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

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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.
The estimated cost of unpaid labor of caregivers annually in 2019 is $470 Billion.

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

- Provide professional caregiving tasks

Lack of Clinician Support

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

Impact

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

Social Support

- Decrease CG burden
- Improve mental health

Reluctance to Reach out

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

COVID-19

- 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 1997\textsuperscript{13}.
- Gatherings held once or twice a month\textsuperscript{6}.
- Most provide refreshments\textsuperscript{6}.
- Many host activities and educational experiences\textsuperscript{6}.
Penn’s Memory Cafe
Benefits of Dementia Cafes

**Sense of Purpose**
- Provides reason for CG and PLWD to leave the house together

**Disease Education**
- Allows CG to learn about dementia from peers and Cafe Programming

**Social Opportunities**
- Allows CG and PLWD to meet people in similar positions

**Flexibility and Accessibility**
- Meets the needs of many types of CG/PLWD
Future Steps

- Research
  - Financial Impact
  - National Plan to Address Alzheimer’s disease (NAPA)
  - Standardization
  - Virtual Cafes/Making the Space more Dementia Friendly
Future Directions in Dr. Hodgson’s Research Team

- 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
Acknowledgements

- Dr. Nancy Hodgson
- Sonia Talwar
- Emily Summerhayes
- Joanne Levy
- Chinwe Nwadiogbu
References


Thank you!

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