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Findings From a Real-World Translation Study of the Evidence-Based "Partners in Dementia Care"

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Abstract

Background and Objectives: Numerous non-pharmacological programs for family caregivers and persons with dementia (PWDs) have been found efficacious in randomized controlled trials. Few programs have been tested in translation studies that assess feasibility and outcomes in less-controlled, real-world implementations. This translation study tested the impact of the partnership version of *BRI Care Consultation*, "Partners in Dementia Care (PDC)," on outcomes for PWDs and their family/friend caregivers. PDC was delivered via partnerships between the Louis Stokes Department of Veterans Affairs Medical Center and the Greater East Ohio Alzheimer's Association Chapter and the Western Reserve Area Agency on Aging. PDC is a personalized coaching program done by telephone, e-mail, and regular mail.
Research Design and Methods: For this translation study, the program was implemented in a manner that mirrored a non-research implementation. The study sample included 148 caregivers and 84 PWDs who used PDC for 12 months. Research data came from 2 structured telephone interviews, one before program implementation and a follow-up after program completion. PWDs and caregivers averaged 14 telephone contacts with Care Consultants over the 12-month study period, and 12 behavioral action steps to address problems or concerns.
Results: Repeated measures ANOVAs showed the use of PDC was related to significant improvements across several outcomes for PWDs and caregivers, with greater benefits in more difficult caregiving situations. Caregivers had decreased levels of isolation, physical health strain, unmet needs; and increased confidence in caregiving capacity, informal helpers, and support service use. PWDs had decreased embarrassment about memory problems and unmet needs; and increased informal support and community service use.
Discussion and Implications: Overall, improved outcomes for PWDs and caregivers in this translation study were similar to findings from previous randomized trials, and affirmed the value of the program when delivered as a regular service offering by health care and community service organizations.

Translational Significance: This pragmatic, translation study implemented and tested the effectiveness of "Partners in Dementia Care" (PDC), a version of the evidence-based program *BRI Care Consultation*. PDC was delivered as a regular program by three collaborating organizations; a VA Medical Center, an Area Agency on Aging, and an Alzheimer's Association Chapter. The translational significance stems from the implementation and evaluation of an evidence-based protocol delivered within a "real-world" context, and the establishment of a unique partnership between a large health system and a community service organization. The partnership enabled the program to address a broad array of medical and non-medical issues, which was associated with improvements in variety of outcomes for persons living with dementia and their family or friend caregivers.

Keywords: Caregiver support, Evidence-based translation studies, Health system and community agency partnerships.

Over 5 million Americans are living with dementia and this number is expected to more than double in the next few decades (Alzheimer's Association, 2018; National Institute on Aging 2016). It is estimated that as many as 15 million Americans serve as a family or friend caregiver for a person living with dementia and provide the vast majority of their needed care that ranges from assisting with daily activities (e.g., household tasks, finances, shopping, meal preparation) to personal care tasks (e.g., bathing, grooming, dressing, toileting) (Centers for Disease Control and Prevention, 2016). The negative effects of informal caregiving have been well documented and include a myriad of negative outcomes including burden, physical and emotional health strain, relationship strain and role captivity, unmet needs, depression and anxiety symptoms, financial strain, decreased mastery, and higher mortality (Aneshensel, Pearlin, Mullan, Zarit, & Whitlach, 1995; Deimling & Bass, 1986; Gaugler, Davey, Pearlin, & Zarit, 2000; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Pinquart & Sorensen, 2003; Schulz, Visintainer, & Williamson, 1990; Zarit, Reever, & Bach-Peterson, 1980). Individuals living with dementia also are at risk for experiencing negative psychosocial outcomes such as depression and anxiety symptoms, relationship strain and role captivity, decreased quality of life, and embarrassment about memory loss (Judge, Menne, & Whitlatch, 2010; Lyketsos et al., 2002; Menne, Judge, & Whitlatch, 2009).

Although there is strong evidence demonstrating the efficacy of non-pharmacological interventions for caregivers of persons with dementia (PWDs), few of these programs have been translated to fit within existing health care and social service organizations. Furthermore, there is a gap in the literature on whether program implementations within existing service organizations achieve comparable results to those obtained in randomized controlled studies that initially demonstrate efficacy (Maslow, 2012; Wethington & Burgio, 2015). It also is important to note that the majority of evidence-based caregiver intervention studies have not included nor directly addressed the care needs of PWDs (Maslow, 2012). As such, examining the impact of programs being implemented in translation studies that address the care needs of both caregivers and PWDs is an imperative next step in determining whether programs are feasible and sustainable within non-research environments.

Within the VA health care system, there are more than 300,000 veterans, as well as their family or friend caregivers, dealing with the devastating effects of dementia (Office of Assistant Under-Secretary for Health, 2004). "Partners in Dementia Care" (PDC) is an evidence-based, care-coaching program to support *both* (PWDs) and their family or friend caregivers. PDC is the partnership version of the evidence-based program, *BRI Care Consultation*, which is delivered by a health care organization and community-service organization working in tandem. PDC creates a bridge between health care and community services by providing comprehensive and coordinated assistance for both medical and non-medical needs; increasing service access and ongoing monitoring of service quality; mobilizing the informal care network; and offering information and emotional support for both PWDs and caregivers.

A social worker, nurse, or other helping professional from each partnering organization serves as the "care consultant" who delivers PDC. Care consultants from partnering organizations work as a team, using a single, shared electronic record that guides delivery and maintains program fidelity. In previous randomized controlled trials, PDC and its parent program BRI Care Consultation proved to be efficacious and effective for improving psychosocial outcomes (e.g., illness-related strain, depression) for both PWDs and their caregivers (Bass, Clark, Looman, McCarthy, & Eckert, 2003; Bass et al., 2013, 2014; Clark, Bass, Looman, McCarthy, & Eckert, 2004). It also reduced hospital readmissions and return emergency department visits by PWDs (Bass et al., 2015). PDC was developed by a research team led by the Benjamin Rose Institute on Aging (BRIA), which now licenses organizations and trains staff to deliver PDC as a regular service offering, rather than as part of a research study.

Although essential for establishing the evidence-base, randomized trials of PDC did not test the feasibility or impact when implemented outside of a controlled research study and within real-world, service-delivery organizations. The lack of real-world translation studies is a limitation of most proven non-pharmacological evidence-based programs (Maslow, 2012; Wethington & Burgio, 2015). In response to this limitation, the Administration on Aging (AoA) in 2008 began a major initiative to promote translation research that tests whether evidence-based programs are effective and feasible when delivered in regular service environments (Gould et al., 2017). The current study of PDC was part of this AoA initiative, which continues as a focus area of the Administration for Community Living (ACL).

In addition to AoA/ACL, recommendations by the recently convened expert panels (Keller-Allen, Li, & Associates, 2017), and the "National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers" (Gitlin & Maslow, 2018) highlight the need for translation studies and pragmatic trials of non-pharmacological evidence-based dementia programs that are conducted in real-world settings. Similar to AoA and ACL, these sources emphasize the gap in knowledge that exists because of potential differences in findings from controlled research studies and translation studies implemented in community settings.

Translation and pragmatic studies are essential for establishing whether programs are feasible for health and social organizations and providers to implement as regular programs or services. Translation studies also test whether real-world replications achieve similar positive outcomes as demonstrated in controlled research studies (Gitlin, Marx, Stanley, & Hodgson, 2015). The lack of findings from translation studies is one factor contributing to the small number of service organizations that have adopted and implemented evidence-based caregiver support programs. Consequently, few families can access these proven sources of support (Schulz & Eden, 2016, pp. 5–18).

This manuscript presents results from a translation study that assessed whether PDC could be successfully delivered in a large-scale community implementation, under real-world, non-controlled conditions. The partnerships for implementation were between the Louis Stokes Department of Veterans Affairs Medical Center (LSDVA Medical Center) and two community service organizations; the Western Reserve Area Agency on Aging (WRAAA) for veterans and their caregivers in greater Cleveland, and the Greater East Ohio Chapter of the Alzheimer's Association for veterans and their caregivers in greater Akron and Canton.

This translation study had four characteristics that made it as similar as possible to a program implementation that is not a research study, although there were baseline and follow-up research interviews with PWDs and caregivers that gathered data kept separate from program delivery (Bass & Judge, 2010; Bass et al., 2015; Fixsen, Naoom, Blasé, Friedman, & Wallace, 2005). First, regular existing employees, rather than research staff, delivered PDC after completing the standard training provided to all organizations licensed to deliver PDC or BRI Care Consultation. As regular employees, they followed all their organizations' established human resources practices and policies (e.g., supervision practices, vacation and sick time policies). Second, PDC was integrated with the other services offered by the partnering organizations. This meant PDC was part of the parent organizations' usual internal referral practices; usual patterns of staff and cross-program interactions; and usual channels for program outreach and marketing. Third, the research protocol put few restrictions on program eligibility (e.g., all level of disease severity), and did not have a control group or use randomization that can affect prospective clients' willingness to enroll. The goal was to have a diverse sample of veterans and their caregivers that represented primary care patients at the LSDVA Medical Center. Fourth, PDC was implemented in ways that were compatible with partnering organizations' recordkeeping systems and reimbursement mechanisms, while maintaining fidelity to the evidence-based protocol.

Similar to prior controlled studies of PDC, the Stress Process Model (SPM) guided study hypotheses and the design of this translation research study (Aneshensel et al., 1995; Judge et al., 2010; Pearlin, Mullan, Semple, & Skaff, 1990). The SPM is a conceptual framework used to study the key determinants of adverse effects of caregiving on family members and friends who provide care for PWDs. The SPM also is used to study the illness experience and associated stress for individuals living with dementia. The model consists of five domains: (a) background and context characteristics (e.g., age race, gender, socioeconomic status, living arrangement); (b) objective and subjective primary stressors (e.g., cognitive, functional, and behavioral symptoms of the illness, caregiver overload, perceived distress and/or disability); (c) role and intrapsychic secondary strains (e.g., family and work role strain, physical health strain, dyad relationship strain, caregiver role captivity, caregiver mastery, embarrassment about memory problems, unmet needs); (d) coping and social support resources (e.g., available community programs, knowledge about the illness, family and friend helpers); and (e) well-being outcomes (e.g., depression, anxiety, quality of life). Similar to prior studies, PDC was conceptualized as a coping and social support resource hypothesized to: (a) reduce negative care-related consequences (i.e., strain, unmet needs, and depression) for both caregivers and PWDs, and (b) increase the number of and satisfaction with support from family members, friends, and community services used. It also was hypothesized that the benefits of PDC would be greater for PWDs and caregivers in more difficult care situations (Bass, McClendon, Brennan, & McCarthy, 1998; Lin, 1986). "Difficult care situations" was operationalized for this study as PWDs having two or more personal care dependencies, which is similar to the definition used in the national report *Families Caring for an Aging America* (Schulz & Eden, 2016, pp. 3–15). This conditional hypothesis was based on prior research findings that found the greatest impact of PDC was for caregivers and PWDs who faced more intense or complex care situations (e.g., severity of cognitive impairment, amount of strain experienced, greater personal care needed) (Bass et al., 2013, 2014).

PDC Program

PDC, like its parent program BRI Care Consultation, is driven by consumer choice, with Care Consultants coaching PWDs and caregivers on solutions to problems or concerns that are important to them. Both PWDs and their caregivers are "clients" of the program; PWDs are engaged whenever possible, despite their dementia (Darlak et al., 2017). However, the program can be used by PWDs without a caregiver, if they are able to communicate by telephone, or by caregivers as the sole program participant, if PWDs are too impaired to participate.

Care Consultants must have at least a bachelor's degree in social work, nursing, or other helping profession. They complete 1.5 days of initial training on the Program's philosophy, protocol, and the electronic record called the *Care Consultation Information System* (CCIS). In addition, ongoing refresher training and fidelity monitoring sessions are provided monthly to assure the Program is delivered as intended. The CCIS is a customized platform developed for this program to help Care Consultants deliver the program according to the evidence-based protocol, maintain a record of all communications with clients, and have ready access to a library of consumer-ready information on all topics related to chronic illnesses and caregiving.

PDC follows a standardized protocol that requires at least monthly telephone, e-mail, or regular mail contact between Care Consultants and PWDs and/or caregivers. More frequent contact is provided whenever needed, based on PWDs' or caregivers' preferences and Care Consultant's perceptions of need. The Program establishes a long-term relationship with families, which can range from 6 to 24 months, or longer. It addresses a holistic range of potential medical and non-medical problems, with assistance tailored to PWD and caregiver preferences. The Program is low-cost to deliver because all contacts between Care Consultants and clients are by telephone, e-mail, and regular mail. All costs to deliver the program (i.e., salaries, benefits, equipment, supplies, training, software, licensing, supervision, and administrative overhead) are recoverable at $60 to $80 per month per family.

PDC has three main components: (a) initial assessment, (b) action plan, and (c) ongoing monitoring and reassessment. However, the first priority is creating and implementing the action plan that begins by addressing the specific care problems or concerns that PWDs and/or caregivers want to address. With coaching from Care Consultants, the action plan is populated with simple behavioral tasks, each of which has an expected due date and person responsible for completion. A copy of the action plan is mailed or e-mailed to PWDs and/or caregivers by the end of week 3 in the Program. New tasks are added to the action plan throughout the period of program use, with ongoing updates sent to PWDs and/or caregivers. The action plan also is copied into the larger medical or service records of organizations delivering PDC.

The action plan is dynamic because the care needs for both the PWD and the caregiver are continuously changing. Adjustments and modifications are embraced, with barriers to task completion considered opportunities for learning and task reformulation. As tasks in the action plan accumulate and are accomplished, not accomplished, or modified, families move toward informing and/or finding solutions to problems they identified. Care consultants provide guidance on the content, and also assign some tasks to themselves. Tasks generally focus on: finding illness- and/or care-related information; mobilizing and coordinating assistance from family members and friends; finding, accessing, and monitoring the quality of community services and resources; and providing emotional support.

Although the priorities of PWDs and caregivers drive the process, the initial- and reassessment processes require Care Consultants to discuss 39 potential problems; 23 for PWDs (e.g., coordinating and accessing services, medication management, getting and understanding the diagnosis), and 11 for caregivers (e.g., finding and accessing community services, care-related strains and depression). Single-item trigger questions can be used to prompt discussion, with more extensive, but optional, detailed questions also provided. All 39 potential problem areas must be discussed during the first 4 months of enrollment, and revisited (i.e., reassessed) at least once every 6 months.

Ongoing monitoring facilitates the long-term relationship between Care Consultants and PWDs/caregivers. Monitoring involves follow-up contacts by Care Consultants to check whether tasks in the action plan were accomplished by the due dates, and to set new tasks as steps in the problem-solving process. If no tasks are being worked on, the prescheduled, ongoing contacts are opportunities for brief check-ins to update any changes and, if needed, to complete the required reassessments.

Method

Design

For this translation study, use of PDC was limited to 12 months. Data were collected by conducting two structured, telephone, research interviews with caregivers, and PWDs who were not too impaired. Trained research interviewers, who were not part of delivering PDC, conducted interviews. The first baseline interview was before beginning PDC (baseline); the second follow-up interview was 12 months post-baseline. Baseline interviews were completed after consent and before PDWs and/or caregivers were contacted by Care Consultants.

This translation study did not include a control or comparison group, as specified by in the funding opportunity, because the efficacy of PDC had been established in the previously completed randomized controlled trials. The goal of the current study was to verify that improvements in outcomes observed in randomized trials are replicated in a real-world, community implementation. However, whether findings are similar to or different from those obtained in prior randomized trials, the lack of a control or comparison group means this study only examined changes in outcomes associated with, rather than caused by, using the program.

Implementation Sites

PDC was implemented in two Ohio sites. One in greater Cleveland delivered via a partnership between the Louis Stokes Department of Veteran Affairs Medical Center (VA Medical Center) and the WRAAA. The other was in the greater Akron and Canton region delivered via a partnership between the VA Medical Center and the Greater East Ohio Chapter of the Alzheimer's Association (Alzheimer's Chapter).

The Care Consultant from the VA Medical Center was a social worker from the Geriatrics Department who committed 0.5 FTEs to each of the two implementation sites (1 FTE total). She partnered with a 0.5 FTE social worker from the WRAAA, and a 0.5 FTE social worker from the Alzheimer's Chapter, to create the two-person delivery team that operated at each site. The Care-Consultant teams used a single electronic record (the CCIS) to guide Program delivery. The CCIS was integrated into the VA computer network; the WRAAA and Alzheimer's Chapter Care Consultants remotely logged into the VA network to access the shared record, after completing all required VA trainings and security checks.

All Care Consultants were regular employees of their respective organizations. As such, they followed all organizational human resources policies and procedures, linked PWDs and caregivers to other programs and services offered by their organizations, informed other employees about the project and the new program offering, incorporated a summary of PWDs' and caregivers' action plans into the larger medical or service record, and transitioned PWDs and caregivers into other existing programs and services upon study completion. Transitioning PWDs and caregivers was simplified because both WRAAA and Alzheimer's Chapter decided to sustain the Program after study completion.

Sample

Identifying potential study participants began by querying the VA electronic medical record in 2015 for veterans with at least one of 45 dementia diagnoses (e.g., Alzheimer's disease, Pick's disease, dementia, vascular dementia). Primary care physicians reviewed and confirmed diagnostic information for their patients. Medical record information also was used to screen for three other required veteran characteristics: (a) receiving primary care from the Cleveland VA, (b) residing in the service area of one of the partnering community organizations (i.e., WRAAA or Greater East Ohio Alzheimer's Association Chapter), and (c) living outside of a residential care facility. There were no restrictions on severity of dementia, and whether veterans had a family or friend caregiver.

There were 901 veterans (hereafter referred to as PWDs) who met the initial study eligibility criteria and received a mailed invitation packet about participating (i.e., letter from their primary care physicians, project summary, and consent forms). Following the mailing, all PWDs received telephone calls from research staff to verify eligibility, and to identify whether PWDs had a primary family or friend caregiver. If there was a caregiver, PWDs were asked permission to also mail them an invitation packet about participating in the project. During this telephone call, 339 PWDs (38%) were determined to be ineligible (i.e., 83 were deceased; 77 resided in a nursing home; 159 could not be reached by phone after at least five attempts; and 20 were too impaired to communicate by telephone and had no responsible family members to serve as a proxy).

From the remaining 562 PWDs, 362 (64%) refused to participate and 200 consented. Consent was obtained from PWDs, or from their responsible family member who acted as a proxy. Of the 200 consenting PWDs, 182 had a family or friend caregiver who also consented, whereas 18 did not have a caregiver and participated themselves.

Baseline telephone research interviews were attempted with all consenting PWDs and/or their family or friend caregivers. As a first step in the research process for PWDs, a telephone screening procedure, which was used successfully in the previous PDC randomized trial (Bass et al., 2014), gauged whether PWDs were able to answer questions about perceptions of their illness and care. This screening approach used the short Blessed Orientation-Memory-Concentration Test, but with an altered scoring procedure that focused more on PWDs' abilities to comprehend and answer questions, rather than the objective accuracy of answers. Research interviews were attempted if PWDs were able to provide answers to all six questions in the short Blessed, even if some answers were incorrect. Correct answers, however, were required for two questions; at least two parts of the three-part "repeat-phrase question," and for either counting backwards from 20 to 15 *or* saying three consecutive months in reverse. There were 84 of the 200 PWDs who passed the screen and completed the baseline research interview.

The same short Blessed Test used at baseline, with the altered scoring, was administered to PWDs prior to attempting the 12-month follow-up interviews. Of the 84 PWDs who completed the baseline interview, 51 passed the screening and completed the 12-month follow-up interview

(60.7% of PWDs who completed baseline interviews). Data from these 51 PWDs (25.5% of the total sample) are used to examine the relationship of PDC use and PWD outcomes. The reasons 33 PWDs did not complete the follow-up interview included: 16 were two too impaired to be interviewed; 9 could not be reached by phone after at least five attempts; 6 died; and 2 refused.

As detailed in the *Analytic Strategy* below, the analysis of outcomes for PWDs was conducted in two ways. First, all 84 PWDs who completed the baseline interview were included in the analysis using an intent-to-treat approach. In the second analytic approach, only the 51 PWDs who completed both the baseline and follow-up interviews were included in the analysis, with results compared with those obtained with the intent-to-treat sample.

All 182 caregivers who consented to participate completed the baseline research interview. Follow-up interviews were attempted with all caregivers whose PWD was still alive at the end of the 12-month study period, which was 148 (81.3%) of the 182 caregivers. Of the 148 caregivers, 121 completed the 12-month follow-up interview (81.8% of caregivers who completed baseline interviews). Reasons for the 27 caregivers not completing the follow-up interview included: 14 could not be reached by phone after at least five attempts; 10 refused; and 3 caregivers were too impaired or died. As described for the sample of PWDs, the first analysis of caregiver outcomes used an intent-to-treat approach, which included all 148 caregivers who completed the baseline. These results were compared with an identical analysis with data from only the 121 caregivers who completed both the baseline and follow-up interviews (see detail in the *Analytic Strategy* subsection).

The sample of 84 PWDs who completed baseline interviews were on average 80 years of age and, as expected in cohort of older veterans, all but three were male. The vast majority (85%) were living in the same household with their family or friend caregiver. Approximately two-thirds were married, with their wife serving as the caregiver (68.1%). There were 79.1% who self-identified their race as white, with nearly all the remaining being African American (17.4%). For education, 46.5% completed or had less than a high school degree, 34.5% attended some college or had vocational training, and 19.0% had a college degree.

The sample of 148 caregivers averaged 67.5 years of age, and nearly all (95.3%) were female. Although most caregivers were the wife of the PWD, 25.7% were adult daughters. A large portion of caregivers self-identified as white (73.5%), with nearly one-quarter (23.6%) identifying as African American. In terms of education level, 38.6% had less than or completed high school, 37.1% attended college or had vocational training, and 24.3% had a college degree.

Measures

Changes in three categories of outcomes were tested: (a) Caregiver Psychosocial Outcomes; (b) PWD Psychosocial Outcomes; and (c) Informal Support and Community and Support Service Use Outcomes. All measures in these three categories had high internal reliability (Cronbach's alpha) and structural validity (high factor loadings on a single factor with low cross-loadings) in the previous randomized trial of PDC (Bass et al., 2013, 2014). As detailed below, internal reliability of each measure was reaffirmed with the current sample. Unless noted below, all measures were developed by the BRIA and were published in previous research studies of PDC.

Caregiver outcomes

Caregiver Depression was measured by the 11-item Center for Epidemiological Studies Depression Scale (Kohout, Berkman, Evans, & Cornoni-Huntley, 1993) (Cronbach's alpha of 0.80 and 0.81, respectively). *Lack of Caregiving Confidence* was the sum of four items, scored on a 4-point scale (strongly disagree to strongly agree). Items included caregiver self-reports of being able to: handle any problems in caregiving; provide proper care; do a good job providing care; and feel confident about the quality of care they provided (Cronbach's alpha 0.72 and 0.67 at baseline and 12 months, respectively). *Isolation* was the sum of seven items, scored on the 4-point scale (strongly agree to strongly disagree). Questions asked about feeling isolated and having time for non-caregiving activities; as well as whether caregiving decreased their participation in group, volunteer, religious, family, and leisure activities (Cronbach's alpha of 0.91 and 0.92, respectively). *Role Captivity* had three items scored on a 4-point scale (strongly agree to strongly disagree). Questions asked if caregivers: wished they could run away from the caregiving situation; wished they were free to live their own life without caregiving, and felt trapped by caregiving (Pearlin et al., 1990) (Cronbach's alpha of 0.85 and 0.90, respectively). *Physical Health Strain* had three items scored on a 4-point scale (strongly agree to strongly disagree) and asked whether caregiving made: their physical health worse; them sick more often; and them have more aches and pains (Cronbach's alpha of 0.78. and 0.80, respectively). *Unmet Need* was the sum of 39 dichotomous questions about the need for more help or information across eight domains: understanding dementia; care tasks; accessing services; legal and financial issues; organizing family care; alternative living arrangements; emotional support; and medications and medical follow-up (Cronbach's alpha of 0.87 and 0.86, respectively).

PWD outcomes

Four self-reported outcomes were constructed from interviews with PWDs. *Depression* was measured by the 10-item Center for Epidemiologic Studies Depression Scale (Kohout et al., 1993) (Cronbach's alpha 0.75 and 0.66 at baseline and 12 months, respectively). *Embarrassment about Memory Problems* was the sum of three dichotomous items asking whether PWDs felt: embarrassed about memory problems, uncomfortable telling others about memory problems, and uncomfortable accepting help for memory problems (Cronbach's alpha 0.70 and 0.57 at baseline and 12 months, respectively). *Isolation* was the sum of four dichotomous items that asked PWDs whether their health problems and care needs made them feel: isolated from other people; less able to participate in group activities; less able to participate in church or religious activities; and less able to visit with family and friends (Cronbach's alpha 0.73 at both baseline and 12 months). *Unmet Needs* was the sum of 24 dichotomous items representing the need for more help or information across eight domains: understanding dementia; daily living tasks; accessing services; legal and financial issues; organizing family care; alternative living arrangements; emotional support; and medications (Cronbach's alpha 0.93 and 0.94 at baseline and 12 months, respectively).

Although not a primary study aim, inclusion of outcomes based on PWD self-reports supports the growing recognition among researchers and clinicians of the importance and feasibility of including outcomes representing PWDs' perceptions of their illness experience. Not all PWDs were able to participate, but the portion who completed baseline and follow-up interviews offer unique information that improves understanding how PWDs can participate in and benefit from supportive interventions.

Informal support, and community and support service use outcomes

Two measures of informal support were created from caregiver responses. One reflected the number of family members or friends who helped the PWD; and the other reflected the number of family members or friends who helped the caregiver. These questions, as well as questions about services use described below, at baseline asked about the 12 months before enrolling in the study, and at follow-up asked about the 12 months during the study.

Two additional measures were created based on caregiver reports of PWD's use of services. One measure was a count of services used by PWDs, based on responses to questions about eight types of community services, including help with personal care and supervision, chores and running errands, health care tasks, finding or arranging for services, health information, emotional support or counseling, involving family members, and changes in living arrangement. The second measure was a count representing whether caregivers used one or two support services, including services that gave them a break from caregiving, and services that provided them emotional support or counseling.

Activity of daily living dependencies

One study hypothesis posited that Program benefits would be greater for caregivers and PWDs in more difficult care situations (Bass et al., 1998; Lin, 1986). For this study, a simple dichotomous measure of activity of daily living (ADL) dependencies was created to represent level of care difficulties. This measure was based on the approach used by Schulz and Eden (2016) in the recent National Academies report on family caregiving. Specifically, PWDs needing assistance at baseline with two or more of six personal care tasks (i.e., caregiver reports of needing assistance with bathing, dressing, grooming, toileting, eating, and mobility inside the house) were considered to have high ADL dependencies and to be in more difficult care situations (31.3% of PWDs). In contrast, PWDs who needed assistance at baseline with one or no ADL tasks were considered to have low ADL dependencies and to be in less difficult care situations (68.8% of PWDs). All information on PWDs' assistance needs came from caregiver reports. As described below, the dichotomous measure of high versus low ADL dependencies is used in the analysis to create interaction terms that tested for differences in outcomes by the level of care- situation difficulty.

Overview of PDC Use

Because the partnering health care organization was the source of all referrals, the VA Care Consultant made the first contact with all participating caregivers and/or PWDs within 48 hr of completing baseline research interviews. The PDC protocol required the community-partner Care Consultants to initiate their first contact by the end of week 3.

During this 12-month translation study, PWDs and caregivers averaged over 14 completed telephone calls with Care Consultants. Care Consultants from the partnering VA Medical Center and community organizations had similar numbers of contacts with PWDs and caregivers. Approximately 80% of all contacts were by telephone, with the remainder primarily involving mailings of educational materials to caregivers or PWDs. E-mailing between Care Consultants and PWDs and/or caregivers was limited in this implementation because of VA privacy and security restrictions.

PWDs and caregivers averaged over 12 action steps. The most common action steps pertained to helping: access community services; understanding VA health care benefits and services; improving care from the informal network; effectively managing symptoms of dementia; and home safety.

Analytic Strategy

Separate repeated measures ANOVAs tested whether the use of PDC was associated with significant, overtime changes in outcomes from baseline to the 12-month follow-up interviews. This included six repeated measures ANOVAs for the Caregiver Outcomes (i.e., Depression, Lack of Caregiving Confidence, Isolation, Role Captivity, Physical Health Strain, and Unmet Needs). Four repeated measures ANOVAs for PWD Outcomes (i.e., Depression, Embarrassment about Memory Problems, Isolation, and Unmet Needs). And, four repeated measures ANOVAs for Informal Support, and Community and Support Service Use Outcomes (i.e., Number PWD Family/Friend Helpers, Number Caregiver Family/Friend Helpers, PWD Community Service Use, and Caregiver Support Service Use).

In addition to the baseline version of the outcome measure, each equation included the dichotomous variable for ADL dependencies (low vs. high). Based on the study hypotheses, of primary interest was testing for change in outcomes from baseline to follow-up, with expected decreases in adverse PWD and Caregiver Outcomes, and increases in Informal Support, and Community and Support Service Use Outcomes. Also, of primary interest was testing whether overtime improvements in outcomes from baseline to 12 months post-baseline were greater for PWDs with high ADL dependencies, which was represented by the interaction of ADL and baseline outcomes.

The study used an intent-to-treat approach to prevent bias due to selective attrition and missing information from baseline to 12-month follow-ups (Alshurafa et al., 2012). An intent-to-treat approach is a statistically conservative method for testing the effectiveness of an intervention, because all subjects who begin a study are included in the final analysis, even those who do not complete the study protocol (Hollis & Campbell, 1999). Several major guidelines for clinical trials recommend this approach as a method for guarding against exaggerated positive program outcomes due to non-random attrition of study subjects (Lewis & Machin, 1993). Moreover, incomplete study participation is more likely for subjects who have negative experiences with an intervention, or who are dealing with more distressing or severe problems (Ranganathan, Pramesh, & Aggarwal, 2016).

Despite the benefits of an intent-to-treat approach, some caution that it may dilute the statistical effect of the intervention for subjects who complete the full study protocol (Gupta, 2011). To balance the positive and negative aspects of intent-to-treat, the current study utilized two analytic approaches. First, results were estimated using an intent-to-treat approach that carried forward valid responses from baseline interviews as replacements for missing information at 12-month follow-ups (Gupta, 2011; Sabin, Lepri, & Phillips, 2000). This approach included all caregivers and PWDs who completed baseline interviews, even if they did not have follow-up data. Second, results were estimated for only subjects who completed the full study protocol, meaning only caregivers and PWDs who completed both baseline and 12-month follow-up interviews. If the two analytic approaches reach the same conclusions, there is greater confidence in the results (Lewis & Machin, 1993; Ranganathan et al., 2016).

Even though two diverse analytic alternatives were used to handle incomplete data, the problem of missing information from baseline to follow-up remains a limitation. It is especially a concern for PWD self-reported outcomes, because a large percent of these participants did not complete follow-up interviews (39.3% of PWDs compared with 18.3% of caregivers did not complete follow-ups). Other alternative approaches for analyzing the impact of missing data on outcomes should be considered in future studies. These include newly evolving simulation approaches that include sensitivity analysis to establish more precise estimates for missing information (National Research Council, 2010).

To further inform the issue of missing data in the current study, comparisons of means for measures in baseline interviews were conducted to test for initial systematic differences between PWDs and caregivers who did and did not complete 12-month follow-up interviews. For example, it was plausible that PWDs who initially were more cognitively and/or functionally impaired would be less likely to complete 12-month follow-up interviews. Tests for differences in means at baseline were examined for: all outcomes used in the main analyses; a wide array of PWD and caregiver socio-demographics; and a variety of PWD health and impairment measures (e.g., PWD Blessed Test scores, caregiver reports of PWD cognitive difficulties and dependencies in instrumental daily activities, and number of chronic conditions). Across all these measures, there were no statistically significant differences in means at baseline. These findings suggest one of three possible explanations. First, it may be that key factors explaining whether participants completed the full study protocol were not measured and therefore absent from the baseline interviews. Another explanation is that there were no systematic differences between participants who did or did not complete the full study protocol. Lastly, it is plausible that factors explaining whether participants completed the full study protocol occurred after the baseline interviews at some point during the 12-month study period.

Results

Table 1 presents scoring, means, and standard deviations for all outcome measures at baseline and follow-up. Tables 2–4 present results of repeated measures ANOVAs for all outcomes using the intent-to-treat sample, which included all PWDs and caregivers who completed baseline interviews. These results were compared with those obtained from parallel analyses of data only from PWDs and caregivers who completed both baseline and follow-up interviews. In terms of statistical significance, results of ANOVAs for the two methods were identical. Thus, results from the more statistically conservative intent-to-treat samples are displayed in the Tables.

Table 2 presents results of the repeated measures ANOVAs for Caregiver Outcomes. Equations show there was no significant change in caregiver depression and role captivity from baseline to follow-up. A significant main effect was found for unmet needs ($F = 51.16$, $p \leq .01$), with caregivers reporting a significant decrease from baseline to

Table 1. Means, Standard Deviations, and Scoring for Caregiver and Person With Dementia (PWD) Outcomes at Baseline and 12 Months in Partners in Dementia Care

		Baseline		12 months	
	Scoring	Mean	*SD*	Mean	*SD*
Caregiver psychosocial outcomes (*n* = 148)					
Depression	0–22, low to high	5.46	3.89	5.32	5.42
Lack of Caregiving Confidence	0–12, low to high	4.77	2.24	4.45	2.02
Isolation	0–21, low to high	10.19	5.02	10.14	4.94
Role Captivity	0–9, low to high	2.90	2.06	2.78	2.01
Physical Health Strain	0–9, low to high	3.34	2.03	3.45	1.98
Unmet Needs	0–39, low to high	17.94	10.03	12.24	9.40
PWD psychosocial outcomes (*n* = 84)					
Depression	0–11, low to high	3.18	2.33	2.92	2.17
Embarrassment about Memory Problems	0–3, low to high	1.16	1.16	1.01	1.01
Isolation	0–3, low to high	1.48	1.45	1.53	1.44
Unmet Needs	0–28, low to high	9.70	7.95	7.37	5.83
Informal support, and community and support service use outcomes (*n* = 148)					
PWD Family/Friend Helpers	0 to ≥10	4.94	2.99	5.38	3.25
Caregiver Family/Friend Helpers	0 to ≥10	4.41	3.25	4.90	3.41
PWD Community Service Use	0–8	2.97	2.31	3.61	2.41
Caregiver Support Service Use	0–2	0.78	0.80	1.06	0.78

follow-up. The average number of unmet needs decreased 31.8% from baseline to follow-up.

Significant interactions, based on PWDs' level of ADL dependencies (low vs. high), were found for lack of caregiver confidence (*F* = 3.90, *p* = .05), isolation (*F* = 8.00, *p* = .01), and physical health strain (*F* = 5.41, *p* = .02). As hypothesized, means for all three of these outcomes indicated caregivers of PWDs with high ADL dependencies experienced greater improvements in outcomes compared with those with low ADL dependencies. Specifically, from baseline to follow-up, caregivers of PWDs with two or more ADL dependencies (high ADL) had increased caregiving confidence, decreased isolation, and decreased physical health strain. The percent change column in Table 2 illustrates these significant interactions. For lack of caregiving confidence, the high ADL group had a 15.5% decrease compared with 3.0% for the low ADL group. For isolation and physical health strain, respectively, the high ADL group had a 12.1% and 9.5% decrease, compared with 5.5% and 9.6% increases for the low ADL group.

Table 3 presents results for PWDs Outcomes. For depression and isolation, there were no significant changes in means. For embarrassment about memory problems, there were significant main and interaction effects. The main effect shows a significant decrease for all PWDs, regardless of level of ADL (*F* = 4.05; *p* = .05). However, the significant interaction (*F* = 8.92; *p* ≤ .01) indicates the main effect is due to a large average reduction of 22.0% in the high ADL group, with the low ADL group having an increase of 12.1%. Significant main (*F* = 12.93; *p* ≤ .01) and interaction effects (*F* = 5.74; *p* = .02) also were found for unmet needs, although the pattern of change is somewhat different from embarrassment. The significant main effect is reflected in an average decrease in unmet needs of 24.0% for all PWDs. The significant interaction shows average decreases in unmet needs for both the high (31.3%) and low (11.7%) ADL groups, although decrease is much larger in the former.

Table 4 presents results for informal support, and community service use by PWDs and support service use by caregivers. Significant main effects, or increases, were found for each of these outcomes including: number of PWD family/friend helpers (*F* = 4.00; *p* = .05); number of caregiver family/friend helpers (*F* = 5.54, *p* = .02); number of PWD community services used (*F* = 8.67, *p* ≤ .01); and number of caregiver support services used (*F* = 20.65, *p* ≤ .01). Percent change in these outcomes from baseline to follow-up show increases in number of family/friend helpers for PWDs of 8.9%, and 11.1% for caregivers. For PWD community service use, there was a 21.4% increase, and for caregiver support service use a 36.2% increase.

Discussion

PDC is the partnership version of the evidence-based program BRI Care Consultation. The goal of this investigation was to test the impact of PDC on PWD and caregiver outcomes in a translation study that mirrors as closely as possible a real-world, non-research delivery context. To replicate a non-research implementation, this translation study: used existing employees, rather than research staff, to deliver the program; followed usual human resource practices and policies of the delivery organizations;

Table 2. Baseline to Follow-Up Changes in Caregiver Depression, Strain, and Unmet Need ($n = 148$)

Outcome	*F*	*p*	Eta squared	Baseline mean	Follow-up mean	Difference	Percent change
Depression	0.31	.58	.002	5.46	5.32	−0.14	−2.6%
Lack of Caregiving Confidence	8.25	.01	.05	4.77	4.45	−0.32	−6.7%
ADL Interaction	3.90	.05	.03				
Low	—	—	—	4.69	4.55	−0.14	−3.0%
High	—	—	—	4.97	4.20	−0.77	−15.5%
Isolation	1.96	.16	.01	10.19	10.14	−0.05	−0.5%
ADL Interaction	8.00	.01	.05				
Low	—	—	—	9.24	9.75	0.51	5.5%
High	—	—	—	12.66	11.13	−1.53	−12.1%
Role Captivity	1.38	.24	.01	2.90	2.78	−0.12	−4.1%
Physical Health Strain	0.12	.73	<.01	3.34	3.45	0.10	3.0%
ADL Interaction	5.41	.02	.04				
Low	—	—	—	3.02	3.31	0.29	9.6%
High	—	—	—	4.20	3.80	−0.40	−9.5%
Unmet Needs	51.16	<.01	.26	17.94	12.24	−5.70	−31.8%

Note. ADL = activity of daily living.

Table 3. Baseline to Follow-Up Changes in Veteran Depression, Strain, and Unmet Need ($n = 84$)

Outcome	*F*	*p*	Eta squared	Baseline mean	Follow-up mean	Difference	Percent change
Depression	1.45	.23	.03	3.11	2.67	−0.44	−14.1%
Embarrassment about Memory Problems	4.05	.05	.10	1.16	1.01	−0.15	−12.9%
ADL Interaction	8.92	<.01	.18				
Low	—	—	—	0.58	0.65	0.07	12.1%
High	—	—	—	1.77	1.38	−0.39	−22.0%
Isolation	1.41	.71	.002	1.48	1.53	0.05	3.4%
Unmet Needs	12.93	<.01	.17	9.70	7.37	−2.33	−24.0%
ADL Interaction	5.74	.02	.08				
Low	—	—	—	6.86	6.06	−0.80	−11.7%
High	—	—	—	12.80	8.80	−4.00	−31.3%

Note. ADL = activity of daily living.

Table 4. Baseline to Follow-Up Changes in Caregiver Reports of Informal Support and Community Service Use (n = 148)

Outcome	F	p	Eta squared	Baseline mean	Follow-up mean	Difference	Percent change
PWD Family/Friend Helpers	4.00	.05	.03	4.94	5.38	0.44	8.9%
Caregiver Family/Friend Helpers	5.54	.02	.04	4.41	4.90	0.49	11.1%
PWD Community Service Use	8.67	<.01	.06	2.97	3.61	0.64	21.4%
Caregiver Support Service Use	20.65	<.01	.12	0.78	1.06	0.28	36.2%

Note. PWD = persons with dementia.

integrated PDC with the other services offered by the delivery organizations; used usual intraorganizational referral and outreach practices; placed few restrictions on eligibility characteristics of PWDs and caregivers; and integrated the program's software into participating organizations' regular computer and recordkeeping systems. Additionally, organizations participating in this translation study are the same types of service delivery sites that most commonly deliver support programs to PWDs and caregivers, including a hospital that is part of a larger health system (i.e., VA Medical Center), an Area Agency on Aging, and an Alzheimer's Association Chapter.

This type of translation study is essential for establishing whether real-world replications of proven evidence-based programs achieve similar positive outcomes as demonstrated in controlled research (Gitlin et al., 2015). Despite the importance of translation studies, few non-pharmacological, evidence-based programs have been tested in real-world settings (Gitlin & Maslow, 2018; Keller-Allen et al., 2017). Although controlled research is central for demonstrating program efficacy and effectiveness, these types of studies are limited in the ability to represent the organizational and community contexts that serve as backdrops for broad-scale implementations, and to determine feasibility and sustainability of programs (Bass & Judge, 2010). If beneficial outcomes are found in translation studies, then administrators, clinicians, service providers, and funders will have greater confidence that innovative, proven programs are feasible, sustainable, and helpful, when implemented by typical health care and/or social service organizations (Wethington & Burgio, 2015). The lack of real-world translation studies is one of the barriers to widespread adoption of available evidence-based programs, which results in many of these programs being inaccessible to most families (Schulz & Eden, 2016, pp. 5–18).

The strength of this study was delivery of PDC in real-world, organizational contexts that mirrored non-research environments. As much as possible, the research study did not artificially alter characteristics of staff who were trained and delivered the program and followed all usual practices and procedures of participating organizations related to human resources and supervision, information technology and security, and the interface with other existing programs and services. Results of this translation study suggest the use of PDC was related to significant improvements in a variety of outcomes for PWDs and caregivers, especially those dealing with more severe levels of impairment as indicated by difficulties completing basic personal care tasks (e.g., dressing, toileting). For caregivers, PDC use was associated with improvements in caregiving confidence, isolation, physical health strain, unmet needs, informal support, and support service use. For PWDs, PDC use was associated with improvements in embarrassment about memory problems, unmet needs, informal support, and community service use. Some outcomes showed greater improvement when PWDs had more personal care difficulties, whereas others improved regardless of levels of personal care difficulties.

A variety of features of PDC, as well as BRI Care Consultation its parent program, may account for these positive program impacts. PDC shifts the focus from a traditional medical model for dementia care to a more holistic approach that can assist with the full range of medical and non-medical needs. This holistic focus is reinforced by the organizational partnership that is established to deliver PDC (i.e., a health care organization and a social service organization). Importantly, this partnership acts as a formal structure for bridging and coordinating services between healthcare and the community organizations. Other key features of PDC and BRI Care Consultation include: establishing an ongoing relationship between Care Consultants and PWDs and/or caregivers; providing coaching and support to find simple and practical solutions to concerns that are most important to PWDs and caregivers; and being a consumer-driven program. The program also is low-cost compared with traditional case management.

Although not the focus of the current study, one limitation of the study is the lack of an equivalent control group. As a result, the study does not conduct between-group comparisons of PWDs and caregivers who did not receive PDC with PWDs and caregivers who did receive PDC. This limitation means it is not possible to know whether observed improvements in outcomes after 12 months were caused by the program, or due to other unmeasured factors or normal changes in outcomes that would have happened had the program not been used.

Despite this important limitation, findings for PWDs and caregivers were very similar to those obtained in previous randomized trials for all three categories of outcomes (Bass et al., 2003, 2013, 2014; Clark et al., 2004). One notable exception was for PWD and caregiver depression, which in the current study did not significantly change from baseline to follow-up. Prior randomized trials found beneficial program effects on depression. One possible explanation for this difference relates to the lack of a control group. In prior randomized trials, program benefits for depression (i.e., differences between treatment and control groups) were in preventing increases, rather than in decreasing, symptoms of depression. Specifically, treatment groups had stable levels of depressive symptoms, whereas the control groups experienced increases (Bass et al., 2013, 2014). Without a control group, it is not possible to replicate this type of beneficial program effect.

Another study limitation stems from the differences in characteristics of this sample study as compared with national representative samples (Wolff & Kasper, 2006). Specifically, sampled PWDs were homogenous and primarily consisted of only white or African American, male veterans. This may limit the generalizability of study findings for PWDs with different backgrounds (e.g., ethnicities, gender identities) who do not receive care from the VA. The caregiver sample primarily consisted of women, who were either spouses or daughters, which is more in line with representative samples. As such, findings may be more generalizable to the population of women caregivers, particularly wife caregivers who tend to be older, more isolated, and at greater risk of physical health issues (Cooley & Asthana, 2010).

Although having a study comprised of veterans may limit generalizability, a strength of the study is the implementation of PDC within the VA healthcare system, which is the largest health care system in the United States (Office of Assistant Deputy Under-Secretary for Health, 2004). Positive findings for PWDs and caregivers suggest that it is possible to create a successful partnership between a large healthcare organization and smaller community-based organizations.

Results from this translation study also reaffirm previous findings from controlled research studies that were able to examine the causal relationships between PDC and improved PWD and caregiver outcomes. As such, results suggest PDC is beneficial when it is delivered as a regular service offering by healthcare and community organizations.

This study also is important because it represents a final step in providing evidence that PDC, and its parent program BRI Care Consultation, are ready for wider distribution and delivery in community implementations that are outside of a research context. Multiple completed randomized trials demonstrated program efficacy, a multisite randomized trial demonstrated program effectiveness, and the current study demonstrates feasibility and effectiveness in a non-controlled real-world implementation. The diversity of evidence provided by these completed studies provides a strong justification for marketing this program to healthcare and community organizations looking to expand or improve their services and support for people living with dementia and their family and friend caregivers.

Since completing the current study, the BRIA has started a process to broadly disseminate the program by marketing to and licensing other service organizations to deliver PDC or BRI Care Consultation. At present, there are over 40 active licensed sites that have served nearly 4,000 families. One licensed site is the Eldercare Services Institute, which is the services arm of BRIA. However, the most common types of organizations licensed to deliver the program are the same as those that partnered in the current study and include healthcare organizations or systems, Area Agencies on Aging, and Alzheimer's Association Chapters or Alzheimer's or dementia support service organizations. Research on the experiences of licensed sites continues, focusing primarily on ways to overcome challenges with getting families to use the program, and finding strategies to financially sustain a program not currently reimbursed by Medicare or Medicaid. The program is one of the selected interventions that has been approved for reimbursement through the Older Americans Act, which is helping to expand its availability to families. Additionally, many licensed delivery sites are finding innovative ways to reach large numbers of caregiving families, such as contracts with employee assistance programs and adapting the program to new populations, such as persons with intellectual or developmental disabilities and their caregivers.

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Conflict of Interest

None reported.

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