

Original Research Article

# Supporting Family Caregivers of Persons With Dementia in the Community: Description of the ‘Memory Care Home Solutions’ Program and Its Impacts

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## Abstract

**Background and Objectives:** Most persons with dementia live at home, cared for by families with limited access to supportive services. We describe “Memory Care Home Solutions” (MCHS), a community-based dementia care program, and evaluate enrollees’ characteristics, strategies provided and implemented, and impact on adverse health-related events (emergency medical calls, emergency room visits, hospitalizations, falls) of persons with dementia.

**Research Design and Methods:** Retrospective observational study of MCHS’ Basic (5 contacts) and Enhanced (additional 4 occupational therapy contacts) services for enrolled caregivers (September 1, 2014 to March 31, 2016). In both programs, caregivers received dementia education, care strategies, and social support. For Enhanced, caregivers had additional opportunities to practice care strategies. Caregivers were interviewed by interventionists at intake, 3 and 6 months (in-person or telephone).

**Results:** Of 717 enrolled caregivers, most were female (73.1%), nonspouses (58.2%), Caucasian (70.8%), 63.02 (standard deviation [*SD*] = 13.20) years old, and caring for persons with dementia of low income (54.1%, <\$39,000). Caregivers reported managing on average 11.64 (*SD* = 4.64) behavioral symptoms and high functional dependence (6 instrumental activities of daily living [IADLs]; 2 activities of daily living [ADLs]). Caregivers opting for Enhanced (*N* = 314, 44.9%) were older (*p* = .025), spouses (*p* = .002), reported greater distress with behaviors (*p* = .051), and managed higher dependence (ADLs, *p* = .018; IADLs, *p* = .002) than caregivers in Basic (*N* = 403, 56.2%). Of 1,462 strategies offered, 68.9% were implemented with no differences in implementation rate between the 2 programs. Of 279 families with follow-up, 53.4% (*N* = 149) reported ≥1 adverse health-related events over 3-months pre-enrollment. By 3-months post-enrollment, 27.2% (*N* = 76) reported ≥1 adverse events; reflecting a 51.0% reduction in caregivers reporting events (*p* < .0005). African Americans, Whites, spouses, and nonspouses benefited similarly.

**Discussion and Implications:** MCHS offers brief supportive services, resulting in fewer adverse health-related events of persons with dementia. Families managing high functional dependence opted for more assistance from occupational therapists. Evaluating real-world programs yields new understandings of caregiver service preferences for staff planning.

**Translational Significance:** Results suggest that family caregivers may benefit from brief community-based supportive services grounded in theory and interventions previously proven in clinical trials. Caregivers are able to self-identify their service needs with those opting for more intensive services reporting greater needs and distress at intake. Evaluating case-mix and benefits of service provision provides important information for planning ways to adequately support families.

**Keywords:** Dementia care, Nonpharmacological management, Caregiving, Supportive services, Community-based programs

Dementia, a neurodegenerative and terminal condition, affects not only the individuals with the disease but also family members who provide most of their long-term care needs with disease progression (Alzheimer's Association, 2016). As there is not a cure or disease modifying treatment to date, supporting families living with dementia at home is a critical public health priority now and into the future (Schulz & Eden, 2016).

A growing evidentiary base suggests that caregiver support programs (Gitlin & Hodgson, 2015) and select non-pharmacological approaches for persons with dementia (Gitlin, Hodgson, & Choi, 2016) can improve quality of life and help families more effectively manage the daily care challenges that commonly occur across the disease trajectory. Home-based strategies shown to be effective include providing caregivers with disease education, instructing in problem-solving approaches to prevent, reduce, address or manage behavioral symptoms, skills training in use of a range of strategies including communication and simplification techniques, environmental modifications, respite, and local resources (Belle et al., 2006; Gitlin & Hodgson, 2015).

These programs have been tested in Phase III efficacy trials, considered the most rigorous methodologically. However, with few exceptions (Gitlin, Reeve, Dennis, Mathieu, & Hauck, 2006), trials have been conducted external to or outside service contexts. This has necessitated a translational phase to adapt interventions for their practical delivery (Gitlin & Czaja, 2016; Nichols, Martindale-Adams, Burns, Graney, & Zuber, 2011; Nichols, Martindale-Adams, Burns, Zuber, & Graney, 2016). Common adaptations include shortening time spent training staff, truncating dose/intensity, eliminating select treatment components, and/or modifying assessments or documentation to conform to reimbursement requirements, clinical exigencies, or tolerability of families (Gitlin, Marx, Stanley, & Hodgson, 2015). The need for translation has contributed to delays in knowledge transfer, with most families in the USA still not receiving evidence-based supportive services.

Another related challenge with efficacy trials is that caregivers who typically volunteer for such studies appear to differ from nonvolunteers providing similar levels of care (Pruchno et al., 2008). Furthermore, most evidence-based programs require extensive training and oftentimes the employment of staff who are not indigenous to the service setting. The need to re-budget to accommodate new hires

and their training as well as new program delivery, typically pose significant barriers to rapid translation, implementation, and system scaling (Gitlin & Czaja, 2016). It remains unclear which programs can be translated for delivery in real-world contexts and whether benefits observed in efficacy trials with convenience and homogeneous samples are similarly obtained in service contexts with more sociodemographically and clinically heterogeneous families.

Another approach for supporting families may be to provide services that are theory-based and informed by evidence generated from clinical trials but which are implemented in ways to conform to local considerations. Two theoretical frameworks utilized in this study include the stress process (Schulz, Gallagher-Thompson, Haley, & Czaja, 2000) and competence-environmental press frameworks. The former suggests that families would benefit from learning effective coping techniques and problem-solving skills to manage daily care challenges and enhance confidence in addressing daily objective stressors (e.g., need to assist with bathing). The competence-environmental press framework suggests that families may benefit from home environmental modifications and specific techniques that help to compensate for declining competencies in the person living with dementia (e.g., decluttering, assistive devices for bathing).

Regardless of theory-base, adopting aspects of evidence-based programs and not others, requires evaluation to determine if benefits can still be achieved within specific delivery contexts. There are few published systematic evaluations of evidence-informed, real-world dementia care services. One exception is a recent systematic evaluation of an occupational therapy service in France involving 421 persons with dementia and their caregivers. Participants received up to 15 home sessions over 3 months to teach caregivers compensatory strategies, environmental simplification, and problem-solving techniques, strategies previously shown to be effective in various evidence-based programs tested in clinical trials. However, the service did not strictly conform to protocols formerly tested in randomized trials but rather drew on specific strategies and components that were then consistently and systematically delivered. Pre-post evaluation of the service showed maintenance of function over 3 months, stabilization of behaviors, and reductions in caregiver burden over 6 months, similar to previous trial findings (Pimouguet, Le Goff, Wittwer, Dartigues, & Helmer, 2017).

To advance an understanding of the practical delivery of dementia care services that have been informed by clinical trials, we conducted a retrospective, observational evaluation of 'Memory Care Home Solutions' (MCHS). MCHS is a community-based service for families of persons with dementia living at home in St. Louis, Missouri, and surrounding area. The purpose of this evaluative study was threefold: to describe family caregivers utilizing the program over the past 2 years; to compare characteristics of those participating in two different program offerings (Basic and Enhanced) and the number and type of care strategies provided and implemented by caregivers; and to evaluate impact of the two program-types on adverse health-related events (911 calls, emergency room visits, hospitalizations, and falls) of persons living with dementia. We expected that families with more care challenges managing functional dependence and behavioral symptoms would opt for the Enhanced program. This program provided additional home sessions by occupational therapists who instructed in specific skills addressing functional dependences and behavioral symptoms, and affording more opportunities to practice strategies at home. We also examined select outcomes by caregiver race (black vs white) and relationship (spouse vs nonspouse) to determine if specific caregivers benefited more than others. Comparing characteristics of caregivers by program-type provides an understanding of case-mix to enable staff and budget planning and determine if there are differential benefits.

Recent national reports, including the National Alzheimer's Plan (US Department of Health and Human Services, 2016) and the National Academy of Medicine's *Families Caring for an Aging Society* (Schulz & Eden, 2016), call for more rapid integration, use, and evaluation of evidence in service contexts to expand their reach and an understanding of impacts on diverse families. Furthermore, practice-based research can advance ways to effectively deliver dementia care services in community settings.

## Methods

### Description of MCHS

Founded in 2002, MCHS is a nonprofit organization whose mission is to extend and improve quality of life at home for people with memory loss or dementia, and their family caregivers. Funding consists of a mix of grants, private donations, and line-item financing from the State of Missouri. MCHS was launched with support from an academic health center, guidance from experts in dementia care, and systematic reviews of conceptual frameworks and caregiver interventions tested in clinical trials including those providing psychosocial and educational caregiver support programs (e.g., Mittelman, Ferris, Steinberg, & Shulman, 1993) and skill-building with outcomes for both caregivers and persons with dementia (e.g., Gitlin et al., 2001).

Several conceptual frameworks inform MCHS program delivery. The stress process model of the Resources for Enhancing Alzheimer's Caregiver Health initiative

(REACH; Schulz, Gallagher-Thompson, Haley & Czaja, 2000) suggests that objective factors (functional dependence, behaviors, and environment) combined with subjective appraisals impact caregiver wellbeing. Caregivers who perceive they are unable to effectively manage objective stressors may feel overwhelmed, burdened, and distressed.

Complementing this model are person-environment fit frameworks postulating that with cognitive decline, persons with dementia experience increased vulnerability to physical and social environments (Lawton & Nahemow, 1973). This decline results in lowered thresholds for processing and tolerating stimuli, and physiological and psychological distress manifesting in behavioral symptoms, poorer function, and lower quality of life (Kales, Gitlin, & Lyketsos, 2015). Strategies provided are designed to reduce objective, environmental stressors, instruct caregivers in effective coping and management techniques, and link families to needed resources to break the downward spiral of the stress process cycle. For example, a caregiver may become distressed providing toileting and bathing assistance to a person living with dementia who may reject needed help. Based on these frameworks, interventionists would instruct caregivers in the use of adaptive shower equipment (e.g., tub bench, grab bars, handheld shower), and visual cues to help remind the person with dementia of shower days and the steps involved. The caregiver would also be taught simple stress reduction techniques to manage situational distress as well as communications strategies such as use of statements versus questions, how to minimize environmental distractions (e.g., remove clutter) and how to use re-direction. These environmental modifications and compensatory techniques may result in a less stressful and more functional environment for both caregivers and persons living with dementia.

MCHS designed two service approaches based on these conceptual frameworks; Basic and Enhanced.

### Basic

This program is informed mostly by psychosocial interventions providing caregiver education, support, validation, and skills training in behavioral symptom management (Burgio et al., 2009; Mittelman, Ferris, Steinberg, & Shulman, 1993). MCHS incorporated components of these interventions including individualized counseling sessions tailored to caregiver needs, ad hoc telephone counseling at follow-up points and as needed, and problem-solving strategies for managing behavioral symptoms, identifying community resources, and using environmental modifications.

The Basic program involves up to five contacts for approximately a total of 5.75 hours over 12 months (Table 1). At an initial telephone contact, a social worker explains program options and obtains demographic and family information. Caregivers are mailed questionnaires to complete independently. A 2-hour home visit (or elsewhere if family prefers) is conducted within 4 weeks of intake by a licensed social worker or occupational therapist

**Table 1.** Overview of MCHS Basic and Enhanced Program Options

Contact # and time spent	Purpose and clinician	Contact type	Month	Session content
Basic 1 30 minutes	Intake MSW	Telecontact	0	<ul style="list-style-type: none"> <li>• Provide overview of Program goals</li> <li>• Invite other caregivers to initial family consultation</li> <li>• Schedule initial family consultation</li> <li>• Mail preassessment packet to assess for physical functional dependence, behavioral symptoms, caregiver strain, health care utilization history, medication list</li> <li>• Provide overview of visit goals</li> <li>• Review pre-assessment packet</li> <li>• Conduct clinical interview (review daily routines, activity interests, caregiver strengths, and challenges)</li> <li>• Observe family communication patterns</li> <li>• If contact in home—evaluate home environment for supports and barriers</li> <li>• If contact in-office—provide education on environmental modifications</li> <li>• Educate on dementia symptoms, behaviors, and progression</li> <li>• Provide referrals to community resources</li> <li>• Issue caregiving guidebook<sup>a</sup> and written educational materials</li> <li>• Instruct in relevant environmental and caregiving strategies</li> <li>• Develop strategy plan which includes family's 3 to 4 priorities and next steps for caregivers and MCHS</li> <li>• Offer OT visits (Enhanced) for additional assistance</li> <li>• Schedule next appointment if interested in OT visits</li> <li>• Provide caregiver satisfaction survey</li> <li>• Send summary report to PCP or referring physician (with family permission)</li> </ul>
2 2 hours with family	Initial family consultation MSW or OT	Home visit or in-office (per family preference)	1	<ul style="list-style-type: none"> <li>• Provide overview of session goals</li> <li>• Review progress from initial family consultation</li> <li>• Identify 3 function or activity goals</li> <li>• Provide instruction in strategies, communication and cueing, use of activity, task simplification, environmental modifications</li> <li>• Use modeling and return demonstration to teach caregivers how to accomplish functional tasks (self-care, therapeutic activities, community integration training)</li> <li>• Provide training in use of adaptive equipment/assistive technology</li> <li>• Make minor home modifications (e.g., declutter, provide labels, add visual contrast, organize, install safety devices such as cabinet latches, door alarms, appliance locks)</li> <li>• Brainstorm and problem-solve with caregiver re: new or recurrent challenges in daily routine</li> <li>• Validate caregiver and person with dementia participation and efforts</li> </ul>
2 hours for care coordination activities				
3 Up to 30 minutes	Follow-up assessment MSW or OT	Telecontact	3	<ul style="list-style-type: none"> <li>• Mail reminder postcard to invite caregiver to call at a convenient time or expect a call from MCHS staff</li> <li>• Review progress toward strategy plan</li> <li>• Determine which recommended strategies were implemented</li> <li>• Discuss barriers if strategies not implemented</li> <li>• Brainstorm and problem-solve with caregiver concerning new or recurrent challenges</li> <li>• Provide education on new strategies or community resources as needed</li> </ul>

**Enhanced**

OT Contacts #3-6 (1 hour with family; 1 hour for prep/documentation)

-Provide overview of session goals

-Review progress from initial family consultation

-Identify 3 function or activity goals

-Provide instruction in strategies, communication and cueing, use of activity, task simplification, environmental modifications

-Use modeling and return

demonstration to teach caregivers how to accomplish functional tasks (self-care, therapeutic activities, community integration training)

-Provide training in use of adaptive equipment/assistive technology

-Make minor home modifications (e.g., declutter, provide labels, add visual contrast, organize, install safety devices such as cabinet latches, door alarms, appliance locks)

-Brainstorm and problem-solve with caregiver re: new or recurrent challenges in daily routine

-Validate caregiver and person with dementia participation and efforts

**Table 1. Continued**

Contact # and time spent	Purpose and clinician	Contact type	Month	Session content
4 Up to 30 minutes	Follow-up assessment MSW or OT	Telecontact	6	<ul style="list-style-type: none"> <li>• Repeat assessments for function and healthcare utilization</li> <li>• Encourage caregiver to call for support or additional brainstorming as needed</li> <li>• Mail reminder postcard to invite caregiver to call at a convenient time or expect a call from MCHS staff</li> <li>• Review progress toward strategy plan</li> <li>• Determine which recommended strategies were implemented</li> <li>• Discuss barriers if strategies not implemented</li> <li>• Brainstorm and problem-solve with caregiver concerning new or recurrent challenges</li> <li>• Provide education on new strategies or community resources as needed</li> </ul>
5 15 minutes	Final survey MSW or OT	Mail	12	<ul style="list-style-type: none"> <li>• Repeat assessments for function and health care utilization</li> <li>• Encourage caregiver to call for support or additional brainstorming as needed</li> <li>• Mail final assessment forms for function, health care utilization, and caregiver satisfaction</li> <li>• Provide closing letter encouraging caregiver to call for support or additional brainstorming as needed</li> <li>• Follow-up by clinician on any remaining concerns reported in final survey</li> </ul>

Note: MSW = masters of social work; OT = occupational therapist; times provided reflect averages based on sample of 717.  
<sup>a</sup>Rzethly, H. (2014) *Memory Care Guidebook: Strategies and solutions for family caregivers*, Memory Care Home Solutions.

(interventionist) depending on staff availability. Families with urgent needs are offered appointments immediately or within 2 weeks. During the consultative session, questionnaires (described below) are reviewed, a clinical interview is conducted, three to four care challenges are identified and prioritized with caregivers, and an action plan with specific strategies to address prioritized concerns is provided. The action plan involves a list of three to seven care strategies tailored to needs and preferences identified by caregivers with guidance from interventionists. Strategies provided are customized to the needs and preferences of each family and may include home-safety recommendations, minor home modifications, dementia education, adaptive equipment use, and skills training to manage functional decline and behavioral symptoms. Each strategy is reviewed, demonstrated, and practiced with caregivers.

At the conclusion of the consultation, all families are offered the option of additional home services with an occupational therapist (Enhanced Program). Families opting for occupational therapy intervention continue with the Enhanced program.

### Enhanced

Following the initial Basic consultative visit, caregivers opting for the Enhanced program, receive up to four, 1-hour, additional home visits with occupational therapists. Visits were mostly informed by the NIH, REACH I Philadelphia site, Skills<sub>2</sub>Care<sup>R</sup> program (Gitlin et al., 2003). Adaptations to this program include varying the number of sessions offered and assessments used. Similar to the original program, however, occupational therapists evaluated the home environment, taught stress reduction techniques, problem solving, and used brainstorming to generate strategies for simplifying communications, physical environments, and daily tasks to support daily functioning of persons with dementia, reduce caregiver distress, better manage behavioral symptoms and health conditions, and prevent avoidable hospitalizations (Gitlin et al, 2001; Graff et al., 2006; Dooley & Hinojosa, 2004). Also, a home-safety assessment emphasizes identification and remediation of fall risk factors. Sessions provide opportunities for more in-depth and hands-on learning and practice of strategies than the Basic program (American Occupational Therapy Association, 2014).

In both Basic and Enhanced, dementia education focuses on preventing common causes of hospitalization such as medication management and errors, dehydration, and urinary tract infections. Caregivers are instructed in proper hydration and toileting techniques and to contact MCHS clinicians with changes in dementia-related symptoms including behaviors or other medical concerns so that health changes can be quickly communicated with the physician to prevent or avoid emergency medical service use. We reasoned that educating caregivers about common conditions leading to hospitalization and providing a safety net by enabling caregivers to contact MCHS with status changes or questions, would result in reductions of adverse health-related events.

### Interventionist Backgrounds, Training, and Monitoring

Interventionists are required to hold a masters of social work or occupational therapy degree and have more than 1 year geriatric practice experience. Training is provided by the program director and follows a policy and procedure manual with orientation lasting 30 to 60 days. Interventionists participate in competency testing concerning use of assessment instruments, documentation, strategies provided, and follow-up protocols. To monitor treatment fidelity, interventionists participate in quarterly supervisory meetings with the program director and clinical peers, and chart audits are completed. An external specialist from Washington University serves as Quality Assurance Advisor. Additionally, interventionists attend bimonthly case conference meetings to present and discuss complex clients, receive ongoing education on local resources, and learn of changes to policies or procedures.

### Study Sample and Procedures

For this evaluation, we included families enrolled in MCHS from September 1, 2014 to March 31, 2016 with data on variables of interest. Families are referred to MCHS from primary care and specialty physicians, ancillary health care providers, community partners including Area Agencies on Aging and the Alzheimer's Association, or by word-of-mouth. To enroll, families contact MCHS and participate in a brief telephone interview to determine eligibility and plan the initial visit. Participants are informal (unpaid family member, friend) caregivers of persons with suspected or diagnosed Alzheimer's disease or related dementias residing at home (i.e., not residential care), and willing to participate in at least one consultative session. Families are encouraged to invite other family members/caregivers to participate and initial visits may occur with or without the presence of persons with dementia as requested by families.

Caregivers are asked to complete questionnaires prior to the initial consultative visit and at 3- and 6-month follow-up visit or telephone assessments. During follow-up assessments, interventionists evaluate program impact, review, and reinforce strategy use, determine if strategies were implemented, troubleshoot, and provide psychosocial support. Families are also encouraged to contact staff at any time if their needs or situation changes, or if they wish additional support, at which point additional telephone or home consultation is provided.

Data are used continuously by MCHS to describe participant characteristics, inform treatment planning, evaluate program impact, and respond to funders. As this evaluation is part of MCHS's on-going quality assurance and evaluative approach and was conducted post hoc, it was exempted from Johns Hopkins University Institutional Review Board oversight.

## Measures

A practical approach to data collection is employed by MCHS in that data capture is integrated into programmatic procedures and needs. Data are used by MCHS to describe client characteristics, understand staffing needs, and determine program impact. Measures selected for use have strong psychometric properties, were previously used in caregiver trials, have clinical utility, and are designed to not be burdensome to families.

For this evaluative study, we examined demographic information collected at initial telephone intake including age, sex, race, education, income, and relationship of caregivers and persons with dementia. Families also completed questionnaires prior to the first home consultative session (baseline). The Modified Caregiver Strain Index (CSI) was used to assess caregiver strain at in-take and previously found to have adequate psychometric properties. Caregivers score 13 items referring to different care challenges on a 3-point scale (0 = No, 1 = Yes, Sometimes, and 2 = Yes, On a Regular Basis; Thornton & Travis, 2003).

To assess the number of behavioral symptoms occurring 3 months prior to program enrollment, 13 of 24 items were used from the Revised Memory and Behavior Problems Checklist (RMBPC; Teri et al., 1992). An additional 11 items were also included reflecting other common behaviors reported by caregivers in the program. Thus, a total of 24 behaviors were assessed as occurring (0 = no; 1 = yes) in the past 3 months. A score was calculated reflecting total number of occurring behaviors. For each behavior occurring, caregivers rated their upset level along five points (0 = not at all, 1 = a little, 2 = moderately, 3 = very much, and 4 = extremely). A mean score was derived by summing scores across items and dividing by the number of behaviors that occurred.

Functional activities of daily living (ADL) and instrumental activities of daily living (IADL) status were measured by the Katz Index and Lawton IADL Index. The Katz Index (Katz, Down, Cash, & Grotz, 1970) measures independence/dependence for six basic living activities, with scores ranging from 0 (low function) to 6 (high function). A total score reflects number of activities in which persons with dementia are independent. The Lawton IADL index measures independence levels for eight IADL (Lawton & Brody, 1969) with scores ranging from 0 (low function) to 8 (high function; Sikkes, de Lange-de Klerk, Pijnenburg, Scheltens, & Uitdehaag, 2009).

Four adverse health-related events of persons with dementia were considered: telephone calls to emergency medical services (911 calls in the USA), emergency room visits, hospitalizations, and falls. These were assessed by asking caregivers to indicate the number of times each event occurred over the past 3 months. Data were collected at baseline, 3- and 6-month follow-up assessments.

As there is no agreed on terminology or classification of nonpharmacological strategies for dementia care, a categorization scheme was developed to evaluate whether strategies recommended to caregivers in both Basic and Enhanced programs were implemented by 6 months. Six MCHS

clinicians (occupational therapists and social workers) each independently grouped recommendations provided to the 717 families of this evaluation into higher order categories. Seven categories (see Table 3 for their definition and examples) were established based on consensus. Disagreement was found for only one strategy, spiritual needs, which was ultimately considered a form of Activity Engagement.

Interventionists either observed implementation of strategies in homes at 3- or 6-month follow-ups or for those not receiving occupational therapy visits, caregivers were asked directly of their use of strategies at telephone follow-ups.

## Statistical Analysis

Data were examined for the total sample and also by program type (Basic/Enhanced). We used Chi-square or *t*-tests to evaluate whether caregivers in the two programs differed by demographic characteristics or functional and behavioral profiles of persons with dementia. We also examined the proportion of recommended care strategies that were implemented for the total group and by program type. A Mann-Whitney *U* test was conducted to determine differences between number of strategies recommended and implemented by caregivers in Basic and Enhanced groups. A Chi-squared analysis was conducted to determine differences between implementation rates by strategy type between the two programs.

We compared the number of each adverse health-related event (hospitalization, emergency room visits, 911 calls, and falls) experienced 3 months prior to and post-enrollment using independent samples *t*-test to explore between group differences (Basic/Enhanced). We also calculated the total number of adverse health-related events and compared the total number of events occurring 3 months prior to and 3 months after enrollment into the program using Wilcoxon Signed Rank Test. We also conducted similar analyses for the subset of caregivers with 6-month follow-up data. Finally, we compared strategy use and adverse health-related events by caregiver race (black/white) and relationship (spouse/nonspouse) at 3-months. Statistical analyses were conducted using SPSS Statistics, version 21 (IBM, 2010).

## Results

### Background Characteristics

As shown in Table 2, of 717 caregivers enrolled in MCHS during the 18-month evaluative period, most were female (73.1%), nonspouses (58.2%), and Caucasian (70.8%), with an average age of 63.02 (*SD* = 13.20). One-quarter self-identified as African American (25.5%). Caregivers expressed on average mild upset with behavioral symptoms (mean = 20.66, *SD* = 15.53, range = 0–83) and strain (mean = 11.24, *SD* = 5.66, range = 0–33) at enrollment. Of 717 persons living with dementia, caregivers reported that most were female (60.4%), and Caucasian (71.5%), of low income (54.1%, <\$39,000), with an average age of 78.97 (*SD* = 9.06).

**Table 2.** Baseline Characteristics of Persons With Dementia and Family Caregivers Overall and in Basic and Enhanced MCHS Programs

	Total (N = 717)	Basic (N = 403)	Enhanced (N = 314)	$\chi^2$	T	p
Persons with dementia						
Gender, n (%)				1.763		0.184
Male	284 (39.6%)	151 (37.5%)	133 (42.4%)			
Female	433 (60.4%)	252 (62.5%)	181 (57.6%)			
Age, mean (SD, range)	78.97 (9.06, 48–99)	79.46 (9.17, 49–97)	78.36 (8.90, 48–99)		1.564	0.118
Race, n (%)				4.299		0.117
Caucasian	513 (71.5%)	299 (74.2%)	214 (68.2%)			
African American	183 (25.5%)	91 (22.6%)	92 (29.3%)			
Other	21 (2.9%)	13 (3.2%)	8 (2.5%)			
Income, (%)				1.657		0.646
\$40,000 and over	116 (16.2%)	62 (15.4%)	54 (17.2%)			
\$20,000 to \$39,999	171 (23.8%)	98 (24.3%)	73 (23.2%)			
Below \$20,000	217 (30.3%)	117 (29%)	100 (31.8%)			
Not available	213 (29.7%)	126 (31.3%)	87 (27.7%)			
Behavior frequency, mean (SD, range)	11.64 (4.64, 1–42)	11.49 (4.824, 1–41)	11.82 (4.365, 2–24)		-0.877	0.381
Katz, mean (SD, range)	4.28 (1.98, 0–12)	4.44 (1.94, 0–6)	4.08 (2.01, 0–12)		2.363	<b>0.018<sup>a</sup></b>
Lawton, mean (SD, range)	2.43 (2.10, 0–10)	2.67 (2.186, 0–8)	2.14 (1.957, 0–10)		3.175	<b>0.002<sup>a</sup></b>
Family caregivers						
Gender, n (%)				1.611		0.204
Male	193 (26.9%)	101 (25.1%)	92 (29.3%)			
Female	524 (73.1%)	302 (74.9%)	222 (70.7%)			
Age, mean (SD, range)	63.02 (13.20, 20–91)	61.53 (12.78, 20–91)	65.28 (13.557, 25–91)		-2.26	<b>0.025<sup>a</sup></b>
Race, n (%)				3.16		0.206
Caucasian	505 (70.8)	294 (73.5%)	211 (67.4%)			
African American	184 (25.8%)	94 (23.5%)	90 (28.8%)			
Other	24 (3.4%)	12 (3%)	12 (3.8%)			
Relationship to person with dementia (%)				9.899		<b>0.002<sup>a</sup></b>
Spouse	300 (41.8%)	148 (36.7%)	152 (48.4%)			
Nonspouse	417 (58.2%)	255 (63.3%)	162 (51.6%)			
Caregiver strain, mean (SD, range)	11.24 (5.66, 0–33)	10.73 (5.865, 0–26)	11.80 (5.375, 0–33)		-2.298	<b>0.022<sup>a</sup></b>
Upset with behaviors, mean (SD, range)	20.66 (15.53, 0–83)	19.41 (15.094, 0–72)	22.05 (15.908, 0–83)		-1.957	0.051

Note: SD = standard deviation.

<sup>a</sup>Bold, significance determined at  $p \leq .05$ .

As to function of persons living with dementia, on average, caregivers reported very high dependence in or low IADL function (Lawton index, mean = 2.43, SD = 2.10) and independence in four of six ADLs (Katz index, mean = 4.28, SD = 1.98). Caregivers also reported at intake an average of 11.64 (SD = 4.64) behavioral symptoms occurring 3 months prior to program enrollment.

### Basic and Enhanced Caregiver Profiles

Caregivers in Basic and Enhanced were similar in gender, race as well as for income levels of persons living with dementia. However, caregivers choosing Enhanced were slightly older ( $p = .025$ ), more likely to be spouses ( $p = .002$ ), and reported greater distress with behaviors

( $p = .051$ ). Caregivers in Enhanced also reported greater dependence in ADLs ( $p = .018$ ) and IADLs ( $p = .002$ ) of persons living with dementia at enrollment.

Although a similar number of behaviors were reported by caregivers in both programs, caregivers in Basic (N = 403, 56.2%), reported different behaviors. Those in Basic reported “trouble remembering recent events” (N = 269, 66.7%), “forgetting what day it is” (N = 259, 64.3%), and “asking the same question” (N = 256, 63.5%) as the most frequently occurring behaviors but indicated most distress with “resistance to bathing, “arguing, irritability and/or complaining,” and “losing, misplacing, hiding things.” Caregivers in the Enhanced program (N = 314, 43.8%) reported “forgetting what day it is” (N = 253, 80.6%), “trouble remembering recent events” (N = 249, 79.3%), and

“asking the same question” ( $N = 239$ , 76.1%) as the most frequently occurring behaviors; they were most distressed by “driving unsafely,” “resistance to bathing,” and “crying and tearfulness.”

### Number and Time of Contacts by Program Type

Caregivers in both programs completed the initial two contacts (30-minute intake call followed by 2-hour consultative session). Staff spent an average of 2.5 hours in direct contact, by telephone at intake and at the in-person initial meeting, with each family, followed by an additional 2 hours to prepare the strategy plan, make referrals, and coordinate care with physicians and other providers for a total time of 4.5 hours per family. All caregivers are offered the option of ad hoc phone counseling between scheduled service contact points. During this evaluative period, 239 (33.3%) caregivers made a total of 543 unscheduled calls to MCHS, for a total of 146.25 hours of telephone counseling, or an average of 16.2 minutes per call.

#### Basic

Caregivers in this program completed on average three contacts (intake, initial consultative session, and contact at 3- or 6-month follow-up). Of the 403 caregivers in the Basic program, 135 (33.5%) participated in scheduled 3-month follow-up assessments by phone, and 79 (19.6%) participated in the scheduled 6-month follow-up. Additionally, 112 (27.8%) caregivers initiated 221 calls to MCHS outside of scheduled follow-up time points for a total of 59.75 hours of nonscheduled phone support. This represents an average of 1.97 unscheduled calls per family, with an average call length of 16.2 minutes.

#### Enhanced

Caregivers in this program completed on average 5.5 contacts (intake, initial consultative session, average of 2.5 occupational therapy visits and contact at 3- or 6-month follow-up). Of 314 caregivers in Enhanced, 144 (45.9%) participated in scheduled 3-month follow-up assessments, and 77 (24.5%) participated in the 6-month follow-up. Additionally, 127 (40.4%) caregivers initiated a total of 322 calls for a total of 86.5 hours of nonscheduled phone support. This represents an average of 2.54 calls per family for an average call length of 16.1 minutes.

### Number and Type of Strategies Offered and Implemented

As shown in Table 3, 489 (68.2%) caregivers provided follow-up data by 6 months concerning implementation of recommended strategies. Missing data were due primarily to caregiver unavailability. For this subsample, a total of 1,462 strategies were offered: 477 strategies or 3.6 per family in Basic, and 531 strategies or 4.2 per family in Enhanced. As expected, caregivers in Enhanced were

recommended significantly more strategies than caregivers in Basic ( $Z = -3.854$ ,  $p \leq .0005$ ).

Of total strategies offered, 1,008 (68.9%) were implemented. Caregivers in Basic implemented 66.5% of recommended strategies, and caregivers in Enhanced implemented 71.3%, though this difference was not statistically significant ( $Z = -1.141$ ,  $p = .254$ ). The most frequently recommended strategy type was for referral and linkages (327 strategies), followed by respite (261 strategies), and environmental strategies (251 strategies). There were no large or statistically significant differences between the two programs as to the types of strategies adopted and both groups implemented similar types of strategies.

There were no large or statistically significant differences in the number of strategies offered and the rate of strategy implementation by race (black vs white). However, while there was no difference in number of strategies offered, nonspouses had a lower rate of implementation than spouses ( $N = 701$ ;  $t = 2.848$ ;  $p = .005$ ).

### Adverse Health-Related Events

Of 717 total caregivers, 279 (38.9%; Basic = 135; Enhanced = 144) caregivers provided 3-month data concerning adverse health-related events among persons living with dementia. A comparison of caregivers providing baseline and follow-up data ( $N = 279$ ) to 438 caregivers who provided baseline data only, revealed no statistically significant differences in demographic characteristics except that as anticipated, spousal caregivers, and caregivers in Enhanced were more likely to participate in follow-up.

For the 279 caregivers in Basic and Enhanced who provided 3-month data, 53.4% ( $N = 149$ ) reported  $\geq 1$  adverse health-related events during the 3 months prior to program enrollment; this involved 51.9% ( $N = 70$ ) in Basic and 54.9% ( $N = 79$ ) in Enhanced. At 3 months post-enrollment, 27.2% ( $N = 76$ ) reported  $\geq 1$  events; 24.4% ( $N = 33$ ) in Basic and 29.9% ( $N = 43$ ) in Enhanced (all  $p < .0005$ ). This represented a decline of 51.0% in the number of caregivers reporting any type of event(s) from baseline to post-enrollment for all cause events.

Similarly, for each type of adverse health-related event (falls, 911 calls, emergency department visits, hospitalizations), a fewer number of caregivers at 3 months reported occurrences for each of these months compared to the 3 months prior to participating in MCHS services ( $p < .0005$ ). Specifically, for falls, 108 caregivers reported this event at baseline compared to 47 (43.5% decrease) post-enrollment; for 911 calls, 54 caregivers reported this event at baseline compared to 30 (55.6% decrease) post-enrollment; for emergency room use, 88 caregivers reported this event at baseline compared to 43 (48.9% decrease) post-enrollment; and for hospitalizations, 79 caregivers reported this event at baseline compared to 26 (32.9% decrease) post-enrollment. Notably, 911 calls showed the largest decrease from baseline to post-enrollment (55.6%), whereas hospitalizations showed the smallest statistically significant decrease (32.9%).

**Table 3.** Strategies Recommended and Implemented by Six months for Total Group and Program Type

Strategy type	Definition of strategy type	Total (N = 489)		Basic (N = 254)		Enhanced (N = 235)	
		# Strategies	N, % implemented	# Strategies	N, % implemented	# Strategies	N, % implemented
Activity engagement	Strategies to identify, set-up, simplify activities and engage persons with dementia	239	176 (73.6)	104	73 (68.3)	135	103 (76.3)
ADLs	Strategies to assist initiation, set-up, and completion of self-care tasks	127	99 (78.0)	55	44 (80.0)	72	55 (76.4)
Behavioral	Strategies for communication, de-escalating agitation, prevention	153	121 (79.1)	89	67 (75.3)	64	54 (84.4)
Referral and linkage	Connections to community resources and support groups	327	164 (50.1)	173	108 (62.4)	154	103 (67.3)
Environmental strategies	Modifications for safety, function (decluttering, visual cues, door alarms/wandering deterrents)	251	164 (65.3)	123	74 (60.2)	128	90 (70.3)
IADLS	Strategies to assist with driving retirement, medication management, meal preparation, finances	104	78 (75.0)	58	44 (74.6)	46	34 (73.9)
Respite	Resources to provide caregivers time-off or assistance with caregiving duties, including linkage with adult day programs, short-term residential care settings, and professional in-home care services	261	159 (61.1)	115	67 (58.3)	146	92 (63.0)
Total number of strategies		1,462	1,008 (68.9)	717	477 (66.5)	745	531 (71.3)

Note: ADLs = activities of daily living; IADLS = instrumental activities of daily living.

There were no large or statistically significant differences ( $t(276) = -.340, p = .480$ ) in type and number of events reported by caregivers between Basic and Enhanced at enrollment or 3 months later; persons living with dementia in both groups experienced a similar statistically significant decrease in health-related adverse events as reported by their caregivers.

An examination of type and number of events by race (black vs white) and relationship (spouse vs nonspouse) also did not reveal statistically significant differences; that is all subgroups had similar and statistically significant decreases from pre- to post-enrollment.

A secondary set of analyses examined program impact on adverse health events for 104 caregivers with data for all three testing occasions (baseline, 3 and 6 months). These analyses yielded comparable results to the 3-month outcomes. We found statistically significant decreases in the

number of caregivers reporting adverse events at 6 months compared to the number reporting these events at baseline.

## Discussion

We present an evaluation of a community-based clinical service, MCHS, a not-for-profit organization, for family caregivers of persons with dementia. The two levels of supportive services offered are grounded in theoretical frameworks and informed by evidence from randomized controlled trials of psychosocial supportive and skill-building interventions. This evaluation offers a snapshot of service provision over 18 months to understand the characteristics of caregivers enrolled in MCHS, which service-type (Basic or Enhanced) is chosen and by whom, and impact on adverse health-related events concerning persons living with dementia.

We learned that most caregivers opted for the brief consultative service, or the Basic program. Caregivers choosing the Enhanced program had more care needs, were primarily spouses and were caring for persons with greater functional dependence than those in the Basic program. An understanding of this case-mix and use of services can help inform staffing, organization of services, and identification of those most in need. Of importance is that both Basic and Enhanced programs yielded similar benefits in terms of number of care strategies offered by interventionists and implemented by caregivers and the impact of services on four adverse health-related events for persons living with dementia.

A strength of MCHS is that families control the level and type of services received. As caregivers in Basic and Enhanced had similar benefits, having caregivers self-identify the level of support they perceive they need appears to be an effective organization approach. Even when families are offered opportunities to obtain additional service contacts, they appear to exercise this option judiciously. Only a little more than a quarter of families in Basic self-initiated additional calls for assistance. More caregivers in Enhanced (40.4%) sought additional assistance; yet, unscheduled calls were under 30 minutes, demonstrating that brief, intermittent support appears to be what caregivers needed and sought, even for those with more care challenges. From a policy perspective, this is good news in that it appears that not all families seek continuous supportive services and that when on-going support is offered, families self-modulate use of this option.

We also found that both programs were relatively brief (up to five telephone or in-person contacts). This is consistent with recent translations of evidence-based programs reporting adjustments to dose and intensity from efficacy trials in order to conform to service delivery restrictions. For example, the 12 session REACH II intervention was truncated to four visits to accommodate staffing, agency budgets, reimbursement structures, and family preferences (Nichols et al., 2016).

MCHS services can be understood using RE-AIM (Reach, Effectiveness, Adoption, Implementation, and Maintenance) which provides a broad framework for understanding public health impact (Glasgow, Vogt, & Boles, 1999). Since its inception, MCHS has provided some level of outreach, education, or service to a total of 92,000 individuals between 2002 and 2016. Although this is impressive, it is not possible to determine reach as we do not know how many families in the region know about its services nor how many have chosen not to participate. Nevertheless, enrollment in MCHS has steadily increased by more than 70% each year since the addition of Enhanced occupational therapy services. A related point is that most caregivers utilizing the service were Caucasian, raising the question as to how to expand reach to more diverse families/communities.

As to effectiveness, our evaluation of a subset of families for which follow-up data were available demonstrates that participation in MCHS resulted in highly meaningful

outcomes. There was a reduction of 51% in the number of caregivers reporting  $\geq 1$  adverse health-related events from time of enrollment to 3 months later. This reduction may reflect significant cost savings to families and society at-large (Jutkowitz et al., 2017).

We consider adoption at the individual, family perspective. We found that close to 70% of recommended strategies were employed by caregivers. Similar to other nonpharmacological studies, families are highly selective concerning what they choose to adopt in terms of nonpharmacological recommendations/strategies to address care challenges. Decisions may be based on a variety of factors including finances and readiness or willingness to make behavioral and environmental changes (Gitlin & Rose, 2016). A common practice in evidence-based caregiver support programs and which is used by MCHS, is to actively involve families in the problem-solving and brainstorming processes for deriving solutions versus being prescriptive. Active involvement in such processes provides insights as to caregiver preferences and values, and also heightens receptivity to and adoption of derived strategies (Belle et al., 2006).

As to implementation, MCHS has written protocols and staff are similarly trained in their use. Staff training and on-going case debriefings offer opportunities to evaluate consistency in service provision. However, there is no implementation data available. A recommendation from this evaluation would be for MCHS (and other community-based supportive programs), to carefully document adaptations made to previously tested interventions and to derive mechanisms for documenting and assuring consistency in delivery.

MCHS makes every attempt to evaluate the number of strategies recommended and implemented by caregivers and the impact of services on adverse health-related events. However, many families find completing questionnaires as burdensome and unnecessary from their vantage point. Thus, it is not possible to evaluate maintenance of effects over time for families.

Several limitations of this evaluation are noteworthy. First, this is an evaluation of a real-world service program and thus, there may be more missing follow-up data than that encountered in efficacy or effectiveness trials. Few families participated in follow-up data collection efforts. As a service program, families may not feel obligated to participate in follow-up evaluations, particularly if they do not perceive its relevance to the services they seek. A limitation of service evaluations is that methodological decisions are necessarily informed by and must conform to the realities of service delivery. Standardized scales of caregiver burden, upset, and depression or of dementia knowledge, and skills typically used in clinical trials may be too lengthy and perceived as burdensome by families. Families also may not be familiar with and respond favorably to Likert-type scales, perceiving them as formal, intrusive, and irrelevant. The purpose of the follow-up contacts made by MCHS staff is to offer families continued support as well as to evaluate impact; however, as to the latter, families often indicated that they did not want to complete questionnaires. MCHS

has found it challenging to collect in particular data concerning caregiver distress and wellbeing.

It is unclear as to the generalizability of results to other communities as we are unable to compare who opts for MCHS to those who do not and as a service program, there is not a control group. Although 25% of the sample self-identified as African American, the relevance of the program to diverse caregivers is still unclear.

Another limitation may be selection bias. In MCHS, families determine their exposure to treatments. On one hand, this may optimize service relevance and reflect a strength of the program; families themselves regulate type and level of support needed. On the other hand, methodologically, this poses a challenge; not all families received all treatment elements and an intent to treat framework for evaluation as in randomized clinical trials cannot be employed. It is not possible to discern if more benefits would have been achieved if more services were received or whether families without follow-up data benefited or not. A related point is that caregivers elect to participate in scheduled follow-ups and as we indicated, many refuse to complete follow-up questionnaires. Nevertheless, a comparison of baseline characteristics of caregivers with follow-up data to those without revealed no large or statistically significant differences.

It is difficult to fully interpret outcomes, particularly adverse health-related events, as there is not a standard comparison group, a context for fully understanding baseline values or control for threats to internal validity. Also, the evaluation necessarily relied on self-report and caregiver recall. Finally, the service is unable to collect important data points including dementia diagnosis, etiology, or disease stage that would enable better characterization of program participants and generalizability. As many people with dementia are not diagnosed, and the organization has a mission to serve as many people who may benefit as possible, a formal diagnosis of dementia is not required to participate in its services. However, the functional scores reported by caregivers appear to indicate that most persons with dementia were in the mild-to-moderate disease stages.

Noteworthy is that our evaluation offers an understanding of how strategies proven in efficacy trials operate in real-world contexts. It is not designed to examine the mechanisms by which strategies achieve benefits. Although theoretical frameworks offer understandings of why programmatic components may be effective, pathways need further explication in efficacy trials.

Given these limitations yet critical importance of continuously evaluating outcomes of real-world supportive care and services, we offer several recommendations for service providers. These involve linking with researchers to prospectively and independently evaluate caregiver satisfaction and other outcomes; including as part of routine documentation continuous assessments of caregiver and service provider-rated progress toward goal attainment; and seeking independent confirmation of adverse health-related events when possible.

Although limitations are inherent in evaluations of service contexts, the strength of practice-based research or service evaluation is that it yields knowledge concerning family engagement under real-world conditions. Moreover, despite missing data, reliance on self-report, and refusal of some families to complete questionnaires, we show significant benefits for those who did participate in follow-up, and relatively little baseline differences between those who provided follow-up data and those who did not.

## Conclusion

MCHS is a community-based service providing theory-based and evidence-informed approaches to support caregivers of persons living with dementia. An evaluation of their service helps to characterize the population served, assure quality and consistency of service provision, and document benefits derived. This evaluation demonstrates that offering brief supportive services to families may result in important health outcomes (reduction of adverse health-related events of persons living with dementia) with potential for important cost savings. As we advance models for dementia care, community-based programs are critically important. This is one of the few services involving the combination of social work and/or occupational therapy for which outcomes of any type have been systematically documented. An evaluation of practices and benefits of community-based services can inform decision-making and staffing considerations and lead to better dementia care services. The limitations of this study also serve as lessons learned from which service providers can advance more methodologically rigorous evaluations of needed services.

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## Conflict of Interest

None reported.

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