Transforming Alzheimer's Disease Care Through Integrating Caregivers



BASS CONNECTIONS

Background

Alzheimer's Disease is a form of dementia characterized by a progressive loss of brain function, marked by memory loss, behavioral changes, and eventual death. The exact cause of Alzheimer's Disease is unknown and there are currently no treatments for the disease. Currently, Alzheimer's is the 6th leading cause of death in the country and costs nearly \$280 billion per year to manage. Since there are no specific treatments for the disease, most of these costs are incurred through caregiving. Nearly 15 million Americans provide unpaid care for individuals living with Alzheimer's Disease. They provide multiple services to those living with the disease, offering emotional, physical, legal, and financial support. Unfortunately, caregivers are often not well integrated into care strategies for those with the disease. It is critical to examine strategies for better incorporating caregivers into Alzheimer's treatment plans. Both through a literature search and stakeholder interviews, the Bass Connections "Integrating Caregivers into Alzheimer's Disease Care" project team seeks to propose effective strategies and considerations to better include caregivers in Alzheimer's Disease management.

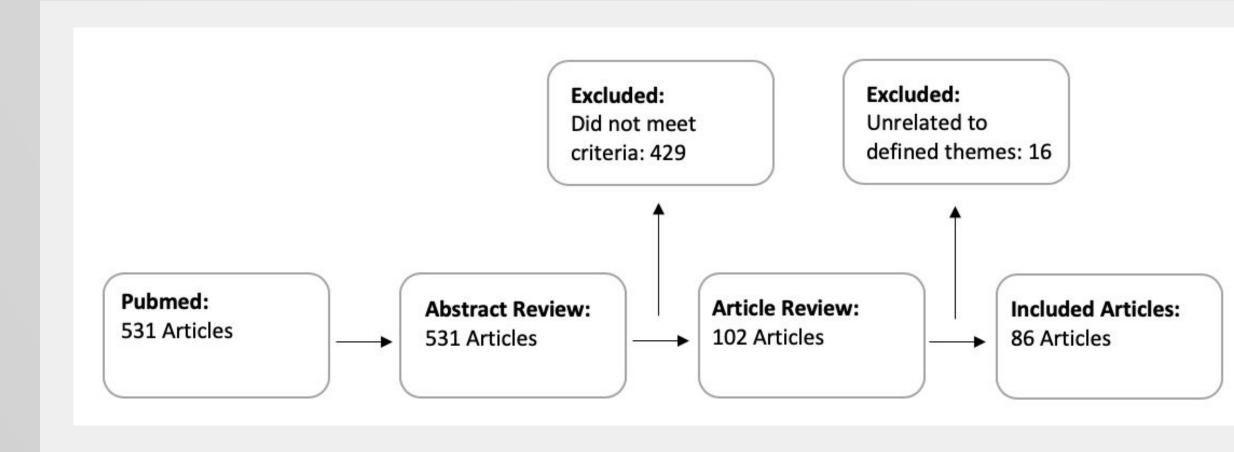
Methods

Literature Review:

Our initial search on the PubMed database yielded 531 articles. The abstracts of all articles were then examined for relevancy relating to topics of informal caregiving and integrating caregivers into Alzheimer's treatment plans, focusing on informal caregivers and in-home caregiving. Only peer reviewed and English language literature was considered. Of the 531 articles, 102 were selected for an article review. Of these articles, 86 articles were included in the final review. All articles were extracted for information on key findings, limitations, and relevant recommendations. Additionally, all articles were grouped into various categories within the broader research question and summarized for common themes. Any recommended interventions to better integrate caregivers into Alzheimer's care were summarized separately.

Caregiver and Healthcare Professional Interviews:

Interview questions were developed separately for both caregivers and healthcare professionals. In deciding which healthcare professionals to interview, careful consideration was given to the role of different healthcare providers in caring for individuals with Alzheimer's Disease. For healthcare professionals, the group resolved to interview primary care physicians, case managers, and nurses. Caregiver interviews were developed considering informal caregiving. Interview transcripts were reviewed by all team members and submitted for IRB approval.



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Themes Role of Caregivers in Role of Caregivers in Research/Clinical Treatment Decisions Trials Communication Considerations Caregiver Burden (Caregiver, Patient, Provider) Care Coordination Perspectives Services/Interventions **Regarding Shared** that Integrate **Decision-Making** Caregivers Caregiver Role in Use of Technologies Outcomes Measurement Interventions

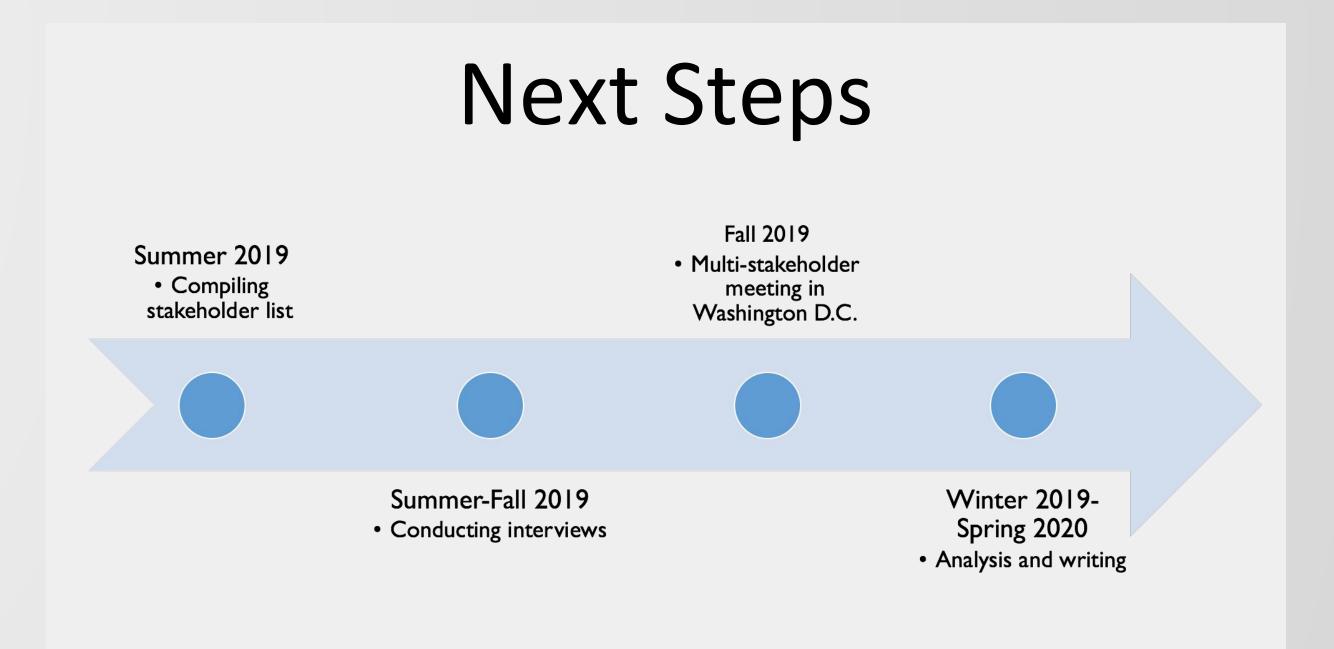
Examples

- → Linking care consultants from local Alzheimer's Associations to caregivers
- \rightarrow Online training modules from medical centers to assist caregivers with daily caregiving
- → Formal training of healthcare professionals to better communicate with caregivers
- → Anticipatory decision making



Challenges/Considerations

- → Lack of communication to caregivers
- → Lack of integration into the care team
- care strategy
- physicians



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Bass Connections in Brain & Society

→ Unclear/confused about the diagnosis (e.g. lack of diagnosis), symptoms, or

→ Caregivers do not receive adequate social or emotional support from

→ Community and regional differences in terms of available resources/services

References