

# Practice Concepts and Policy Analysis

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## Translation of a Dementia Caregiver Intervention for Delivery in Homecare as a Reimbursable Medicare Service: Outcomes and Lessons Learned

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**Purpose:** Families of dementia patients receiving skilled homecare do not receive supportive services. We evaluated whether a proven intervention, Environmental Skill-building Program (ESP), which reduces caregiver burden and enhances skills managing patient functioning, can be integrated into homecare practices of occupational therapists (OTs) and reimbursed through Medicare Part B. **Design and Methods:** A 2-year translational project with a homecare practice was conducted. Five translational activities included refining ESP, site preparation, therapist training, establishing referral mechanisms, and evaluating outcomes using Reach, Effectiveness, Adoption, Implementation, Maintenance (RE-AIM). **Results:** Of 30 OTs approached for participation, 23 (77%) agreed, 22 (96%) completed training, and 21 (95.5%) used ESP and

intended to continue use. Of 69 eligible caregivers, 41 (59%) agreed to participate averaging 4.7 sessions. Of 20 returned caregiver surveys, enhancements were reported in all targeted areas of knowledge and skills. Fidelity monitoring revealed inconsistency in therapists use of problem solving, yet caregiver enactment of ESP strategies was high. ESP sessions integrated within patient-directed therapy were reimbursed by Medicare Part B. **Implications:** RE-AIM indicators suggest moderate translational success. As ESP was reimbursed through Medicare B, its delivery may be sustainable and meet the needs of family caregivers of dementia patients receiving therapies at home.

**Key Words:** Caregiving, Medicare, Sustainability

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Families provide the majority of care to individuals with dementia and become at risk themselves for depression, poor health, diminished quality of life, and mortality (Schulz & Beach, 1999). Despite proliferation of proven interventions, families continue to be underserved or receive services that are not evidence based (Brodsky, Green, & Koschera, 2003; Centers for Disease Control and Prevention, 2008; Sörensen, Pinquart, & Duberstein, 2002). Dementia caregiver interventions are not fully integrated into community-based services, and fewer still are evaluated for sustainability within existing funding streams (Burgio et al., 2009).

Translation of proven caregiver programs primarily train care managers or social workers for delivery through the aging service network (Burgio et al., 2009), Veterans Association (Nichols, Martindale-Adams, Burns, Graney, & Zuber, submitted), or hospital discharge (Stevens, Lancer, Smith, Allen, & McGhee, 2009). Evidence-based programs have not been translated for delivery in home care nor involved training health professionals with routine contact with dementia patients and their families.

Furthermore, translational efforts are supported through government agency (Administration on Aging) and foundation (Rosalynn Carter Institute/Johnson & Johnson) grants. Unclear is whether existing reimbursement mechanisms, such as Medicare, support delivery of programs. Although the Medicare Alzheimer's Disease Demonstration Evaluation involved care management as an extended Medicare benefit, few differences in caregiver outcomes and only at certain participating sites were found (Newcomer, Yordi, DuNah, Fox, & Wilkinson, 1999). No further involvement of Medicare in caregiver programming has been evaluated.

This article reports on the translation of the Environmental Skill-building Program (ESP) for delivery by occupational therapists (OTs) in private practice, Fox Rehabilitation, which provides house calls using Medicare Part B reimbursement.

Fox, an independently owned private practice, provides physical therapy, occupational therapy, and speech-language pathology services to older adults in homes, assisted living, or adult medical day centers in five mid-Atlantic states. Fox employs more than 350 clinicians of whom 120 are OTs. Therapists provide an average of 2,800 visits to approximately 930 patients weekly. Approximately 40% of individuals living at home referred for Fox's services have significant cognitive impair-

ment. Although therapists provide basic caregiver education as standard care, a systematic or proven approach to identify and address caregiver concerns is not used.

Previous research shows that patient functional decline, caregiver distress, and physical strain are strong predictors of nursing home placement (Spillman & Long, 2009). Thus, training therapists in a proven program to help distressed caregivers improve skills to manage patient-related concerns, may enhance caregiver well-being, and quality of care provided to patients.

This is the first translational effort to our knowledge that involves integrating a proven caregiver intervention into a large private home care practice as part of routine therapeutic services provided to dementia patients through Medicare Part B.

Medicare, a major public resource for long-term care reimbursement, provides part-time skilled home care including physical, speech, and occupational therapy to participants in outpatient clinics or homes. Whereas Medicare Part A provides reimbursement for traditional home health services and requires participants to be home bound, with Part B, a physician referral is required and patients with functional decline and/or safety concerns qualify for this service which can occur in outpatient settings or the home (Centers for Medicare and Medicaid Services [CMS], 2008). For Medicare Part B, referral by a physician to occupational therapy may occur after an acute episode, such as a hospitalization or fall or in the absence of an acute episode, to address functional decline with progression of a chronic condition. Referral to occupational therapy, and successful reimbursement, is for the impairment, functional limitation, or disability of the patient and not specifically to treat the diagnosis of dementia. Dementia is a chronic progressively deteriorating disease in which management of functional decline is critical. Although Medicare Part B currently does not have a separate Current Procedural Terminology code specifically for "caregiver training," caregiver training is allowed and reimbursed when it is directly related to supporting the patient's functional tasks or performance of instrumental and basic activities of daily living. As stated in Medicare Benefit Policy Manual chapter 15, rehabilitative services may include family training to augment rehabilitative treatment. According to Medicare policy, education of family should be ongoing through treatment and instructions may have to be modified intermittently if the patient's status changes (CMS, 2010).

Referral to occupational therapy services was not made for the ESP caregiver intervention specifically, as ESP was not provided as a separate program or intervention. Rather, ESP was integrated into existing OT patient treatment plans for patients with dementia and overwhelmed caregivers.

Approximately 5.1% of community-dwelling Medicare beneficiaries have a dementia diagnosis, although this estimate is low given that dementia is not typically the primary diagnosis for referrals. In 2005, Medicare spent \$91 billion on beneficiaries with dementias. This number is predicted to double to \$189 billion by 2015 (Gruber-Baldini, Stuart, Zuckerman, Simoni-Wastila, & Miller, 2007).

ESP, tested by the National Institutes of Health Resources to Enhance Alzheimer's Caregivers Health (REACH I) and subsequent randomized trials, provides caregivers specific knowledge and skills to support daily function and manage neuropsychiatric behaviors of dementia patients, enhance home safety, and alleviate caregiver upset and care concerns (Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; Gitlin et al., 2003). ESP meets Medicare Part B reimbursement requirements as it links caregiver training to patient functional goals. Thus, there is potential to sustain delivery through this funding mechanism.

Prior to implementing ESP agency wide, we conducted a 2-year translational phase to evaluate proof of concept at one Fox location. Specifically, we sought to evaluate adequacy of a training program for therapists with full caseloads, whether ESP could be integrated with fidelity into standard patient care encounters, and reimbursed through Medicare Part B. This article describes the key translational activities, outcomes, and challenges and lessons learned.

To evaluate outcomes, we applied a public health framework, Reach, Effectiveness, Adoption, Implementation, Maintenance (RE-AIM) that designates multiple criteria at the individual, agency, and societal levels to understand impact (Glasgow, 2002; Glasgow & Emmons, 2007). Application of this model involves understanding program "reach" (number of caregivers approached and enrolled); effectiveness (perceived benefits); adoption (training adequacy and number of therapists using program); implementation (fidelity); and maintenance (sustainability).

### **Environmental Skill-building Program**

As described elsewhere, ESP involves up to eight home sessions over 4 months by OTs who assess

specific needs, concerns, and challenges of caregivers, the physical and social environment, caregiver management approaches, and dementia patient functionality. Based on assessments and prioritization of caregiver-identified concerns (resistance to care), therapists tailor disease education, instruction in problem solving, and implementation of strategies. Strategies introduced include environmental simplification (decluttering and safety proofing), communication (tactile and verbal cueing), task simplification, engaging patient in activities, and stress reduction. Findings show that ESP reduces frequency of behavioral symptoms and functional dependence in dementia patients, caregiver upset, and need for assistance from others and improves caregiver skill, efficacy, and mood (Gitlin et al., 2001, 2003; Gitlin, Hauck, Dennis, & Winter, 2005)

ESP is grounded in five immutable treatment principles: client centered (areas targeted for intervention are caregiver identified); problem solving (caregivers learn how to identify concerns and strategies); tailoring (dose, intensity, and strategies are customized to person-environment configurations); action-oriented (caregivers learn skills by practicing with therapists); and cultural relevance (therapists identify values guiding care decisions to assure appropriateness of tailored strategies). The visit schedule and number of sessions are flexible, although a minimum of three is recommended.

### **Key Translational Activities**

Five activities were necessary to integrate ESP into homecare. One set of activities involved intervention refinements such as identifying mutable (number and timing of sessions) and immutable (five treatment principles) elements, refining the treatment manual, streamlining treatment documentation, and establishing monitoring procedures to fit within agency's structure. Another set of activities involved preparing agency for implementation including educating staff about caregiver needs, fidelity, establishing tracking mechanisms for sessions and reimbursement, and mechanisms for accessing and returning completed ESP documentation. A third set of activities involved establishing criteria for selecting and certifying therapists and establishing a training program to fit limited therapist time. Yet a fourth set of activities involved developing referral mechanisms and informational flyers for families. A final set of activities involved evaluating training and delivery outcomes using RE-AIM.

## Procedures

We identified 30 Fox OTs who met these criteria: employed at Fox for greater than or equal to 6 months, in good standing with Fox procedures, policies and documentation requirements, and caseloads within the targeted geographic region. Of these, 23 (77%) agreed to participate and were trained. Training consisted of three components: readings on dementia, caregiving, and ESP (4 hr), on-line asynchronous training involving lectures and active learning exercises on intervention components (8 hr), and 1.5 days of face-to-face training to practice delivery and documentation completion. After 1 year, therapists completed a confidential survey concerning adequacy of training and challenges implementing ESP.

Trained therapists subsequently identified caregivers from their respective active caseloads. Fox physical therapists in the targeted region also referred eligible patients and caregivers.

Eligible caregivers lived with or in close proximity to patients referred by a physician for therapy, were overwhelmed or burdened, or needed disease management skills. Therapists approached caregivers following completion of initial patient assessment or in subsequent patient sessions. In the final home session, caregivers completed a brief seven-item self-administered survey concerning satisfaction with ESP, whether number of sessions was appropriate; strategies were being used; and perceived benefits (not at all, somewhat, and great deal), placed the completed survey in an envelope, sealed it, and handed it to therapists.

To enhance fidelity, we followed [Lichstein, Riedel, and Griev \(1994\)](#) recommendations and provided manual of procedures, guiding scripts, treatment documentation forms, and training through active learning with the original primary investigator and research interventionist. Following training, therapists participated in three individual telephone calls with the research interventionist and five monthly group conference calls to discuss challenging cases, provide coaching, and reinforce fidelity to core treatment principles. Although seldom used, therapists could pose questions to the research interventionist via e-mail.

To evaluate fidelity, we examined therapist delivery, caregiver receipt, and enactment. For delivery, therapists documented each session providing evidence of use of assessments and protocols.

Documentation was reviewed by the agency project coordinator and research interventionist following case completion. Select items from the caregiver posttreatment survey were used as indicators of receipt (treated with respect, adequate number of sessions received) and enactment (strategies used). Also, for each caregiver-identified problem, therapists asked caregivers upset with and confidence managing it to evaluate pretreatment and posttreatment benefits.

## Results

### *Reach*

Over 2 years, therapists identified and approached 69 eligible caregivers for participation from active caseloads. Of those, 41 (59%) agreed to participate. Reasons for refusal included not identifying as caregivers, not perceiving need, or fear participation detracted from patient therapy, although this was explained as not true.

### *Effectiveness*

Of 41 caregivers in ESP, posttreatment surveys were available for only 20 due to therapists initially leaving surveys for caregivers to mail to agency.

Of 20 caregivers with surveys, more than 80.0% reported a “great deal” of knowledge and skill enhancement in dementia understanding, home safety, and communication. Also, 68.4% reported enhanced ability to engage dementia patients in daily activities. Similarly, most caregivers reported “a great deal” of overall benefit, enhanced confidence managing behaviors and caring for patients, reduced upset, and self-care (Table 1).

### *Adoption*

Of 23 Fox OTs who volunteered for and completed ESP training, 7 had more than 10 years clinical experience and were considered “very experienced”; 9 had 3–10 years clinical experience and were considered “experienced”; and 7 had less than 3 years of clinical experience and were considered “novice.”

Of these, 22 completed the post-training survey (one therapist moved from area). Of those surveyed, therapists indicated training components supported learning ESP (100%) and face-to-face training strategies (role-play, videos, case stories, and PowerPoint presentations) helpful (95%).

**Table 1. Caregiver Gains (N = 19)<sup>a</sup>**

	Somewhat (%)	A great deal (%)
Knowledge and skills		
Better understand memory loss	16.7 <sup>b</sup>	83.3
Home safer	11.1 <sup>b</sup>	88.9
Communicate more efficiently	15.8	84.2
Engage family member in activities	31.6	68.4
Efficacy		
More confidence managing behaviors	26.3	73.7
Enhanced ability to care for family member	10.5	89.5
Everyday life easier	33.3 <sup>b</sup>	61.1
Less upset	47.4	52.6
Take better care of self	42.1 <sup>c</sup>	52.6
Overall program benefit	31.6	68.4

<sup>a</sup>One caregiver survey had missing data on these reported items.

<sup>b</sup>n = 18.

<sup>c</sup>One participant in Year 2 rated caregiver takes better care of self as “not at all.”

Almost all trainees indicated need for ongoing coaching.

Also, although most indicated amount of training was adequate, 18.18% indicated training could be shorter, whereas 31.82% indicated training could be longer (Table 2).

Most therapists expressed no difficulties introducing ESP (72%), integrating ESP into patient treatment sessions (60%), completing assessment forms (56%), identifying caregiver concerns (62%) and depression (62%), educating about stress (88%), and practicing stress reduction (60%). However, therapists indicated “some” to “a lot of difficulty” using treatment documentation (75%) and using problem solving (62%) with caregivers. Most (95.5%) therapists indicated intent to continue using ESP (Table 3).

### Implementation

Of 20 caregivers with surveys, close to 90% believed that ESP did not require too much effort; 78% indicated just right number of sessions; 17% indicated that it was too much; and 5% too little. Additionally, 100% indicated being treated respectfully and gaining knowledge and skills. Over a third (38%) reported using strategies “most to all of time” and 57% reported “sometimes” using strategies (treatment enactment). Importantly, 100% would recommend ESP to other caregivers.

**Table 2. Therapists Ratings of ESP Training Following 1 Year (N = 22)**

	Agree (%)	Disagree (%)
1. Training elements		
Readings prepare therapists for face-to-face session	100	—
Face-to-face training session facilitates ESP implementation	100	—
Manual of operations supported learning	100	—
PowerPoint presentations supported learning	95.45 <sup>a</sup>	4.55
Videos and case stories were helpful learning methods	100	—
Demonstration/role-playing on stress management techniques was helpful	90	10
Overall, training provided knowledge and skills to work with caregivers of persons with dementia	100	—
2. Time allocated to training		
Shorter training session preferred	18.18	81.82
Longer training session preferred	31.82	68.18
Need for ongoing support/debriefing on challenging cases	90.91	9.09

Notes: ESP = Environmental Skill-building Program.

<sup>a</sup>n = 21.

### Maintenance

The 41 caregivers completed a total of 193 sessions (average 4.7 sessions per caregiver). As ESP was designed to link caregiver training to the patient’s functional goals, through careful documentation, skilled therapists certified in ESP demonstrated patient functional improvement and justified use of ESP as a Medicare Part B reimbursable intervention for the patient. All ESP sessions were reimbursed through the Medicare Part B carrier. This demonstrates the potential to sustain delivery through this funding mechanism when existing Medicare Part B requirements are met.

### Challenges and Solutions

Three key challenges were encountered. The first involved balancing training needs with limited therapist time. Although ESP builds upon OT foundational knowledge and skills, it is not traditional practice and requires training in its assessments, protocols, and treatment principles. As agency revenue and therapist salaries are based on patient contact, we needed to develop a training approach that minimized revenue loss. Our three-pronged

Table 3. Perceived Therapist Difficulty Implementing ESP (N = 22)

Component	Not at all difficult (%)	Somewhat difficult (%)	Very difficult (%)
Introducing ESP to caregivers	72.22 <sup>a</sup>	22.22	5.56
Integrating ESP into existing patient treatment	60	33.33	6.67
Identifying caregiver's "level of readiness"	56.25 <sup>b</sup>	25	18.75
Following session by session form	25 <sup>c</sup>	56.25	18.75
Completing ESP assessment form to identify caregiver concerns	62.50 <sup>c</sup>	18.75	18.75
Completing problem solving and brainstorming protocol	37.5 <sup>c</sup>	50	12.5
Conducting depression screen	62.50 <sup>c</sup>	25	12.5
Educating caregivers on stress management techniques	87.5 <sup>c</sup>	12.5	—
Practicing stress management techniques	60 <sup>b</sup>	40	—

Notes: ESP = Environmental Skill-building Program.

<sup>a</sup>n = 18.

<sup>b</sup>n = 15.

<sup>c</sup>n = 16.

approach (readings, web based, and face to face) optimized independent learning. However, as ESP requires a high level of clinical reasoning, face-to-face practicing and follow-up coaching opportunities were essential. Most therapists indicated that time devoted to training was sufficient.

A second challenge involved fitting fidelity checks within agency and therapist practices. Randomized trial methodologies (rating audio-taped sessions and direct observation) were not cost-efficient or part of agency culture. In addition to strategies for strengthening and monitoring fidelity, we manualized aspects of ESP not previously developed (scripts for providing education materials).

A third challenge was adapting ESP to conform to Medicare Part B requirements while retaining fidelity. To meet Medicare guidelines, ESP had to be integrated within therapies targeting dementia patients. Therapists must link caregiver concerns to patient therapeutic goals. Many caregiver concerns (safety, functional decline, and behavioral management) are patient focused, whereas others are not (sleep deprivation, and respite needs). Therapists needed training to link caregiver concerns to patient therapeutic goals accurately and appropriately and the types of concerns that could and could not be addressed within Medicare. ESP was integrated within a patient therapeutic contact and billed as a component of "self-care/home management training" that included caregiver training. Conversely, ESP was originally tested using flexible visit schedules determined by caregiver needs. Thus, length and scheduling of sessions were easily adapted to patient therapeutic schedules.

A related point is that caregivers received ESP for as long as patients needed therapy. Upon

patient termination, ESP was discontinued even if additional caregiver training was warranted as its provision could not be reimbursed if provided independently.

### Lessons Learned

This translational phase was diagnostic and necessary prior to full implementation of ESP in a multistate homecare agency (Woolf, 2008). From this phase, we were able to determine training adequacy and identify areas for which additional therapist support (problem solving) and coaching (explaining ESP to reluctant caregivers) were necessary. Also, this phase was necessary to evaluate proof of concept; specifically, whether ESP could be integrated into homecare sessions and reimbursed through Medicare Part B for Fox to determine feasibility of implementing ESP agency wide.

We learned that translation was labor intensive, requiring a series of integrated activities involving key stakeholders from research and agency sites. Consistent with other translational reports, open negotiations and shared understandings were essential to success (Kitson et al., 2008). Specifically, research partners needed to obtain a fine-grained understanding of practice site characteristics and reimbursement requirements, whereas agency partners needed to understand the mutable and immutable components of ESP and its training requirements. Also, as fidelity and evaluating caregiver outcomes must be embedded within agency practices for sustainability, developing and implementing all procedures required a collaborative approach. Thus, forming and sustaining a strong partnership based on a shared vision, mutual

respect and trust was essential (Fixen, Naoom, Blasé, Friedman, & Wallace, 2005).

Translation occurs within a changing organizational context. Therapists and administrators may leave or change positions and practice rules, and regulations are not static. Also, using an evidence-based program requires changing professional and agency behaviors. Thus, organizational readiness to use evidence-based programs and agency support including transformative agency leadership, a dedicated agency-based coordinator, and early adopters (therapists who volunteered to be trained) is essential. Additionally, specific agency-based mechanisms must exist including but not limited to supervisory structures, training support and referral, client-tracking, and billing infrastructures.

We also learned the importance of timing therapist training to coincide with availability of eligible caregivers. As approximately five cases are necessary to achieve proficiency in ESP, immediate access to caregivers enhances therapist adoption capacity. We found that therapists needed booster training who had limited opportunities to implement ESP due to caseload mix or caregiver refusals, resulting in a gap of 1 or more months between training and delivery.

Finally, translation had unforeseen benefits. It resulted in agency-wide enhancements including improved dementia education training of all Fox clinicians, development of an agency-wide depression and suicide protocol, and enhanced knowledge and skills of therapists. ESP-trained therapists indicated that even when not using ESP, the knowledge gained about dementia and caregiving enriched their practice and changed their approach to families. For research partners, translation enhanced understanding of how to manualize ESP, train novice to expert therapists, explain ESP to caregivers who may differ from research-based convenience samples, and scale training and fidelity monitoring for the next phase of full implementation.

## Conclusions

The purpose of this project was to move ESP from the randomized trial arena to the practice setting. We found that a translational phase was necessary to establish proof of concept. Without proof of concept, the practice setting would have no rationale or economic basis for moving forward with full implementation of ESP agency wide. This translational phase was necessary given the divide between requirements in conducting clinical trials and the realities of practice settings, particularly as it concerns home-care services

and reimbursement policies for patients and family caregivers. We contribute to implementation science by showing the importance of a preimplementation translation phase that is carefully evaluated in order to prepare for scaling up to full implementation.

This is the first translation to our knowledge that embeds a proven caregiver program into homecare. Using RE-AIM, we show that translation was modestly successful. Caregiver reach (59% of eligibles participated) and therapist adoption (70%) were moderately high, both therapists and caregivers uniformly perceived ESP as beneficial, indicators of fidelity suggest therapist delivery was inconsistent (e.g., use of problem solving was challenging); nevertheless, caregiver receipt and enactment indicators were highly positive, and most therapists reported intent to continue using ESP with maintenance possible through Medicare Part B.

Several limitations should be noted. We were unable to adequately evaluate reach and effectiveness as evidenced by the lack of data available on basic participant characteristics and that only 50% of posttreatment surveys were returned. As data collection had to fit agency daily practices and routines, we were limited in what data could be collected and how. This illustrates the methodological challenges in designing translation and implementation projects such that they do not compromise clinical practices but also attain methodological rigor.

Nevertheless, given our focus on external validity and proof of concept, the project yielded useful information. Fox was able to determine that implementation of ESP agency wide would be feasible and highly desirable. The research team was able to determine how to scale training and fidelity oversight for full implementation in the future.

Another limitation may be the volume of eligible caregivers (69 caregivers identified over 2 years by 22 therapists). Although it was lower than anticipated, it reflected Fox's census in the targeted region at the time.

Of significance was reimbursement through Medicare Part B. Despite limitations of this funding mechanism, we reached caregivers who would not otherwise have received systematic skills training related to dementia care. Caregiver testimonies demonstrate benefits.

*. . . [The therapist] made me more aware of difficulties facing me; for example how to find friends and what my needs are as far as social interaction with other people. She had little tips of how to calm myself and my husband [the patient] when he is difficult to deal with.*

... I think our home is much safer. He wanders so much, but now I know what to do.  
 ... I gained more confidence managing mom and can now take a little time for myself.  
 ... [The OT] was a wonderful resource since she was already providing services to my mom. It made for a better training and understanding.

Several policy issues arise. First, not all patients have Medicare or can afford its co-pays. Second, caregiver training must be linked to patient treatment goals. Once patients reach therapeutic goals, caregiver sessions must terminate even if ongoing training is warranted. Thus, one recommendation is to extend Medicare coverage for caregiver training independent of patient therapeutic goals. Another policy issue is that patients were not referred to OT for their dementia but rather for other comorbid chronic conditions contributing to functional decline. As dementia is a chronic illness accompanied by functional decline and subsequent home safety issues, referral for OT for this diagnosis should not be denied.

Methodological questions concern the following. Previous research consistently shows passive dissemination (publications and presentations) is inadequate for uptake of proven programs. Yet, unclear is how to translate proven programs in practice settings. We believe a translational phase necessary to align programs with the ecological exigencies of practice settings, including reimbursement parameters, agency culture, and training needs of adopters. Our five translational activities (intervention refinements, agency preparation, therapist training, referral mechanisms, and evaluation) may be applicable to other efforts. Research is necessary to formally evaluate different translational approaches and relationship to a subsequent stage of full implementation and ways to rapidly move evidence-based family caregiver programs from clinical trial to translation to full implementation in delivery settings.

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