

The SHARE program for dementia: Implementation of an early-stage dyadic care-planning intervention

Dementia

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journals.sagepub.com/home/dem**Silvia Orsulic-Jeras, Carol J Whitlatch and Sarah M Szabo**

Benjamin Rose Institute on Aging, Cleveland, OH, USA

Evan G Shelton

Department of Psychology, Cleveland State University, Cleveland, OH, USA; Benjamin Rose Institute on Aging, Cleveland, OH, USA

Justin Johnson

Benjamin Rose Institute on Aging, Cleveland, OH, USA

Abstract

This article describes the implementation of SHARE (Support, Health, Activities, Resources, and Education), a counseling-based care-planning intervention for persons living with early-stage dementia and their family caregivers (CGs). The foundation of SHARE is built upon assessing and documenting the person living with dementia's care values and preferences for future care. Using the SHARE approach, CGs are given an opportunity to achieve an understanding of their loved one's desires before the onset of disease progression when the demand for making care decisions is high. Through working together with a SHARE Counselor, the care dyad begins to identify other sources of support, such as family and friends and service providers, in order to build a more balanced and realistic plan of care for the future. Data were collected from 40 early-stage dementia care dyads to determine the acceptability of having structured discussions about future care in the early stages of dementia. Findings from this study demonstrate the importance of planning in the early stages when persons with dementia can voice their care values and preferences for future care. Finally, this paper illustrates the use of supportive strategies such as rapport building, establishing buy-in, and communication to initiate care-related discussions with care dyads in the early stages that will help lead to more effective decision making in the future.

Keywords

early-stage dementia, care planning, decision making, caregiving, values

Corresponding author:

Silvia Orsulic-Jeras, Benjamin Rose Institute on Aging, 11890 Fairhill Road, Cleveland, OH 44120, USA.

Email: sjeras@benrose.org

Introduction

It has been estimated that approximately 5.3 million Americans are living with dementia (Alzheimer's Association, 2015). With recent updates in diagnostic criteria, medical advancements that allow for earlier diagnosis, and policies aimed at increasing diagnostic rates, we can anticipate the number of people diagnosed with Alzheimer's disease and related disorders will dramatically increase (American Psychiatric Association, 2013; McKhann et al., 2011; Reiman et al., 2011; Sloane et al., 2002). Most research on early-stage dementia focuses on the biological and pathological aspects of the disease, even though evidence suggests that proactive care should begin early on when the window of opportunity is open to involve the person living with dementia in their own care (Steeman, Casterlé, Godderis, & Grypdonck, 2006).

The early stages of dementia are marked by the onset of symptoms and challenges in the prediagnostic phase. Many times, a serious event such as an accident or getting lost while driving occurs that causes concern, or family and friends begin to notice changes. Eventually, during this prediagnostic period, the person seeks help and subsequently receives a diagnosis for the concerning symptoms (Steeman et al., 2006). The prediagnostic and diagnostic phases mark the first of many difficult transition periods that lie ahead for persons with dementia (PWDs) and their family caregivers (CGs) (Teel & Carson, 2003; Whitlatch, 2014). Current challenges with daily tasks combined with the fear of future impaired functioning can threaten a PWD's self-identity, future independence, and perceived views and expectations of normal aging (Clare, 2003; Harman & Clare, 2006; Steeman, Tournoy, Grypdonck, Godderis, & De Casterlé, 2013). Anticipation of losses involving identity and social roles, combined with a lack of education on dementia, information, resources, and support, lead many PWDs to struggle to cope with and accept their situation (Stokes, Combes, & Stokes, 2014; Vernooij-Dassen, Derkse, Scheltens & Moniz-Cook, 2006).

Evidence suggests that PWDs oftentimes do not understand the diagnosis, may feel uncertain about the accuracy, and are not given much information about what to expect in the future (Aminzadeh, Byszewski, Molar, & Eisner, 2007; Antoine & Pasquier, 2013; Byszewski et al., 2007). In addition, PWDs are rarely asked by family, friends, or health professionals about their preferences for how they would like to be cared for should the time come when they are no longer able to make decisions for themselves (Fetherstonhaugh, Tarzia, & Nay, 2013). Yet, despite all of the coping challenges and stressors present in early dementia, PWDs are often willing and able to state their values and preferences for the care they will receive in the future (Clark, Tucke & Whitlatch, 2008; Feinberg & Whitlatch, 2001).

The significant life changes brought about by the PWD's diagnosis begin a transition from a traditional familial relationship between two loved ones (such as spouse or adult child) to that of a *care dyad*. As the person in the role of providing care makes the transition to "caregiver," thoughts about what lies ahead can become overwhelming. CGs often experience stress during this post-diagnosis period due to a lack of information and knowledge about the diagnosis, and formal resources and support (Ducharme et al., 2011; Robinson, Clare, & Evans, 2005). Thus, while PWDs may be willing and able to state their preferences for future care, and CGs would benefit from this knowledge of their loved one's wishes, these conversations rarely take place. Discussions about healthcare preferences are often put off until the later stages of the disease when families may be forced to make critical

decisions in a crisis or emergency situation (e.g., the CG suddenly becomes unable to provide care), and often without input from the person receiving care (Pearce, Forsyth, Boyd, & Jackson, 2012).

Research suggests that CGs often do not fully understand what PWDs view as important and to what extent it relates to care. CGs also tend to minimize PWDs' abilities to make their own decisions even in the early stages (Reamy, Kim, Zarit, & Whitlatch, 2011). In many cases, the PWD assumes the "sick role" while the CG takes over as primary decision maker too early in the disease process (Chrisp, Tabberer, & Thomas, 2013). This can inhibit the PWD's autonomy, while at the same time create a more stressful caregiving experience. As a result, many CGs begin to take action unilaterally without consideration of their loved one's wants or needs, rendering PWDs passive recipients of their own care (Menne & Whitlatch, 2007).

As dementia progresses, CGs who have been providing care for many years are often forced to make crucial care-related decisions without knowing their loved one's preferences (Whitlatch & Feinberg, 2003). These decisions oftentimes lead to negative care experiences, CG guilt, and overwhelming burden (Whitlatch, 2010; Wolfs et al., 2010). Missing the opportunity to learn a PWD's values and preferences for care early in the disease process greatly reduces the likelihood of providing authentic person-centered care in the future, when the window of capacity closes (Maslow, 2013). Being unprepared for this decision-making role during the disease trajectory leaves many CGs feeling guilty, stressed, and overburdened, and may even lead some to resist seeking supportive services when they need help (Wackerbarth, 1999; Wolfs et al., 2012).

An increasing number of studies focus on how care dyads experience the illness and its profound effect on their existing relationship (Braun et al., 2009; Menne, Judge, & Whitlatch, 2009; Moon & Adams, 2012; Whitlatch, 2013). This focus has led to the development of psychosocial interventions designed to provide critical education and support to PWDs and CGs for coping with current and future challenges (Gitlin et al., 2008; Judge, Yarry, & Orsulic-Jeras, 2010; Judge et al., 2011; Whitlatch, Judge, Zarit, & Femia, 2006; Zarit, Femia, Watson, & Rice-Oeschger, & Kakos, 2004). Although such dyadic interventions have been shown to be effective for providing education and support and promoting engagement and independence, few educate families about the importance of discussing future care in the early stages with the PWD's values in mind.

The importance of working together

An optimal structure for discussion of future care is one in which the dyad works as a team. Building on Wilson's (1989a, 1989b) temporal model of caregiving in dementia, Keady and Nolan (2003) have described the notion of "working together" and "working separately." Working together describes "the best case scenario when there is shared and early recognition of the symptoms and help is sought jointly" (p. 29).

Working separately describes the instances where the PWD is working alone to keep things hidden, and the carer is also actively increasing vigilance so that a situation occurs where both parties are investing considerable effort but are working separately, each trying to make sense of and respond to their circumstances (p. 29). Despite their best efforts, working separately can result in working alone, often in opposite directions, leaving both care partners exhausted and without progress (Keady & Nolan, 2003).

Helping care dyads work together to create a realistic plan of care based upon the PWD's values, feelings, and principles can positively impact the quality of future care in a truly person-centered way (Kitwood, 1997). Designing proactive, dyadic interventions that address the future early in the disease process leads to more effective decision making, and provides an opportunity to document and validate the PWD's care preferences (Ducharme et al., 2011; Wackerbarth, 1999; Whitlatch et al., 2006). This approach, grounded in the PWD's documented care values and preferences, not only preserves the personhood of the PWD, but may also prove valuable in alleviating CG stress and burden when time comes to enact future care and end-of-life decisions (Denning, Jones, & Sampson, 2011).

The current study describes a counseling-based care-planning intervention for care dyads in early-stage dementia, SHARE (Support, Health, Activities, Resources, and Education). The seven-session SHARE protocol proactively encourages care dyads to "work together" to discuss care value and preferences, address sensitive topics through education, strengthen communication skills, and ultimately develop a plan of care that can be adjusted as needed throughout the care trajectory. In this paper, we describe the implementation of the SHARE intervention, its unique core strategies, and the potential impact SHARE can have on care planning for PWDs and their families.

Structure and implementation of the SHARE program

SHARE (formerly referred to as EDDI, the Early Diagnosis Dyadic Intervention program; Whitlatch et al., 2006) was designed to take advantage of the unique opportunity in early-stage dementia when the PWD is able and willing to take an active role in discussing values and preferences for the future. The core of this intervention centers around the initial assessment (before the sessions begin) of the PWD's care values and preferences and the CG's perceptions of those care values and preferences. Once the PWD's care values and preferences for care are documented, the strength-based SHARE protocol introduces a sequential, step-by-step method for assisting care dyads in discussions that will ultimately lead to a plan of care for the future.

SHARE's proactive approach focuses on empowerment and self-efficacy for both care partners, beginning with the identification and acknowledgment of the PWD's care values. A strong emphasis is placed on giving PWDs a voice in planning their own care. Simultaneously, allowing CGs an opportunity to hear, acknowledge, and validate PWDs' voices gives them a starting point from which to frame discussions on decision making. With assistance from a SHARE Counselor, this approach creates a safe and comfortable environment that enables care dyads to work at their own level of readiness to discuss and plan for what lies ahead. Once this strong foundation is built, the focus moves to enhancing the care dyad's communication skills, increasing their knowledge about dementia and available services in the community, and ultimately developing a mutually agreed-upon future plan of care.

Data collection

Participant characteristics

Participants were recruited over a 20-month period from various social service agencies in Northeast Ohio. To be included in the study, dyads had to be community-dwelling,

English-speaking, and able to read printed material. PWDs were required to have symptoms consistent with progressive memory loss and/or a diagnosis of dementia, and a Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) score between 21 and 27. Some individuals with MMSE scores below 21 were included who demonstrated overall functioning typical of early-stage dementia during a telephone screen and in-person interview. PWDs who scored above 27 on the MMSE were eligible if they had a confirmed diagnosis of a progressive cognitive impairment. CGs self-identified as the person with primary responsibility for providing care to the PWD and helping make care-related decisions.

Forty-nine dyads were enrolled in the study and completed a Time 1 interview. Of the nine dyads who did not complete the study, four refused, three reported high levels of family stress, and two cited no time to participate. Seven of the nine dropped out before participating in any SHARE sessions. The sample for this analysis comprised 40 dyads who completed both a Time 1 (baseline) and Time 2 (two weeks after completion of SHARE) interview (approximately four months apart; see Table 1 for sample demographic characteristics).

Table 1. Sample characteristics of SHARE participants.

Characteristic	CGs (n = 40)			PWDs (n = 40)		
	M	SD	Percentage	M	SD	Percentage
Age (years)	61.3	15.8		74.2	8.7	
Gender (female)			85			57.5
Relationship of CG to PWD						
Wife			37.5			
Husband			12.5			
Daughter			30			
Son			1			
Other			7			
Ethnicity/Race						
White			80			80
Non-White			20			20
Percentage of CG and PWD			67.5			
living together						
College graduate			67.5			52.5
CG employed			45			
PWD employed						17.5
Memory diagnosis						
Alzheimer's disease						12
Dementia, Other						10
Undiagnosed						18
PWD MMSE Time 1				24	3.3	

Note: CG: caregiver; MMSE: Mini-Mental Status Examination; PWD: person with dementia; SHARE: Support, Health, Activities, Resources, and Education.

SHARE Counselors

SHARE Counselors ($n=5$) included one master's level Counseling graduate with over 15 years of experience working with older adults and PWDs, and four counselor trainees studying for a master's degree who had no previous experience with the study population. All SHARE Counselors received extensive training from project staff on counseling aging persons, dementia signs and symptoms, caregiving, care values and preferences, and working with a dyadic unit.

The SHARE Counselors also received training on SHARE protocols and procedures, and participated in weekly one-hour face-to-face supervision sessions with the Principal Investigator (PI) and the Project Director (PD) to maintain fidelity to study protocols and prevent drift. Supervision also helped SHARE Counselors to ensure all content was covered while accommodating each dyad's tolerance for discussing sensitive topics. In addition, counselor trainees met weekly with their licensed counseling supervisor to complete their clinical training requirements. Materials provided to SHARE Counselors included a *SHARE Counselor Manual*, *Counselor's Guide*, and set of *magnetic boards* used to facilitate the care values and preferences discussions.

Care values and preferences assessments

Care values. SHARE begins with both care partners completing the Care Values Scale (CVS), previously known as the Values and Preferences Scale (Menne & Whitlatch, 2007; Reamy et al., 2011, 2013; Whitlatch, 2010; Whitlatch, Feinberg, & Tucke, 2005; Whitlatch, Piiparinen, & Feinberg, 2009). The CVS enables the PWD to rank five core care values: Independence, Who Helps Out, Activities with Family and Friends, Not Being a Burden, and Safety. The CVS also assesses CGs' perceptions of what is most important to their care partner (see Table 2 for a complete description of SHARE care values).

Care preferences. Next, care partners complete the Preferences for Care Tasks Scale (PCTS; Whitlatch, 2010), which assesses the PWDs' preferences for whom they would choose to help with 19 different care tasks in the future. Again, the CGs' perceptions of whom they think their care partner would choose are assessed. Care tasks include personal activities of daily living (PADLs) and instrumental activities of daily living (IADLs) such as bathing, dressing, toileting, managing medications, making healthcare and legal/financial decisions, handling general household tasks, and other meaningful daily activities. Socioemotional care tasks include enjoyable activities, emotional support, and companionship. The three sources of support care partners can choose from and that are later represented as three distinct *Care Circles* are: *Caregiver*, *Family or Friends*, or *Service Providers*. Typically, PWDs and CGs select the CG as the person they would prefer, or in the case of CGs, whom they think the PWD prefers for handling most of the care tasks. This preference often leads to a care picture that depicts an overloaded CG circle (see Figure 1). Responses to the CVS and PCTS serve as the starting point for discussions that begin the process of creating a future care plan.

Session structure

Each SHARE session is structured similarly, starting with the dyad together to review the goals of the session (opening phase). In the middle phase, the CG and PWD meet jointly

Table 2. Description of SHARE care values.

Value	Value label	Value components
Autonomy	Being independent	Do things for yourself Organize your own routines Spend money how you want Have something to do Come and go as you please
Activities	Activities with family and 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 friends and family
Burden	Not being a burden	Avoid being a physical burden Avoid being an emotional burden That CG not put life on hold for you Avoid being a financial burden Have money to leave the family
Safety	Keeping safe	Feel safe where you live Have access to care in case of an emergency Be safe from crime Prevent fall/injury Have someone around in case you need help
Who helps	Having a say in who helps out	Keep the same doctor Choose the family members who help you Have reliable help Choose who you do not want to help you

Source: The Care Values Scale© (CVS). Adapted from Whitlatch, Feinberg, and Tucke (2005). Copyright 2005 by Oxford University Press on behalf of The Gerontological Society of America.
 SHARE: Support, Health, Activities, Resources, and Education.

(joint) or separately (mixed) with the SHARE Counselor to cover specific material. The session ends with the final phase, when the dyad comes together again to review material discussed, ask questions, and preview the next session. During “joint” sessions, the CG and PWD meet together for the entire session. Joint sessions help solidify the relationship between the SHARE Counselor and the care dyad, and ensure that rapport is established and trust is in place. In “mixed” sessions, each person meets separately with the SHARE Counselor. This allows each care partner to focus more intensively on the content areas and express their thoughts and feelings openly with the SHARE Counselor. Discussions that take place during mixed-session segments are summarized to both care partners when they are brought back together.

SHARE core strategies

The SHARE Program is based on the premise that a strong, open, and trusting relationship within a care dyad is the foundation for ensuring the goals of the program are achieved. The following core strategies are integral to maximizing the potential benefits of SHARE for dementia care dyads.

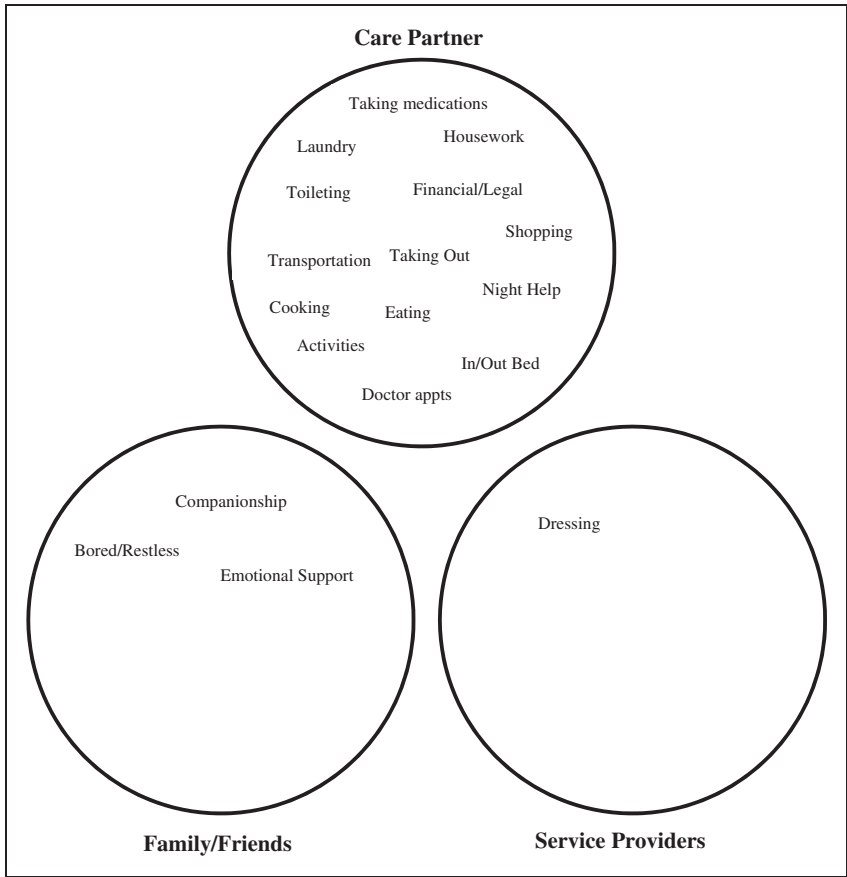


Figure 1. A typical SHARE Care Circles profile at baseline when assessed using the Preferences for Care Tasks Scale.

Building rapport. Rapport building begins with the very first contact a SHARE Counselor has with a care dyad and continues throughout all SHARE sessions. Part of the rapport-building process includes identifying a common language and terminology about dementia the care dyad finds acceptable. For example, some care dyads are very comfortable saying “dementia” or “Alzheimer’s disease”; others will not be as aware or ready to use the specific terms and will instead use terms such as “problems that can happen as you get older.” It is important for the SHARE Counselor to accept this terminology so that care dyads feel comfortable and safe talking about it. Once a positive rapport has been established, education about diagnosis and symptoms can proceed most effectively. Other strategies for building rapport include acknowledging and addressing topics important to each care partner, remaining nonjudgmental, being sensitive to the needs and feelings of each person while not taking sides, using appropriate tone of voice, and being aware of body language.

Establishing buy-in. The process of building rapport and gaining participant buy-in can be subtle and difficult to operationalize. Establishing buy-in for the purposes of SHARE is

defined as helping care dyads understand that: (1) the SHARE Program is designed to address issues pertaining to their specific care situation, and (2) planning for the future can provide benefits for both the CG and the person living with dementia. In addition, focusing first on the PWD's values for care before discussing other topics illustrates to both care partners the importance of communication in the process of care planning, and the SHARE Counselor's role is to support them through difficult discussions. When both positive rapport and buy-in are successfully established, care dyads become more amenable to engaging with their SHARE Counselor in sensitive discussions related to future care.

Effective communication. SHARE Counselors are trained to identify each care dyad's communication strengths and weaknesses, educate dyads about how dementia impacts communication skills, and model effective communication techniques in each SHARE session. Focusing on both positive verbal and nonverbal communication skills creates a solid foundation for communication between SHARE Counselors and care dyads, and supports positive communication between care partners. Examples of these communication skills include keeping communication short and simple, making eye contact, validating communication strengths and successes, and using nonverbal cues and clues.

The SHARE protocol

Session 1: Understanding memory loss (joint). Session 1 begins with introductions and informal conversation between the SHARE Counselor and care partners, thus beginning the rapport-building process. An overview of the entire SHARE Program is provided, which helps to confirm that the care partners are still interested in moving forward. This process helps establish the care dyad's buy-in to the program, thus opening the door for sensitive discussion regarding symptoms and diagnosis. The overall goal of Session 1 is to address questions care partners have about dementia, discuss treatment options, and explore needs for and ways to find reliable information. SHARE Counselors identify the care dyad's existing communication strengths while introducing new strategies specific to the communication challenges faced by PWDs.

Session 2: Care values (mixed). Prior to Session 2, the PWD's and the CG's CVS responses are used to generate individualized *Care Values Magnet Boards*, a visual representation of the PWD's care values and the CG's perceptions of the PWD's care values. This exercise helps to delineate PWDs' values for care while they still have the capacity to assert and discuss them. A second objective is for the CG to begin to understand the PWD's values and how their perceptions might be similar or different. These values are first discussed with each care partner individually. The care partners are then brought together not to achieve absolute agreement on the values themselves or on the importance of them, but rather to come to an understanding of what is most important to the PWD in terms of current and future care needs.

To illustrate the care values process further, the magnet board ranking helps the PWD see using the magnet board whether or not Independence, for example, is more important to him or her than Safety. This visual representation of how the five care values are ranked helps solidify the PWD's values for care and prepares him or her to begin discussing with the CG which values are most important. Similarly, the CG will be introduced to the PWD's actual values for care using a side-by-side comparison which lists their own perceptions of PWD's care values. This visual representation and the values discussion that follows serve as the

foundation of SHARE from which all future topics will be discussed. This values discussion typically goes smoothly, even in cases where the values and perceptions are incongruent and it appears care partners hold divergent views. Having these discussions with a trained professional early on helps to clarify any misconceptions and assumptions CGs have developed on their own, without consulting the PWD. Ensuring the PWD's care values are understood by the CG will serve as the foundation for the upcoming discussion on care preferences.

Session 3: Care preferences (joint). Responses to the PCTS questions in the pre-session interview are used to generate individualized *Care Preferences Magnet Boards*, which contain the three *SHARE Care Circles* representing the CG, family or friends, and service providers as care options. In a process similar to that for care values in Session 2, these responses are used to depict the PWD's preferences for care tasks and the CG's perceptions of them. Each care partner is shown the magnet board depicting their responses and asked what they notice about the circles. As previously noted, the typical *SHARE Care Circles* profile, for the PWD and CG, shows most, if not all, of the care tasks in the CG circle. The SHARE Counselor leads the dyad through a care-planning exercise to identify ways of decreasing the burden on the CG by moving certain tasks out of the CG circle and into other circles for seeking help from other family members, friends, and service providers. Typically, this exercise results in a more balanced and reasonable visual plan of care for the future and creates a feeling of hope and relief for both care partners (see Figure 2).

Session 4: Taking care of yourself/taking care of each other (mixed). Building on Sessions 2 and 3, in Session 4, the care partners are introduced to the concept of taking care of oneself to manage the stresses of a chronic illness. The CG and PWD work together with the SHARE Counselor to learn how staying active in pleasant activities is an important strategy for preserving optimal health and well-being. The SHARE Counselor also meets individually with each care partner to identify activities they can participate in on their own, together with their care partner, and with others. The one-on-one time is used to set individual goals, brainstorm about barriers to engaging in activities, and generate possible solutions to those barriers. Care values remain a focal point of these discussions in order to help care partners achieve their wellness goals. For example, a PWD who has always loved bike riding outdoors may value independence. However, he also expresses concerns about safety and therefore believes he should no longer ride his bike. The SHARE Counselor can encourage the PWD both to maintain this value of independence and acknowledge the safety concern by suggesting CG and family/friend support to help brainstorm about ways to continue to participate in this activity with safety precautions in place.

Session 5: Family and friends (joint). Preliminary discussions related to future care planning that took place in Sessions 2 and 3 mainly involved creating a balanced visual picture to empower care partners and introduce them to care-related decision making. In Session 5, using the *Care Preferences Magnet Boards* as a guide, this process assists care dyads to name and list specific family and friends they could call upon to help now or in the future. The SHARE Counselor encourages dyads to explore effective ways to communicate with family about care-related concerns, how to ask for help, and how to explain changes associated with dementia that may not be easily understood by family and friends.

Session 6: Community resources (mixed). The care dyad continues developing the care plan by considering the possibility of supplementing the help provided by the CG and other family members with help from service providers. Each care partner first meets the SHARE Counselor individually to explore willingness to discuss paid help options and identify

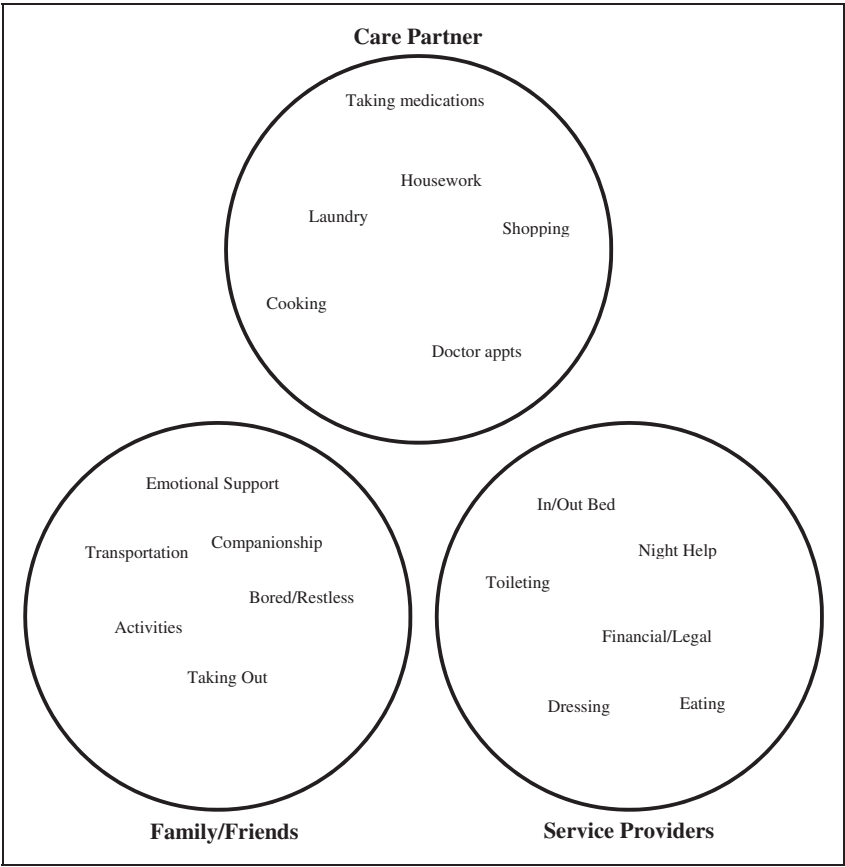


Figure 2. SHARE Care Circles profile after Sessions 1–3 of the SHARE Program have occurred, depicting a more balanced and realistic plan of care.

resistance to all or certain types of paid services. This discussion includes identifying appropriate community resource and service options and anticipating barriers to accepting this type of support. At the end of Session 6, most care dyads will have become more open to the possibility of seeking and receiving help from formal service providers. In addition, they will have worked together to create a realistic plan of care that not only includes the CG, but also support from family and friends, and identified service providers in case they are needed in the future.

Session 7: Looking to the future (joint). The final SHARE session is designed to empower care dyads to continue building their support network of family and friends as well as their awareness of the availability of many types of formal support services. Summarizing strengths, challenges, and accomplishments, SHARE Counselors review the progress made while also addressing barriers the dyad faces when asking for or receiving help. Care dyads are reminded that by supporting the PWDs' communication strengths and allowing their voices to be heard in their own care planning, CGs will be better equipped to make choices consistent with the PWDs' values and preferences when they need help in the future.

Findings

Findings examined in this paper include: (1) general acceptability and feasibility of the program; (2) whether or not the strategies of building rapport, establishing buy-in, and effective communication were helpful in supporting early-stage decision making and care planning; (3) emerging themes coded from CG and PWD comments on the benefits and drawbacks of SHARE; and (4) data from baseline SHARE Care Circles derived from the Care Preferences Scale (CPS) were compared to those post-intervention to determine if the goal of creating a more balanced and realistic plan of care was achieved.

Acceptability and feasibility

The 40 dyads who completed the full SHARE protocol attended, on average, 6.4 sessions ($SD=1.01$). Among the dyads, 26 (65%) completed SHARE using the standard seven-session structure. The remaining 14 (35%) dyads completed the study protocol in fewer meetings with their SHARE Counselor. Dyads spent an average of 82 minutes ($SD=12.75$) in each session, and an average total of 9.44 hours ($SD=2.35$) over all the sessions. We found that 80% of CGs and 65% of PWDs reported that the number of sessions were either just right or that they would have liked more sessions. CGs and PWDs rated as very convenient the location of their SHARE sessions and the times of day sessions were scheduled; they also found the length of the sessions acceptable. Using a 5-point Likert scale (4 = very satisfied, 3 = somewhat satisfied, 2 = neither satisfied nor dissatisfied, 1 = somewhat dissatisfied, and 0 = very dissatisfied), CGs rated highly their SHARE Counselor's level of skill, helpfulness, and friendliness, as well as the usefulness of session information and materials. Means for these items ranged from 3.03 to 3.77. Similar findings were reported by PWDs and means ranged from 2.83 to 3.76. Finally, CGs and PWDs were asked "In general, how satisfied were you with the sessions?" Ratings on the 5-point scale indicated a high level of acceptability for both the CGs ($M=3.46$; $SD=.76$) and PWDs ($M=3.65$; $SD=.60$).

SHARE strategies

This study explored whether early-stage care dyads were amenable to discussing future care needs and acknowledging the importance of a plan of care that takes into account the PWD's wishes. SHARE Counselors aim to build a strong therapeutic relationship with both members of the care dyad, help them establish buy-in to the program goals, and model supportive and effective communication skills in order to meet the goals of the program. We hypothesized that the use of these core strategies would empower care partners to be receptive and feel sufficiently supported to begin the sensitive discussions needed to follow through with the decision-making process. Questions representing each core strategy were asked using a 4-point Likert scale (4 = strongly agree; 3 = agree slightly; 2 = disagree slightly; 1 = strongly disagree).

Results indicate that SHARE Counselors successfully built sufficient rapport with care partners, as evidenced by 100% of CGs and 97% of PWD's stating they felt understood by and were comfortable having discussions with their SHARE Counselor. Almost all CGs and PWDs (97%) felt there was enough time to discuss the topics they were interested in. Similarly, with respect to establishing buy-in to the program, most CGs (90%) and PWDs (94%) agreed the topics discussed in SHARE were relevant to their care situation and as a

result would highly recommend the program to others in a similar situation (100% and 94%, respectively).

Findings about items related to communication were more varied. Most CGs (97%) and PWDs (94%) felt the SHARE Program gave them an opportunity to express their thoughts and feelings. Similarly, almost all CGs (97%) and PWDs (100%) felt comfortable discussing things with their care partner, indicating a supportive structure conducive to having difficult discussions with one another. On the other hand, 82% of CGs and 81% of PWDs felt that their relationship with each other had improved, and only 74% of CGs and 70% of PWDs felt their relationship with other family members had improved. This is not surprising given that SHARE aims to increase effective communication by focusing primarily on relationship quality rather than addressing long-standing strain or disagreement between the dyad or within the larger familial unit.

Impact on decision-making and care-planning skills

Questions representing decision making and care planning were asked using a 4-point Likert scale (4 = strongly agree; 3 = agree slightly; 2 = disagree slightly; 1 = strongly disagree). The information gathered from care dyads in the current study indicated the majority of care dyads strongly agreed they understood the illness better (CG = 97%; PWD = 90%), felt more control over the care situation (CG = 90%; PWD = 88%), felt better prepared for what lies ahead (CG = 95%; PWD = 94%), and were ultimately more confident making care decisions (CG = 92%; PWD = 90%).

Benefits and drawbacks

In order to better understand if the goals of the program were understood by care dyads and whether the topics covered in SHARE were relevant and helpful, all care partners were asked at Time 2 to list up to three benefits and three drawbacks that would best represent their experiences in SHARE. All responses were subsequently coded into themes (see Tables 3 and 4 for a list of themes and participant comments). The themes that emerged from CG and PWD comments related to the benefits of participating in SHARE aligned closely with the intended goals of the program: communication, education, resources and services, support, satisfaction, and care planning. Similar themes emerged for drawbacks: program/session length (too long or too short), time constraints, stress (related to topics discussed), program not relevant, PWD impairment, and dissatisfaction. Having significantly fewer drawbacks reported than benefits by both CGs and PWDs further indicates a high level of acceptability of the program material and the willingness of care dyads in the early stages to begin planning future care. However, comments also validate the sensitive nature of the discussions that take place in SHARE, demonstrating that not all care dyads are ready to discuss certain topics early in the care trajectory.

SHARE Care Circles

One of the main goals of SHARE is to achieve a balanced care plan, depicted in the movement of care tasks out of the CG circle, resulting in the differences shown between Figures 1 and 2. To determine if changes in task assignments from T1 to T2 were significant, we calculated the total number of tasks for which the PWD preferred the CG assist with at

Table 3. Themes emerging from caregivers and persons with dementia reports on the benefits of SHARE.

Benefit themes	Percentage CG (number of responses)	Percentage PWD (number of responses)	Comments
Communication	26% (23)	16% (8)	"Putting things we need to talk about on the table." (CG) "I increased communication with my sister." (CG) "My Mom finally learned that she can ask for help." (CG) "He let me talk freely." (PWD) "It opened communications between me and my wife." (PWD)
Education	26% (23)	14% (7)	"I learned a lot about memory loss." (PWD) "It helped me understand the causes of my memory problems." (PWD) "I learned things about her issues and frustrations that I wouldn't have even thought to ask about." (CG)
Support	18% (16)	12% (6)	"I believe the sessions helped to reassure my wife of my commitment to her." (CG) "She trusts me now. When I left to go back home, Mother and I were like sisters." (CG) "It greatly improved the understanding between us." (PWD)
Resources	14% (13)	4% (2)	"We are more aware of outside help." (PWD) "Knowing there are people/places in the community to help us." (CG) "Showing us how to evaluate available help now and in the future." (CG)
Satisfaction	7% (7)	41% (21)	"I felt very comfortable with her being in my home." (CG) "The sessions were meaningful." (PWD) "She was so helpful. She broke things down for me." (PWD)
Care planning	8% (8)	14% (7)	"My wife and I agree on major issues. We agreed on living arrangements." (PWD) "It got us thinking about the future and more in a planning mood." (PWD) "Learning who she accepts as a helper." (CG) "We confronted possible scenarios in the future and how we want to handle them." (CG)

Note: Total number of CG responses = 90; Total number of PWD responses = 51. CG: caregiver; PWD: person with dementia; SHARE: Support, Health, Activities, Resources, and Education.

Table 4. Themes emerging from caregivers and persons with dementia reports on the drawbacks of SHARE.

Drawback themes	Percentage CG (number of responses)	Percentage PWD (number of responses)	Comments
Emotional stress	34% (13)	14% (2)	"It left me depressed at times." (PWD) "Brought up issues not resolved." (CG) "Some discussions were pretty depressing." (CG) "It did not help me overcome the feeling of helplessness with his situation. I can't do anything to slow down his deterioration." (CG)
Dissatisfaction	16% (6)	50% (7)	"Somewhat conflicting at times." (CG) "Visuals need to be improved." (CG) "I didn't feel they went deep enough." (PWD) "Don't tell me what to do." (PWD)
PWD impairment	13% (5)	–	"He doesn't remember the sessions." (CG) "Remembering session content from one week to the next was difficult." (CG) "My Mom had a hard time saying what she feels." (CG)
Not relevant	11% (4)	14% (2)	"Some of the questions are for people who have problems and I don't have those conditions." (PWD) "Much of the information did not apply to her situation." (CG)
Scheduling	11% (4)	–	"It was hard because I always had something to do around the house." (CG) "Making time for sessions was difficult." (CG)
Session/program length	13% (5)	21% (3)	"Would like to have more of them." (CG) "Ending the program without an opportunity for Mom to continue receiving a benefit." (CG) "Very time consuming." (PWD)

Note: Total number of CG responses = 38; Total number of PWD responses = 14. CG: caregiver; PWD: person with dementia; SHARE: Support, Health, Activities, Resources, and Education.

T1, and again at T2. A paired-samples *t* test revealed that PWDs preferred the CG to assist with significantly fewer care tasks at T2 ($M=6.9$) than at T1 ($M=12.3$), $t(39)=5.40$, $p<.001$. A subsequent analysis was conducted for CGs' perceptions about the PWDs' preferences. Similarly, CGs perceived that PWDs preferred them to assist with significantly fewer tasks at T2 ($M=7.8$) than they did at T1 ($M=13.7$), $t(39)=6.00$, $p<.001$. These promising findings indicate that care partners who work together in the early stages to discuss future care decisions can create a preliminary plan of care that is

balanced, realistic, and based on the PWD's care values. In addition, these discussions introduce the concept of CG burden and address reducing burden in a meaningful and understandable way.

Discussion

Research has found that family CGs are often called upon to make crucial care-related decisions for their loved ones who are no longer able to make decisions for themselves (Denning et al., 2011). However, these same family CGs are often unprepared for this decision-making role. Further, studies have shown that PWDs in the early stages are often willing and able to participate in their own care-related decisions, and thus, can most effectively plan for the future together with their CG in a care partnership (Feinberg & Whitlatch, 2001; Fetherstonhaugh et al., 2013; Menne & Whitlatch, 2007; Reamy et al., 2011). The findings from this study indicate that the dyadic, counseling-based SHARE Program is a viable option for beginning the decision-making and care-planning process in the early stages of dementia.

While talking about the future can create uncertainty and fear, the structured values assessment and subsequent discussion and documentation of the values described in the current study help ground the care dyad to the present, thus opening the door to discuss future care in a safe and supportive way. Having a trained professional, the SHARE Counselor, who creates a structure of support and a foundation of trust gently guides care dyads' toward exploring the PWDs' values and ensuring the CGs' understanding of what their loved ones think is important. Once understanding is achieved, discussion can more easily progress toward identifying other potential helpers in addition to the CG, as a strategy for reducing CG burden while assuring that the PWD's values and preferences are documented. Other strengths of SHARE include using visual tools to aid learning; using an informal, clinical focus on PWD and CG readiness to engage in care-related discussions; and capitalizing on the unique window of opportunity that early-stage dementia provides to discern the values and preferences of the person living with dementia.

Although the findings of the current study are promising, they are not without their limitations. First, the study design was not a randomized controlled trial, making it impossible to determine if participation in SHARE leads to positive outcomes for PWDs or their CGs. In addition, the sample size of 40 dyads was small, thus weakening the generalizability of findings. Finally, care dyads were not followed over time to determine whether or not they referred to or used their care plan as their care situation changed. Thus, we are unable to address the effectiveness of the care plans created in this study and whether or not they were referred to or utilized when the care situation changed and the PWD needed more care. Despite study limitations, the current study offers hope that intervening early in the disease process is not only acceptable to families, but also provides a structured and systematic approach to care planning.

Future research directions include a randomized controlled trial to determine the efficacy and effectiveness of the SHARE protocol, a formal assessment of care partners' readiness to engage in care-related discussions, and the addition of a family session to strengthen the informal support network and solidify the care plan. Although SHARE was originally designed to address care preferences related to instrumental and personal activities of daily living and social-emotional needs for persons with dementia, the SHARE approach is adaptable for other types of care situations (Sebern & Riegel, 2009), and could be extended

further into Advanced Care Planning (ACP) and end-of-life decision making (Van der Steen et al., 2014). Thus, future directions also include adapting the SHARE Program for persons living with chronic conditions (e.g., diabetes, arthritis, HIV/AIDS) and their family CGs.

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Silvia Orsulic-Jeras is a senior research analyst II and SHARE program manager in the Center for Research and Education of the Benjamin Rose Institute on Aging. She has 20 years of experience conducting research related to dementia and caregiving in an applied research setting. Included in those years of experience is a specific emphasis on the development, testing, and implementation of a variety of psychosocial interventions focused on improving the quality of life of individuals with dementia and their family caregivers.

Carol J Whitlatch is the assistant director of the Center for Research and Education of the Benjamin Rose Institute on Aging in Cleveland, Ohio. For over 25 years, she has studied a variety of topics related to family caregiving including: developing and evaluating interventions, choice and decision making in diverse caregiver–care receiver dyads, and topics related to early-stage dementia. She is an adjunct associate professor of Sociology at Case Western Reserve University.

Sarah M Szabo is a senior research analyst I and IRB coordinator at the Center for Research and Education of the Benjamin Rose Institute on Aging. She has more than seven years of experience working with families and persons living with dementia. Her work has focused on the coordination of participant recruitment, enrollment, and retention, as well as the training of project assessors and overseeing data collection.

Evan G Shelton is a doctoral candidate in the Adult Development and Aging PhD program at Cleveland State University and a pre-doctoral research fellow in the Center for Research and Education of the Benjamin Rose Institute on Aging. His research interests include non-pharmacological approaches to intervention for individuals with dementia and their caregivers, including readiness to change and care-related preferences as they relate to meeting the changing demands of living with dementia.

Justin Johnson is a senior research assistant II in the Center for Research & Education of the Benjamin Rose Institute on Aging. He received his BA in Psychology from the University of Akron in 2003, and has been employed with the Benjamin Rose Institute on Aging for over 14 years. He has published on issues related to individuals with dementia in peer-reviewed journals and presented on a range of gerontological topics at both state and national conferences.