OUTCOMES OF A DEMENTIA RESOURCE AND EDUCATION PROGRAM IMBEDDED IN A HEALTH CARE SYSTEM

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- on behalf of our study team including Terry R Barclay, PhD, Anna Forsberg, Avis Thomas, Jean Crow & Heidi Haley-Franklin, MSW
Memory PREP
Patient Resource & Education Program

• Most families wait until a crisis to seek education and connection to resources, often years after a diagnosis
• Education and planning for the management of this chronic, progressive disease - imbedded in the health system, after a new diagnosis of dementia
• 2 Goals:
  – Understand the potential benefits of this program
  – Determine if meeting by phone could be as beneficial as meeting in-person
## Memory PREP Curriculum

<table>
<thead>
<tr>
<th>Visit Type</th>
<th>Visit</th>
<th>Task</th>
<th>Time (min)</th>
<th>Handouts</th>
<th>Homework</th>
</tr>
</thead>
</table>
| **In-person Or By Phone** | Week 0 | - Introduction  
- Build rapport  
- Explain structure  
- Disease Education  
- Legal/Financial topics  
- Community Resources | 60-90     | - Power of Attorney-Attachment #3  
- Health Care Directive-Attachment #4  
- Basics-Attachment #5  
- Communication–Attachment #6  
- Stages of AD-Attachment #7  
- Living Well-Attachment #8 | - Complete power of attorney  
- Complete healthcare directive  
- Take 1 Action step |
| **Phone**           | Week 2-3 | - Review action steps  
- Identify barriers/successes  
- Living Well-Reduce Stress | 15-30     | - Medication Log-Attachment #9  
- MASP-Attachment #10  
- Driving Resources-Attachment #11  
- Right Level of Care-Attachment #12  
- Brain Tips-Attachment #21 | - MASR  
- Driving Evaluation  
- Take 1 action step |
| **In-person Or By Phone** | Week 4-6 | - Review homework  
- Goals of care  
- Partnering with MD  
- Navigating healthcare system  
- Avoiding the potholes  
- Next steps | 60-90     |                                                                  |                                                                         |
| **Phone**           | Week 8-10 | - Review action steps  
- Living Well  
- Finding meaning and purpose | 15-30     |                                                                  |                                                                         |
| **Phone**           | Week 12-15 | - Review action steps  
- Living Well  
- Establish a routine | 15-30     |                                                                  |                                                                         |
| **Ad-hoc**          | Week 0-32 | Patient-initiated phone support | ~15       |                                                                  |                                                                         |

Research Measurement Visits @ 0, 4, and 8 months
Study Flow

Recruited 90 patients and their care partners
- Physician Referral
  - 93 patients referred → consent 34
- Letters mailed to patients
  - 2,427 patients contacted → consent 56

Randomized: 46 in-person and 44 phone-only
79 completed the program
- 4 death / terminal illness
- 7 voluntary withdrawals / loss to follow-up
Participation resulted in:

- ↑ Knowledge of Alzheimer’s disease
  Care partners, Alzheimer’s Disease Knowledge Scale

- ↑ Feeling Emotionally Supported
  Care partners, Medical Outcomes Study Social Support Survey

- ↑ Completion of Care Planning
  e.g. power of attorney, driving and safety plans

- ↑ Use of Community Resources
  Alzheimer’s-related support groups, day programs, etc.
The program was equally effective when administered by phone as it was when administered in-person.
93% were likely to recommend this program to others

**CARE-PARTNER COMMENTS**

- Anyone going through this needs this program.
- It's been a relief to be asked “How are you doing?” for a change. Concern has been focused on [the patient] for years now. I also am aging!
- This program has been an invaluable resource.
- I don't know how it would have been possible to navigate all the concerns, issues with the information available. I feel very grateful to have had access to this program.

**PATIENT COMMENTS**

- I think anyone with dementia onset will benefit greatly from this program.
- Helped us communicate with family and friends. Provided a structure for having difficult conversations.
- Provided practical information