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Translating Evidence-Based Dementia Caregiving Interventions into Practice: State-of-the-Science and Next Steps

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Over the past 3 decades, more than 200 dementia caregiver interventions have been tested in randomized clinical trials and found to be efficacious. Few programs have been translated for delivery in various service contexts, and they remain inaccessible to the 15+ million dementia family caregivers in the United States. This article examines translational efforts and offers a vision for more rapid advancement in this area. We summarize the evidence for caregiver interventions, review published translational efforts, and recommend future directions to bridge the research-practice fissure in this area. We suggest that as caregiver interventions are tested external to service contexts, a translational phase is required. Yet, this is hampered by evidentiary gaps, lack of theory to understand implementation challenges, insufficient funding and unsupportive payment structures for sustaining programs. We propose ways to advance translational activities and future research with practical applications.

Key words: Dementia, Caregiving, Interventions, Translation

For more than 5 million persons in the United States living with dementia, there are over 15 million family members providing on-going support including care coordination,

transportation and accompaniment to health visits, daily assistance with bathing and feeding, and end-of-life care (Alzheimer's Association, 2014; Reinhard, Samis, & Levine,

2014). The U.S. health care system is based on the premise that families will assume responsibilities for day-to-day care and assure quality of life and safety of people with dementia (Carbonneau, Caron, & Desrosiers, 2010).

The consequences for families providing protracted care for this complex condition are extensive and well documented. With disease progression, families are at elevated risk for many jeopardies including financial (early retirement, reduced paid working hours; Chen, 2014; Moore, Zhu, and Clipp, 2001), impaired life quality (depressive symptomatology, burden, stress; Schulz, O'Brien, Bookwala, & Fleissner, 1995), physical morbidities (Dassel & Carr, 2014; Vitaliano, Zhang, & Scanlan, 2003), suicidal ideation (O'Dwyer, Moyle, Zimmer-Gembeck, & De Leo, 2013), and dementia (Norton et al., 2010).

In response, over the past three decades, modest government investments have been directed at developing and testing caregiver interventions. This investment has yielded a robust corpus of intervention studies demonstrating small but clinically and statistically significant benefits for families. Interventions have in turn been summarized in 7 meta-analyses and 17 systematic reviews (Gitlin & Hodgson, in press), suggesting that a strong evidence base exists. A strong evidence base is an important requisite for knowledge translation or moving evidence from research to practice (Grimshaw, Eccles, Lavis, Hill, & Squires, 2012). Nevertheless, few interventions have been implemented in practice.

Subsequently, over the past decade, efforts have been directed at purposively transporting proven caregiver interventions from the randomized trial to social service and clinical environments, an action referred to as T3 research. T3 research seeks to translate proven interventions for consistent delivery “. . . to all patients in all settings of care and improve the health of individuals and populations” (Dougherty & Conway, 2008, p. 2319). Despite increased interest in translation, a persistent and widespread gap exists between what is known about effective strategies that support families and diminish the burdens of dementia care, and real-world practices and policies for this population. Families of individuals with dementia do not have access to optimal and evidence-based care, resulting in continued elevated individual, familial, and societal costs.

This Forum article examines the state of translational efforts to stimulate more rapid movement in this area. As T3 activities depend upon the scope and nature of evidence previously generated, we begin by briefly reviewing the quality of empirical evidence of caregiver interventions as it concerns implications for translation. Next, we review the small body of published translational activities from which to identify key activities of this research phase and breaches hampering the field. We suggest that translational efforts

are necessary yet burdened by evidentiary gaps, insufficient funding, lack of theoretically guided activities, and payment structures that exclude families from receiving support. Finally, we provide recommendations for moving translation forward and future research with practical applications.

Case Vignette

Mrs. Smith, an African American in her early 50s, lives with and provides cares for her father (Mr. Smith) at her urban home. Her father was diagnosed with probable Alzheimer's disease 4 years ago; with disease progression, he is more agitated, aggressive, and physically dependent, rejects care, repeats questions, and has nothing to do. Mrs. Smith cut back work hours to provide care, struggles to make ends meet and is juggling care demands with need for employment. She does not fully understand the disease process and has difficulty managing her father's physical dependencies and behavioral symptoms. Mrs. Smith has grown children busy with family life who can provide little help. Her church is a source of support but she cannot attend as previously. Mrs. Smith is overwhelmed, anxious, and becoming depressed. A physician initially provided Mr. Smith anticholinesterase medication, which was halted due to poor tolerance, and antianxiety medication that has not addressed behaviors most challenging to Mrs. Smith.

How Can We Help Mrs. Smith?

This case snapshot of a real family captures the U.S. dementia caregiving experience. However, a wide array of proven interventions exist that could help Mrs. Smith, although the exact number is unclear. In a comprehensive review, Maslow (2012) identified 44 interventions targeting individuals with dementia and/or their family caregivers and suggested more publications of tested programs were forthcoming. Brodaty and Arasaratnam (2012) identified 23 caregiver interventions demonstrating positive outcomes for families. Gitlin and Hodgson (in press) identified more than 200 interventions reviewed in 24 meta-analyses and systematic reviews conducted between 1966 and 2013. Interventions reviewed in any one article ranged from 4 to 127 and are complemented by 10 newly tested interventions with positive caregiver outcomes published between 2013 and 2014, which were not included in reviews.

Although there is no agreed-upon classification system, treatment modalities of proven programs can be categorized as professional support, psycho-educational, behavior management/skills training, counseling/psychotherapy, self-care/relaxation techniques, and environmental redesign; most involve multiple treatment components. Benefits reported by studies overall are small to moderate. However,

improvements compare more than favorably to pharmacologic trials, benefits outweigh risks, and improvements are often documented for caregivers and persons with dementia (Salloway et al., 2014). Gitlin and Hodgson (in press) found pooled effect sizes (d) ranging from 0.01 to 0.68 depending upon measures and caregiver outcomes. Brodaty and Arasaratnam (2012) found significant treatment effects across 20 caregiver interventions for reducing behavioral symptoms (effect size = 0.34, $p < .01$) and caregiver negative reactions to behavioral symptoms (effect size = 0.15, $p = .006$).

Exemplars of interventions that could address Mrs. Smith's challenges include, but are not limited to, her need for care management (Maximizing Independence at Home, Samus et al., 2014; Partners in Care, Bass et al., 2014), disease education (Savvy Caregiver, Smith & Bell, 2005), skills to manage functional dependence (Care of Persons with Dementia in their Environments [COPE], Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010a; Skills₂Care[®], Gitlin et al., 2003), strategies to address behavioral symptoms (Advancing Caregiver Training, Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010b), activities to effectively engage Mr. Smith (Tailored Activity Program, Gitlin et al., 2009), and counseling and support (Belle et al., 2006; Mittelman, Haley, Clay, & Roth, 2006).

Additionally, proven programs exist that could improve Mr. Smith's life quality (Gitlin, Hodgson, & Choi, in press) and physician approach, which, in turn, would benefit Mrs. Smith. These include, but are not limited to, the Physician Consortium for Performance Improvement's Dementia Performance Measurement Set recommending routine screening of behavioral symptoms, cognitive and functional abilities, and provision of caregiver education (Odenheimer et al., 2014), practice guidelines and algorithms for systematically addressing behavioral symptoms (Gitlin, Kales, & Lyketsos, 2012; Kales, Gitlin, & Lyketsos, 2014), and collaborative primary care (Callahan et al., 2006) to address dementia patients' comorbidities and caregiver burden. To date, Mrs. Smith, her father, and physician do not have knowledge of or access to these proven programs and approaches.

Knowledge Gaps

This case vignette also brings to light important limitations in the evidence impacting translation. First, for the most part, study samples are not well characterized, particularly concerning persons with dementia. As interventions are not purposively linked to disease stage or etiology nor classified in a meaningful way, it is difficult for clinicians such as Mr. Smith's physician to discern which programs to prescribe, for what outcomes, and at what point along the disease trajectory.

Secondly, studies rely on volunteer samples who differ on critical characteristics from caregivers at-large; thus, generalizability of interventions may be questionable (Pruchno et al., 2008). Furthermore, there is limited evidence concerning intervention benefits for demographic subgroups (men, minority populations, rural, long-distance and multiple carers) whose prevalence is increasing.

Third, with few exceptions, intervention costs, cost effectiveness, or cost benefits are unknown (Gitlin, Hodgson, Jutkowitz, & Pizzi, 2010; Mittelman & Bartels, 2014; Nichols et al., 2008). Service providers are unable to quantify needed resources for implementation and understand financial implications or possible cost savings. Further, unknown is what families such as Mrs. Smith are willing to pay.

Fourth, most studies do not evaluate outcomes of relevance to stakeholders. Health care organizations including social service agencies, or Centers for Medicare and Medicaid Services, are most concerned with utilization and harm reduction. Correspondingly, it is difficult to discern clinical significance of small changes in common outcomes such as burden, upset, self-efficacy, or mastery. Also, unclear is what constitutes a meaningful benefit to Mrs. Smith; it may be having more time during the day, help at home, opportunities for exercise, self-care, or church attendance. Financial distress and physical burdens of care, as Mrs. Smith experiences, are significant triggers for nursing home placement in population-based studies, but no interventions address these (Reinhard et al., 2014; Spillman & Long, 2009).

Fifth, few studies examine long-term effectiveness or formally test performance with a delivery context.

Translational Efforts

With few exceptions (Burns, Nichols, Martindale-Adams, Graney, & Lummus, 2003; Callahan et al., 2006; Gitlin et al., 2006), developing and testing interventions have occurred outside of care systems. Hence, a translational phase is necessary to modify complex protocols and interventionist training to derive a better fit with service environments and identify environmental supports and barriers to implementation.

Funding Mechanisms

As this diagnostic phase requires resources (investigator and service partner time), funding is essential. Nevertheless, grant support for translational efforts specific to dementia caregiver interventions has been limited to four sources. The Administration on Aging (AoA) through the Congressionally mandated Alzheimer's Disease Supportive Services Program developed a funding category in 2008 devoted to translating caregiver interventions tested in

randomized trials and reported in peer-reviewed publications. Under this initiative, eight grants were funded in eight states involving translation of six interventions: Coping with Caregiving (AZ), New York University Caregiver Intervention (NYUCI) (MN), Reducing Disability in Alzheimer's Disease (RDAD-OH), Resources for Enhancing Alzheimer's Caregiver Health II (REACH II; Georgia, NC), Savvy Caregiver (California, ME), and Skills₂Care[®] (NJ, Gould, Hughes, O'Keeffe, & Wiener, 2013).

The National Institute on Aging, in collaboration with AoA, initiated a program announcement (*Translational Research to Help Older Adults Maintain their Health and Independence in the Community*) in February, 2011 (PA-11-123), renewed March, 2014 (PA-14-159). Although not specific to dementia caregiving, translation of National Institutes of Health (NIH) REACH or other dementia caregiver interventions was noted as areas of interest. It is not possible to discern funded translational efforts specific to dementia caregiving through this mechanism; we are aware of one recent grant award for translation of the COPE intervention (Gitlin et al., 2010a) for publicly funded home care clients and families (PI, Dr. Fortinsky, University of Connecticut).

The U.S. Department of Veterans Affairs funded translation of one intervention to our knowledge, REACH II, involving 15 states, 114 sites, 355 trained staff, and 127 family caregivers (Nichols, Martindale-Adams, Burns, Graney, & Zuber, 2011).

Finally, the Rosalynn Carter Institute through Johnson & Johnson funding (2007–2009) supported nine small translational projects involving four interventions: REACH I-Skills₂Care[®]; REACH II and its variants (REACH OUT; REACH adapted for Hospital); NYUCI in multiple sites; and the Benjamin Rose Care Consultation program.

Unclear is whether funding for translational efforts will endure. Funding limitations has and will continue to significantly limit translational activity.

Translational Activities

Only a few reports of translational activities are published to date. The AoA 2013 report (Gould et al., 2013) summarizes outcomes of eight evidence-based funded grants. Although efforts are in progress, to date, 2,567 caregivers participated in translational efforts, ranging from 34 in REACH II (NC) to 1,210 in Savvy Caregiver (CA). Demographic data available for five grants indicate most were women (59% for NYUCI-MN to 88% for REACH II-NC) and non-Hispanic White (50% for REACH II-NC to 98% for NYUCI-MN); men and all race and ethnic minorities were underrepresented. Reported outcomes included increased caregiver knowledge and understanding of memory problems (Coping with Caregiving-AZ, RDAD-OH, Savvy Caregiver-CA, Savvy Caregiver-ME),

decreased caregiver stress and depression (NYUCI-MN, REACH II-NC, REACH II-GA, Savvy Caregiver-CA, ME), and better behavioral symptom management (NYUCI-MN, REACH II-GA, Savvy Caregiver-CA, Skills₂Care[®]-NJ).

Using a rapid review process (Harker & Kleijnen, 2012), we conducted searches in major databases (CINAHL, PsychINFO, Embase, PubMed, Google Scholar, Scopus) to identify publications that purposively described translational efforts of proven dementia caregiver interventions. We identified 16 publications using key words (dementia, Alzheimer's disease, caregiver, carer, translation, translational research, intervention, replication, RE-AIM) and their combination. Summarized in Table 1, studies report translations of six programs (REACH II, Skills₂Care[®], NYUCI, Savvy Caregiver Program, RDAD, and STAR-C); three describe works-in-progress and 13 report outcomes.

As Table 1 suggests, only 6 of 200+ proven interventions (<3%) have been submitted to a translational process resulting in publication. This number is disconcerting yet consistent with other health fields in which an estimated 14% of evidence becomes integrated into practice (Institute of Medicine, 2008). Unclear is why some caregiver interventions are translated and others not as most were tested in randomized trials resulting in positive outcomes.

As to design, translational efforts used pre-post designs, but it is unclear why. A quality improvement framework may be more appropriate in which adaptations to an intervention are continuously made in response to environmental demands and systematically documented and evaluated.

Of 16 published translational studies, five key changes to delivery characteristics of the original intervention are mentioned: (a) change to session number and/or duration; (b) change in session location (from home to clinic or combination); (c) change in delivery mode (from face-to-face to telephone); (d) elimination of treatment elements (group support; technology applications); and (e) change in interventionist training. Although modifications are notated, the decision-making processes for deriving adaptations are not articulated. In all cases, modifications are designed to simplify complex interventions to fit the delivery environment, and not the other way around. This serves as an important lesson for intervention development; attention to context and involvement of stakeholders early on in intervention development may minimize future translational challenges.

Translation also appears to be characterized by eight actions as shown in Table 2: (a) identifying and involving key stakeholders to guide program integration in a site; (b) streamlining and modifying treatment manuals and training procedures; (c) evaluating readiness and preparing sites for implementation; (d) identifying immutable and mutable treatment elements to improve intervention efficiency and dosing; (e) evaluating uptake or

Table 1. Summary of Published Translational Studies of Dementia Caregiver Interventions

Citation	Name of program	Site of translation	Theory of translation	Study design	Modifications to original intervention	Reach (number of caregivers)	Effectiveness	Sustainability addressed
1. REACH II Altpeter, Gwyther, Kennedy, Patterson, and Derence (2013)	NC-REACH II	NC (three regions): community setting	RE-AIM	Mixed-methods, mid-course assessment: eight-steps reviewing implementation process Fidelity evaluated and use of REACH II consultant	<ul style="list-style-type: none"> Streamlined intervention guides and tools Shifted the mandatory weekly coaching sessions to "as needed" Reduced number of sessions and length of time More flexibility with timing and delivery of program content 	In progress	In progress	NC-REACH II embedded in NC Project C.A.R.E., a comprehensive dementia-specific respite program with AOA demonstration funding
Burgio et al. (2009)	REACH OUT	AL: AAAA	Not indicated	Single group design, pre-post (4 months) Fidelity evaluated: case manager recorded the number of home visits and phone calls. Treatment components were "checked off" if used during visit	<ul style="list-style-type: none"> Shortened number of sessions from 12 to 4 visits and 3 telephone calls 	272 enrolled with 236 (87%) completing at least three of four home visits	<p><i>Caregiver:</i> Improvements in burden, social support, depression, positive aspects of caregiving, health, frustration</p> <p><i>PuD:</i> Improvements in behavior problems, mood, risk behaviors (supervision, wandering)</p>	Seeks integration into usual service delivery, but no sustainability data available

(Continued)

Table 1. Continued

Citation	Name of program	Site of translation	Theory of translation	Study design	Modifications to original intervention	Reach (number of caregivers)	Effectiveness	Sustainability addressed
Cheung et al. (2014)	Reaching out Dementia Caregiver Support Project (REACH-HK)	Hong Kong (11 NGOs across 18 districts)	RE-AIM	Single group design, pre-post (6 months)	<ul style="list-style-type: none"> Eliminated support groups 	243 completed baseline interview with 201 (83%) completing follow-up interview	<p><i>Caregiver:</i> Improvements in perception of positive aspects of caregiving, depression, burden, bother, and caregiving risks</p> <p><i>Pt/D:</i> Abatement in behavioral problems</p>	No sustainability in per-data available
Easom, Alston, and Coleman (2013)	GA-REACH	Rural Georgia (11 counties): community setting	Not indicated	Single group design, pre-post (6 months)	<ul style="list-style-type: none"> Eliminated specialized computer-integrated telephone system After first 2 sessions, subsequent sessions conducted in counseling rooms of NGOs vs. caregivers' homes 	161 caregivers enrolled with 85 (53%) caregivers completing intervention	<p>Improvements in caregiver depression, burden, health, and confidence in caregiving skills.</p> <p><i>Pt/D:</i> Decrease in behavioral problems</p>	<p>Noted that sustainability could be achieved with future research and concerted efforts through partnership with governmental departments, universities, service providers, and funding bodies</p> <p>No sustainability data available</p>

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Table 1. Continued

Citation	Name of program	Site of translation	Theory of translation	Study design	Modifications to original intervention	Reach (number of caregivers)	Effectiveness	Sustainability addressed
Lykens, Moayad, Biswas, Reyes-Ortiz, and Singh (2014)	REACH II	North TX: community setting Alzheimer's Association	Not indicated	Single group design, pre-post (6 month) Fidelity not indicated	<ul style="list-style-type: none"> • Modifications in delivery • Change terminology in by substituting "dementia care specialists" for "counselors" • Caregiver notebooks also printed in Spanish • Nine 1-hr in-home visits 	494 families enrolled with 177 completing the program	<p><i>Caregivers:</i> Improvement in caregiver depression and burden</p> <p><i>Caregiver:</i> Noted that additional VAMCs requested REACH-VA training and that the VA is discussing rollout at a national level</p>	No sustainability data available
Nichols et al. (2011)	REACH: Department of Veterans Affairs (REACH-VA)	15 States: HBPC programs across 24 VAMC facilities	Not indicated in text	Single group design, pre-post (6 months)	<ul style="list-style-type: none"> • Three 0.5-hr telephone, and five 1-hr monthly telephone group support sessions. • Technology not provided • No homevisits 	127 enrolled with follow-up data available for 105 (83%)	<p><i>Caregiver:</i> Improvements in burden, depression, impact of depression on daily lives, frustration</p> <p><i>Pt/D:</i> Fewer reported problem behaviors</p>	Noted that additional VAMCs requested REACH-VA training and that the VA is discussing rollout at a national level
Stevens, Smith, Trickett, and McGhee (2012)	Scott and White FCP, REACH II in Texas	Scott and White White Health care system: integrated health care setting including hospitals, clinics, and AAA	RE-AIM	Single group design, pre-post (6 months)	<ul style="list-style-type: none"> • Abbreviated assessment 	164 enrolled caregivers with 72 (44%) completing all treatment contacts	<p><i>Caregiver:</i> Improvements in risk score, caregiver burden, and care recipient safety</p> <p><i>Pt/D:</i> Patient problem behaviors decreased</p>	Noted continued institutional support through monetary, organizational and educational efforts. FCP expanded into two more service regions
				Fidelity evaluated: intervention materials and treatment delivery schedule followed original, core components.	<ul style="list-style-type: none"> • Did not provide technology component • Did not provide support groups 			

(Continued)

Table 1. Continued

Citation	Name of program	Site of translation	Theory of translation	Study design	Modifications to original intervention	Reach (number of caregivers)	Effectiveness	Sustainability addressed
2. Skills ₂ Care® Gitlin et al. (2010)	Skills ₂ Care®	Mid-Atlantic states: private practice home care	RE-AIM	Single group design, pre-post (4 months) Fidelity evaluated: provided manual of procedures, guiding scripts, treatment documentation forms, and training with PI and research interventionist. Evaluated through examination of therapist delivery, caregiver receipt, and enactment. Documentation reviewed by project coordinator and PI.	Training of interventionists collapsed from 2 weeks to 2 days Name changed from environmental skill-building Optional PT visit to train in proper body techniques absorbed by occupational therapist No telephone option for one session	41 completed one or more sessions but post-treatment surveys available for 20	<i>Caregiver:</i> Improvements in caregiver knowledge and skills (e.g., understanding memory loss, ability to engage PwD in activities, more confidence managing behaviors, and taking better care of self)	Skills ₂ Care® sessions were reimbursed through Medicare B as part of care provided to patient with dementia education and serves as a mechanism for sustainability
3. NYUCI Klug, Halaas, and Peterson (2014)	ND Dementia Care Services Program	ND (eight regions): Alzheimer's Association	Not indicated in text	Lack of structured intervention: 6-month to 42-month time frame Fidelity not indicated	<ul style="list-style-type: none"> Diagnosis does not have to be confirmed No limit to number of consultations received No limit to amount of time in program Fewer consultations with longer period of time 	1,750 caregivers and 951 persons with dementia with 101 caregivers completing survey of self-reported empowerment	<i>Caregivers:</i> Improvements in caregiver competence and confidence	No sustainability data available
Mittelman and Bartels (2014)	MN Family Memory Care (FMC)	MN: 4 project sites selected by the Minnesota Board on Aging and the AAAs	Not indicated in text	Pre-post (4, 8, and 12 months) Fidelity not indicated	<ul style="list-style-type: none"> Reduced from six sessions to four sessions 	228 enrolled, of whom 117 (51%) had completed the minimum number of sessions and had at least one follow-up assessment	<i>Caregiver:</i> Improvements in social support, tangible assistance, reaction to behaviors <i>PwD:</i> Decrease in frequency of depressive problems, disruptive behaviors	Noted that the state has committed to continue providing the intervention on which this translational study was based but payment model not specified

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Table 1. *Continued*

Citation	Name of program	Site of translation	Theory of translation	Study design	Modifications to original intervention	Reach (number of caregivers)	Effectiveness	Sustainability addressed
Paone (2014)	New York University Caregiver Intervention called Family Memory Care in Minnesota	MN : 14 program sites, community-based setting	RE-AIM	Mixed-methods, process evaluation (4–8 months) Fidelity not indicated	Protocol, assessment, training, and reporting tools were modified	137 caregivers completed core components of FMC interventions with 105 completing post-intervention survey	<i>Caregivers:</i> Reported that the intervention was helpful in discussing problems related to caring for PwD, handling changes in PwD behavior, and increasing knowledge of Alzheimer's disease	Lack of on-going funding source and grant expiration contributed to lack of sustainability of program
4. Savvy Caregiver Program								
Samia, Aboueiisa, Halloran, and Hepburn. (2014)	MSCP	ME: project sites included hospitals and AAAs)	RE-AIM	Single group design, pre-post, mixed-methods	<ul style="list-style-type: none"> Shortened from weekly 2-hr group psych-education sessions more than 7 to 6 weeks. 	770 accessed the program, of whom 676 (88%) agreed to post-test	<i>Caregiver:</i> Improvements in competence, personal gain, management of the situation, directing, letting thing slide, keeping the PwD busy, management of more reasonable expectations, and positive aspects of caregiving, depression (for those with baseline elevated scores)	MSCP is integrated into two Aging and Disability Resource Centers/Agencies on Aging Family Caregiver Program
Smith and Bell (2005)	Savvy Caregiver Program	CO: 25 communities (rural and urban) Alzheimer's Association	Not indicated in text	Rural vs. urban pre-post (6 months) Fidelity evaluated	<ul style="list-style-type: none"> Shortened length of training to 1-, 2-, or 3-week sessions 	-54 rural and 42 urban caregivers	Caregivers- improvement in rural caregivers' depression scores, whereas urban caregivers' scores did not improve	No sustainability data available

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Table 1. Continued

Citation	Name of program	Site of translation	Theory of translation	Study design	Modifications to original intervention	Reach (number of caregivers)	Effectiveness	Sustainability addressed
5. RDAD Menne et al. (2014)	Reducing Disability in Alzheimer's Disease-OH	OH: Alzheimer's Association services and AAA	Not indicated in text	Single group design, pre-post (3 months) Fidelity evaluated: noted that fidelity was monitored and intervention adhered to original RDAD program including original content, same delivery schedule, tools, readings, and handouts	No changes made to core components	326 participants enrolled with 219 (67%) completing pre-post surveys	<i>Caregiver:</i> Improvement in caregiver strain. More sessions associated with decrease in unmet needs after intervention	No sustainability data available
Teri et al. (2012) ^a	RDAD	OH: home-based	Not indicated in text	Fidelity evaluated: manuals with clear, comprehensive details for program adoption	Assessment procedures were modified (e.g., assessments not blinded)	405 (at time of Teri et al., 2012 publication)	Outcome data not yet reported.	Noted as an important area of inquiry for the outcome study
STAR-C Teri et al. (2012) ^a	STAR-Community Consultants (STAR-C)	OR: home-based	Not indicated in text	Fidelity evaluated: audio-taped sessions of STAR-C reviewed by University of Washington trainers	Assessment procedures were modified (e.g., assessments not blinded)	70 (at time of Teri et al., 2012 publication)	Outcome data not yet reported.	Noted as an important area of inquiry for the outcome study

Notes. AAA = Area Agencies on Aging; AoA = Administration on Aging; C.A.R.E = Caregiver Alternatives to Running on Empty; FCP = Family Caregiver Program; HBPC = Home-Based Primary Care; MSCP = Maine Savvy Caregiver Project; NGO = Non-government organization; PI = principal investigator; PwD = person with dementia; RDAD = Reducing Disability in Alzheimer's Disease; REACH = Resources for Enhancing Alzheimer's Caregiver Health; REACH OUT = Resources for Enhancing Alzheimer's Caregiver Health Offering Useful Treatments; RE-AIM = Reach, Efficacy/Effectiveness, Adoption, Implementation, and Maintenance; VAMC = Veterans Affairs Medical Center.

^aThis publication presents two translational studies that are currently under way with no outcome data reported at time of publication.

Table 2. Key Domains and Activities of a Translational Phase for Caregiver Interventions

Domain	Key activities
Identify stakeholders and partners	Involve key stakeholders including potential interventionists, administrators, and end users (family caregivers) to identify best way to name and frame program, market it, integrate it into practice or service site routines
Intervention refinements	<ul style="list-style-type: none"> • Identify immutable and mutable aspects of the intervention guided by theory and empirical analyses (e.g., mediation; moderation, dose response) • Streamline dose and intensity based on contextual requirements and available evidence
Manual refinements	<ul style="list-style-type: none"> • Adapt and streamline treatment manual for consumption by practice site and interventionists • Standardize all aspects of the intervention and manual for scaling up
Establish training program	<ul style="list-style-type: none"> • Streamline training time to fit service context • Identify criteria for being an interventionist • Identify approach to certifying training • Identify future training strategies for scaling up
Site preparedness	<ul style="list-style-type: none"> • Evaluate readiness of site to implement an evidence-based program • Identify staffing, supervision, training, quality control needs, and associated site costs
Examine payment mechanisms	<ul style="list-style-type: none"> • Identify costs and costs savings for intervention delivery • Identify and evaluate reimbursement mechanisms and other payment approaches
Establish an approach to fidelity	<ul style="list-style-type: none"> • Develop a fidelity plan commensurate with resources and context of service setting • Integrate plan within site routines if possible involving supervisory and monitoring structures in place
Evaluate translational activities	<ul style="list-style-type: none"> • Use theoretical or conceptual models to understand translational processes and outcomes • Evaluate uptake by interventionists and adoption at site • Evaluate outcomes for end users (participants, clients, families)

adoption by interventionists, agencies, and families; (f) evaluating fidelity; (g) evaluating participant benefits; and (h) exploring sustainable payment models. (Table 2) Future translational efforts should explicitly address each of these tasks so that interventions can be more uniformly translated. Comparisons across translational efforts could then be derived from which to advance more nuanced understandings of which interventions work and in what contexts.

Outcomes

Outcomes of published translational activities can be evaluated using RE-AIM criteria (reach, effectiveness, adoption, implementation, maintenance), a broad public health model to appraise the impact of moving evidence to practice (Glasgow, Vogt, & Boles, 1999).

As to “reach” or whether the right population is engaged, there is a lack of diversity in caregivers represented in efforts to date. Most participants of translational efforts are Caucasian and women. Of these 16 studies, 1 study occurred in Hong Kong and 15 in specific regions in 28 (56%) U.S. states (NC; AL; GA; 2 = TX; 15 states with VAs; three Mid-Atlantic states: NJ, DE, PA; ND, MN, ME, CO, OH, and OR).

Effectiveness, or program impact, is the primary focus of publications. Of 13 studies reporting outcomes, all indicated participant benefits commensurate with original trials; this is the good news.

As to “adoption” of interventions by interventionists, agencies, and families, little evidence is provided such that conclusions and lessons learned cannot be gleaned. One indicator may be attrition. Although translational efforts are small in scope, of 13 publications reporting data, 4,809 caregivers were enrolled and 2,179 (45%) provided post-test data. Of six published translational activities involving REACH II, 1,461 caregivers were enrolled with 876 (60%) completing post-tests. It is unclear whether attrition is from programs or data collection efforts. This is a critical distinction. If attrition is from programs, then the issue of perceived relevance is a concern. As perceptions of an innovation predict rate of diffusion, this would pose a significant barrier (Berwick, 2003). Alternately, attrition from data collection presents a methodological challenge for documenting translational activity.

For “implementation,” or consistency of program delivery, fidelity monitoring plans are indicated by nine (56.3%) studies, although adherence rates are not necessarily reported. Fidelity is an important consideration to ensure intervention delivery is consistent with the original tested program. When translating interventions, some degree of flexibility is warranted to ensure optimal delivery. For example, achieving a fixed dose may be beyond the ability of interventionists. Yet, it is unclear how much flexibility can be tolerated to address implementation barriers without altering active ingredients of original interventions (Washington et al., 2014).

Table 3. Recommendations for Advancing Translation of Dementia Caregiver Interventions

1. Conceptual clarity
 - Standardize activities that compose a translational phase
 - Develop agreed-upon criteria for reporting translational activity
 - Use different theoretical frameworks for understanding translational activities and evaluating outcomes
 - Develop standard approach to manualizing treatment manuals
 - Evaluate cost, quality of care, and other key outcomes
 - Evaluate needs to prepare workforce and standardize curriculum for using evidence-based dementia caregiver interventions
 - Develop agreed-upon criteria for determining which interventions to move forward with translation
2. Funding allocation
 - Allocate more funds for translating existing proven programs
 - Expand research to develop and test caregiver interventions that target unaddressed needs along disease trajectory
3. Improve clinical relevance of evidence
 - Evaluate cost and cost benefits of interventions
 - Employ new trial designs such as embedded, pragmatic, hybrid designs that combine efficacy, effectiveness with implementation testing phases to shorten translational phase
 - Use mixed methodologies to simultaneously examine intervention effects, adoption, and implementation facilitators and barriers
 - Better align epidemiological findings from national representative data sets with new intervention development for dementia caregivers
 - Examine dose response and role of treatment components
 - Explore use of simulation models to examine cost savings, identify new intervention targets, or identify interventions most likely to improve targeted outcomes
 - Use mediation to evaluate intervention treatment components
 - Use moderation analyses to identify who benefits for what outcomes and from which to derive tailoring strategies
4. Dissemination and policy considerations
 - Coordinate with health organizations and the aging network to disseminate proven caregiver interventions
 - Coordinate with professional organizations to identify core competencies for using dementia caregiver interventions and their integration within professional training
 - Develop a meaningful classification system and central registry for proven caregiver interventions for use by organizations and agencies
 - Develop bundled or reimbursement payment mechanisms for providers to use proven caregiver interventions

Another aspect of implementation concerns identifying core ingredients of interventions that cannot be altered (Gearing et al., 2011). Pinpointing “active ingredients” or what makes an intervention work is challenging although integral to achieving effective translation and maintaining fidelity. The methodology used to identify immutable intervention components is not clearly described in reports.

Of 16 studies, only 6 (37.5%) report using a conceptual model to inform implementation, with RE-AIM being the singular approach employed. The lack of use of knowledge transfer frameworks significantly inhibits a full understanding of facilitators and barriers to program implementation (Grimshaw et al., 2012). Further, as there are no common metrics on what should be evaluated at a translational phase, utilizing theoretical frameworks could help close this gap. Although RE-AIM has high utility, it does not address the myriad of translational concerns. Other conceptual models, for which there are many, could be employed to guide measurement and obtain a better understanding of contextual supports and barriers to implementation; exemplars include Promoting Action on Research Implementation in Health Services (PARiHS Model, Kitson et al., 2008), PRECEDE-PROCEED Model (Green & Kreuter, 2005), CFIR (Consolidated Framework for Implementation

Research, Damschroder et al., 2009), PRISM (Practical, Robust Implementation and Sustainability Model, Feldstein & Glasgow, 2008), Normalization Process Theory (May et al., 2009), or Theoretical Domains Framework (Michie et al., 2005). Unfortunately, lack of theory-informed translational activity is not uncommon. Davies, Walker, and Grimshaw (2010) revealed that only 6% of studies they reviewed used theory to inform design and/or implementation of knowledge transfer interventions.

Finally, the “maintenance” of proven interventions is unknown. The possibility for sustainability was mentioned by 8 of 13 (61.5%) studies. Six (46.1%) had a sustainability mechanism in place at the federal (REACH-VA, NC-REACH II, Skills₂Care®), state (NYUCI-FMC), or organizational level (REACH-FCP, Savvy Caregiver Program-MSCP). Existing care systems are not currently designed to fund or reimburse evidence-based practices. Policy makers are critical stakeholders who need to be engaged to change payment mechanisms that reflect family needs and scientific evidence.

Regardless of these small incremental positive results overall, there do not appear to be any next steps or plans for wide-scale practice change. Moreover, Mrs. Smith does not live in a state with translational activities.

Recommendations

Table 3 outlines four key recommendations for advancing translation of proven dementia caregiver interventions. First is the need to obtain conceptual clarity and consensus as to the activities constituting translation. As an interim study phase to move interventions from randomized trials to implementation, establishing criteria for identifying which interventions to move forward for translation, standardizing what activities occur in this phase, achieving consistency in reporting translational efforts, and articulating theoretical frameworks for guiding translation would be important. A partnership between researchers and stakeholders to derive consensus as to what this phase includes is imperative.

Second is the urgent need for funding. Despite the strength of extant interventions, there remain significant gaps in our knowledge of optimal interventions for diverse family caregivers. Consequently, there is a need to balance resource allocation between discovery (developing/testing new interventions) and translating existing efficacious programs. Given that more than 200 interventions with strong evidence are available, funds for translation appear a worthy investment.

Third is the need to improve clinical relevance and implementation potential of evidence. For existing interventions, this may involve conducting economic evaluations, determining which subgroups benefit the most (moderating analyses), and identifying mechanisms by which interventions achieve benefits (mediational analyses).

For future interventions, this should involve aligning intervention targets to those identified in population-based studies and involving stakeholders and end users (families and interventionists) early on in developmental phases. Also, adopting flexible and rapid testing strategies of new interventions such as embedded, practical trial or hybrid designs combining effectiveness and implementation queries could be pursued (Curran, Bauer, Mittman, Pyne, & Stetler, 2012; Riley, Glasgow, Etheredge, & Abernethy, 2013).

Finally, to advance translation, a host of dissemination and policy considerations are necessary. Advancing a meaningful classification system of proven programs might help to inform agencies as to delivery characteristics, resources needed for implementation, costs, and potential benefits (Maslow, 2012). Creating a central repository for proven programs from which to access training information and intervention details may also promote dissemination and use. Further, as training or preparation of a workforce is critical, identifying common core competencies for delivery of proven programs and introducing these into health professional educational programs may offset the extensive training that programs typically require. Of importance is revamping reimbursement policies or bundling programs

into payment structures to incentivize providers to offer proven programs (Table 3).

Conclusions

The 2013 World Alzheimer's Report concluded that

Caregiver multi-component interventions (comprising education, training, support and respite) maintain caregiver mood and morale, and reduce caregiver strain. . . Nevertheless, we are aware of no governments that have invested in this intervention to scale-up provision throughout the dementia care system, and hence coverage is minimal (p. 5).

The overreliance of the health care system on the family's therapeutic role in dementia care combined with negative consequences of this prolonged activity, as illustrated by Mrs. Smith, requires a strong and overdue societal response. Although a wide range of interventions with strong evidentiary support could help dementia caregivers now, few have access to these programs. Just over half of U.S. states have participated in translational studies with efforts limited to small regions. In the United States, 4,566 caregivers (4,809 including Hong Kong) have participated in translation studies. Although this is a beginning and other translational efforts are underway, it represents an extremely small percentage (0.0003%) of the 15+ million U.S. dementia family caregivers. Mrs. Smith will continue to not receive any benefits from proven interventions if our course of action remains the same.

The case of Mrs. Smith, which typifies U.S. caregiver experiences, illustrates the balance needed between investing in translation/implementation and discovery/intervention development/testing. Despite the need for more and better interventions, the good news is that there are concrete programs to support Mrs. Smith and other families right now.

The translation of caregiver interventions can be considered a test phase for advancing proven programs. From all accounts, the state-of-the-science of this phase is incipient; theory, activities, design, and measurement considerations are not well delineated. Further, there is a limited understanding of why some interventions over others are selected for translation, processes for modifying interventions, and what interventions work best in which settings. Knowledge of translational challenges and decision making is critical to inform not only future translational efforts and wide-scale implementation, but also the future design and testing of new interventions that are more suitable for delivery in practice settings.

One initial step to address the chasm between practice and existing knowledge involves greater attention to the science of translation. This first wave of translational

activity has focused on demonstrating effectiveness (outcomes similar to original trial). Although important, other aspects of translation as discussed must be considered. Advancing translational efforts will require greater investment of funds, attention to theory, inserting translation and widespread implementation as milestones in the National Alzheimer's Plan and NIH mission, and changes to payment structures.

On a final note, upon reflection of the state-of-science of translation, other more fundamental considerations emerge. First, a translational phase is implicitly based on the notion that interventions are advanced in a linear, incremental, progressive basis and that with adequate evidence, practice change will occur. As McCannon, Berwick, and Massoud (2007) point out, this is faulty reasoning and not empirically grounded. Dementia caregiver intervention researchers, policy makers, and service providers may benefit from drawing upon science-based models of widespread diffusion and global examples of rapid change in health practices to make a real difference in the lives of families.

Second, it may be that a translational phase could be eliminated by designing and testing interventions differently in future endeavors. By involving key stakeholders (including families) upfront in intervention design, testing interventions within practice contexts, and adopting rapid, responsive designs that are more dynamic than the static randomized trial, better efficiencies may be achieved. This may result in greater reach, adoption, and impact on families.

Furthermore, by identifying the principles shared by existing proven interventions (e.g., caregiver-centered, problem-oriented, tailoring to needs, conditions, environments), guidelines and best practices could emerge. Guidelines may be more useful to service providers than adopting evidence-based programs, which typically require specialized training, fidelity monitoring, and on-going researcher involvement. As stakeholders (families, clinicians, administrators) have the ultimate say as to what evidence is adopted and used, facilitating use of evidence-informed guidelines may offer a more flexible approach to improving care (Berwick, 2003). This combined with better preparation of a health care workforce in family-centered dementia care may ultimately make the difference for Mrs. Smith and the families she represents.

Given our dementia epidemic, attention to family caregivers is a public health imperative. The time is now to move on all fronts—new ways of advancing novel interventions, translating and implementing proven programs, and preparing a workforce and systems change. Families and persons with dementia should demand our utmost attention and perseverance in changing practice to adequately and fully support their gallant efforts.

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