Society of Medical Education & Research

2024, Volume 4, Page No: 198-210
ISSN: 3108-4818

International Journal of Social and Psychological Aspects of Healthcare

Pilot Study on Promoting Caregiver Adoption of an Evidence-Based Intervention for Medicaid Recipients with Alzheimer's Disease

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Abstract

This preliminary trial focused on adjusting a program that involves family or unpaid caregivers in collaborating with healthcare professionals to deliver support aimed at preserving or boosting daily physical abilities in people diagnosed with Alzheimer's or related forms of dementia. As far as we are aware, this marks the initial documentation of applying this program to individuals affected by these conditions. Over a period of five months, we carried out a mixed-methods follow-up study involving a selected group of healthcare providers, unpaid caregivers, and care recipients at three sites offering Medicaid-funded in-home and community services in Michigan. The program was refined by two specialists in the field along with five caregivers. We provided instruction to 116 providers on how to involve caregivers effectively and educated 50 caregivers on supporting the delivery of the revised program to 52 individuals living with Alzheimer's or other dementias. Data evaluation involved qualitative theme identification, summary statistics, comparative proportions, t-tests, and McNemar's tests to review participant characteristics, provider learning and contentment with instruction and program application, caregiver confidence, program practicality, appeal, ease of use, overall contentment, and changes in care recipient status (before and after). The revised program showed strong practicality (participation rates ranging from 78.5–86.7%), appeal (ratings 7.55–8.35 [SD 1.50–2.06]), and ease of use (ratings 7.85–8.81 [SD 1.50–2.6]) based on a 1-to-10 scale where higher scores indicate better outcomes. Provider understanding remained consistently strong before and after (scores 12.33 to 12.28, SD 1.80–2.84; difference -0.52, SD 1.95). Caregiver confidence showed a notable rise (gain of 0.81 [SD 0.62], $p < 0.01$). No meaningful changes—either positive or negative—were detected in care recipient measures ($p > 0.05$). Incorporating unpaid caregivers to work alongside healthcare providers in administering a program customized for people with Alzheimer's or related dementias proved practical, appealing, and easy to implement. Larger-scale evaluation involving more diverse groups with dementia across different environments is recommended.

Keywords: Alzheimer's disease, Medicaid recipients, Healthcare, Caregiver

Introduction

Worldwide, roughly 60 million adults aged 65 or older are affected by Alzheimer's disease or associated dementias, with estimates suggesting this figure will climb to 139 million by the middle of the century [1-3]. As these conditions advance, affected individuals commonly face challenges with physical abilities and thinking skills, often relying on assistance from family members or other non-professional caregivers [1]. This results in about 16.3 million such caregivers supporting someone with dementia [1, 4, 5]. Programs that build caregiver understanding and boost their confidence can lead to higher-quality support for the person with dementia [4]. Nevertheless, many existing efforts for caregivers concentrate mainly on building their assurance or easing feelings of strain, anxiety, or low mood. Accordingly, there is limited research on strengthening caregiver expertise and abilities in applying proven

Access this article online https://smerpub.com/

Received: 16 August 2025; **Accepted:** 19 November 2025

How to cite this article: Stevens PJ, Howard RK. Pilot Study on Promoting Caregiver Adoption of an Evidence-Based Intervention for Medicaid Recipients with Alzheimer's Disease. Int J Soc Psychol Asp Healthc. 2024;4:198-210. https://doi.org/10.51847/7S0f3oiBvP

programs, particularly when supporting individuals with Alzheimer's or related dementias.

From 2018 through 2022, we implemented a research-supported program intended to sustain or enhance daily physical abilities as part of a study funded by the National Institutes on Aging (main trial) [6, 7]. During that effort, 20.1% of those who qualified chose not to participate because of thinking difficulties or challenges in following guidance [7]. Impairments in thinking and trouble adhering to instructions are among the first indicators of dementia [1]. To our knowledge, the program applied in the main trial had not been previously assessed in people with dementia. For this reason, we performed a preliminary trial (2021–2022) to explore the practicality, appeal, and ease of implementation of developing caregiver expertise and capabilities so they could partner with providers in offering the program to those with dementia. This effort is essential, given the pressing demand for fresh approaches to support the increasing number of people living with dementia.

Parent trial

Previously published work [6, 7] detailed the intervention from our main trial, designed to support or improve physical functioning in older adults enrolled in Michigan's Medicaid Home and Community-Based Services (HCBS) waiver. Clinicians were trained to deliver this intervention, supported by various implementation approaches, alongside participants' routine care. Key focuses included how well the intervention was adopted and maintained within the program. Evaluations covered changes in clinicians' confidence and views on evidence-based methods (pre- and post-intervention), plus participant results in areas like instrumental activities of daily living (IADLs), basic activities of daily living (ADLs), depressive symptoms, pain levels, fall incidents, emergency department (ED) use, and hospital admissions.

The medicaid HCBS program

Under Section 1915(c) waivers, Medicaid HCBS programs help low-income older or disabled adults remain in their communities [8]. In Michigan, this initiative serves around 12,000 individuals who qualify for nursing facility care, require support with IADLs or ADLs, have incomes under 300% of the federal poverty guideline, and rely on an informal caregiver [9]. Typical services involve care coordination by registered nurses (RNs) and social workers (SWs), plus access to 19 additional supports such as transportation, counseling, meal delivery, personal assistance, and medication oversight [9]. Within this population, more than 15% (over 1,800 individuals) carry a diagnosis of Alzheimer's disease (AD) or another dementia, with likely underreporting [10].

The intervention approach

The approach built on ABLE (Advancing Better Living for Elders), originally featuring five occupational therapy (OT) sessions at home across 12 weeks—focused on supplying adaptive equipment, making environmental adjustments, and teaching energy-saving strategies—along with a single physical therapy session for mobility needs [6, 11, 12]. CAPABLE (Community Aging in Place, Advancing Better Living for Elders) extended this framework to six OT sessions, introduced four RN sessions targeting medical barriers to function, and involved a handyman for practical home changes (such as installing aids or altering surroundings) over 16 weeks [13, 14]. For Michigan's HCBS context, further adaptations incorporated social workers to handle psychosocial issues, included a self-management resource kit on aging-in-place topics (e.g., hygiene, bowel health, mood), and allowed variable session counts and formats based on participant requirements [15]. Home modifications were constrained by Medicaid rules to only those considered essential for health reasons [15].

Study aims

This article reports on a pilot project that incorporated informal caregivers to assist clinicians in delivering the adapted intervention to participants living with dementia. Four specific aims guided the work. Aim 1: Develop and integrate specialized content addressing Alzheimer's disease or related dementias into the core intervention. Aim 2: Incorporate strategies for involving informal caregivers into training materials for clinicians; deliver this training; and evaluate aspects like practicality, acceptance, ease of use, and clinician satisfaction. Aim 3: Assess how feasible, acceptable, usable, and satisfying informal caregivers found their role in supporting intervention delivery for those with dementia. Aim 4: Explore the practicality of implementing the intervention with dementia-affected participants and review their resulting outcomes.

Materials and Methods

Design overview

We carried out a 5-month pilot using mixed methods. For Aim 1, we applied descriptive summaries and qualitative analysis to feedback from specialists and five successively recruited informal caregivers of HCBS participants with Alzheimer's disease, refining the intervention accordingly. Successive recruitment has shown value in real-world studies [16-18]. Aim 2 relied on descriptive metrics and responses to open questions to track clinician learning (through before-and-after knowledge checks), plus perceptions of intervention practicality, ease of application, and training quality. Aim 3 used descriptive data alongside before-and-after comparisons to gauge caregiver views on practicality, acceptance, usability, and overall satisfaction with their involvement. Aim 4 employed a before-and-after framework to review outcomes for the participants themselves.

Ethical considerations and consent to participate

The study received approval from the Institutional Review Boards (IRBs) of the university (#20-213-H) and the State of Michigan (#201811-08-EA-R1). All participants—clinicians, informal caregivers, and beneficiaries—provided informed consent following a complete explanation of the study procedures.

Study setting and participants

The pilot took place at three Michigan HCBS sites selected from the parent trial. Participants comprised content experts (for intervention refinement), five informal caregivers of beneficiaries diagnosed with Alzheimer's disease (who contributed to toolkit modifications), and a convenience sample of clinicians, beneficiaries with an AD diagnosis, and their corresponding informal caregivers.

Eligibility criteria

Eligibility applied to three groups: clinicians, informal caregivers, and beneficiaries. Clinicians included registered nurses (RNs), social workers (SWs), and occupational therapists (OTs) employed at the participating sites. Informal caregivers were required to be aged 18 years or older, English-speaking, and providing care to a beneficiary with a diagnosed Alzheimer's disease or other dementia. Beneficiaries needed to be 65 years or older with a confirmed AD or dementia diagnosis.

Exclusions covered clinicians not working at the sites; caregivers younger than 18, non-English speaking, or supporting individuals without dementia; and beneficiaries younger than 65 or lacking a dementia diagnosis.

Modification of the intervention

Effective strategies for engaging caregivers include delivering concise evidence-based programs, employing skilled clinicians, and providing tailored supportive resources [19]. The original intervention from the parent trial already incorporated an evidence-based framework and trained professionals [6, 7, 11-15], satisfying two of these elements. However, it lacked dementia-specific materials in the toolkit.

A further challenge is that informal caregivers frequently fail to meet key needs of older adults with dementia, particularly in 44.3% of activities of daily living (ADLs, such as bathing and grooming) and instrumental activities of daily living (IADLs, such as shopping and banking) [20]. This gap may stem from mismatches between typical caregiver education and required skills. Essential competency areas for caregivers encompass medical/nursing tasks, assessment, collaboration, and communication [21], yet many training initiatives emphasize problem-solving, resource navigation, and communication alone [22]. Additional focus on assessment, basic nursing techniques, home-based exercises, and care planning could therefore prove beneficial.

Experts recommend toolkits to facilitate intervention implementation [23], as they enhance fidelity to evidence-based practices [24]. To resolve these shortcomings, dementia-tailored content and nursing-related skills (e.g., assessment techniques) were incorporated into the toolkit before involving caregivers in supporting clinicians' delivery of the intervention.

Procedures

For the first objective, study personnel integrated new content into the toolkit, drawing from the Alzheimer's Disease Education and Referral (ADEAR) Center website [25] and relevant publications [26]. The draft toolkit was distributed electronically to content experts and (post-consent) sent in hard copy to informal caregivers for feedback. Responses—including suggested edits, additions, removals, clarifications, and other recommendations—were gathered via Excel

spreadsheets. An iterative review process involving content experts and study staff led to consensus on revisions. The updated toolkit underwent IRB approval before final production. Printing costs for each four-color, wire-bound copy (broken down by section) totaled $25.32.

To meet the second objective, a one-hour online training module for clinicians was developed. Five HCBS supervisors evaluated it and offered suggestions to ensure alignment with learning goals, resulting in a finalized version. Surveys (baseline, pre-/post-knowledge tests, and satisfaction) were created in Qualtrics. Clinicians received emails outlining the study, inviting participation, and providing links to consent forms, initial surveys (baseline and pre-test), the training module, the toolkit, and concluding surveys (post-test and satisfaction). Willing clinicians first completed informed consent (before any data collection), followed by pre-surveys, module review, and post-surveys.

For objectives three and four, site managers identified potential beneficiaries with AD and their informal caregivers. Managers initially contacted the pairs by phone to describe the study. Interested parties completed a screening form, which managers forwarded to study staff. Staff then mailed consent documents and a toolkit to the caregiver, followed by a one-week pause and a joint phone call to the caregiver and beneficiary to discuss and obtain informed consent. Signed forms were returned by mail. When beneficiaries lacked capacity to consent, caregivers served as surrogates—a standard approach in Alzheimer's research [27-29]. Upon receiving consents, staff conducted baseline phone surveys (month 1) and notified sites to initiate intervention delivery by clinicians. Follow-up surveys occurred monthly (months 2–4) and at exit (month 5) via phone, while pre-intervention Minimum Data Set-Home Care (MDS-HC) outcome data were extracted from electronic health records.

Data collection and measures

Qualitative insights into toolkit revisions came from detailed field notes capturing input from experts and caregivers. Feasibility indicators were recorded on screening forms for caregiver-beneficiary pairs and through digital surveys for clinicians. Clinicians provided details on age, gender, racial and ethnic background, professional role, knowledge gains (via before-and-after quizzes), and overall satisfaction—using structured survey questions for numbers and free-text fields for opinions.

Phone-based interviews with caregivers gathered baseline information on age, gender, race/ethnicity, educational background, and their connection to the beneficiary. Their sense of self-efficacy was tracked at start and end points with the General Self-Efficacy scale (GSE) [30]. Ratings of the toolkit's acceptability, ease of use, and value were scored from 1 to 10 (higher scores better) during check-ins in months 2 through 4 and at study close, along with verbal feedback.

For beneficiaries, basic profile data (age, gender, race/ethnicity) and key health indicators (matching the parent trial metrics) were pulled from the Minimum Data Set-Home Care (MDS-HC) record closest to enrollment (before starting) and from caregiver updates during the final phone discussion (after completion). Further details on the GSE [30] and MDS-HC [31] appear in the parent trial design paper [6]. The GSE features 10 questions with internal consistency (Cronbach’s alpha) ranging 0.79–0.90 [30]; here, the caregiver version showed 0.91 at baseline. The MDS-HC serves as a resident-focused tool for gathering core care information, with proven reliability and validity, and ongoing application in HCBS settings since 1993 [31].

Analysis approaches

Open-ended notes and comments were explored through thematic review to identify patterns. Basic summaries (means, frequencies, etc.) described participant backgrounds and satisfaction levels. Feasibility emerged from rates of agreement to join among those screened and contacted, plus completion rates for final evaluations among enrollees. Toolkit usage frequency, as reported by caregivers in months 2–4 and at exit, served as a marker for acceptability. Shifts in caregiver self-efficacy over time were tested statistically with paired t-tests. Early signs of intervention impact—when supported by caregiver toolkit involvement for those with Alzheimer's or dementia—were assessed via paired t-tests for ongoing measures and McNemar’s tests for yes/no measures.

Results and Discussion

Toolkit revisions (Objective 1)

A pair of specialists worked with research team members to adapt the original intervention and draw from ADEAR resources [25] for dementia-focused enhancements. This

led to nine entirely new toolkit chapters dedicated to dementia care: advance care directives; evaluation techniques; Alzheimer's overview; managing agitation/aggression; delirium recognition; addressing hallucinations, delusions, or paranoia; exercise benefits for AD; handling rummaging/hoarding; and wandering prevention. Six established chapters also gained dementia-relevant updates: personal hygiene, reducing falls, household safety, drug administration, discomfort management, and sleep issues. Wording throughout was revised to suit access by the person with dementia or their family supporter.

Feedback on these 15 updated chapters came from five family caregivers. They averaged 46.4 years old (ranging 33–61, SD 6.60), with 80% women, 80% White (20% African American), 60% holding associate degrees, and 40% high school graduates. In total, they offered 131 recommendations for changes or improvements, grouped by chapter. Every reviewer noted that "the toolkit will be very beneficial to new caregivers."

The team and experts collaboratively evaluated these ideas in rounds until settling on inclusions. This resulted in 30 accepted changes, producing the final version ready for pilot testing.

Results for clinicians (Objective 2)

Building on parent trial preparation [6, 7], clinicians had previously completed training on intervention delivery across the Michigan program. A 2021 session added education on dementia origins, signs, and management. This pilot module extended those efforts with a recap of core intervention elements and dementia fundamentals, while introducing new material on partnering with family caregivers during service provision.

Supporting resources included the revised toolkit and a compact reference card outlining beneficiary selection criteria and caregiver collaboration strategies.

Participation rates **(Figure 1)** demonstrated solid feasibility: 78.5% of invited clinicians (106 out of 135) joined. Retention reflected strong acceptability, as 95.3% of participants (101 out of 106) finished every required step.

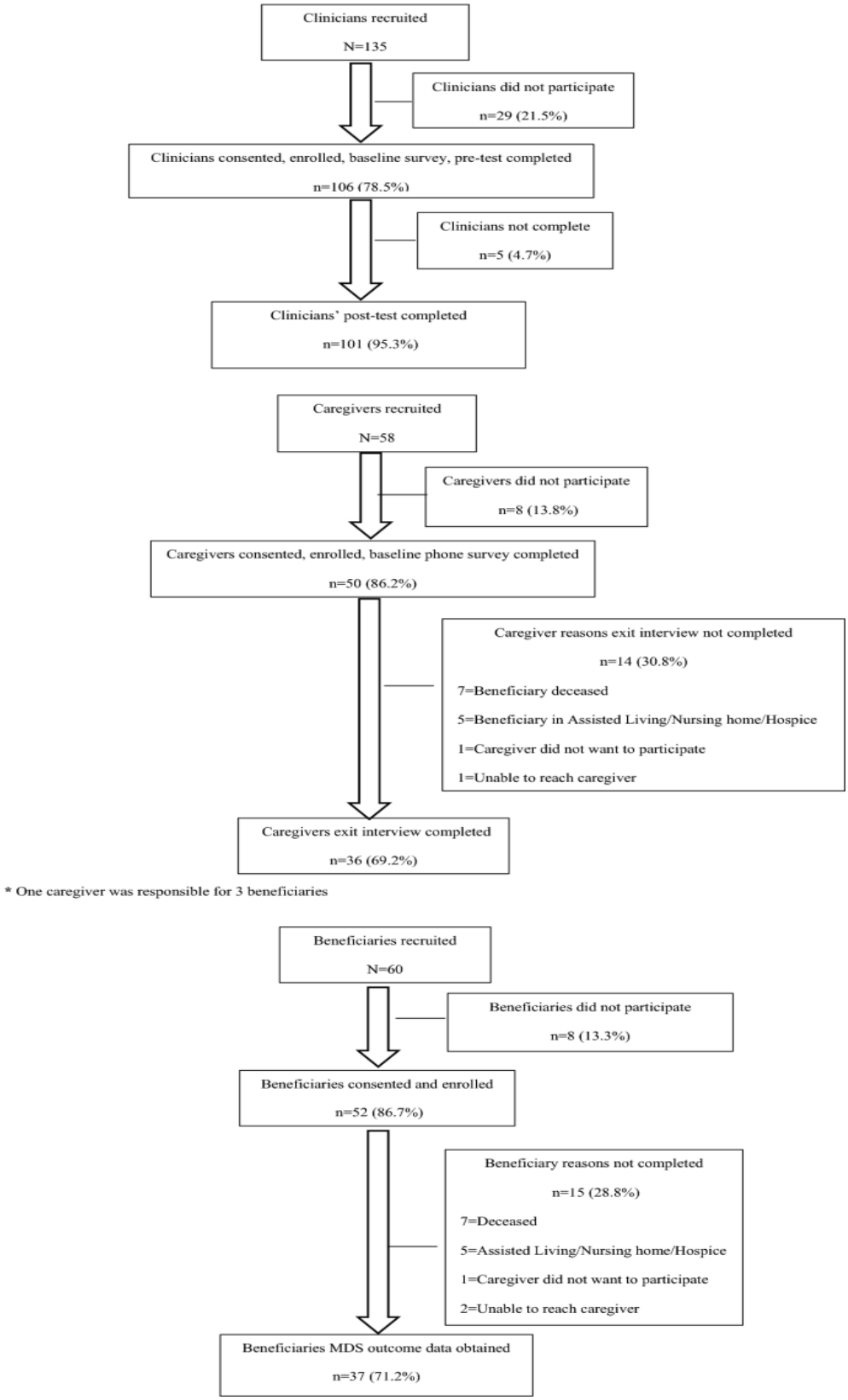

Figure 1. CONSORT flow diagrams illustrating the participation of clinicians, caregivers, and beneficiaries in the study.

The characteristics of the participating clinicians are summarized in **Table 1**. Participants had an average age of 45.78 years (SD = 10.48), with the majority being female (97.2%) and identifying as White (93.4%). The sample consisted of roughly comparable proportions of registered nurses (55.2%) and social workers (42.9%). No significant change was observed in clinicians' knowledge scores from pre- to post-test (mean difference = −0.52, SD = 1.95), as scores remained high at both time points. Participants reported strong satisfaction with the training's content (mean = 8.09, SD = 1.60) and delivery format (mean = 7.55, SD = 2.06). Clinicians indicated that the material covered in the module was largely novel, both for caregivers (mean = 8.35, SD = 1.50) and for themselves (mean = 7.85, SD = 1.92). Intent to apply the intervention in practice was also high (mean = 8.23, SD = 1.71), reflecting favorable perceived usability among the clinicians.

Table 1. Clinicians' demographics, training satisfaction, role understanding, novelty of content, intention to apply learning, and knowledge scores

Characteristic / Measure	N (%) or Mean (SD)
Age (years)	45.78 (10.48)
Sex	
Female	103 (97.2)
Male	3 (2.8)
Race	
White	99 (93.4)
Black or African American	2 (1.9)
Other	5 (4.7)
Ethnicity	
Hispanic	5 (4.8)
Professional Discipline	
Social Worker	58 (55.2)
Registered Nurse	45 (42.9)
Other	2 (1.9)
Training Satisfaction*	
Content	8.09 (1.60)
Format	7.55 (2.06)
Role Clarity*	8.35 (1.50)
Perceived Novelty of Content*	7.85 (1.92)
Intent to Apply Training*	8.23 (1.71)
Knowledge Score	
Pre-test	12.33 (1.80)
Post-test	12.28 (2.84)
Change (pre-/post-test)	−0.52 (1.95)**

*Measured on a 1–10 scale

**Post-test knowledge scores were significantly lower than pre-test scores ($p < 0.05$)

In the satisfaction survey, clinicians provided a total of 12 comments. Through an iterative qualitative analysis, two primary themes emerged: (1) "the toolkit will be helpful to caregivers" (n = 9, 75 percent), and (2) "self-management strategies" (n = 3, 25 percent). Several comments highlighted the intervention's usability. For example: "The toolkit will assist caregivers in identifying problems and addressing issues before reaching out to me." "The information in the toolkit is organized in a practical and useful way."

Caregiver outcomes (Objective 3)

Among the caregivers who were recruited, 86.2% (52 out of 58) participated in the study (indicating feasibility), and of those enrolled, 69.2% (36 out of 50) finished the full study protocol (indicating acceptability) **(Figure 1).** Following obtainment of consent from both the caregiver

and beneficiary, study personnel notified the clinicians at the respective site that the pair was prepared to start using the intervention. The timing of initiation was determined jointly by the clinician, caregiver, and/or beneficiary.

Caregiver results are presented in **Table 2**. Participants had an average age of 63.28 years (SD = 11.29); most were female (80 percent), White (88 percent), and had completed high school (52 percent) or college (46 percent). More than half (58%) were adult children of the beneficiary, while 16% were spouses and the remaining 26% held other relationships. Over the 5-month period, caregiver self-efficacy showed significant improvement (from 2.67 [SD = 0.62] to 3.42 [SD = 0.38]; mean change = 0.81 [SD = 0.62]; $t(34) = 7.70$, $p < 0.01$). Satisfaction ratings for the toolkit's content (range: 8.60–9.07) and delivery format (range: 8.95–9.07) were consistently high. The majority of caregivers reported that the toolkit was helpful (range: 7.98–8.81), supporting its usability. No significant differences ($p > 0.05$) were observed between caregivers who withdrew and those who completed the final assessment. However, a trend suggested higher dropout rates among male caregivers compared to females ($\chi^2(1) = 3.00$, $p = 0.08$).

Table 2. Caregivers' characteristics, self-efficacy (baseline, exit; change baseline to exit); and satisfaction and helpfulness of toolkit

				N (%) or mean (SD)
Age				63.28 (11.29)
Sex				
Female				40 (80)
Male				10 (20)
Race				
White				44 (88)
Black or African American				4 (8)
Native American or Alaskan Native				1 (2)
More than 1 race				1 (2)
Ethnicity				
Hispanic				1 (2)
Education (highest level)				
High School				26 (52)
College				23 (46)
Middle School				1 (2)
Relationship to beneficiary				
Daughter/Son				29 (58)
Other*				13 (26)
Spouse				8 (16)
	Baseline Mean (SD)		**Exit Mean (SD)**	**Change Baseline to Exit Mean (SD)**
Self-efficacy	2.67 (0.62)**		3.42 (0.38)	0.81 (0.62)***
	Month 2 Mean (SD)	**Month 3 Mean (SD)**	**Month 4 Mean (SD)**	**Exit Mean (SD)**
Satisfaction with toolkit				
Content	8.78 (1.70)	9.03 (1.65)	9.07 (1.44)	8.60 (2.27)
Format	8.95 (1.77)	9.58 (0.84)	9.28 (1.25)	9.33 (1.71)
Helpfulness of toolkit	7.98 (2.16)	8.81 (1.79)	8.79 (1.88)	8.23 (2.34)

*One caregiver supported three beneficiaries (categorized as "other" for all).
**Caregiver self-efficacy scale Cronbach's alpha = 0.91 at baseline.
***Increase in self-efficacy is statistically significant: $t(34) = 7.70$, $p < 0.01$.

All sections of the toolkit were accessed by caregivers on multiple occasions **(Figure 2).** In total, the toolkit recorded 813 instances of use. This comprised 433 accesses (ranging from 12 to 21 per caregiver) during the second month, 189 (ranging from 4 to 11) in the third month, 74 (ranging from 3 to 7) in the fourth month, and

117 (ranging from 20 to 42) at the fifth-month exit assessment. Caregivers averaged 3.1 uses in the second month, 4.2 in the third month, 2.7 in the fourth month, and 3.1 at exit.

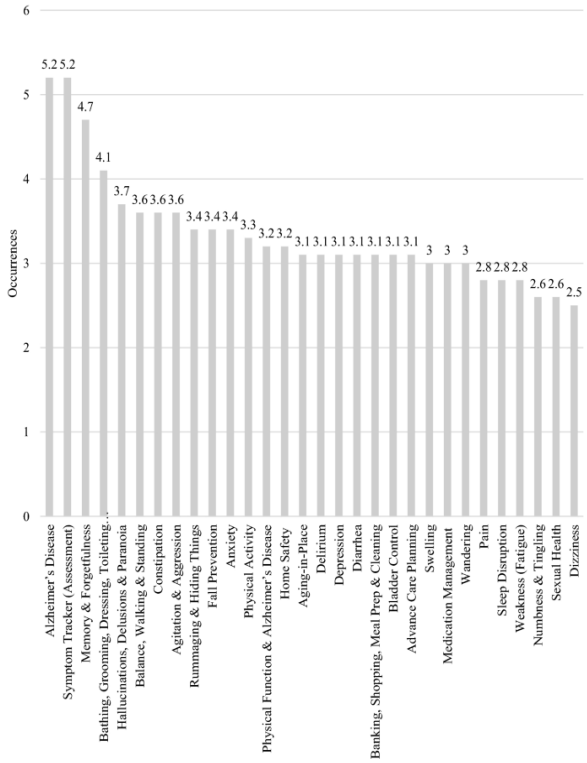

Figure 2. Mean frequency of access to each toolkit section by caregivers across months.

A total of 188 distinct remarks were gathered from caregivers via telephone interviews. An iterative thematic analysis revealed five key themes: the predominant one being that the "toolkit proved useful" (n = 103, 54.8 percent), followed by comments noting they "reviewed the full toolkit and expected most parts to become relevant eventually" (n = 51, 27.1 percent), references to "employing the evaluation guidelines and matrix" (n = 20, 10.6 percent), admissions of "not engaging with the toolkit" (n = 8, 4.7 percent), and mentions of "challenges related to COVID" (n = 6, 3.2 percent). Slightly more than half the caregivers (n = 27, 52 percent) indicated that the toolkit would offer the greatest value to those "new to the caregiving role."

Several caregivers offered insights on ease of use. Examples included: "I believe this resource will significantly improve how I care for my mother," "This should enable caregivers to deliver higher-quality support," "Since I'm effective at solving problems, it will allow me to handle caregiving tasks more autonomously," and "I've started maintaining a record of my mother's behaviors and notes to discuss with her doctor and monitor changes." Additionally, four caregivers admitted they had been "unfamiliar with the progression stages of Alzheimer's disease" prior to the corresponding toolkit content, and five remarked that certain materials "could also aid in their personal well-being" (for instance, addressing depression or physical activity).

Beneficiary outcomes (Objective 4)

Of the beneficiaries approached for recruitment, 86.7% (52 out of 60) engaged in the study (indicating feasibility), while 71.2% (37 out of 52) of participants completed the full protocol (suggesting acceptability) **(Figure 1)**. As described earlier, clinical staff at the site were alerted once the caregiver-beneficiary pair was prepared to initiate the intervention, with the start timing decided collaboratively by the clinician, caregiver, and/or beneficiary.

Results for beneficiaries are detailed in **Table 3**. Compared to the parent trial cohort [7], this group was older on average (mean age 81.23 years, SD 9.27), largely female (77 percent), and White (88 percent). No significant changes ($p > 0.05$) occurred in outcomes post-intervention (usability). Incidence rates remained substantial for falls (29% baseline to 38% exit), emergency department visits (23 percent to 32 percent), and hospital admissions (13% to 12%). Composite measures also showed stability, including depression (5.52 to 4.54, SD 8.75 to 4.47), instrumental activities of daily living (42.69 to 42.22, SD 9.67 to 11.40), basic activities of daily living (22.44 to 23.49, SD 17.09 to 19.56), and pain levels (2.85 to 5.56, SD 2.91 to 3.36). Direct feedback from beneficiaries on the modified intervention was not obtained here; relevant usability remarks from beneficiaries were included in the primary trial report [7].

Table 3. Beneficiaries' characteristics, ADLs, IADLs, pain, depression, falls, ED use, and hospitalizations at baseline and exit

	N (%) or Mean (SD)

Age		81.23 (9.27)	
Sex			
Female		40 (77)	
Male		12 (23)	
Race			
White		46 (88)	
Black or African American		4 (8)	
Native America or Alaskan Native		1 (2)	
Asian		1 (2)	
Ethnicity			
Hispanic		1 (2)	
	Baseline Mean (%)	**Exit Mean (%)**	**Change Baseline to Exit Mean (%)**
Falls			
None	37 (71)	23 (62)	(−9)
One or more	15 (29)	14 (38)	(−9)
ED usage	12 (23)	12 (32)	0 (+ 9)
Hospitalizations	7 (13)	8 (12)	(−1)
Depression summed score	5.52 (8.75)	4.54 (4.47)	−1.46 (9.92)
IADL summed score	42.69 (9.67)	42.22 (11.40)	−1.00 (7.86)
ADL summed score	24.44 (17.09)	23.49 (19.56)	−1.05 (11.55)
Pain summed score	2.85 (2.91)	5.56 (3.36)	2.69 (3.75)

Beginning with the initial concerns about potential issues and extending through the gradual shifts in cognition, behavior, and social interactions experienced by individuals affected by Alzheimer's disease (AD) or related dementias, these conditions can profoundly impact overall well-being [1, 4]. Implementing a proven strategy, such as the one tested in the original study (CAPABLE) [13-15], has the potential to extend periods of comfort, preserve dignity, and sustain autonomy for those living with AD or other dementias, while equipping family caregivers with essential tools and expertise to deliver more effective support [3, 5].

The approach and professional preparation from the original study (CAPABLE) [13, 14] were adjusted to promote greater involvement from family caregivers, enabling them to collaborate with professionals in delivering support to people with AD or related dementias. Additional materials addressing identified shortcomings in caregiver abilities [21] (such as evaluation techniques, basic care procedures, home-based activities, and advance preparation) along with dementia-specific guidance (for instance, handling disruptive behaviors) were incorporated into the professional preparation resources and supporting materials [19, 21].

Since this represented the initial application of the approach (CAPABLE) [13-15] to people with dementia, adaptations were made to the strategy, followed by an assessment of its practicality, appeal, and ease of application. Relative to comparable investigations [32, 33], rates of practicality (78.5–86.7%), appeal (7.55–8.35 [SD 1.50–2.06]), and ease of use (7.85–8.81 [SD 1.50–2.6]; 1-low) were elevated within this selected group enrolled in the HCBS initiative.

A potential upper-limit constraint in professional expertise scores (pre-/post-assessment 82.2 to 81.9%) might stem from existing familiarity with the strategy, given that several participants achieved scores close to the maximum [34]. Consistent with previous findings, professionals reported strong approval of the preparation process and expressed commitment to applying the acquired insights in supporting participants from this group [7].

In line with prior research [35], family caregivers demonstrated gains in confidence throughout the investigation. Caregivers frequently consulted the resource materials (at least 3 times monthly) over an extended duration (5 months), aligning with patterns observed in other investigations of resource packs for those supporting individuals with AD [36, 37]. Importantly, caregivers drew from all parts of the materials, extending beyond sections specifically focused on dementia-related support.

Beneficiary measures showed no changes (before/after the strategy) during the investigation, and there was no evidence of worsening. That said, reports of discomfort rose modestly, though not to a meaningful degree considering the group size. As noted in related work [38], this pattern could reflect shifts from professional in-person evaluations using the MDS-HC (before) to family reports (after).

While the examined strategy (CAPABLE) employed varied methods and addressed multiple targets, it overlapped with other programs shown to support (or stabilize) daily abilities and well-being among those with dementia [39]. Shared elements included professional preparation, family caregiver assistance, a structured yet personalized framework tailored to individual dementia requirements, and mechanisms for recognizing and addressing challenges [39].

Subsequent investigations into refined strategies like the present one stand to gain from insights gathered here. As new methods emerge and existing ones evolve, ongoing appraisal of their effectiveness and risks remains essential, alongside efforts to identify optimal and streamlined options, prepare professionals and caregivers for proper implementation, broaden access for those most likely to benefit, and prioritize well-being for individuals with AD or related dementias as the core of support.

Limitations

A potential drawback of the resource materials involves printing expenses ($25.32), which could pose challenges in resource-limited environments. Study constraints encompass the exploratory before-after structure. Natural progression with aging typically leads to declining measures, yet the absence of a comparison group limits interpretations. Additionally, reliance on varying sources—professionals at entry and caregivers at completion—may have shaped findings, as caregivers' views of a person's abilities might vary from professional observations.

Conclusion

Notwithstanding these constraints, within this group from the Michigan Medicaid HCBS initiative, the revised strategy proved practical, appealing, easy to apply, and elicited strong approval from all involved parties (professionals, caregivers, and recipients). These results offer early indications that incorporating family caregivers to support professionals in delivering a validated strategy (CAPABLE) aimed at sustaining or enhancing daily abilities could prove viable for individuals with AD or related dementias. Additional evaluation in larger and more diverse groups and contexts is required before broader application.

Acknowledgments: None

Conflict of Interest: None

Financial Support: None

Ethics Statement: None

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