

# The Need for Preservation of Medical Decision Making with Diminished Capacity

Jennifer Jin<sup>1,2</sup>, Gillian Hue<sup>1</sup>

1. Neuroscience & Behavioral Biology (NBB) Emory College of Arts and Sciences
2. Master of Arts in Bioethics (MAB), Center for Ethics, Emory University



EMORY

## Introduction

As a result of an aging world population, Alzheimer's Disease (AD) and other neurodegenerative diseases are reaching epidemic proportions. Progression of AD 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<sup>1</sup>, 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<sup>2</sup>. Thus, in both medical and research contexts, individuals with AD 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, and 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<sup>3</sup>.

## Aims

1. to identify themes that emerge when discussing medical agency in AD with different stakeholders, 2. to assess similarity and differences between stakeholder perspectives.

## Methods

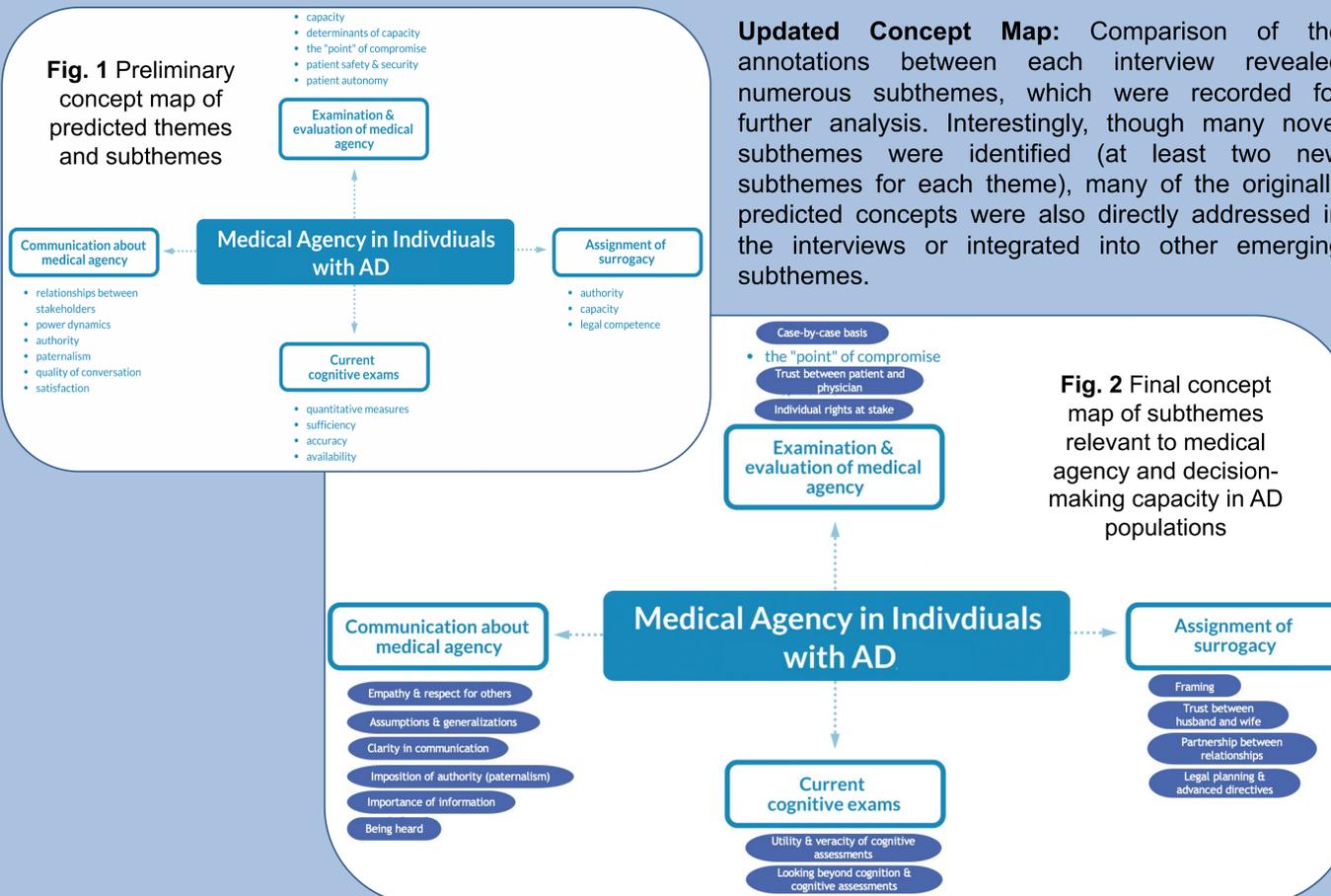
**Participants:** Six individuals were interviewed and answered semi-structured questions regarding their personal experiences with medical agency and decision-making capacity. For this case study, interviews were conducted with six individuals from a convenience sample. Background and demographics information was collected from participants during the interview process. One geriatric neurologist, one neuropsychology researcher as well as two dyads of a caregiver and an impaired individual were recruited for this study.

**Qualitative Assessment of Stakeholders:** Four key topics with significant knowledge gaps were revealed from a thorough literature review:

1. examination and evaluation of medical agency, 2. assignment of surrogacy, 3. current cognitive exams, 4. communication with various stakeholders about medical agency.

Semi-structured interviews were conducted to better understand stakeholder experiences regarding these themes. Diversity in stakeholder backgrounds was prioritized to emphasize the value of varying perspectives. Interview transcripts were reviewed and annotated using the four topics of the original concept map.

## Results



### Examination & evaluation of medical agency

"I think it has to be done on an **individualized basis** or thought about as an **individual way**."

"I want doctors to **take the time and do everything case by case**."

"I never had a problem with [doing what the doctor said] because **[he] always explained** to us why he's doing this."

"**Individuals' autonomy and independence**...are important pieces in terms of **quality of life**."

### Assignment of surrogacy

"The **whole culture has to be changed** in terms of how physicians and medical students and nurses are trained about [AD]... and they **have to be able to do a lot more** than just [giving] the diagnosis."

"[My husband and I] have a **united front**... [and] **everything I do is to preserve him** and to have the best quality of life possible."

"The kinds of documents that need to be in place for older adults are **documents that everybody needs**."

### Current cognitive exams

"We have some very good tests and ways of assessing that these days that **we probably didn't have 10 or 15 years ago**."

"[With these tools] I...have **objective evidence** [for the families]."

"[The cognitive assessments]... [ask] questions about **recognition memory and other aspects of recall memory** as the kind of critical piece just because **memory is so important for everything**."

### Communication about medical agency

"You have to always put yourself in the position of that human being. **How would you want to be treated?**"

"People don't know how to act with somebody who has [AD]... **We have [not] equipped them** with how they should be developing the information about how to make these decisions."

"[There's] a lot of stuff that I didn't know about that I **should have known about**."

"**Make sure** we understand before we leave that room and **[don't] just talk over our heads**."

## Conclusion

Participant responses provided interesting insight into **further unanswered questions** and **new potential themes** to explore and research regarding medical agency and decision-making capacity in AD populations. The interview guides **successfully addressed**, either indirectly or directly, all four themes.

### Amplifying voices & early provision of diagnosis:

- Advocating for a **greater space for dyad voices**
- **Lack of conversations** with dyads about medical agency
- Relevance of disability rights tenet: "**nothing about us without us**"

It was found that impacted individuals and their families were **not being equipped with important information** needed to make such big decisions. This can create **tension and distrust between the stakeholders** involved but can be easily remedied by **placing a greater emphasis on notifying patients early enough** with information regarding their diagnosis and prognosis to process through them and discuss with their families on how to move forward. Notifying individuals earlier of their diagnosis could help **empower them** by giving them the **opportunity to make their own decisions** without having their decision-making capacity questioned due to the potential onset of cognitive impairments. 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 sense of self worth**.

## Next Steps

Conducting a **broader study** with more participants will generate a greater collection of data. Then, a **saturation point of relevant themes from a diverse participant pool** can be achieved, consequently establishing **greater confidence** in study findings.

It is imperative to **develop 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 on medical agency in their lives and **introduce their viewpoint in the broader perspective to protect their individual right to autonomy and capacity to make their own decisions**.

## Author Contribution

JJ designed the study and methods with guidance and oversight by GH. JJ interviewed participants and analyzed the data. All authors approved of this presentation.

## References

1. 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](https://doi.org/10.1016/s1474-4422(12)70228-4)
2. 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>
3. 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>