

Vaccine Decision-Making Experiences of Informal Alzheimer's Disease Caregivers During the COVID-19 Pandemic

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Introduction

- ➔ Alzheimer's disease (AD) is a progressive and neurologically degenerating brain disease
- ➔ About 6.9 million Americans are living with AD as of 2025
- ➔ AD-related burden is largely shouldered by informal caregivers, including spouses, children, grandchildren, siblings, and close friends.
- ➔ COVID-19 has greatly impacted AD and caregiving by:
 - Increasing risk of morbidity and mortality
 - Requiring quarantine and social distancing
 - Causing pathologic changes to the brain
 - Adding additional medical decisions, i.e. COVID-19 vaccines and boosters

Aims

- ➔ AIM 1
Explore the lived experiences of informal caregivers and medical decision-making (MDM) for their care recipient (CR) with AD during the COVID-19 pandemic.
- ➔ AIM 2
Examine the attitudes and perceptions related to caregivers' decision-making process regarding the COVID-19 vaccination and booster shots for their CR with AD.
- ➔ AIM 3
Identify the perceived aspects of COVID-19 vaccination related to the caregiving burden for informal caregivers of individuals with AD.

Methodology

- A descriptive phenomenological qualitative design was employed. Five informal AD caregivers were recruited through criterion and convenience sampling and participated in semi-structured interviews. Interview data were analyzed using Colaizzi's seven-step framework to identify essential themes:

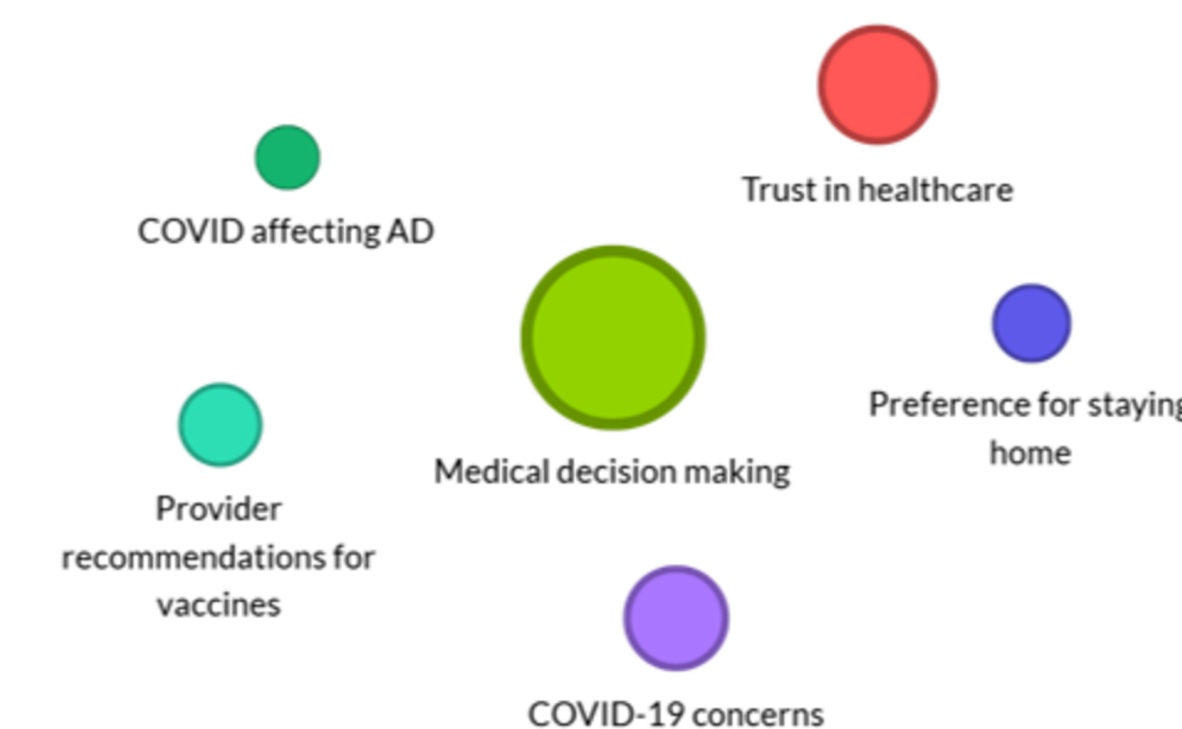
- 1 Familiarization
- 2 Identifying significant statements
- 3 Formulating meanings
- 4 Clustering themes
- 5 Developing an exhaustive description
- 6 Producing the fundamental structure
- 7 Seeking verification of the fundamental structure

Data Analysis

Coding and Clustering

1

Medical decision-making in a pandemic context



Significant Statements

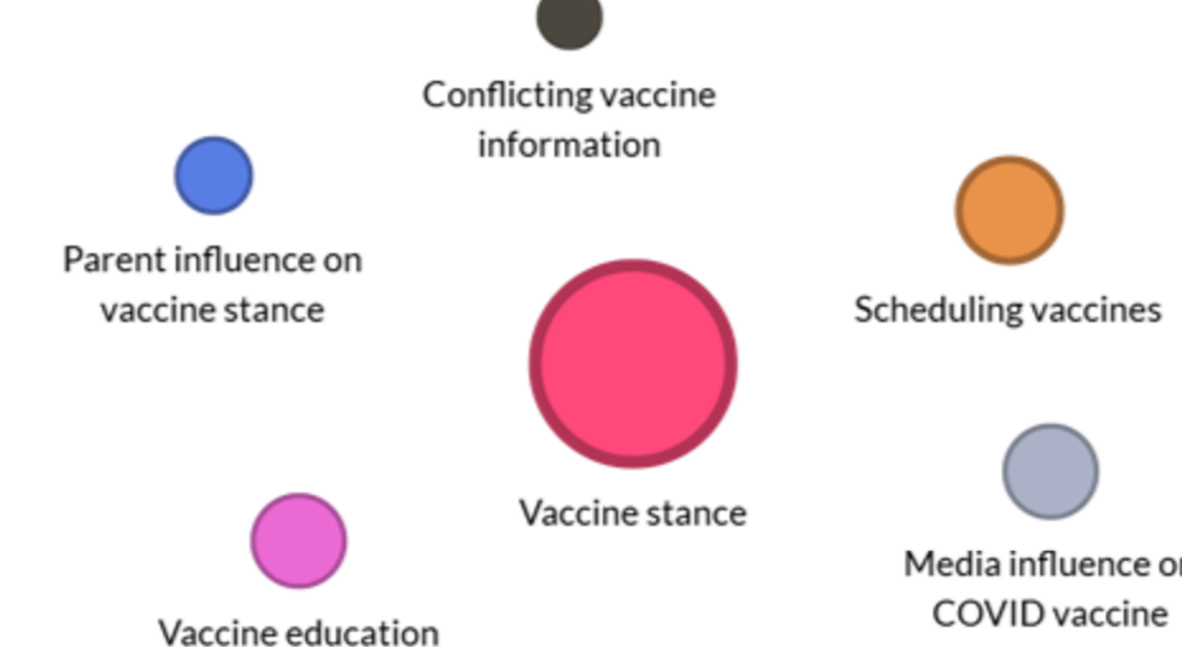
“I did ask our PCP if the [COVID vaccine] was safe. She said, 'yes, absolutely.' So that was it. I just accepted it. I trusted her.”

“Once we got the official diagnosis, I was making all of the [medical] decisions. She just couldn't.”

“If he got COVID, it could worsen his condition... I was very worried. I was worried about me, too.”

2

Perceptions and attitudes on COVID-19 vaccine decision-making



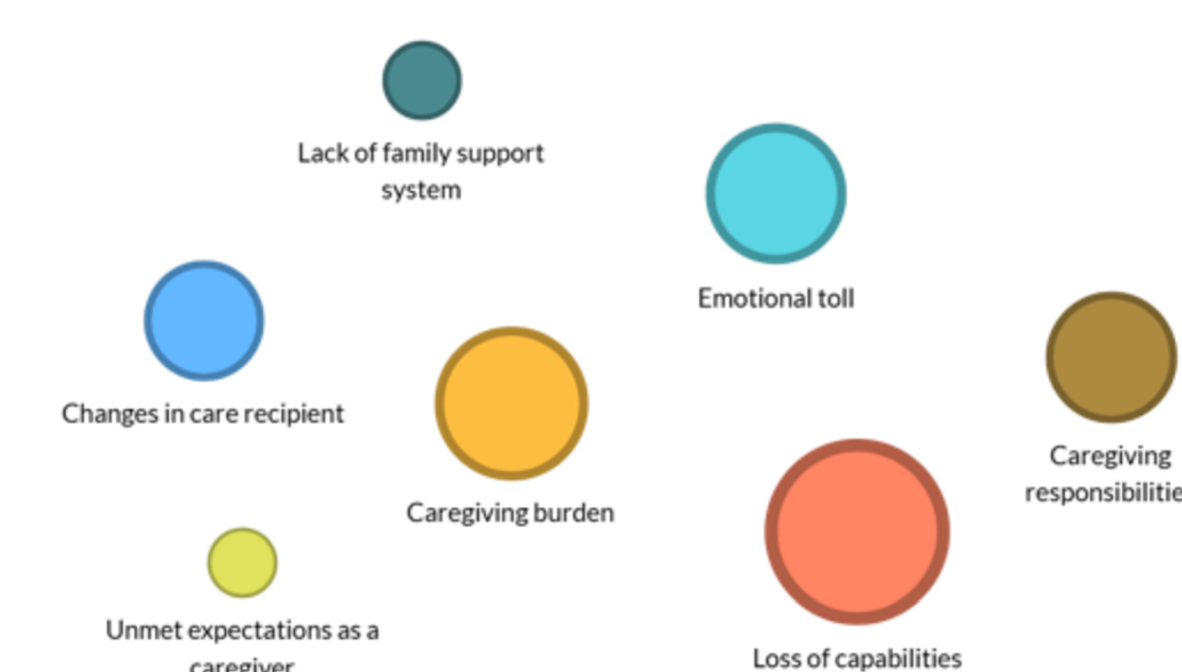
“When the COVID vaccines came out, I made every effort for us to be among the first to get vaccinated.”

“I was brought up during polio and measles. As soon as that [COVID] vaccine came out, I was first in line because of my mom's example.”

“There's no barriers [to getting vaccines]. No issues. I mean, they're always easily scheduled.”

3

The emotional and practical challenges of caregiving during the pandemic



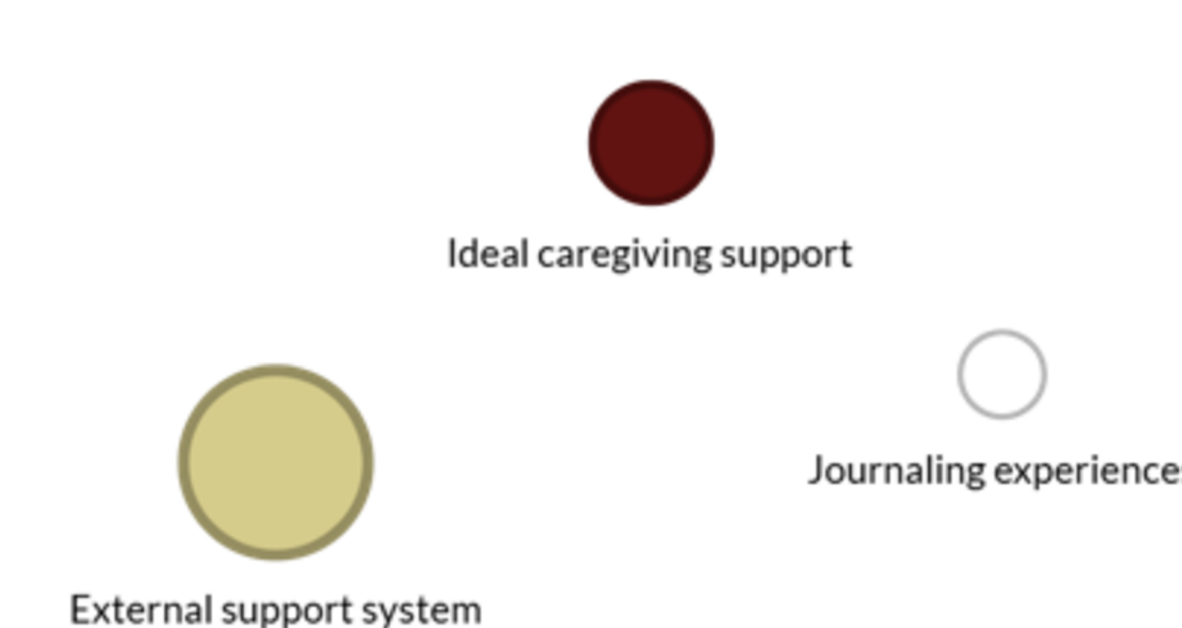
“He can't do anything. His memory is totally gone. The big changes were in his inability to do things.”

“I now feel anger, frustration... and I'm not an angry person. But [caregiving] pushes all of your buttons. Emotionally, it's awful.”

“We didn't really have any family to help us [due to quarantine]. Just me and my wife. We were it.”

4

Seeking and navigating support systems during the pandemic



“I took some caregiving classes on Zoom through the Alzheimer's Association. It was very educational. I learned a lot.”

“I have [formal] caregivers who come three days a week. Which helps so much because I still work.”

“I would love to learn from someone who's been there and done this. That would be very helpful.”

5

Dedication to caregiving as a defining identity



“He's been my husband for 20 years. I will do what I need to do for him. And I need to take care of me so I can take care of him.”

“Taking care of my mom was something I wanted to do. I felt it was my turn to take care of her.”

“I figure we're doing what we can do. I do my best for him. And I figure, yeah, we'll make it.”

Demographics

Characteristic	n (%)
Race	
White	5 (100)
Ethnicity	
Hispanic	2 (40)
Non-Hispanic	3 (60)
Sex	
Male	2 (40)
Female	3 (60)
Age group	
50-59	1 (20)
60-69	2 (40)
70-79	2 (40)
Relation to care recipient	
Spouse	3 (60)
Child	2 (40)
Years as an informal caregiver	
3-4 years	3 (60)
5-6 years	1 (20)
7+ years	1 (20)
Employment status	
Retired	3 (60)
Employed Full-Time	2 (40)

Discussion

- Caregiving was perceived as both a source of burden and a core component of personal identity.
- Caregivers faced complex emotional, physical, financial, and medical decision-making responsibilities, often with limited social support.
- COVID-19 vaccine decisions were shaped by prior life experiences, trust in healthcare systems, media influences, and conflicting information.
- Despite pandemic-related uncertainty, caregivers demonstrated a strong sense of duty and commitment to their care recipients.

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References



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