompetent, the court assigns a guardian or surrogate authority to make decisions on the individual’s behalf and effectively denies individual autonomy in making decisions. However, capacity refers to making decisions regarding medical treatments or other aspects of care. It is specific to each context and must be continuously re-evaluated. Thus, an assessment of an individual’s capacity cannot be seen as interchangeable with a competent status.

Significance of project

The wide spectrum of AD/ADRD presentations makes it difficult to establish a blanket guideline regarding informed consent. This has continued to raise many important ethical, legal, and moral concerns. Even though these concerns have been robustly examined, all of the current literature only sheds light on the traditional authority opinion, shared by physicians, researchers, and other professionals who have dedicated their careers to treating and uncovering more about this disease. On the other hand, public attitudes on the matter are not well understood. Experts know more, and their knowledge is better organized and integrated, which allows them to access the knowledge and use it in more sophisticated strategies (Persky & Robinson, 2017). However, it is still imperative to study public opinions since these individuals are usually the most important stakeholders, as family members and oftentimes, caregivers for such individuals with AD/ADRD. Considering that nearly 83% of caregiving help comes from family members, friends or other unpaid caregivers (Friedman et al., 2015), these are the people who make the most direct contact with individuals with AD/ADRD. Their opinions and perspectives will shape how they provide care and act on behalf of their loved ones when making important medical decisions. Caregivers' understanding of individual autonomy and authenticity is also critical to protecting the rights and independence of individuals with AD/ADRD. Thus, examining and evaluating multiple viewpoints will provide crucial information for families, health providers, and even policymakers. As AD/ADRD prevalence continues to rise, this information will allow us to respect patient autonomy while considering their cognitive ability to consent.

Research Goals

The main goal of the current study is to identify themes that emerge when discussing medical agency in AD/ADRD with different stakeholders. A sub goal aims to assess similarity and differences between stakeholder perspectives.

Methods

Basic Methodology

In this study, a two-pronged approach was used to gather information. The ethical, legal, and moral concerns surrounding medical agency in individuals with AD/ADRD were robustly examined, and a thorough analysis of literature was completed to gain an acute understanding of expert assessment and the key issues at stake. Second, qualitative data was collected through comprehensive interviews with six stakeholders with different backgrounds and experiences regarding medical agency. The interview pool consisted of a geriatric neurologist and a retired neuroscientist, as well as two dyads of caregivers and impaired individuals.

Reasoning for a Case Study Approach

For the purpose of the thesis project, the broader study proposal was condensed into a smaller case study. Case study research is a type of study design that focuses on the account of one or a small number of individuals. The analysis of the data should be detailed and cover manifold aspects of the case, providing a comprehensive, in-depth account and analysis (Ylikoski & Zahle, 2019). A case study approach was chosen to maximize the limited time for data collection. For this study I prioritized the diversity in participant backgrounds over the quantity of participants as the most important recruitment factor. For the abbreviated duration of data collection, I weighed the value of varying perspectives on the topic of medical agency, against quantity and sought to interview fewer, but different stakeholders that would more likely introduce diversity in themes. Thus, perspectives from a clinician, researcher, caregiver, and impaired individual were collected. This approach would also establish a good baseline of results for each “type” of stakeholder, which can then be used to build a framework for future studies.

Obtaining Consent

The study was conducted under IRB protocol STUDY00001938. Verbal informed consent was received prior to starting the interviews. The consent form (Appendix A, B) was reviewed in detail to ensure that each interviewee understood what the study was for and what participation would entail. Interviewees were reminded that they may opt out of the study and discontinue participation at any time. They were also notified of the protection measures in place and that there would still be a risk of breach in confidentiality because the data would be stored online. All interviewees consented to being interviewed.

According to the Institutional Review Board, individuals with AD/ADRD must be treated as a vulnerable population since their cognitive impairments may compromise their capacity to understand the information presented to them and their ability to make a reasoned decision to participate in the study (Penslar, 1993). Thus, extra precautions had to be implemented to limit risk and ensure that these individuals' rights as participants would be protected. Impaired individuals were interviewed with their designated caregivers. During the informed consent procedure, impaired individuals were asked a set of questions to ensure that they understood the study. The questions were adapted from studies that required assessment of capacity to consent in participants with intellectual or developmental disorders (ID/D) and were as follows (Horner-Johnson & Bailey, 2013):

- Please tell me, in your own words, what is this study about?
- What will you be doing if you take part in this study?
- What are the risks of being in this study?
- When I say your taking part is completely voluntary, what does that mean to you?
- When I say that your answers will be kept confidential, what does that mean to you?
- What can you do if you start the study but do not want to finish it?

In this particular case study, both impaired individuals were able to demonstrate sufficient understanding to independently provide consent. In the future, if the impaired individuals are unable to answer these questions, further instruction will be provided. If after multiple rounds of instruction, the individuals are still unable to answer, they will be omitted from the study. If the impaired individuals insist on participating, the caregivers may provide consent on their behalf. However, to protect against coercion, verbal assent from the individuals will also be secured.

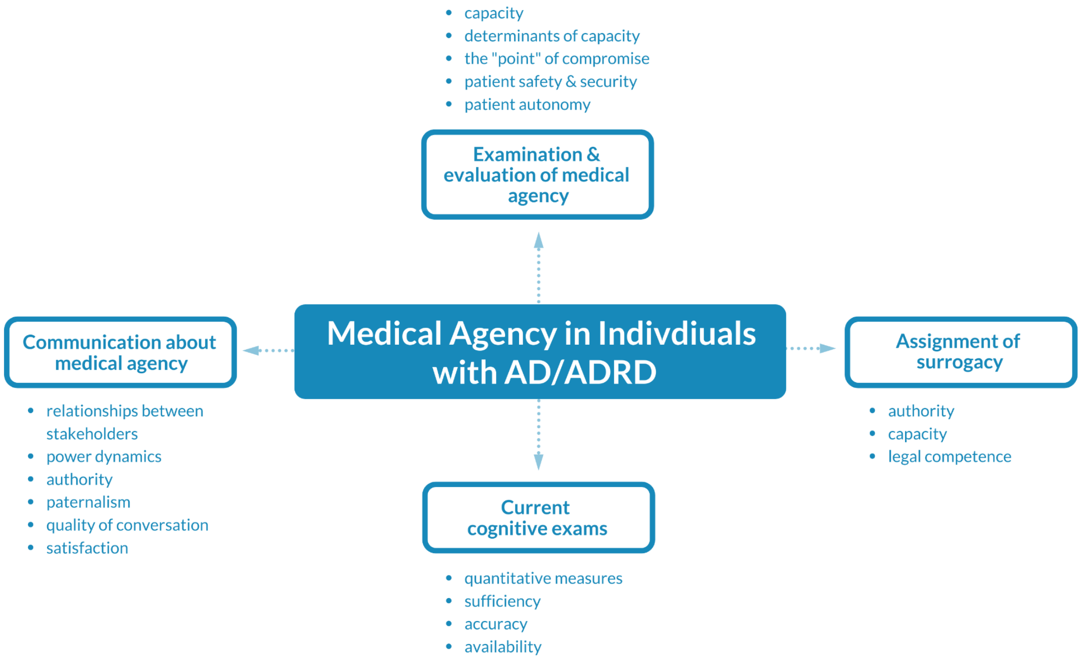
Data Collection

In order to follow COVID-19 guidelines and protect participants from the risk of exposure, all interviews were held over Zoom and recorded. Prior to starting the recording, the interviewer received permission from the participants to record the interview. The recordings were saved to the interviewer's password-protected Zoom account. Afterwards, the interviews were transcribed, and the recordings were deleted to avoid security breaches. The transcripts were stored in the interviewer's password-protected laptop. To protect the identities of study participants, all identifiers from study materials were replaced with code. The key was only made available to the research team and kept in a password protected OneDrive folder.

Concept Map/Interview Guideline and Structure

The initial literature review revealed four key topics with significant knowledge gaps, particularly in regard to the general public opinion: 1. examination and evaluation of medical agency, 2. assignment of surrogacy, 3. current cognitive exams, 4. communication with various stakeholders about medical agency. These four issues were used as the foundation for a preliminary concept map, consisting of relevant key theories, concepts, and questions pertaining to each broader topic. The concept map was then used to develop two distinct interview guidelines (Appendix C, D). Separate sets were designed to accommodate for potential differences in experience between dyads and traditional authorities, such as the clinician and researcher. Interviews were semi-structured and aimed to follow a natural flow. However, all topic areas and questions from the guideline were still addressed during the interview. Each interview lasted between 45 minutes to 1 hour.

Figure 2: Preliminary concept map



Data Analysis

Qualitative research utilizes non-numerical data to identify and analyze common themes from shared experiences (Sutton & Austin, 2015). In this study, the interview transcripts were the primary data collected and analyzed. As the transcripts were reviewed, they were annotated using the four key topics of the original concept map: 1. examination and evaluation of medical agency, 2. assignment of surrogacy, 3. current cognitive exams, 4. communication with various stakeholders about medical agency. Comparison of the annotations between each interview revealed numerous subthemes, which were recorded for further analysis. Upon completion of data analysis, direct quotes from each interview were separated and categorized according to theme and subtheme. This thesis, a case study, sets the stage for the broader study to come; in which a more detailed annotation and analysis methodology will be implemented to allow for data saturation and greater confidence in the results.

Results

Though there were many common themes that arose from the stakeholder interviews, the results from this qualitative study are not meant to be generalizable. The data collected will be used to create a preliminary concept map and establish a baseline for the perspectives of each "type" of stakeholder. These will help build a framework for data collection and analysis for future studies, which will allow for the application of iterative processes, which will increase credibility in future study results. The themes are separated by relevance into the four broader key topics of the original concept map.

Table 1: Overview of participants

Participant ID	Stakeholder Category	Relevance to Subject Matter	Diagnosis
DF1	Neurologist, Geriatrics Primary Care	Clinician's point of view. Leads projects for minority outreach and engagement.	
RM1	Retired neuroscientist	Researcher's point of view Potentially unique perspectives in AD/ADRD advocacy.	
CF1	Wife & caregiver of IM1	Caregiver's point of view.	
IM1	Impaired Individual	Impaired individual's point of view. Very mild memory loss, but still reliant on CF1	Mild Cognitive Impairment (MCI) from stroke
CF2	Wife & caregiver to IM2	Caregiver's point of view.	
IM2	Impaired Individual	Impaired individual's point of view. Advanced dementia and significant reliance on CF2.	Dementia

Table 2: Themes and Subthemes

Themes	**Examination and evaluation of medical agency**	**Assignment of surrogacy**	**Current cognitive exams**	**Communication about medical agency**
Subthemes	Case-by-case evaluation	Framing	The utility and veracity of cognitive assessments	Imposition of authority (paternalism)
	The "point" of compromise	Trust between husband and wife	Looking beyond cognition and cognitive assessments	Empathy and respect for others
	Trust between physician and patient	Partnership within relationships		Assumptions and generalizations
	The individual rights at stake	Legal planning and advanced directives		Clarity in communication
				Importance of information
				Being heard

Theme 1: Examination and evaluation of medical agency

Subtheme #1: Case-by-case evaluation

DF1	● It's highly variable with the individual. **Everybody's level of cognitive impairment is different** depending upon what disease they have and depending upon what stage of the disease they're in. So it's a case by case determination.
RM1	● [The progression of compromise] is going to be different for each individual, and that has to be determined for each individual… I think **it has to be done on an individualized basis or thought about as an individual way**.
CF1	● **I want doctors to take the time and do everything case by case**. Don't lump everybody into the same group. ● I want them to do [everything] case by case so we can develop accurate treatments and better gauges and better ways to find out where you are with [the memory loss].

Both DF1 and RM1 spoke about the importance of evaluating individuals on a case-by-case basis. The progression of AD/ADRD is different for every individual. DF1 stated that AD/ADRD is "highly variable with the individual" and "everybody's level of cognitive impairment is different depending upon what disease they have and depending upon what stage of the disease they're in." Thus, discussion about treatment for each case must look different for every individual as well. RM1 also reported that this should impact how we approach the progression towards compromise of decision-making capacity, stating that "it has to be done on an individualized basis or thought about as an individual way." From their perspectives, because of AD/ADRD's various presentations, a more careful, case-by-case approach is imperative for proper evaluation and treatment.

As a caregiver, CF1 also expressed a desire for "doctors to take [their] time and do everything case by case." She noted that without this conscientious effort, physicians could easily begin "[lumping] everybody into the same group." She also believed this approach could help "develop accurate treatments and better gauges" to ascertain the level of cognitive impairments. Thus, for dyads, a case-by-case evaluation could correlate to a higher level of care, which could lead to greater patient satisfaction and trust towards medical professionals.

Subtheme #2: The "point" of compromise

DF1	● If at any time, somebody is not understanding the terms that you're using to explain whatever it is you're explaining, particularly if it's something very simple, that's something that indicates that that person needs assistance making that decision. ● As a clinician, **if I don't feel that my patient thoroughly understands what I'm asking him or her to do, I will stop.** And I will ask to have somebody who can represent that person's interest to step in the room and explain things.
RM1	● One would think of [decision-making capacity] as being progressively compromised with the severity of the conditions. ● There are these activities of daily living that we always refer to… as the first… level of intervention. **And if people can't do those simple things of dressing, bathing, brushing [their] teeth, and managing [their] finances, then that suggests that there has to be an intervention.** ● I'm a scientist, so **my approach is to try it and test the data.** [I] develop my hypothesis… [We're] going to try this, but if it doesn't work, then we'll go to plan B… My sense always is you try to **provide the thing that provides the most autonomy and independence that you think is reasonably safe**… We can try this [and] if it turns out you're outside those guardrails, and we'll know it pretty quickly, we'll shift.

CF1	- I would say **when it becomes more like a battle between the caregiver and the person who's being cared for.** [If] we're trying to make decisions and one person [is] in denial that there's even a problem,… that combativeness makes it more difficult to provide care for that person.
IM1	- (It would be necessary for somebody to make decisions on my behalf) **if in everyday life, I might hurt myself.**
CF2	- I mean once you have it so bad that you don't remember, [then] you can't make a decision. - When [my husband] started shifting to a place where **he couldn't do those lifestyle things anymore** like driving or doing the yard, that's when [I] started to take over his medical decisions.

During the interviews, every participant was asked to describe at what point they thought medical decision-making capacity could be compromised in individuals with AD/ADRD. Each stakeholder offered a different perspective, but a deeper probe revealed two distinct types of opinions. The first highlighted the significance of comprehension and communication. DF1 stated that if at any time "[her patient was] not understanding the terms that [she was] using to explain...or if [she did not] feel that her patient thoroughly [understood] what [she was] asking him or her to do, [she would] stop." To her, this inability to comprehend the simple, layman's language she typically uses with her patients "[would indicate] that that person needs assistance making that decision." She would then "ask to have somebody who can represent that person's interest." It was clear that DF1 would never proceed with a discussion or treatment decision before ensuring her patient's ability (or inability) to comprehend everything she was saying. For CF1, she believed that if the impairments progressed to a point where conversations "become more like a battle between the caregiver and the person who's being cared for," this could indicate that decision-making capacity may be compromised. Combativeness deriving from "denial that there's even a problem" could become a severe detriment to communication and in CF1's experience, "makes it more difficult to provide care."

The second demonstrated the importance of everyday behaviors. RM1 expressed that inability to perform simple, everyday activities including "dressing, bathing, brushing your teeth, and managing your finances" may "suggest that there has to be an intervention." CF2 shared similar sentiments and shared that she took over her husband, IM2's medical decisions when she recognized that he was "shifting to a place where he couldn't do those lifestyle things anymore." She explained that prior to his dementia diagnosis, her husband would also regularly do the yardwork and loved to drive. However, after his dementia progressed, she expressed that she no longer felt comfortable with him continuing those activities. IM1, another impaired individual, believed that it would be necessary for somebody to make decisions on his behalf if "in [his everyday life, [he] might hurt [him]self." While RM1's reasoning for underscoring ability to perform daily activities comes from his background in neuroscience and the study of habit memory, for both caregivers and impaired individuals, this emphasis may be because to them, a decline in capacity to complete everyday tasks is synonymous with a decline in capacity to make medical decisions.

Subtheme #3: Trust between physician and patient

CF1	● We have never run into where somebody would try to override what we thought was best. They always offered options and went with what we wanted to. ● I appreciated that **[the physicians] took the time to explain and not just run over us with information**.
IM1	● Well, when I go to the doctor, **[the] first thing I have to do is trust the doctor.** And If I trust the doctor, I let them make the decision for me… [I'll trust them] with…whatever I need and they say I need… But if [they're] flaky and all that, I don't.
CF2	● I never had a problem with [doing what the doctor said] because **[he] always explained to us why he's doing this.**
IM2	● [Ultimately] **I trust what the doctor says** [and decides].

Both dyads indicated that trust must be at the foundation between them and the physician. Once this trust was established, they would feel comfortable considering the physician's recommendations. For example, IM1 expressed that when he goes to a doctor, the "first thing [he has] to do is trust the doctor." Only then would he allow the doctor to make decisions for him and proceed with whatever the doctor believes is necessary. CF1 stated that for her, she was able to trust her husband’s medical team because “[the physicians] took the time to explain and not just run over [them] with information.” CF2 shared CF1’s perspective, including that she “never had a problem with [doing what the doctor said] because [he] always explained to [them] why [he was] doing this.” Thus, before physicians begin making suggestions, they should first try and establish a rapport with the dyads and build trust between all parties. If this trust is not established, dyads may feel uncomfortable taking physicians’ recommendations into consideration. It could also likely hinder the dyad’s willingness to approach other difficult conversations with physicians in the future.

Subtheme #4: The individual rights at stake

DF1	● I think autonomy is always important to consider, but **I don't think autonomy trumps safety and security.** ● Somebody’s safety, somebody's overall wellbeing may be threatened because of their cognitive deficits, and if that looks like it's a problem, I immediately intervene. ● I try to preserve the individual's sense of self, autonomy, and dignity as much as possible, but again **I may not be as meticulous about honoring that if they are a danger to themselves or to other people.**
RM1	● I consider [autonomy] a part of [the] quality-of-life measure. **Individuals’ autonomy and independence...are important pieces in terms of quality of life**, so I rate them very high. ● The fundamental idea should be that the person wants their autonomy. And the question is, how can we provide that in as good, as safe, as high quality-of-life kind of condition as we can.

When one’s decision-making capacity is questioned, their autonomy and ability to be independent also becomes vulnerable. Both DF1 and RM1 believed that patient autonomy is a key individual right that should be protected. DF1 shared that in her clinical practice she does “try to preserve the individual’s sense of self, autonomy, and dignity as much as possible.” RM1 said that “individual's autonomy and independence…are important pieces in terms of quality of life.” However, they also clarified the importance of patient safety and security. RM1 stated that we should try to protect autonomy “in as good, as safe, as high quality-of-life of [a] condition as we can.” DF1 took a more rigid stance, asserting that if her patients ever became a “danger to themselves or to other people" and their "safety…[and] overall wellbeing [were] threatened because of their cognitive deficits," she would immediately intervene. Thus, to her, patient autonomy is superseded by safety and security.

Theme 2: Assignment of surrogacy

Subtheme #1: Framing

DF1	● There are some families where they say "Mommy...you worked a long time, and I think that your children should fix your meals every day… **We are happy to do this**." She's going to swallow that a whole lot differently than "You can't use a stove anymore." or "You can't be left alone anymore."
RM1	● [we have to] try to **develop [a] reframing of that culture for physicians and...medical students and other people to be able to do a lot more than just [giving] the diagnosis**. They have to give support and a whole bunch of other things as well be a resource. ● **The whole culture has to be changed** in terms of how physicians and medical students and nurses are trained about dementia. ● Just think about how the diagnosis could be. "Look, **here's what you have, but life isn't over.** There's lots of things you can do…[and we're going to] help you continue to live your life as well as you possibly can, for as long as you possibly can… This is what I'm going to suggest that we do over the next few months and we'll come back and reassess that with you." That's a whole different story than "[You've] got Alzheimer's Disease. **There's nothing you can do, but I'll see you in six months and we'll see how you're doing.** Just try to eat well and get some exercise." That's essentially what people say right now. So it's a whole different culture that has to evolve.

The interviews with DF1 and RM1 demonstrated the pivotal role of framing in conversations regarding not only medical decision-making, but also quality of life in individuals with AD/ADRD. DF1 stated that families should approach conversations with impaired individuals from a perspective of "we are happy to [help]" and expressing gratitude for what they have already contributed to the family. However, if family members come in, trying to take over and aggressively diminish independence, like stating "you can't use a stove anymore" or "you can't be left alone anymore," impaired individuals may become defensive and reluctant to continue talking.

RM1 spoke more on the responsibility of medical staff and authorities to frame conversations more positively and comprehensively while also addressing the emotional needs of their patients. He suggested that "the whole culture has to be changed in terms of how physicians and medical students and nurses are trained about dementia" because what they are currently doing is not enough. In his experience, he has mostly witnessed physicians "just [giving] the diagnosis." Rather than the physicians themselves, RM1 finds responsibility in the culture and current medical training regarding AD/ADRD and other neurological diseases for this lack of support and resources from physicians to the impaired individuals. Studies involving other diseases have also shown that physicians rarely respond empathetically to concerns raised by patients and instead respond with objective, medical statements (Morse et al., 2008). RM1 believes that we must stop framing a diagnosis of AD/ADRD as life-ending. We must instead try and shift the focus from this incurable condition to the options that can help preserve quality of life.

Subtheme #2: Trust between husband and wife

CF1	● I don't ever want him to feel insecure about what's going on. And where he trusts me so much, I don't want him to start not trusting me. ● We usually don't combat in front of the people. You know, we talk about it and...we ask [if they could] excuse us for a few minutes… And then we would talk about whatever it is. But **we would have a united front** when whoever came in. ● I want my husband to know that **everything I do is to preserve him and to have the best quality of life possible**.
IM1	● I know that [CF1] looks and hears everything they're saying so **I know she'll make a good decision**.
CF2	● Me and [my husband] talked about [the potential for care homes] before a while back and **we made a decision together**. ● **I know what's best for [my husband] so I'm going to do what's best for him**.

When speaking with the dyads, it was obvious how trust and unity from their marriage relationships played crucial roles in their conversations and decision-making processes. A commonality among the dyads was that the couple would make each important decision together after thoughtful discussion that allowed both parties to speak freely. CF1 spoke about how important it is for her and IM1 to show a "united front," especially in front of physicians. This highlights how they desire to work as one partnership because they recognize that a choice that affects the life of one of them ultimately affects the life of both of them. Both caregivers mentioned that they always try and act in the best interest of their husbands. After being married for decades, they were confident in their knowledge and understanding of their husbands wishes and would try, to the best of their abilities, to carry those wishes out.

An unexpected, but interesting phenomenon arose, when comparing the dyad interviews to that with DF1. DF1 mentioned that she has oftentimes run into difficulty when discussing decision-making capacity and independence with the children of impaired individuals. She mentioned that when children, even adult children, "[recognize] that their mother or father has a problem, [their] impulse is to come in there and take over" rather than looking for avenues for discussion and giving their parents the benefit of the doubt. It seems that the dynamic between spouses is very different from that between parents and children. This will be addressed in the discussion later.

Subtheme #3: Partnership within relationships

DF1	● I think that when older adults need assistance, **how their family navigates that space with them can be a challenge.** But there are families [that] are aware of things, and they have good relationships, and **they...discuss how they're going to manage certain things moving forward.**
CF1	● So far [my husband and I] have been okay trying to determine what needs to be done next. We've been in agreement, so I am grateful for that… **My husband and I have been on the same page as to what to do and how.** ● [My family] understands that I'm the one...with him most of the time…and making the decisions. Nobody ever will say, "Well, I don't think [you're] making the right choice."
IM1	● **Me and my wife are together on the same page**, so I don't see anything wrong and nothing's come up. So I would say everything's fine.

	● When we go to see a doctor and if I'm not able to [make decisions], we tell them up front that I'm not able and my wife will make decisions for me.

To expound upon the previous subtheme of trust between the husband and wife, various stakeholders also expressed the importance of cooperation and partnership between both family members and spouses. DF1 recognized the challenges of "navigating that space" with "older adults [who] need assistance." However, she stated that it is possible to have productive conversations about "how...to manage certain things moving forward" if the family comes in with good relational foundations and aware of the issues at hand.

CF1 shared that her family knows not to question her judgement because they acknowledge that she is "the one...with him most of the time" and thus, best understands IM1's perspectives and desires. Additionally, CF1 and IM1 have thus far been in agreement. They both stated that they are "together on the same page" "as to what to do and how." CF1 expressed that she feels very grateful for this and it has also eased the burden of managing IM1's cognitive impairments.

Subtheme #4: Legal planning and advanced directives

DF1	● We always talk about durable powers of attorney for health care and for finance in terms of older adults, but **the kinds of documents that need to be in place for older adults are documents that everybody needs**. ● Those kinds of decisions really need to be [made] earlier rather than later… **All of us really need to have those documents in place so that your autonomy is preserved** so that even if you're not able to speak for yourself, what you want can be done.
CF2	● I talked to an attorney about [getting power of attorney]. And I didn't get [it] because the lawyer said that when you have dementia, you have to get that power of attorney before the dementia really develops.

Because AD/ADRD can cause cognitive deficits that affect decision-making capacity, it is imperative to either implement or update advanced directives. Such directives include establishing a health care power of attorney, who can make healthcare decisions, or appointing a legally authorized representative, who can consent to research participation, on behalf of the impaired individual (Darby & Dickerson, 2017). DF1 stated that this type of legal planning can actually be beneficial for everyone, encouraging these decisions to "be [made] earlier rather than later." She believed that having these documents in place actually ensures that "your autonomy is preserved so that even if [you are] not able to speak for yourself, what you want can be done." CF2's experience with trying to appoint a power of attorney depicted a common struggle that impaired individuals and their families experience. CF2 was unable to appoint herself as her husband's power of attorney because her lawyer said that "when [someone has] dementia, you have to get that power of attorney before the dementia really develops." The issue is again, it is difficult to assess their capacity to make such legal decisions. In addition, many people are unprepared to undergo such legal processes until it is too late and the disease has further progressed (National Institute on Aging, 2020).

Theme 3: Current cognitive exams

Subtheme #1: The utility and veracity of cognitive assessments

DF1	● I think **[the diagnostic assessment tools] are pretty accurate because they do a battery of tests**. They don't just do one thing. They do several things. ● In my experience with medicine as a clinician, when it seems [like] somebody is having a little bit of a problem, a lot of family members don't believe what you're saying… **[I have] to document…and prove or have evidence that there is a problem with somebody's cognition and/or capacity to make decisions**. **I will have objective evidence** from other subspecialists like neuropsychologists or radiologists who will have looked at an MRI or CT scan.
RM1	● You have to have some **objective way of measuring** these things…and [these assessments] give you at least a baseline for how to make a plan for that individual. But I think **the challenge always is overinterpreting those things**. ● [The cognitive assessments] more or less all [are] asking **questions about recognition memory and other aspects of recall memory** as the kind of critical piece just because memory is so important for everything. ● I think we have some very good tests and ways of assessing that these days that we probably didn't have 10 or 15 years ago.
CF1	● I thought [the assessments] were good. It was **not anything that led to diagnosing anything**.

	● I think that **[the assessments] were very accurate**. Before the stroke, [my husband] would have aced everything…but since the stroke and whatever degeneration [had] occurred, I say his ability is not the same.

Generally, attitudes towards cognitive assessments were positive and stakeholders believed that such tests were accurate, particularly in assessing cognitive ability. In her clinical practice, DF1 stated that she mostly uses quick screening tools like the MoCA or a clock drawing test but thought that the available diagnostic tools are “pretty accurate because they [incorporate] a battery of tests” to assess each individual. For DF1, the results of these assessments are particularly useful as documentation and “objective evidence” that she could refer to when speaking to family members to dispel any doubts or disbelief about an impaired individual’s “cognition and/or capacity to make decisions.”

As someone who has been immersed in the field of neuroscience research for decades, RM1 has witnessed the remarkable development of current cognitive assessment tools. He stated that now we have “some very good tests...that we probably didn’t have 10 or 15 years ago” that focus on the “recognition memory and other aspects of recall memory.” This concentration in memory is beneficial because “memory is so important for everything” and the results could help establish “a baseline for how to make a plan” for impaired individuals. He only warned against “overinterpreting those [tests],” which could lead to unnecessary restrictions on personal autonomy. CF1 also believed that the cognitive tests her husband was administered did an accurate job of generally ascertaining his cognitive ability. These opinions demonstrated that various stakeholders all shared similar sentiments regarding the utility, or usefulness, and veracity, or accuracy (Pearsall, 1999), of current cognitive assessments. They all appreciated these assessments’ efficacy in determining the cognitive abilities of individuals with AD/ADRD.

Subtheme #2: Looking beyond cognition and cognitive assessments

DF1	● A lot of what I use to determine whether somebody has the capacity are external things. Not so much asking them questions, but…there are soft things or non-verbal cues that I look for. Those are things that clinicians pay attention to. It's not so much what they say to you. It's what you observe about them when they come in the room. ● One of the very first things that most clinicians do is t**ry to determine whether or not their patients are oriented**. ● Just having a negative screen test for cognition or...a normal screen test doesn't mean that you don't have cognitive impairment… Having trouble with...memory doesn't necessarily or automatically mean that person has difficulty making medical decisions. ● When you start dealing with people, **you have to assess people in their totality**. **You can't just use a questionnaire or a survey**. ● **If they're requiring greater supervision**, there might be something off… **If you find that [instrumental activities of daily living] aren't happening**, then you may be concerned about their capacity and their abilities to make decisions. So it's not something that you're going to get by giving them a questionnaire. **There are going to be other things that you look** at that may indicate that they're not able to make the decisions.
RM1	● I think **the more realistic [assessments] are ones that actually look at the behaviors** and scale how well you can do some of these behaviors because that really reflects more than just your cognitive ability, but your abilities, period. **It's more than just cognition**. Remember, these cognitive abilities tend to be declarative kinds of memory abilities, but we run on habit more than we run on declarative. ● I think **cognition is important, but overall behavior is becoming more important**… It's just not whether you can remember three words. It's being able to manage getting through the day okay… **You've got to take into account the big picture**.

Through study participants generally agreed that current cognitive assessments were useful and accurate in determining cognitive capacity, DF1 and RM1 both expressed reservations in complete reliance upon such measures. Again, DF1 believed that both screening and diagnostic tools play important roles in providing objective, quantitative evidence of one's cognitive decline. However, in her clinical experience, DF1 has recognized the even greater importance of patient presentation and orientation. In order to assess decision-making capacity, DF1 mostly relies on external, non-verbal cues including how patients are dressed or groomed, and whether or not the patient is oriented to person, place, and time.

RM1 is a firm believer in the importance of activities of daily living (ADL), which are basic, routine tasks that independent individuals should be able to perform without assistance (Katz, 1983). These basic ADLs include personal hygiene like bathing and brushing teeth, toileting, dressing, and feeding. As cognitive impairments worsen, affected individuals may find themselves unable to perform these tasks independently. This decreased ability may lead to a decrease in quality of life and potentially unsafe living conditions (Edemekong et al., 2020). Again, RM1 recognized that current cognitive assessments are more accurate and comprehensive than they were a decade ago. However, he considered those that “actually look at the behaviors and scale how well [individuals] can do [them]” were realistic in reflecting not just “cognitive ability, but [an individual’s] abilities, period.”

DF1 supported this more holistic approach as well, stating that external factors like “requiring greater supervision” or being unable to perform instrumental ADLs, should also raise concerns about impaired individual’s “capacity and...abilities to make decisions.” To DF1, “just [using] a questionnaire or a survey” or some type of assessment is not enough. This is especially considering that a “negative...or normal screen test [for cognition] does not mean that [someone doesn’t] have cognitive impairment,” just as “having trouble with...memory [also does not] necessarily or automatically mean that [someone] has difficulty making medical decisions.”

Overall, though both DF1 and RM1 acknowledged the importance of cognition in medical agency, they also expressed the increasing relevance of taking “into account the big picture” (RM1) by observing “overall behavior” (RM1) and assessing people “in their totality” (DF1).

Theme 4: Communication about medical agency

Subtheme #1: Imposition of authority (paternalism)

RM1	● There's an MD point of mind that they are in charge and they know better essentially than anybody else. It's certainly not true of everybody, of course, of every MD. But there is that kind of sense… so that's the culture. **The culture is that MD's have a corner on the market of wisdom and knowledge and you don't question them. But we know that's not true.** And we just have to get them to understand it's not true.
CF2	● Even though they told me I couldn't [get power of attorney]... I really think that at that time I could have gotten it. **But since the attorney told me I couldn't, I didn't bother**. ● I didn't agree with all of [what the attorney said], but **since she's the attorney I figured that she knows better**.

Individuals with AD/ADRD are sometimes considered incapable of making informed decisions on their own. This makes them vulnerable to undue influence from outsiders and paternalistic actions, particularly by those considered to be authority figures. RM1 shared from his experience with doctors in particular and the attitudes of superiority that can sometimes come across. He argued that this is because generally there is an "MD point of mind that they are in charge and they know better essentially than anybody else." He pointed out that physicians do tend to think that they "have a corner on the market of wisdom and knowledge" and because of this, it is difficult to question them and their decisions. This dynamic and culture is even seen within doctor-nurse relationships (Keddy et al., 1986).

This imposition of authority was also observed when CF2 recounted her experience of trying to appoint a power of attorney. Ultimately, she was unsuccessful because the lawyer that she consulted said her husband's disease had progressed too much for him to consent to any legal proceedings. She recalled disagreeing with the lawyer's perspective, thinking that "at that time, [she] could have gotten it." However, CF2 "figured that [the lawyer knew] better," and because of that, did not want to challenge her authority with further questioning and consultation.

These types of imposition of authority can potentially discourage impaired individuals and even family members from freely sharing their thoughts. Especially with impaired individuals, they may already be experiencing decreases in sense of self and autonomy from their impairments and even family members. Exploiting a position of authority may further invalidate their feelings and diminish their confidence.

Subtheme #2: Empathy and respect for others

DF1	● You have to **always put yourself in the position of that human being**. **How would you want to be treated?**... There are people on the end of whatever it is [you're] doing. [You] need to respond to them accordingly.
CF1	● Know **this is a person you're talking to.** This is not just some senior citizen and...and my husband will let them know that this is not just somebody who you're going to just talk over.

DF1 and CF1 expressed the need for empathy in any conversation regarding medical agency. DF1 stated that we must ask ourselves how we "would want to be treated" and apply that same ethos to the care of others. CF1, when asked what she would want physicians, researchers, and others in positions of authority to know about treating her husband, simply asked them to understand that every patient before them "is a person,...not just some senior citizen." Each patient is a human being who has thoughts, feelings, and emotions. We must be sure to look beyond the disease and the effects of impairments and treat each individual with the same kind of compassion, empathy, and respect that we would want to be shown.

Subtheme #3: Assumptions and generalizations

RM1	● That's the problem. **When you see people who need help doing these things, the thought is that they can't do anything**. And so you just shift the whole thing to "the person needs complete help" and overhaul when that's not the case. **There's lots of people who can do lots of things still, even though they have some impairments**. ● **It's not that you just have dementia**. **You just have to be more subtle about it than that.** It's not this catch-all category. But there's really several different kinds of existences and you have to be mindful of those things.

CF1	● Understand that if you're dealing with anything that has to do with memory, before you want to label it Alzheimer's and label it dementia, know that not all seniors go through Alzheimer's and not all seniors go through dementia. **People should not be lumped in a category**. ● I think they should not want to lump all seniors based on a test into particular categories.
IM1	● Understand that I am getting old. I'll be 73 this year. But **don't treat me like I'm an old man or a young child**.

Along with having empathy, many of the stakeholders also urged against making assumptions and generalizations when treating and speaking with people with AD/ADRD. RM1 noted that oftentimes when we interact with impaired individuals who "need help doing these [ADLs], the thought is that they can't do anything." This triggers a shift in perspective to thinking that the individual "needs complete help" instead of trying to examine what their needs are on a case-by-case basis. RM1 argued that there is no need for an "overhaul" because many of these individuals "can do lots of things still, even though they have some impairments."

CF1 and IM1 shared many of the same perspectives. CF1 suggested that when dealing with anything that has to do with memory, it can be too easy to "label it Alzheimer's and label it dementia" and lump people into a category, even when "not all seniors go through" those things. We often forget that forgetfulness and mild memory loss are natural signs of aging (National Institute on Aging, 2020). IM1 referred to this by asking others to simply "understand that [he] is getting old," but that this and his memory loss should not cause others to "treat [him] like...an old man or a young child." Thus, we must be cognizant of catching our own assumptions before further investigation into each individual's unique limitations.

Subtheme #4: Clarity in communication

DF1	● After many years of practice, I realized that people who were perfectly literate didn't understand the terms that I was using. So **I started to explain things differently so that they would better understand**. I'm keenly aware of whether somebody understands me or not. And this is just something I've developed over many years and decades. ● I think that **families need to have discussions with older adults** about how they want things to be.

CF1	● I want them to **explain the condition so we understand it**, and then explain the treatment options and what could happen long term.
CF2	● I discuss it with him. **There's nothing that I just take on as "okay this is it"**. I'll explain to him why we're doing this or that, you know. ● I **always explain to him why I'm doing certain things**. I don't just do something and say well that's because I should. I always explain why.

Clarity in communication seemed to be one of the most important things that all stakeholders desired in conversations with one another, but particularly in those regarding medical agency. Whether it is communication between patient and doctor or husband and wife, it is clear that many of these stakeholders put special care into explaining intentions and reasoning for each decision they make. However, this is not always the case with every family and every medical professional. Because perhaps clear communication is not the norm, these particular stakeholders have learned to make the extra effort to do so with the impaired individuals they interact with.

DF1, for example, shared that through her experience in geriatric practice, she began to realize that even "people who were perfectly literate" could not understand the terms she was using. Thus, she trained herself to "explain things differently" in simple, layman's terms so that her patients "could better understand" and thus, be better informed. CF1 also mentioned how important it was for her husband's medical team to "explain the condition" as well as "treatment options and what could happen long term" so that "[they] understand it." This communication as well as transparent and thorough explanation to patients and family is clearly key in fostering trust and even respecting patient autonomy by presenting them with all the information they need to make informed, rational decisions about their own medical care (Amer, 2019).

CF2's interview highlighted the importance of clear communication between a caregiver and a care recipient. She is the primary decision-maker for her husband, who has dementia. She shared that she would always discuss everything with him before making a decision for him, stating that “[there is] nothing that [she] just [takes] on” without first explaining to him “why [she is] doing certain things.” She understood how important it was for her husband to feel like his opinions and understanding of the circumstances still mattered and helped preserve his sense of autonomy even though he was no longer able to make decisions for himself.

Subtheme #5: Importance of information

DF1	● When I’m making a referral to the neuropsychologist or psychiatrist **I've already recorded my observations**, and these are the things that I think are important to note and may compromise this person's safety in an independent environment. And **I let the family know and I let the providers know and after that, I've done what I need to do**.
RM1	● One of the things that **people don't know is how to act with somebody who has [AD/ADRD]**. You know, what do you say, what do you not say or what do you do, what do you not do. ● The challenge is that **we haven't equipped people who see themselves in the position of making these decisions**. We haven't equipped them with how they should be developing the information about how to make these decisions.
CF2	● **[There’s] a lot of stuff that I didn't know about that I should have known about**.

The importance of information was a common theme that arose across many of the interviews. As a physician, DF1 shared that detailed documentation is essential to good clinical practice. For every patient, she “[records her] observations” of what she thinks “are important to note.” These observations also note what “may compromise [a patient’s] safety in an independent environment.” She makes sure to share these notes to any referring physicians, such as neuropsychologists or psychiatrists, who may perform comprehensive, diagnostic cognitive assessments. By providing these observations along with patient information, she is ensuring that these physicians are given the relevant context they need to assess each patient in their totality. She also “[lets] the family know and...the providers know” so that they can use the information to make appropriate lifestyle decisions with the impaired individual. She knows she has “done what [she needs] to do” as a physician and medical provider when she has guaranteed that all involved parties are aware of the impaired individual’s unique medical circumstances.

RM1 and CF2 shared thoughts during their interviews that pointed to a broader issue of the current culture surrounding AD/ADRD and cognitive impairments in general. As mentioned in “Subtheme #1: Framing” (p. 21), RM1 argued that physicians, the newer generation of medical students, and other medical staff must be given better, more extensive training in treating individuals with AD/ADRD. He believed that what is currently being done of just giving the diagnosis is not enough, later stating that “people don't know...how to act with somebody who has [AD/ADRD].” Most of us do not know “what [to] say, what [to] not say, or what [to] do [and] what [to] not do.” This lack of understanding has extremely broad effects that influences every stakeholder. It impacts how physicians give and manage care, how patients receive and perceive such care, and how families approach decisions with the individual or for the individual in light of the new circumstances. RM1 stated that stakeholders can experience tension and are unable to effectively communicate with empathy and understanding because “we have [not] equipped them with how they should be developing the information about how to make these decisions.” This lack of information is also reflected in CF2’s experience as a caregiver. When speaking about her attempts to establish a power of attorney for her husband, she shared that she oftentimes felt depressed not only because of her husband’s dementia, but also because there was “a lot of stuff that [she] [did not] know about that [she] should have known about.” Thus, if CF2 had been given more resources and support from the medical staff at the time of her husband’s diagnosis, she could have felt better prepared in assisting him and taking care of any necessary planning for their future, including implementing those legal documents.

Subtheme #6: Being heard

CF1	● **Make sure we understand before we leave that room and [don’t] just talk over our heads** and then go on to the next person and leave us like we were run over by a Mack truck.
CF2	● From IM2’s perspective: [There were things] on your mind, but **you just didn't have enough courage or**

	whatever to come and say it (because of the way physicians were treating him). ● I really enjoyed this because **it gave me a lot to think about**. You don't always think about things like this. ● Well we never had anybody come to us to talk about stuff like this.

An intriguing commonality was observed when analyzing the interviews from the two caregivers in this study, CF1 and CF2. They both desired a space for their voices and their husband's voices to be heard. CF1 insisted that doctors should not "talk over [their heads]" before moving on to the next patient and instead, should take the time to "make sure [that they] [understood]" everything. By doing so, she and her husband would be able to process through the information, ask any pertinent questions, and voice their opinions before making an informed decision together. IM2 even shared in his interview that in doctor's appointments, he would have thoughts to share, but felt like he "[did not] have the courage...to say [them]." Though he could not remember any particular instances, IM2 distinctly remembered the feeling of being unable to talk about his own opinions to physicians because of their treatment towards him and communication with him. If physicians fill this space with their own perspectives and medical jargon, it could discourage impaired individuals and even their caregivers from feeling like they can speak freely about their own perspectives, which diminishes patient autonomy and respect.

CF2 and IM2 also expressed gratitude in being able to participate in the study because they "never had anybody come talk to [them]" about medical agency and how it uniquely affects individuals with AD/ADRD. CF2 shared that the interview "gave [her] a lot to think about" and it made her think about medical agency in a new light because she never knew how important this conversation and issue was until now.

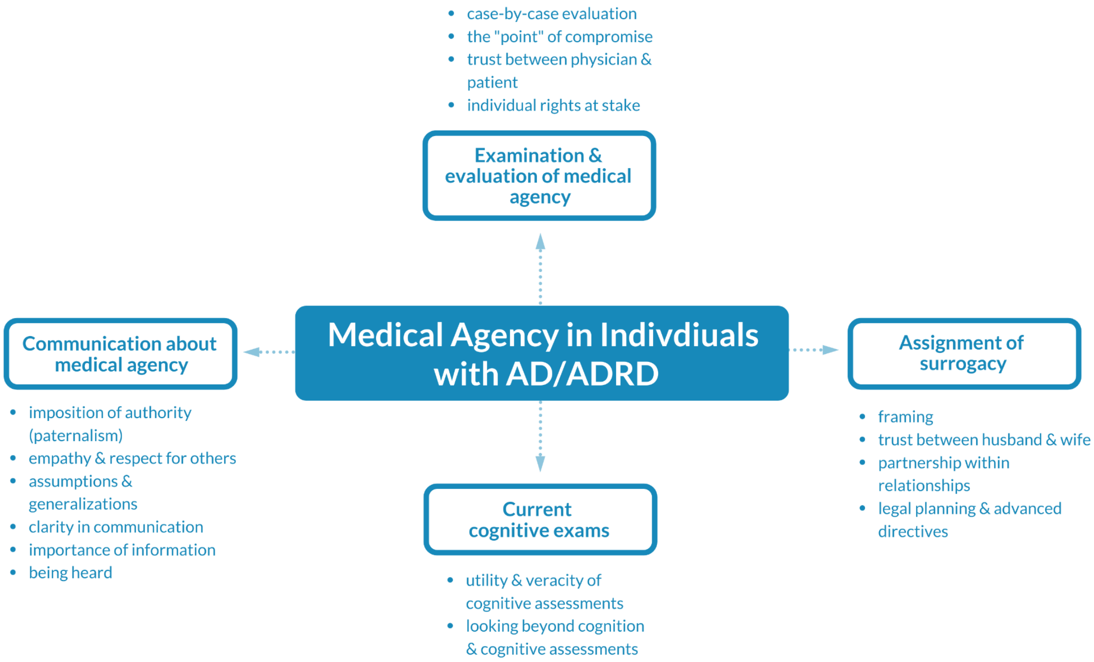
Discussion

The purpose of this study was to identify themes regarding medical agency and compare the perspectives of various stakeholders. Specifically, this study focused on gathering and analyzing the perspectives of a clinician and researcher as well as impaired individuals and their primary caregivers. To do this, semi-structured interviews were conducted with each of the research participants. After all qualitative data were collected, the resulting interview transcripts were analyzed with the four broad themes of the initial concept map: 1. examination and evaluation of medical agency, 2. assignment of surrogacy, 3. current cognitive exams, 4. communication with various stakeholders about medical agency. Several subthemes were identified for each theme and any relevant quotes were identified and categorized.

Addressing study goals

The primary goal of this study was to identify themes that emerge when discussing medical agency in AD/ADRD with different stakeholders. Prior to starting interviews, a preliminary concept map was created based on four broad topics determined to have significant knowledge gaps from the literature review. The literature review also revealed several relevant theories, concepts, and questions for each broader topic that the research team predicted would emerge as subthemes from stakeholder interviews. After data analysis, the initial concept map (p. 14) was updated to list the actual subthemes that emerged.

Figure 3: Updated concept map



Interestingly, though many novel subthemes were identified, many of the originally predicted concepts were also directly addressed in the interviews or integrated into other emerging subthemes. For instance, in the theme of *examination and evaluation of medical agency*, the predicted subthemes of *patient safety & security* and *patient autonomy* were both acknowledged during conversations about the *individual rights at stake* for individuals with AD/ADRD. In addition, under *communication about medical agency*, quotes relevant to *imposition of authority* also referred to *power dynamics*, *authority*, and *paternalism*. Another notable observation was that some of the predicted subthemes actually shifted in relevance to a different broad theme. For example, the research team initially believed that *relationships between stakeholders* would fall under *communication about medical agency*, but it became much more relevant to the theme of *assignment of surrogacy* because of the way stakeholders discussed *partnerships in relationships*.

The secondary goal of this study was to assess similarity and differences between stakeholder perspectives. It was surprising to observe that many of the stakeholders actually shared similar perspectives, especially regarding *communication about medical agency*. Every “type” of stakeholder wanted to share experiences that were relevant to at least one of the subthemes. For instance, DF1, CF1, and CF2 all advocated for clear communication while in conversations with one another. DF1 and CF1 urged for greater empathy when caring for individuals with AD/ADRD, while RM1, CF1, and IM1 warned against making sweeping generalizations about impaired individuals' cognitive capacity and ability to be independent.

The biggest differences in perspective were observed when talking about the theme of current cognitive exams and the subthemes of the “point” of compromise. This is most likely due to the fact that DF1 and RM1 have specific training and experience that give them a deeper understanding of field-based information. For instance, as a neurologist, DF1 knows which cognitive exams are relevant in the clinical setting and which, in her experience, have yielded accurate results of patients’ cognitive and decision-making capacity. As a researcher specializing in memory and AD/ADRD research, RM1 also would have an extraordinary understanding of how the brain is affected by neurodegenerative diseases and how this damage translates into patient presentation and ability. Thus, when speaking on the utility and veracity of current cognitive exams or the need to look beyond such exams, they are drawing from years of experience understanding how those exams work and even fall short. In addition, when asked to describe at what point they thought medical decision-making capacity could be compromised in individuals with AD/ADRD, DF1 and RM1 had the necessary education and expertise to support their claims with objective evidence. On the other hand, the caregivers and impaired individuals spoke just from their personal experiences, which are extremely insightful, but are more subjective in nature.

This lack of circumstantial knowledge was also reflected in the subtheme of *legal planning and advanced directives*. DF1 stated that implementing important legal documents such as power of attorney is not just for older adults. They eventually “need to be in place” for everyone, so she encouraged people to make those kinds of decisions “earlier rather than later.” However, she is coming from a place of “knowledge authority” in that she has this information to act accordingly. However, from CF2’s testimony, it is clear that she, as a person of “impact” who was directly affected by her husband’s dementia, was not made aware of the necessity of such documents until it was too late. Thus, even if DF1 believes it is important for everyone to have some sort of legal plan of action, it may just be that oftentimes, “normal” or everyday people just do not know what legal planning encompasses or necessitates until it actually becomes relevant to their lives, which at that point, may be too late.

The wealth of personal experiences of caregivers and impaired individuals become apparent when looking at the subthemes regarding *trust* and *being heard*. As people who have been directly impacted by the effects of AD/ADRD, dyads offer unique perspectives as to how impaired individuals are treated and cared for. Particularly apparent in the subtheme of being heard, the caregivers, CF1 and CF2, have learned to become fierce advocates for their impaired husbands after encounters with physicians and other medical staff who have overlooked and disregarded their opinions and their husbands’ opinions. They did not want their perspectives to be confused or lost in a sea of medical jargon and opinions. In addition, dyads talked about the importance of a foundation of trust, particularly between a physician and patient. It was interesting that the dyads explicitly noted that before anything else could happen, they must first determine if they trust the doctor. Only after this trust was established would they allow them to recommend treatment options or even make decisions on their behalf. It could be that culturally, dyads have a lack of trust towards medical authorities and thus, are especially cautious to ensure that their physicians do truly have their best interests in mind.

Another noteworthy development was that originally, the study was designed to compare the perspectives of experts to those of novices. The clinician and the researcher were labeled as experts because they had received years of training and garnered additional years of experience, developing a foundation of knowledge that would not likely be achieved by the general public. As a result, dyads were assigned the label of novice since they did not share this same level of field expertise. However, analysis of the data revealed that dyads are experts in their own ways. Caregivers are experts in helping manage care while impaired individuals are experts in actually living with a disease such as AD/ADRD. Thus, the research team shifted the framing of this study away from “expert vs. novice” and towards assessing the multiple perspectives of the personal experiences of each stakeholder.

Other major research findings

Personalized medicine

Several of the stakeholders advocated for a case-by-case approach towards evaluating and treating individuals with AD/ADRD. This type of approach is the hallmark of personalized medicine, which aims to tailor medical treatment to the needs and characteristics of each, unique patient (*The Age of Personalized Medicine*, n.d.). Currently, personalized medicine has extended into the world of genetics by developing therapies based on an individual's molecular profile, which is not relevant to the current study. However, the underlying tenet of tailoring treatment to each individual is extremely pertinent. DF1 and RM1 both recognized that evaluating on a case-by-case basis is crucial in treating individuals with AD/ADRD because the disease presentations are highly variable. According to DF1, “everybody’s level of cognitive impairment is different.” Thus, treatment plans should be developed for the distinct needs of each case.

The contrasting argument against this approach supports standardization of care, which encourages routinization and reproducibility in the treatment of similar diseases (Wears, 2014). Utilizing general policies of dealing with the average allows for physicians and health institutions to prioritize efficiency and frees up attentional resources for perhaps more complex or urgent issues (Hollnagel et al., 2013). However, what we gain in efficiency, we can equally lose in efficacy, especially in the treatment of AD/ADRD. Though standardizing care in certain diseases may be beneficial, in the treatment of AD/ADRD, it could prove to be costly by underestimating impaired individuals’ decision-making capacity, which could impede upon their patient autonomy and quality of life. In addition, because there are no effective therapeutic or preventative measures for AD/ADRD yet, taking into account unique environmental and behavioral factors as well as disease onset and progression are all the more important in effectively providing treatment for individuals with AD/ADRD (Reitz, 2016).

Differences in relationship dynamics between spouses vs. parents and adult children

Initially, the research team predicted that there would be tension observed between the impaired individuals and their primary caregivers when discussing medical agency. We predicted that this divide could occur due to potentially contrasting opinions on the impaired individual's *perceived* cognitive capacity compared to the *actual* capacity. However, the interviews with the two dyads demonstrated an extraordinary focus on partnership and unity between the caregivers and their husbands. For instance, CF1 stated that she and her husband always “have a united front” when facing doctors and IM1 understands that even with his impairments, he and CF1 are still always “together on the same page” regarding his medical decisions. CF2 also mentioned though she is her husband’s designated decision-maker, she still consults him with everything and always explains her intention and purpose behind each decision.

However, DF1 mentioned that in her clinical practice, she still observes the predicted tension and difficulty, particularly when speaking to the children of impaired individuals about decision-making capacity and independence. She noted that in her experience, the adult children have a tendency to “come in there and take over” when they recognize that their parents are developing issues with memory. However, such parents will reject those efforts because they “don’t necessarily accept that they have impairments that would require them to have some assistance or supervision” (DF1). DF1 demonstrated a typical response from an impaired parent: “Well I’m the mom and not the child. You’re the child so you shouldn't be telling me things like this. Who are you to tell me what to do?” Thus, it could be that though a spousal relationship, which rests on a foundation of partnership, has a strikingly different approach towards medical agency than a parent/child relationship, which comes from a history of the parents’ ability to have authority over their children.

When considering the tensions that could arise from disagreeing opinions between a spouse compared to a child or parent, one landmark bioethical case, the case of Theresa Schiavo, offers some perspectives. This case is centered around ethical dilemmas arising from end-of-life decisions, so it is not identical to the circumstances of the current study. However, the case does highlight that there are indeed differences from a spouse’s outlook than a parent or child’s outlook when caring for and making decisions on behalf of their incapacitated loved one. Terry Schiavo went into cardiac arrest after her dramatic weight loss, which resulted in massive brain damage due to lack of oxygen to her brain during her cardiac episode (Ouellette, 2013, p. 273-

274). She was left comatose and after a few months, declared to be in a persistent vegetative state. Over the next three years, doctors unsuccessfully attempted various types of physical and occupational therapy, and in time, her husband began to consider withdrawing artificial life support by removing her feeding tube, which in the state of Florida was legally permissible. Because Ms. Schiavo had no written advanced directive, her husband was appointed as her guardian shortly after her accident. But once he expressed his decision to remove end-of-life care, Ms. Schiavo's parents immediately intervened and challenged his guardianship over their daughter. Mr. Schiavo and his in-laws had enjoyed an amicable relationship leading up to this point. However, their opposing views on what they thought Ms. Schiavo would have wanted created a massive rift between them and ultimately resulted in a drawn-out, hostile media and legal battle. Examining this case allows us to understand how opinion and obligations in a spousal relationship may diverge from those within a parental relationship. These tensions can quickly escalate especially when discussing highly sensitive issues like end-of-life care or medical agency.

Amplifying voices

Interviews with the caregivers, CF1 and CF2, resulted in themes that highlighted important aspects of social justice and disability rights. They advocated for a greater space for their voices and their husbands' voices to be amplified and considered as equally relevant, compared to other traditional authorities, including doctors, researchers, and lawyers. Additionally, CF2 and IM2 expressed that they had "never had anybody come talk to [them]" about medical agency and how it uniquely affects individuals with AD/ADRD. It was clear that before these interviews, the dyads had never considered how important medical agency was to discuss and how relevant it was to their actual circumstances. This lack of exposure and understanding is starkly contrasted to the abundance of scientific literature regarding the limitations to decision-making capacity and informed consent when treating individuals with AD/ADRD or enrolling them in research studies. Thus, the commonly repeated disability tenet of "nothing about us without us" (Charlton, 1998) must be applied and we must provide every stakeholder, especially vulnerable and often overlooked stakeholders like the impaired individuals or their caregivers, with an equal opportunity to be active participants in discussions that ultimately affect their medical treatment and lives.

Limitations and future research

While this case study yielded promising results, there were still significant limitations that must be addressed in future studies. First, only two dyads were recruited, and both were African American and had strong opinions against elderly homes, preferring to personally provide care for their husbands. It could be beneficial to recruit a diversity of dyads from different races, cultures, and socioeconomic classes to observe if these also have an impact on their experiences regarding medical agency. In addition, interviewing RM1, a retired neuroscientist, revealed shortcomings in the interview guide. Many of the questions were not relevant to his experience as a researcher. Thus, more detailed interview guides that are tailored to each "type" of stakeholder should be developed.

Finally, because this study only interviewed a small number of stakeholders, the results are not meant to be generalizable. The original plan for the study was to interview several individuals per "type" of stakeholder, but due to limited time as well as restrictions in recruitment and scheduling conflicts, only six individuals were able to be interviewed and analyzed in the time frame. However, an immense amount of information resulted from just these six interviews, which shows great potential for the broader study. In this broader study, more interviews should be conducted. A greater collection of data will allow for more established methods of analyzing qualitative data, such as Grounded Theory or Interpretive Phenomenological Analysis, to be used. By conducting more interviews and utilizing such methodologies, data can be collected until saturation occurs and no new themes arise. Thus, future results would have greater credibility, or greater confidence in the research findings, and widespread generalizability (Korstjens & Moser, 2017).

Conclusion

This qualitative study was successful in identifying themes regarding medical agency in AD/ADRD and comparing the perspectives of different stakeholders. The results demonstrated the relevance of the original four key topics: 1. examination and evaluation of medical agency, 2. assignment of surrogacy, 3. current cognitive exams, 4. communication with various stakeholders about medical agency. They also confirmed predicted subthemes while producing several novel subthemes. Further work is undeniably necessary to first, substantiate the findings of this case study, and second, provide credible, generalizable results. However, we are optimistic that this research will help to develop a deeper understanding of a diversity of stakeholder perspectives while also providing an opportunity for dyads to learn about the importance of medical agency in their lives and introduce their viewpoint in the broader conversation.

References

Alzheimer's Association. (2018). Legal Plans: Assisting a Person with Dementia in Planning for the Future [Ebook]. Alzheimer's Association. https://www.alz.org/national/documents/brochure_legalplans.pdf.

Alzheimer's Association. (2019). 2019 Alzheimer's disease facts and figures. Alzheimer's & Dementia, 15(3), 321-387. https://doi.org/10.1016/j.jalz.2019.01.010

Amer, A. (2019). The Ethics of Veracity and It Is Importance in the Medical Ethics. Open Journal Of Nursing, 09(02), 194-198. https://doi.org/10.4236/ojn.2019.92019

Beauchamp, T., & Childress, J. (2009). Principles of Biomedical Ethics (6th ed., p. 100). Oxford University Press.

Black, H. (1979). Black's Law Dictionary (5th ed., p. 257). West Publishing Company.

Charlton, J. (1998). Nothing About Us Without Us: Disability Oppression and Empowerment. University of California Press.

Darby, R., & Dickerson, B. (2017). Dementia, Decision Making, and Capacity. Harvard Review Of Psychiatry, 25(6), 270-278. https://doi.org/10.1097/hrp.0000000000000163

Dautzenberg, G., Lijmer, J., & Beekman, A. (2019). Diagnostic accuracy of the Montreal Cognitive Assessment (MoCA) for cognitive screening in old age psychiatry: Determining cutoff scores in clinical practice. Avoiding spectrum bias caused by healthy controls. International Journal Of Geriatric Psychiatry, 35(3), 261-269. https://doi.org/10.1002/gps.5227

Edemekong, P., Bomgaars, D., Sukumaran, S., & Levy, S. (2020). Activities of Daily Living. Retrieved from https://www.ncbi.nlm.nih.gov/books/NBK470404/.

Ellajosyula, R., & Hegde, S. (2016). Capacity issues and decision-making in dementia. Annals Of Indian Academy Of Neurology, 19(5), 34. https://doi.org/10.4103/0972-2327.192890

Fields, L., & Calvert, J. (2015). Informed consent procedures with cognitively impaired patients: A review of ethics and best practices. Psychiatry And Clinical Neurosciences, 69(8), 462-471. https://doi.org/10.1111/pcn.12289

Friedman, E., Shih, R., Langa, K., & Hurd, M. (2015). US Prevalence And Predictors Of Informal Caregiving For Dementia. Health Affairs, 34(10), 1637-1641. https://doi.org/10.1377/hlthaff.2015.0510

Gilbert, T., Bosquet, A., Thomas-Antérion, C., Bonnefoy, M., & Le Saux, O. (2017). Assessing capacity to consent for research in cognitively impaired older patients. Clinical Interventions In Aging, 12, 1553-1563. https://doi.org/10.2147/cia.s141905

Grisso, T., & Appelbaum, P. (1998). Assessing competence to consent to treatment. Oxford University Press.

He, S., & Shi, S. (2017). Lineage-Dependent Electrical Synapse Formation in the Mammalian Neocortex. Network Functions And Plasticity, 321-348. https://doi.org/10.1016/b978-0-12-803471-2.00014-x

He, W., Goodkind, D., & Kowal, P. (2016). An Aging World: 2015 [Ebook]. U.S. Census Bureau. Retrieved 30 March 2021, from https://www.census.gov/content/dam/Census/library/publications/2016/demo/p95-16-1.pdf.

Hollnagel, E., Braithwaite, J., & Wears, R. (2013). Resilient health care. Ashgate Publishing.

Holm, S. (2001). Medicine, Health Care And Philosophy, 4(2), 153-159. https://doi.org/10.1023/a:1011402102030

Horner-Johnson, W., & Bailey, D. (2013). Assessing Understanding and Obtaining Consent From Adults With Intellectual Disabilities for a Health Promotion Study. Journal Of Policy And Practice In Intellectual Disabilities, 10(3), 260-265. https://doi.org/10.1111/jppi.12048

Howe, E. (2012). Informed consent, participation in research, and the Alzheimer's patient. Innovations In Clinical Neuroscience, 9(5-6), 47-51. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3398682/.

Kara, M. (2007). Applicability of the principle of respect for autonomy: the perspective of Turkey. Journal Of Medical Ethics, 33(11), 627-630. https://doi.org/10.1136/jme.2006.017400

Karlawish, J. (2007). Measuring Decision-Making Capacity in Cognitively Impaired Individuals. Neurosignals, 16(1), 91-98. https://doi.org/10.1159/000109763

Katz, S. (1983). Assessing self-maintenance: activities of daily living, mobility, and instrumental activities of daily living. Journal Of The American Geriatrics Society, 31(12), 721-727. https://doi.org/10.1111/j.1532-5415.1983.tb03391.x

Keddy, B., Jones, M., BN, P., Burton, H., & Rogers, M. (1986). The doctor-nurse relationship: an historical perspective. Journal Of Advanced Nursing, 11(6), 745-753. https://doi.org/10.1111/j.1365-2648.1986.tb03393.x

Kinsinger, F. (2009). Beneficence and the professional's moral imperative. Journal Of Chiropractic Humanities, 16(1), 44-46. https://doi.org/10.1016/j.echu.2010.02.006

Korstjens, I., & Moser, A. (2017). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. European Journal Of General Practice, 24(1), 120-124. https://doi.org/10.1080/13814788.2017.1375092

Leo, R. (1999). Competency and the Capacity to Make Treatment Decisions. The Primary Care Companion To The Journal Of Clinical Psychiatry, 01(05), 131-141. https://doi.org/10.4088/pcc.v01n0501

McCormick, T. (2018). Principles of Bioethics. depts.washington.edu. Retrieved from https://depts.washington.edu/bhdept/ethics-medicine/bioethics-topics/articles/principles-bioethics.

Mitchell, A. (2009). A meta-analysis of the accuracy of the mini-mental state examination in the detection of dementia and mild cognitive impairment. Journal Of Psychiatric Research, 43(4), 411-431. https://doi.org/10.1016/j.jpsychires.2008.04.014

Morrison, J., & Hof, P. (2007). Life and death of neurons in the aging cerebral cortex. International Review Of Neurobiology, 81, 41-57. https://doi.org/10.1016/s0074-7742(06)81004-4

Morse, D., Edwardsen, E., & Gordon, H. (2008). Missed Opportunities for Interval Empathy in Lung Cancer Communication. Archives Of Internal Medicine, 168(17), 1853. https://doi.org/10.1001/archinte.168.17.1853

Moya-Alvarado, G., Gershoni-Emek, N., Perlson, E., & Bronfman, F. (2016). Neurodegeneration and Alzheimer's disease (AD). What Can Proteomics Tell Us About the Alzheimer's Brain?. Molecular & Cellular Proteomics, 15(2), 409-425. https://doi.org/10.1074/mcp.r115.053330

Murgic, L., Hébert, P., Sovic, S., & Pavlekovic, G. (2015). Paternalism and autonomy: views of patients and providers in a transitional (post-communist) country. BMC Medical Ethics, (16), 65. https://doi.org/10.1186/s12910-015-0059-z

National Institute on Aging. (2020). Legal and Financial Planning for People with Dementia. Retrieved from https://www.nia.nih.gov/health/legal-and-financial-planning-people-alzheimers#:~:text=Health%20care%20directives%20may%20include,can%20no%20longer%20do%20so.&text=A%20DNR%20order%20is%20signed,in%20a%20person%27s%20medical%20chart.

National Institute on Aging. (2020). Memory, Forgetfulness, and Aging: What's Normal and What's Not?. Retrieved from https://www.nia.nih.gov/health/memory-forgetfulness-and-aging-whats-normal-and-whats-not.

Oruche, U. (2009). Research With Cognitively Impaired Participants. Journal Of Nursing Law, 13(3), 89-94. https://doi.org/10.1891/1073-7472.13.3.89

Ouellette, A. (2013). Bioethics and Disability: Toward a Disability-Conscious Bioethics (pp. 273-274). Cambridge University Press.

Pearsall, J. (1999). The Concise Oxford Dictionary (10th ed., p. 1591). Oxford University Press.

Penslar, R. (1993). Protecting human research subjects: institutional review board guidebook. U.S. Dept. of Health and Human Services, Public Health Service, National Institutes of Health, Office of Extramural Research, Office for Protection from Research Risks.

Persky, A., & Robinson, J. (2017). Moving from Novice to Expertise and Its Implications for Instruction. American Journal Of Pharmaceutical Education, 81(9), 6065. https://doi.org/10.5688/ajpe6065

Personalized Medicine Coalition. The Age of Personalized Medicine [Ebook]. http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/pmc_age_of_pmc_factsheet.pdf.

RajMohan, V., & Mohandas, E. (2007). The limbic system. Indian Journal Of Psychiatry, 49(2), 132. https://doi.org/10.4103/0019-5545.33264

Reiman, E., Quiroz, Y., Fleisher, A., Chen, K., Velez-Pardo, C., & Jimenez-Del-Rio, M. et al. (2012). Brain imaging and fluid biomarker analysis in young adults at genetic risk for autosomal dominant Alzheimer's disease in the presenilin 1 E280A kindred: a case-control study. The Lancet Neurology, 11(12), 1048-1056. https://doi.org/10.1016/s1474-4422(12)70228-4

Reitz, C. (2016). Toward precision medicine in Alzheimer's disease. Annals Of Translational Medicine, 4(6), 107-107. https://doi.org/10.21037/atm.2016.03.05

Skullerud, K. (1985). Variations in the size of the human brain. Influence of age, sex, body length, body mass index, alcoholism, Alzheimer changes, and cerebral atherosclerosis. Acta Neurologica Scandinavica. Supplementum, 102, 1-94. https://pubmed.ncbi.nlm.nih.gov/3887832/.

Sutton, J., & Austin, Z. (2015). Qualitative Research: Data Collection, Analysis, and Management. The Canadian Journal Of Hospital Pharmacy, 68(3). https://doi.org/10.4212/cjhp.v68i3.1456

Traykov, L., Rigaud, A., Cesaro, P., & Boller, F. (2007). Neuropsychological impairment in the early Alzheimer's disease. L'encéphale, 33(3), 310-316. https://doi.org/10.1016/s0013-7006(07)92044-8

Vaughn, L. (2017). Bioethics: Principles, Issues, and Cases (3rd ed., pp. 10-11). Oxford University Press.

Villano, I., Messina, A., Valenzano, A., Moscatelli, F., Esposito, T., & Monda, V. et al. (2017). Basal Forebrain Cholinergic System and Orexin Neurons: Effects on Attention. Frontiers In Behavioral Neuroscience, 11. https://doi.org/10.3389/fnbeh.2017.00010

Vollmann, J. (2001). Medicine, Health Care And Philosophy, 4(2), 161-167. https://doi.org/10.1023/a:1011491100267

Wears, R. (2014). Standardisation and its discontents. Cognition, Technology & Work, 17(1), 89-94. https://doi.org/10.1007/s10111-014-0299-6

Ylikoski, P., & Zahle, J. (2019). Case study research in the social sciences. Studies In History And Philosophy Of Science Part A, 78, 1-4. https://doi.org/10.1016/j.shpsa.2019.10.003

Appendix

Emory University
Oral Consent Script
For a Research Study
(For Experts)

Study Title: *Expert and Novice Opinions on Medical Agency in Alzheimer's Disease and Related Dementia*
IRB #: 00001938
Principal Investigator: Dr. Gillian Hue, Department of Neuroscience and Behavioral Biology
Funding Source: Department

Introduction and Study Overview

Thank you for your interest in our Alzheimer's research study. We would like to tell you everything you need to think about before you decide whether or not to join the study. It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study.

The purpose of this study is to identify themes that emerge when discussing medical agency in individuals with Alzheimer's and Related Dementias (AD/ADRD) with various stakeholders in the community. The study is funded by Emory University's Department of Neuroscience and Behavioral Biology. This study will take about 30 minutes to 1 hour to complete.

If you join, you will be asked to participate in a recorded interview to discuss various topics and gain your opinion on medical agency in individuals with AD/ADRD.

Our discussion may bring up potentially triggering or difficult personal experiences, which may cause some discomfort. However, if this does occur, we will ask if you would like to take a break or conclude the interview.

Upon completion of the interview, participants will be compensated with a $25 gift card as a token of our appreciation. This study is not intended to benefit you directly, but we hope this research will benefit people in the future.

Study records can be opened by court order. They also may be provided in response to a subpoena or a request for the production of documents. Certain offices and people other than the researchers may look at study records. Government agencies and Emory employees overseeing proper study conduct may look at your study records. These offices include the Emory Institutional Review Board and the Emory Office of Research Compliance. Study funders may also look at your study records. Emory will keep any research records we create private to the extent we are required to do so by law. A study number rather than your name will be used on study records wherever possible. Your name and other facts that might point to you will not appear when we present this study or publish its results.

We will disclose your information when required to do so by law in the case of reporting child abuse or elder abuse, in addition to subpoenas or court orders.

De-identified data from this study (data that has been stripped of all information that can identify you) may be placed into public databases where, in addition to having no direct identifiers, researchers will need to sign data use agreements before accessing the data. We will remove or code any personal information that could identify you before your information is shared. This will ensure that, by current scientific standards and known methods, it is extremely unlikely that anyone would be able to identify you from the information we share. Despite these measures, we cannot guarantee anonymity of your personal data.

Your data from this study may be useful for other research being done by investigators at Emory or elsewhere. To help further science, we may provide your deidentified data to other researchers. If we do, we will not include any information that could identify you. If your data are labeled with your study ID, we will not allow the other investigators to link that ID to your identifiable information.

Once the study has been completed, we will send you a summary of all of the results of the study and what they mean. We will also be available to go over the results individually if any questions arise. We will not send you your individual results from this study.

Contact Information

If you have questions about this study, your part in it, or if you have questions, or concerns about the research you may contact the following:
Jennifer Jin, Co-Investigator: 201-615-4909

If you have questions about your rights at research participant, complaints about the research or an issue you rather discuss with someone outside the research team, contact the Emory Institutional Review Board at 404-712-0720 or toll-free at 877-503-9797 or by email at irb@emory.edu.

Consent

Do you have any questions about anything I just said? Were there any parts that seemed unclear?

Do you agree to take part in the study?

Participant agrees to participate: Yes No

If Yes:

____
Name of Participant

____ ________________
Signature of Person Conducting Informed Consent Discussion Date Time

____
Name of Person Conducting Informed Consent Discussion

Emory University
Oral Consent Script
For a Research Study
(For Dyads)

Study Title: *Expert and Novice Opinions on Medical Agency in Alzheimer's Disease and Related Dementia*
IRB #: 00001938
Principal Investigator: Dr. Gillian Hue, Department of Neuroscience and Behavioral Biology
Funding Source: Department

Introduction and Study Overview

Thank you for your interest in our Alzheimer's research study. We would like to tell you everything you need to think about before you decide whether or not to join the study. It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study.

The purpose of this study is to identify themes that emerge when discussing medical agency in individuals with Alzheimer's and Related Dementias (AD/ADRD) with various stakeholders in the community. The study is funded by Emory University's Department of Neuroscience and Behavioral Biology. This study will take about 30 minutes to 1 hour to complete.

If you join, you will be asked to participate in a recorded interview to discuss various topics and gain your opinion on medical agency in individuals with AD/ADRD.

Our discussion may bring up potentially triggering or difficult personal experiences, which may cause some discomfort. However, if this does occur, we will ask if you would like to take a break or conclude the interview.

Upon completion of the interview, participants will be compensated with a $25 gift card as a token of our appreciation. This study is not intended to benefit you directly, but we hope this research will benefit people in the future. [For dyads] We also hope that this study may be a way for you to share your personal stories and experiences regarding medical agency.

Study records can be opened by court order. They also may be provided in response to a subpoena or a request for the production of documents. Certain offices and people other than the researchers may look at study records. Government agencies and Emory employees overseeing proper study conduct may look at your study records. These offices include the Emory Institutional Review Board and the Emory Office of Research Compliance. Study funders may also look at your study records. Emory will keep any research records we create private to the extent we are required to do so by law. A study number rather than your name will be used on study records wherever possible. Your name and other facts that might point to you will not appear when we present this study or publish its results.

We will disclose your information when required to do so by law in the case of reporting child abuse or elder abuse, in addition to subpoenas or court orders.

De-identified data from this study (data that has been stripped of all information that can identify you) may be placed into public databases where, in addition to having no direct identifiers, researchers will need to sign data use agreements before accessing the data. We will remove or code any personal information that could identify you before your information is shared. This will ensure that, by current scientific standards and known methods, it is extremely unlikely that anyone would be able to identify you from the information we share. Despite these measures, we cannot guarantee anonymity of your personal data.

Your data from this study may be useful for other research being done by investigators at Emory or elsewhere. To help further science, we may provide your deidentified data to other researchers. If we do, we will not include any information that could identify you. If your data are labeled with your study ID, we will not allow the other investigators to link that ID to your identifiable information.

Once the study has been completed, we will send you a summary of all of the results of the study and what they mean. We will also be available to go over the results individually if any questions arise. We will not send you your individual results from this study.

Contact Information

If you have questions about this study, your part in it, or if you have questions, or concerns about the research you may contact the following:

Jennifer Jin, Co-Investigator: 201-615-4909

If you have questions about your rights at research participant, complaints about the research or an issue you rather discuss with someone outside the research team, contact the Emory Institutional Review Board at 404-712-0720 or toll-free at 877-503-9797 or by email at irb@emory.edu.

Consent

Do you have any questions about anything I just said? Were there any parts that seemed unclear?

Do you agree to take part in the study?

Participant agrees to participate: Yes No

If Yes:

____
Name of Participant

____
Name of Legally-Authorized Representative

____
Relationship of Legally-Authorized Representative to Participant

____ ________________
Signature of Person Conducting Informed Consent Discussion Date Time

____

Name of Person Conducting Informed Consent Discussion

Appendix C: Interview Guideline (Traditional Authority)

Physician/Researcher Interview

- Please explain your profession.
- If I said medical agency, what would you think I meant?
- Medical agency is essentially making decisions about medical treatment and care. Do you think that this decision-making capacity can/will change in individuals with AD/ADRD? If so, at what point do you think it becomes compromised?
- Have you ever recommended to an impaired individual that he/she should appoint a surrogate authority (either legally appointed representative or designated caregiver) to make treatment decisions on his/her behalf? If so, when did you recommend it? If not, at what point would you recommend this appointment?
- What are some factors you would recommend that the individuals consider when determining who should be given this responsibility? What are some factors you personally would use to determine this "point"? (Mention if none come to mind) For example, are there standards/guidelines in the specialty that you would follow, outcomes of cognitive assessment tools, subjective opinion based on your professional experience/interactions with the patient?
- In these instances when you are weighing an impaired individual's ability to make sound medical choices, do you consider patient autonomy as a factor? How would you rate it in importance against other factors such as safety, quality of life, quantity of life, etc.?
- In cases when an impaired individual's decision-making capacity is questioned, what individual rights do you think are at stake?
- What are your opinions on the current tests or tools available to measure cognitive capacity? (Mention if none come to mind) For instance, the Mini Mental Status Exam, GPCOG, Mini-Cog Test. How much would you consider the outcomes of such tests when speaking with families about their care recipient's decision-making capacity?
- For anytime you have had to talk to family members and their impaired care recipients about their ability to make medical decisions, do you think it was a good conversation? Were you satisfied with how the conversation went? Do you think they were satisfied?

Appendix D: Interview Guideline (Dyad)

Dyad Interview

Individual with AD/ADRD	**Caregiver**
- What is your official diagnosis?	- What is your relation to [affected individual]?
- How has your life been affected by your diagnosis and memory loss?	- How has your life been affected by [affected individual]'s diagnosis and his/her memory loss?
- If I said medical agency, what would you think I mean?	- If I said medical agency, what would you think I mean?
- Medical agency is making decisions about your medical treatment and care. Do you think this decision-making capacity can/will change with time in individuals with memory loss such as yourself? If so, at what point do you think it becomes compromised?	- Do you think this decision-making capacity can/will change with time in individuals with memory loss such as [affected individual]? If so, at what point do you think it becomes compromised?
- Was there ever a time when a medical choice you made was overruled? What was the reason it was overruled? How did you feel?	- Was there ever time where you would have preferred to make the choice on [affected individual]'s behalf? What was the reason you felt this way?
- Was there ever a time when you would have preferred to have a medical choice made for you? Would you trust your surrogate authority (either legally appointed representative or designated caregiver) or your physician more to make that decision?	- Did you feel more competent to make a medical choice on [affected individual]'s behalf than the physician team? Can you say why? What factors contributed to that? (Lifestyle/circumstances knowledge)
- Have you ever experienced a time when you felt like your ability to make choices about your medical treatment/care, was questioned? Can you tell me that story or stories? Do you think it should have been questioned in the first place?	- Have you ever questioned [affected individual]'s ability to make medical decisions? What were the circumstances that made you question it?
- Have you considered assigning a surrogate authority (legally appointed representative or a designated caregiver) to make treatment decisions on your behalf? If so, at what point would you consider appointing one?	- Are you [affected individual]'s designated surrogate authority to make treatment decisions on his/her behalf? If so, at what point did you decide to make that decision? If not, at what point would you consider initiating that conversation with [affected individual]?

• Have you had anyone measure your cognitive capacity using a test or a tool? Your cognitive capacity is determined by factors such as attention and concentration, memory, language, visual construction, calculation, and orientation. You might have been asked to perform tasks like drawing a clock with a specific time or recalling a set of words. If so, can you tell me about that experience? If not, would you consider taking one? Do you think they are accurate?	• Have you watched [affected individual] take a cognitive capacity assessment? If so, can you tell me about that experience? In your opinion, how accurate do you think tools or tests are?
• Have you ever had to speak to a physician about your medical decision making? Can you tell me these stories?	• Have you ever had to speak to a physician about [affected individual]'s medical decision making? Can you tell me these stories?
• Have you ever had to speak to a lawyer about your medical decision making? Can you tell me these stories?	• Have you ever had to speak to a lawyer about [affected individual]'s medical decision making? Can you tell me these stories?
• For anytime you have had to talk to physicians or family members about your ability to make medical decisions, do you think your voice and opinions were heard? Do you think they understood how to treat you?	• For anytime you have had to talk to [affected individual] about his/her ability to make medical decisions, do you think it was a good conversation?
• What would you like physicians, other experts like lawyers and researchers, or even your own family members to better understand about you?	• What would you like [affected individual] to better understand in such conversations?