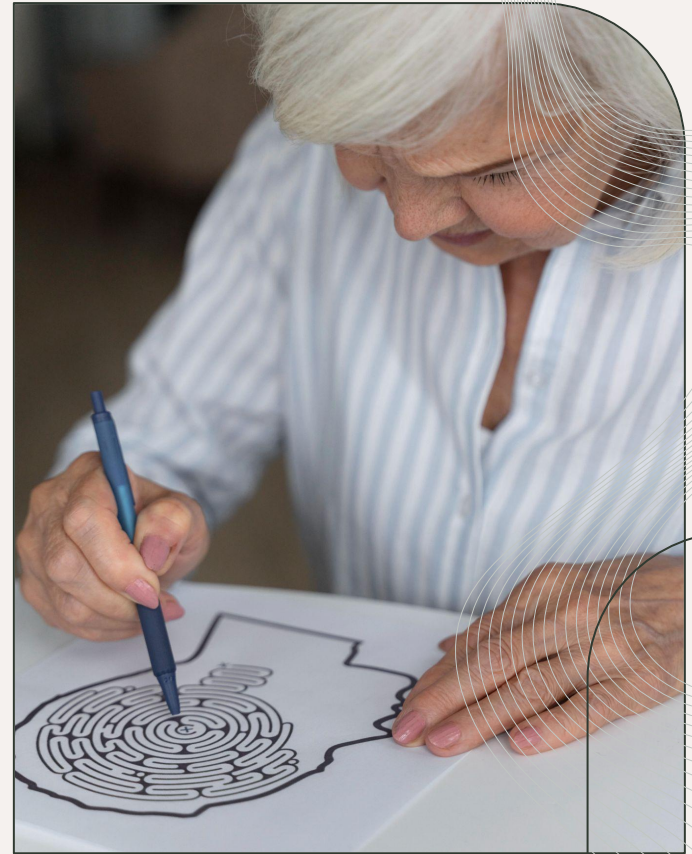


The Social and Emotional Needs of Elderly Caregivers of People Living with Dementia

Anam Rawoof



Meet the Researchers!



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Terms/Abbreviations

- CG-Caregivers
- PLWD- People Living With Dementia

Methods

01

Search

Conducted a search with the key words “caregiver”, “older”, “elderly”, “dementia”, “carer”, and “spousal” on PubMed and found 41 articles that were sorted by date.

02

Filter

Read through the first few to find background information then focused on ones that had titles or abstracts which mentioned the emotional or social health of caregivers or included terms such as “social isolation”.

03

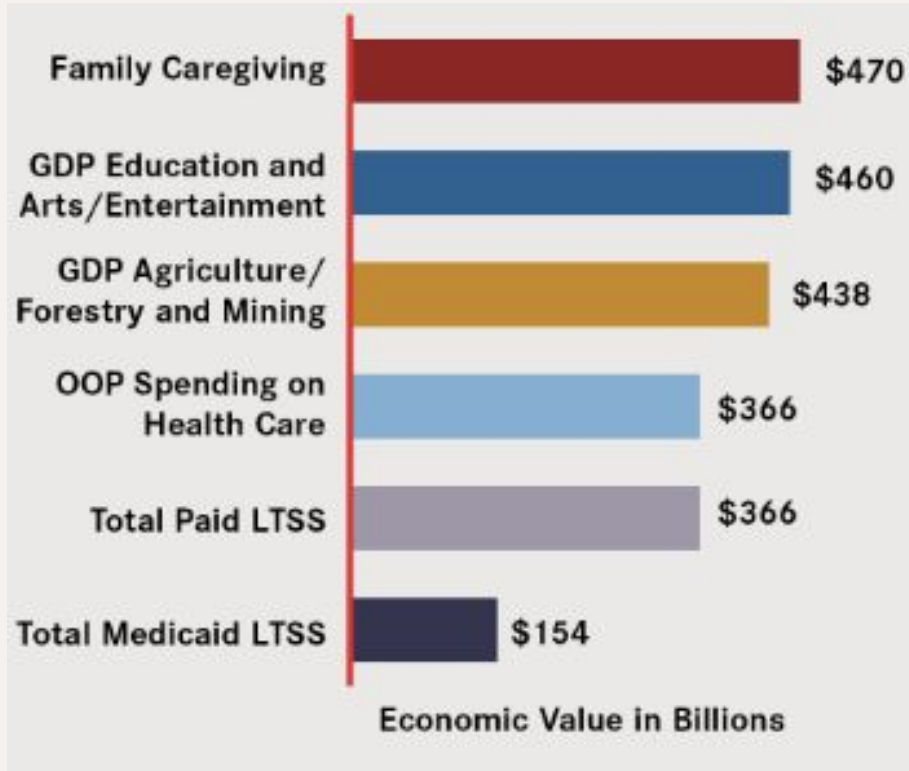
Find

Looked at the references of the most relevant articles to find new sources.

04

Focus

After coming across an article that mentioned memory cafes, I conducted a second search in PubMed with the key word “memory cafe” and read the first four papers.



\$470 Billion

The estimated cost of unpaid labor of caregivers annually in 2019¹³

Source: *Valuing the Invaluable: 2019 Update: Charting a Path Forward*, AARP Public Policy Institute



The Problem

Lack of Education and Caregiver Burden

Lack of Preparation ³

- Provide professional caregiving tasks

Lack of Clinician Support ⁸

- Insufficient support from CG medical team
- Insufficient support from PLWD medical team/poor diagnosis practices

Impact⁴

- Realistic expectations
- Sense of competency
- Lower rates of depression

Social Isolation

Social Support ^{10,16}

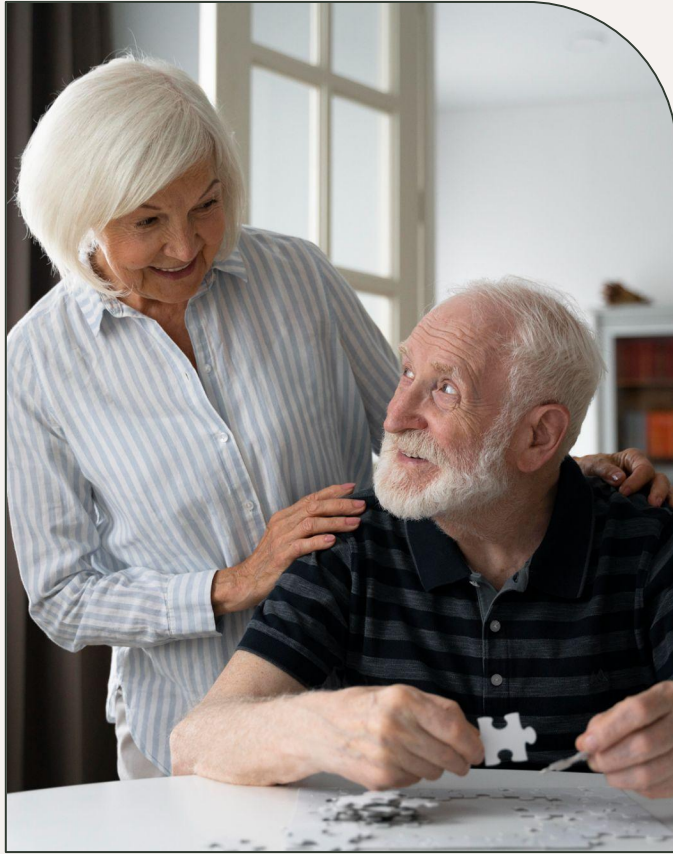
- Decrease CG burden
- Improve mental health

Reluctance to Reach out ²

- Shame about PLWD behavior
- Desire to assert independence
- Fear of burdening others
- Guilt when leaving PLWD

COVID-19 ⁷

- Increase in isolation and boredom
- Increased depression and anxiety in CG
- Impacted PLWD as well



Unique Challenges of Older CG

- Frailty, health concerns, and cognitive impairment ^{10,16}.
- Spousal CG experience grief and loss of security ^{1,5}.
- Lack of spousal support ².



Memory Cafes as the Solution

Memory Cafes

- First started in the Netherlands in 1997¹³.
- Gatherings held once or twice a month⁶.
- Most provide refreshments⁶.
- Many host activities and educational experiences⁶.



Penn's Memory Cafe⁹



Benefits of Dementia Cafes

Sense of Purpose ⁶



Provides reason for CG and PLWD to leave the house together

Disease Education ⁶



Allows CG to learn about dementia from peers and Cafe Programming

Social Opportunities ⁶



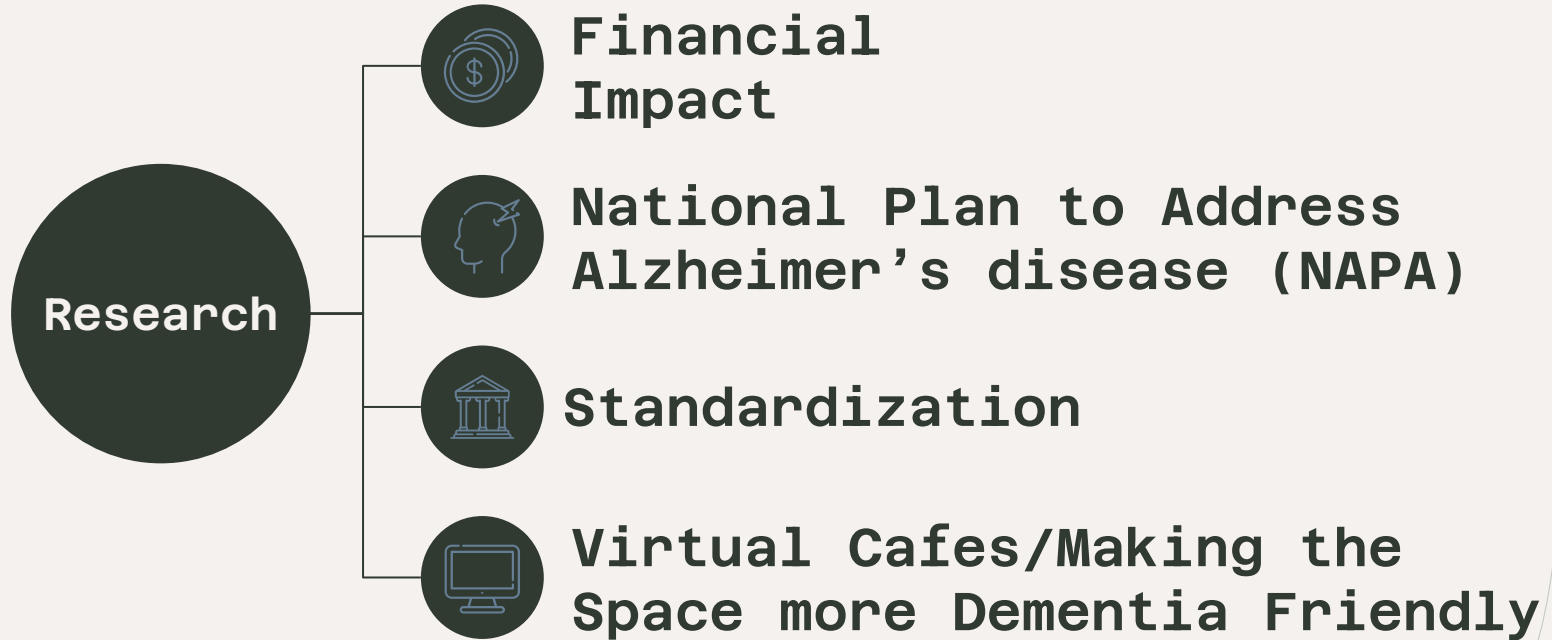
Allows CG and PLWD to meet people in similar positions

Flexibility and Accessibility ⁶



Meets the needs of many types of CG/PLWD

Future Steps



Future Directions in Dr. Hodgson's Research Team

The Social and Emotional Needs of Elderly Caregivers of People Living With Dementia

Financial Impact of Informal/Family Caregivers

Informal/Family caregivers (CG) save the government billions of dollars through their unpaid labor. Decreasing the burden of the caregivers of people living with Dementia (PLWD) is an effective way of prolonging the time a patient spends outside of institutionalization and the Emergency Department (Braithwaite 1992).

The estimated cost of the unpaid labor of caregivers annually is

\$470 Billion (Reinhard et al., 2019)



Caregiver Education and Burden

Many caregivers enter their role with very little preparation and are asked to complete tasks which were previously only executed by professionals (Griffin and Hodgson et al 2018). Despite the importance of their role, many caregivers are not provided with proper education and support from the PLWD's medical team (Lee et al, 2022). Increased caregiver knowledge is associated with more realistic expectations of the caregiving process, increased sense of competency, and lower rates of depression (Graham et al. 1997). The burden of caregiving creates increased levels of distress, anxiety, and depression when compared to non-caregiving counterparts (Vedhara et al. 1999) (Lee et al 2022).

Challenges of Older Caregivers

Older caregivers experience unique difficulties because of their own health concerns, frailty, and cognitive impairment (Pfeilsong et al 2022) (Wang and Nguyen 2022). Some older caregivers are spousal caregivers and therefore experience the depression and anxiety that comes with caregiving accompanied by the grief and loss of security from slowly losing their partner (Braithwaite 1992) (Greenwood et al. 2019).

Social Isolation

Social support can play a large role in decreasing the burden of elderly caregivers and improving mental health (Kuros and Noyes 2022) (Pfeilsong et al 2022). However, many caregivers struggle to reach out to friends due to shame about their care recipient's (CR) behaviors, a desire to assert their independence, fear of burdening others, and guilt when leaving the CR (Di Lonzo et al 2021). Older caregivers do not always have spousal support and sometimes experiences increased reluctance to ask for help due to a sense of marital duty (Di Lonzo et al 2021).

Social isolation increased during the COVID-19 pandemic and social support services were stopped. This increase in isolation and boredom also led to higher rates of depression and anxiety in caregivers and had impacted CR as well (Kostyal et al 2022).

Dementia Cafes



Dementia cafes provide a safe space for caregivers and PLWD to receive peer support and provide socialization opportunities where the behaviors of PLWD are normalized and there is no need for shame or embarrassment (Greenwood et al 2017). First started in the Netherlands in 1997 (Tatechi 2022), dementia cafes are gatherings held once or twice a month where PLWD and their caregivers can meet (Greenwood et al 2017). More recently, their value has been recognized by various countries and they are included in some national dementia plans (Tatechi 2022). There are many different types of Dementia Cafes, but most provide refreshments and many host different activities and educational experiences (Greenwood et al 2017).

Benefits of Dementia Cafes

- Provides attendees (both CG and PLWD) with a sense of purpose to their day as well as a reason to leave the house together (Greenwood et al 2017).
- Dementia Cafes can allow CG to learn about the disease either through the cafe staff or from their peers. Some attendees find it helpful to attend a cafe soon after the PLWD is diagnosed so that they could learn more about the disease from other caregivers (Greenwood et al 2017).
- The flexible nature of dementia cafes increases their accessibility and attendance. For example, some caregivers only attend the cafe for the sake of their care receiver whereas others find social fulfillment themselves (Greenwood et al 2017).

Future Directions

- National Plan to Address Alzheimer's disease (NAPA): Some countries have included Dementia Cafes in their National Plan to Address Alzheimer's, however America's plan is primarily centered on PLWD and scientific research goals. There are limited resources, research, and goals directed towards improving the quality of life of caregivers (Tatechi et al 2022) (U.S. Department of Health and Human Services). More attention should be placed on caregivers and resources in the NAPA.
- Research: There is no standard type of Dementia Cafe, and therefore it can be difficult to track their efficacy and impact. This lack of standardization also prevents governments from understanding how much financial support Dementia Cafes might require. More research should be conducted to determine which format of Dementia Cafes are most effective (Tatechi et al 2022).
- Financial Standardization: Lack of standardization prevents governments from understanding how much financial support Dementia Cafes might require. The Government should put more resources towards understanding the needs of the specific Dementia Cafes in their region by speaking to organizers and administrators. More research should also be conducted to determine whether dementia cafes reduce healthcare costs.
- Virtual Cafes: As a result of the COVID-19 pandemic, many cafes have become virtual. More research must be conducted on the impact of virtual cafes as opposed to in-person meetings.

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- Publish Policy Brief
- GSA Presentation
 - Compare emotional health of elderly caregivers vs their younger counterparts

Lessons Learned

- Mixed Methods Research
 - Coding interviews using NVivo
 - Conducting Surveys
- Challenges in research
 - Working with outside clinical spaces
 - Burnout in clinicians
- Writing an abstract
- Policy Brief
- The increasing population of Alzheimer's patients and their unmet needs
- Financial impact of caregivers

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Thank you!

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