SHARE: An Evidence-Based Program to Support Persons with Early-Stage Dementia and Their Care Partners

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Workshop Objectives

Describe the **SHARE Program**, who it serves, and how it fills a gap in available services for this population.

Identify the **strategies, materials, and tools** that are unique to SHARE.

Describe the research evidence that supports the **feasibility, acceptability, and effectiveness** of SHARE.

Through **case studies**, learn how SHARE has had a positive impact on the lives and experiences of families.
What is SHARE?

SHARE is a 5-session psycho-educational program designed to help families in the early stages of dementia discuss and plan for the later stages of the illness.
Background

- Early-stage dementia: Facts and figures.
- Usefulness of an early-stage dyadic approach.
- Challenges facing families as they seek diagnosis.
Early-stage dementia: Facts and figures.

- In 2013, there were an estimated **44.4 million people** with dementia worldwide.
- **5.2 million Americans** have Alzheimer’s Disease or other dementia. Half may not know they have dementia.
- Alzheimer’s Disease is currently under diagnosed. As a result, there is a large push for early detection and diagnosis on a national and international level.

[Source: Alzheimer’s Association (2014)]
Usefulness of an early-stage dyadic approach.

- Persons with mild to moderate levels of impairment are able to take care of most self-care needs.
- There are nearly 15 million family caregivers who provide hands-on care, and these family caregivers are at risk for significant physical and mental health consequences.
Background

Challenges facing families as they seek diagnosis.

• Medical technologies have made it possible to diagnose dementia earlier and more accurately.
• Families vary in their expectations and reactions
  o *The experience or observation of first symptoms.*
  o *Looking for someone or something to blame.*
  o *Unrealistic expectations of the person.*
  o “*Why is she doing this to me?”*
A psycho-educational program designed to engage both the person with early-stage dementia and their care partner in discussions about:

- symptoms
- communication
- care values
- preferences for care
- healthy activities
- planning for the future
Advantages to Early Intervention

Provides an opportunity to engage families while the person with dementia *is able to communicate* preferences and participate in discussions.
Two Critical Questions

1. Are persons living with dementia in the early stages able to and interested in engaging in discussions about their condition?

   **YES**

2. Do persons with dementia and their care partners talk about care options and preferences?

   Well......not really
SHARE Basics

5 SHARE sessions + optional Family Session in the home

Sessions are held weekly, lasting 60-90 minutes

SHARE Counselors serve as the SHARE partners’ guide, resource, and support during each session
**SHARE Partners**

**Appropriate for SHARE**
- People with a diagnosis of dementia such as: Alzheimer’s disease, dementia, vascular dementia, Lewy body dementia, MCI
- Persons with dementia who are self-aware, willing, and able to participate actively in the program
- People without a diagnosis, but show progression of symptoms

**Not a good fit for SHARE**
- Persons with Frontotemporal Dementia (take on a case-by-case basis)
- Persons with dementia and caregivers who are in denial and thus are not “ready” for the program.
- Persons with dementia and caregivers with severe or untreated mental health symptoms
SHARE Objectives

- Empowers care partners by providing information about diagnosis and progression of symptoms.
- Builds relationship quality and fosters emotional well-being.
- Decreases each person’s feelings of stress about the future.
- Connects SHARE partners to helpful resources that might be needed in the future.
SHARE Protocol

Sessions

1. Welcome to SHARE
2. SHARE Preferences for Care
3. Building your SHARE Plan
4. Caring for Yourself and Each Other
5. Maintaining your SHARE Plan

First Contact Call:

Determining SHARE partners’ appropriateness for the program and collecting information about Care Values.
The SHARE Tool Kit for Counselors

Counselor Online Training Course

- *9-module training course*

Program Manual

- *Reference guide to SHARE’s 5+ session program*

Counselor’s Guide

- *Guides counselor through the SHARE protocol*

Guide for Families

- *Resource/workbook for SHARE partners*

iPad app

Magnet Boards

Coaching & Support is provided to counselors so they can maximize their skills and abilities.
The SHARE Approach

- Provides early-stage support that can reduce the stress common in the later stages of dementia.
- Bolsters the relationship, which is critical for the ultimate care and well-being of the person with dementia.

- The person who has dementia and his/her care partner discuss future care issues together.
- Discussions help and empower the care partner to know what type of assistance his or her partner wants in the future.

- SHARE Counselors develop a strong therapeutic relationship that encourages families to connect to resources early.
- Provides professional a powerful tool that helps families during this critical time in the disease process.

Targeted people living with dementia and their care partners early in the disease process.

Allows the partner with dementia to be an active participant in the planning of his own care.

SHARE Counselors, who are dementia care professionals, conduct the SHARE sessions.
SHARE Counselors

Help - problem-solve through difficult decisions.

Assist - determine if what they plan is realistic.

Guide - towards decisions that are mutually acceptable.

Create a safe environment for care partners to share their points of view.

Help them communicate more effectively.

Provide support and validate their feelings and experience.

Answer questions about dementia and available resources.

Build - connection to services (support groups, early-stage programs, etc).

Help - understand that they are not on this journey alone.
75 year-old husband diagnosed with Alzheimer’s Disease 4 months ago

Caregiving wife, 71 years old

Referred to SHARE from a caregiver resource center

“I don’t see it as much as he feels it. He says he can’t complete his thoughts. He uses his sense of humor more. He can’t remember places or what day it is. He needs reminders.”

- Caregiver

**Important information from First Contact Call:**

- Care partners interested and are a good fit for SHARE
- Large, supportive support system present
- 3 children (1 daughter, 2 sons)
- Participation delayed slightly because person with dementia suffered a TIA after First Contact Call.
Case Example (cont’d)

• Symptoms began year prior
• Partner with dementia openly verbalizes feelings of frustration and shows good insight
• He was deeply affected by watching Glen Campbell documentary – fearful of the future
Session 1: Welcome to SHARE

Session 1 Goals

• Overall Program
• Dementia Education
• Communication Strategies
• Care Values
• Preferences for Care Tasks Scale

SHARE Strategies to Keep in Mind:

*Assessing readiness
*Establishing buy-in

“I liked everything about this session. It was the first opportunity I had to talk with a counselor about my problem.”

~ Husband with dementia
Session 1: Welcome to SHARE

Explore and gain an understanding of the Care Values of the person with dementia

Acknowledge the importance of values when making future care decisions

- **Being independent**
  - Do things for yourself.
  - Organize your own routines.
  - Spend money how you want.
  - Do hobbies & activities that you like.
  - Have time to yourself.

- **Activities with family & friends**
  - Do things with others.
  - Be with family and friends.
  - Be part of celebrations.
  - Keep in touch with the past.
  - Keep in touch with distant family and friends.

- **Not being a burden**
  - Avoid being a physical burden.
  - Avoid being an emotional burden.
  - That CG not put his/her life on hold for you.
  - Avoid being a financial burden.
  - Have money to leave the family.

- **Having a say in who helps out**
  - Keep the same doctor.
  - Choose the family and friends who help you.
  - Have reliable help.
  - Choose who you do not want to help you.

- **Keeping safe**
  - Feel safe where you live.
  - Have good access to care in case of an emergency.
  - Be safe from crime.
Care Values in Action

The SHARE Program highlights five core Care Values that are most important to families when making decisions and planning for future care.

- not being a burden
- independence
- safety
- activities with family and friends
- who helps out
### Session 1: Welcome to SHARE

**CASE EXAMPLE**

<table>
<thead>
<tr>
<th>Care Values of SHARE partner with dementia</th>
<th>Wife’s Perceptions of Partner’s Care Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>safety</td>
<td>not being a burden</td>
</tr>
<tr>
<td>activities with family and friends</td>
<td>who helps out</td>
</tr>
<tr>
<td>independence</td>
<td>independence</td>
</tr>
<tr>
<td>not being a burden</td>
<td>activities with family and friends</td>
</tr>
<tr>
<td>who helps out</td>
<td>safety</td>
</tr>
</tbody>
</table>
Session 1: Welcome to SHARE
CASE EXAMPLE

Assessing Readiness

**CG’s Readiness**

<table>
<thead>
<tr>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
<th>Level 4</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>

- **Level 1**
  - Pre-contemplation
  - Things are OK
  - PWD is just old
  - PWD has always been like this
  - PWD is manipulative
  - PWD does not listen

- **Level 2**
  - Contemplation
  - Aware of issues but struggling to understand the situation
  - Reading/learning about diagnosis
  - Hoping to learn and understand more

**PWD’s Readiness**

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</tr>
</tbody>
</table>

- **Level 1**
- **Level 2**
- **Level 3**
- **Level 4**

- **Level 3**
  - Preparation
  - Intends to take action soon
  - Is willing to listen to information
  - Asks questions
  - Has some skills to use in the future

- **Level 4**
  - Action/Maintenance
  - Is actively seeking resources
  - Trying own ideas/uses behavior or environmental strategies
  - Has committed time/energy and working to improve
Session 2: SHARE Preferences for Care

Session 2 Goals

- Balancing Best Interests
- Preferences for Care
  - Person with dementia’s preferences
  - Caregiver’s perception
- Care circles
- Family Session - possibility

SHARE Strategies to Keep in Mind:

* Balancing Best Interests
* Communication Strategies
* Overcoming Challenges
Session 2: SHARE Preferences for Care

Balancing Best Interests

- Taking someone’s best interests into account is a way of ensuring that their well-being is protected.
- SHARE helps families recognize the need to balance best interests as they plan for the future.
Preferences for Care Tasks

19 care tasks reflecting Instrumental and Personal Activities of Living: shopping, chores, finances and bathing, feeding toileting, etc.
Session 2: SHARE Preferences for Care

Who would you prefer to help you with these tasks?

- housework
- In/out of bed
- medical decisions
- bathing
- dressing
- eating
- toileting
- night help
- spirituality
- health appts
- taking meds
- laundry
- cooking
- support
- finances
- activities
- shopping
- Legal matters
- transportation
Preferences for Care Tasks

Case Example

Person with dementia’s INITIAL Preferences for Care

• Is this a realistic picture?

Aha!

• How does this compare to his wife’s perception?
Preferences for Care Tasks

Case Example

Caregiver’s INITIAL perception of husband’s Preferences for Care

- Is this a realistic picture?

Aha!

- A more balanced layout might be more practical
Preferences for Care Tasks

Case Example

Care partners’ FINAL Preferences for Care

Care Circles are:

- discussed by both care partners
- honors the husband’s care values
- a more realistic plan that preserves the well-being of both care partners
Session 3: Building your SHARE Plan

Session 3 Goals

- Identify sources of support
- Create SHARE Plan
- Overcome barriers and obstacles
- Develop a strategy for sharing Plan with others

SHARE Strategies to Keep in Mind:

- Communication Strategies
- Overcoming Challenges
“The SHARE Program is like buying insurance. You hope you never have the worse happen, but if it does, you’re better able and better prepared for it.”

~ SHARE Counselor
Session 4: Caring for Yourself and Each Other

Session 4 Goals
• Discuss importance of caring for yourself and being active
• Identify and engage in enjoyable activities
• Revise SHARE plan to include pleasant activities

SHARE Strategies to Keep in Mind:
* Maximizing participation
* Overcoming challenges
* Balancing best interests
Exercise, social interactions, support from others in the same situation can help enhance well-being by reducing:

• Stigma
• Isolation
• Anxiety
• Fear

“[We] need to be more active with family and friends and planning things to do with them.”

~ Husband whose wife has young-onset dementia
Both care partners exercise regularly and have healthy diets

Both enjoy spending time with family

Husband has sleep problems due to chronic pain

Reviewed activity list and set goals

Finalized details for upcoming Family Session
Activity Goals

Case Example

- Checked off all activities on checklist
- Task breakdown
- Adjusting expectations

WHAT CAN YOU DO TO SUPPORT YOUR HEALTH AND WELL-BEING?

Check the activities you like to participate in or add your own. If the activity is something you haven’t done in a while or have never done but would like to try now, go ahead and check it! If it is something you feel you can’t do, you and your SHARE counselor can brainstorm ways to overcome these challenges.

- Walking
- Riding a bike
- Fishing
- Gardening
- Knitting
- Outdoor or yard work
- Drawing or painting
- Going out to eat
- Cooking or baking
- Sitting quietly
- Going to a barber/beautician
- Having houseguests/entertaining
- Going to a museum/exhibit
- Talking about sports
- Fitness
- Golfing
- Have or take care of a pet
- Computers/technology
- Meals with family
- Going on vacation
- Watching TV
- Going to the movies
- Working on a hobby

__________________________
SHARE Family Session

Why a Family Session?

- To increase support for both partners
- To help family understand care situation
- To improve communication around decision-making

SHARE Strategies to Keep in Mind:

* Maximizing participation
* Establishing buy-in
* Effective communication
SHARE Family Session

Family Session Goals

• Describe the SHARE Program
• Answer family’s questions about dementia and current challenges
• Present the SHARE Plan
• Increase support for the Plan

Family Session is optional
Family Session
Planning Schedule

Session 1: Introduce family session

Session 2: Explore the possibilities

Session 3: Make the decision. Begin planning

Session 4: Confirm date, finalize agenda

Hold Family Session

Session 5: Review the family session
Family Session
CASE EXAMPLE

Person with dementia

Caregiver

Children
Son #1
Daughter in law
Son #2
Daughter
Son in law

Friends
Friend #1
Friend #2
Friend #3
Neighbor

On speaker phone from another state
Family Session

CASE EXAMPLE

Accomplishments

• Person with dementia overcame anxiety and insecurity
• Partners open with family and friends
• Family and friends shared feelings of love, admiration, and support; also fear
• Reviewed Plan; made emergency plan
• Agreed to get together regularly to maintain and modify as needed

Challenges

• Not enough time to plan the family session in sessions
• Counselor uncomfortable with drinking beforehand – but accurately assessed the situation and had a productive session
Session 5: Maintaining Your SHARE Plan

SHARE Strategies to Keep in Mind:

* Effective communication
* Overcoming challenges

Session 5 Goals

- Review progress in SHARE
- Discuss outcome of Family Session (if applicable)
- Identify and address future challenges
- Discuss maintaining the SHARE Plan
Session 5: Maintaining Your SHARE Plan

CASE EXAMPLE

- SHARE partners felt overall program goals were met
- SHARE partners were able to meet activity goals
- Decided to review plan every 6 months or as needed
- Caregiver will keep Plan in file cabinet and will give copies to family/friends when revised
- SHARE partners will remain in touch with SHARE Counselor through ongoing relationship with organization

“I was worried it would be a downer, but it was completely the opposite.”

~ Person living with dementia
Feasibility, Acceptability, and Effectiveness

SHARE partners of all backgrounds...

- Were actively engaged, practiced communication techniques, worked through misunderstandings and disagreements.
- Felt comfortable discussing sensitive topics and able to work together to develop a “SHARE” plan.
- Attended all sessions with very few exceptions (62% families held a counselor-led Family Session).
- Reported higher satisfaction with program than control group (Treatment-as-Usual).
- Experienced better outcomes compared to control group (increased use of services, lower relationship strain, and CG depression).
Feasibility, Acceptability, and Effectiveness

SHARE Counselors were...

- Able to be trained using the online training course and additional SHARE coaching
- Highly satisfied, enthusiastic about the program
- Able to utilize the iPad to facilitate SHARE sessions and maintain case files

Clinicians must have a thorough understanding of issues and challenges common to early dementia.
Future Directions

- SHARE for chronic conditions (Retirement Research Foundation)
- SHARE group format
- SHARE Dutch version

“I learned more about what issues my husband is facing and hope he will be more open to sharing his feelings about my disease with me.”

~Wife with dementia
THANK YOU!
Acknowledgments

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