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Resources for Enhancing Alzheimer's Caregiver Health (REACH): Overview, Site-Specific Outcomes, and Future Directions

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Established in 1995, Resources for Enhancing Alzheimer's Caregiver Health (REACH) is a unique, multisite research program sponsored by the National Institute on Aging and the National Institute on Nursing Research. The primary purpose of REACH is to carry out social and behavioral research on interventions designed to enhance family caregiving for Alzheimer's disease (AD) and related disorders. Specifically, REACH has two goals: to test the effectiveness of multiple different interventions and to evaluate the pooled effect of REACH interventions overall. REACH developed from a National Institutes of Health initiative that acknowledged the well-documented burdens associated with family caregiving as well as the existence of promising family caregiver interventions reported in the literature.

Six sites (Boston, Birmingham, Memphis, Miami, Palo Alto, and Philadelphia) developed and evaluated a variety of multicomponent interventions for family caregivers of persons with AD at the mild or moderate level of impairment. The interventions implemented across the six sites included: (a) Individual Information and Support Strategies, (b) Group Support and Family Systems Therapy, (c) Psychoeducational and Skill-Based Training Approaches, (d) Home-Based Environmental Interventions, and (e) Enhanced Technology Support Systems (see Table 1). Although the interventions were derived from diverse theoretical frameworks, they are all consistent with basic health-stress models in which the goal is to change the nature of specific stressors (e.g., problem behavior of the care recipient), their appraisal, and/or the caregivers' response to the stressors. All of the REACH interventions were guided by detailed treatment manuals and certification procedures that ensured that the interventions were delivered as intended and consistently over time at each site. Careful attention was also paid to the issue of

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treatment fidelity. Different strategies were used at each site to induce and assess all three fundamental aspects of treatment implementation: delivery, receipt, and enactment (Burgio et al., 2001). In addition, because the caregiving experience in race and ethnic minority families is particularly neglected in this field, a strong emphasis was placed on the inclusion of African American and Hispanic caregivers (see Tables 2 and 3 for descriptions of caregivers and care recipients). Thus, assessments as well as interventions were tailored at each site to meet the needs of culturally diverse racial/ethnic majority and minority populations, briefly described in Table 1.

All of the REACH sites shared several common goals, including: (a) designing theory-driven caregiving interventions to test hypotheses about intervention processes and their effect on family caregivers, (b) specifying intervention components that help us understand the pathways through which interventions produce desired outcomes, (c) developing a standardized outcome protocol to assess the impact of different strategies on caregivers and their care recipients within each site and across sites, and (d) creating a common database and measurement intervals that would facilitate the pooling of data across sites. In addition, standard selection criteria were adopted by REACH (Wisniewski et al., in press).

Although REACH has some of the features of a traditional multisite randomized controlled clinical trial (e.g., random assignment of participants to treatment and control conditions, common database and outcome measures, and identical measurement intervals across sites), it differs on one key dimension—the interventions varied across sites. REACH was designed to examine the feasibility and outcomes of multiple different intervention approaches, rather than to provide definitive information on the efficacy of one specific intervention strategy for enhancing caregiver outcomes. The strength of this approach is that it efficiently yields information about the effectiveness of different approaches to AD caregiving as well as the combined effects of active treatment versus controls.

Four articles currently in press provide a detailed description of the REACH program overall (Wisniewski et al., in press), as well as report treatment effects based on two widely used indicators of caregiver status, depression, and burden (Gitlin et al., in press; Belle et al., in press). Wisniewski et al. (in press) provides a detailed description of the project and the interventions, the randomization strategies used, the standardized battery of measures, and the characteristics of the 1222 caregivers and care recipients recruited into the study. Using a preplanned meta-analytic approach (Gitlin et al., in press), and based on a conceptual framework that enables cross-site comparisons of intervention components (Czaja, Schulz, Lee, & Belle, in press; Belle ct al., in press), the following results were obtained:

- Among all caregivers combined, active interventions were superior to control conditions in reducing caregiver burden.
- Among all caregivers combined, active interventions that emphasize active engagement of caregivers had the greatest impact in reducing caregiver depression.
- Women and those with high school or lower education who were in active interventions reported reduced burden compared with similar individuals in control conditions.
- Caregivers in active interventions who were Hispanic, those who were nonspouses, and those who had less than a high school education reported lower depression scores than those with the same characteristics who were in control conditions.

The purpose of the six articles that follow is to report the site-specific effects of the REACH interventions. Although the analyses reported by Gitlin et al. and Belle et al. provide an overall view of active treatment versus controls across all sites, they are limited with respect to exploring the impact of individual interventions, the range of outcomes examined, and the

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depth of analyses carried out at each site. The papers that follow provide a detailed description of each intervention and the associated treatment effects at each of the six sites.

The first article (Mahoney et al., 2003) reports the results of the intervention study carried out in the Boston, Massachusetts area and shows that wives who exhibited low mastery and high anxiety benefited the most from an automated telecare intervention. A behavioral skills training intervention carried out in Birmingham, Alabama showed differential effects for African American and non-spouse caregivers (Burgio et al., 2003), with each of these groups showing greater benefits than comparison groups of White and spousal caregivers, respectively. Burns et al. (2003) examined long-term outcomes among caregivers residing in the Memphis, Tennessee area and showed that a long-term education intervention based in a primary care setting was effective in reducing caregiver stress and burden. The Miami intervention study (Eisdorfer ct al., 2003) demonstrated that information technology has a promising role in alleviating the distress and depression among White and Cuban American AD caregivers. Researchers from Palo Alto, California (Gallagher-Thompson et al., 2003) were able to demonstrate improved coping among female caregivers who participated in an intervention designed to enhance skills for managing distress. Finally, an environmental skill-building intervention carried out in Philadelphia, Pennsylvania (Gitlin et al., 2003) resulted in less upset with memory-related behaviors and improved affect in intervention care-givers when compared with individuals in the control condition. Also, women in intervention tended to benefit more than men did in areas of mastery and ability to manage daily caregiving tasks. Overall, these studies provide a rich array of effective intervention strategies that can be used to enhance different outcomes for caregivers of persons with dementia. They also emphasize the interactive nature of different treatment approaches with caregiver characteristics and provide important leads about which types of interventions work with which types of caregivers.

The lessons learned from REACH were instrumental in designing the follow-up study, REACH II. In contrast to REACH, the primary goal of REACH II is to test a single intervention at multiple sites with an ethnically diverse caregiver population. Thus, REACH II is a traditional randomized clinical trial with all sites implementing the same intervention and collecting the same data. The design of the intervention was based on a careful analysis of outcomes in REACH as well as a review of the current literature in this area (Schulz, et al., 2002; Sörensen, Pinquart, Habil, & Duberstein, 2002). The overriding message from both of these sources is that caregiving presents multiple challenges that are not easily addressed. As a result, there is no single, easily implemented, and consistently effective method for achieving clinically significant effects among care-givers or care recipients.

One of the disappointments in the caregiving intervention research literature has been the relative lack of success in achieving clinically meaningful outcomes. Researchers have achieved small-to-moderate statistically significant effects on a wide variety of indicators such as depressive symptoms, burden, and other indicators of psychological well-being. The lack of strong findings is in part due to the misapplication of intervention approaches borrowed from medical and psychotherapeutic trials. With rare exception, caregivers typically do not fall into single syndromal clinical categories that lend themselves to a clearly targeted intervention. For example, although most caregivers have elevated levels of depressive symptoms, they do not meet criteria for clinical depression. Thus, unless one targets specific subgroups of caregivers who are clinically depressed, the ability to demonstrate large effects is constrained by the moderate level of the problem being addressed and the limited range of improvement possible. In general, caregivers can be characterized as having problems in multiple interrelated domains that exist at varying, but typically not extreme, levels of intensity. The intervention approach selected for REACH II is based on this assumption and is designed to maximize

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outcomes in multiple different domains by tailoring the intervention to respond to individual variation in risk.

Many caregiving interventions involve several treatment elements aimed at simultaneously addressing multiple problems. Multicomponent interventions delivered in high doses are generally more effective than more narrowly targeted interventions (Schulz, 2000; Sörensen et al., 2002). Although we subscribe to the multicomponent approach to caregiver interventions, we diverge from the existing literature in an important way. Based on our assessment of the existing literature and the experience of REACH, we believe a “one size fits all” approach to caregiver interventions is likely to be ineffective. Because of the diversity of challenges inherent in the caregiving situation, interventions need to allow for some degree of tailoring of intervention components to meet the specific needs of the individual. Thus, we subscribe to a structured—but at the same time, tailored—approach to delivering interventions that are responsive to individual risk profiles.

In order to assess the variability in the needs of caregivers/care recipients, we use a risk appraisal approach in REACEI II to determine how much emphasis we place on each of the treatment components. Our intervention approach targets multiple components of the stress-health process and focuses on five areas linked to caregiver health outcomes: safety, self-care, social support, emotional well-being, and problem behaviors. The risk appraisal helps us prioritize these intervention components. Thus, the intervention is standardized with respect to the treatment components available, but varies with respect to the dosing or depth of treatment delivered for each of the available treatment components. For example, persons in active treatment who have minimal problems with depression will receive only a small dose of the intervention component designed to enhance emotional well-being. This will enable the interventionist to concentrate on those areas where risk factors are highest. In order to deliver the intervention in a cost-effective manner, we use a combination of in-home visits augmented by telephone-based technology found to be effective in REACH.

We are currently in the early stages of implementing REACH II, and it is therefore too early to report findings from this effort. However, we strongly believe that the REACH II research program will generate effective intervention strategies for care-givers of persons with dementia, and at the same time will advance the science of conducting complex randomized clinical trials in the social and behavioral sciences.

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Appendix

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Table 1

REACH Interventions by Site

Site	Description of Active Interventions and Control Conditions	Site-Specific Outcomes
Birmingham	*Skill Training Condition* — Problem-solving training designed to increase caregivers' ability to manage care recipients' behavioral excess and deficits, and to increase caregivers' ability to cope with these and other daily stressors. *Control:* Minimal Support Condition — Telephone-based minimal intervention that provides caregivers with contact and support such as active listening and empathy and written information about dementia and caregiving.	Behavioral skills training intervention showed differential effects for African American and nonspouse caregivers with each of these groups showing greater benefits than comparison groups of White and spousal caregivers, respectively.
Boston	*REACH for TLC (Telephone Linked Computer) System* — Telephone-based intervention designed to reduce caregiver stress. The system provides automated monitoring of caregiver stress levels, a voice-mail caregiver bulletin board, an ask-the-expert call option, and care recipient behavioral distraction to reduce disruptive behaviors. *Control:* Usual Care — Caregivers receive written information on dementia caregiving and referral resources.	Wives who exhibited low mastery and high anxiety benefited the most from an automated telecare intervention.
Memphis	*Behavior Care* — Caregivers receive written information plus skills training and materials in patient behavior management (periodic consultations and phone calls with behavior management interventionist to manage care recipients' behaviors). *Enhanced Care* — Caregivers receive written information and skills training plus behavioral modification strategies to decrease stress for the caregiver (relaxation training, coping strategies). *Control:* Usual Care (Information and Referral) — Caregivers receive written information on dementia caregiving and referral resources.	A long-term education intervention based in a primary care setting was effective in reducing caregiver stress and burden.
Miami	*Family-based Structural Multi-system In-home Intervention (FSMII)* — In-home family systems therapy designed to reduce caregiver's distress of managing and living with care recipient, and enhance family functioning. *FSMII + Computer Telephone Integration System (CTIS)* — Designed to augment FSMII with a computerized telephone system. The CTIS system is used to facilitate communication among the therapist, caregiver, family, and other support systems by providing messaging, conferencing, access to prestored information, and respite functions. *Control:* Minimal Support Condition — Telephone-based, minimal intervention that provides caregivers with contact and support such as active listening and empathy and written information about dementia and caregiving.	Caregivers in the combined family therapy and technology intervention experienced a significant reduction in depressive symptoms at 6 months. The 18-month follow-up data indicated that the intervention was particularly beneficial for Cuban American husbands and daughter caregivers.
Palo Alto	*Coping With Caregiving Class* — Psychoeducational class designed to teach caregivers coping and mood management skills. *Enhanced Support Group* — Support group patterned after local community support groups (standardized meeting frequency, duration, length of time in group and educational materials). *Control:* Minimal Support Condition — Telephone-based, minimal intervention that provides caregivers with contact and support such as active listening and empathy and written information about dementia and caregiving.	Improved coping among female caregivers who participated in an intervention designed to enhance skills for managing distress.
Philadelphia	*Environmental Skill-building Program* — Home-based intervention that provides caregivers with skills and technical support to modify the home to manage excess care recipient behaviors. Problem areas addressed may include managing ADLs, excess agitation, wandering or incontinence, and caregiver need for respite. *Control:* Usual Care — Caregivers receive written information on dementia caregiving and referral resources.	Environmental skill-building intervention resulted in less upset with memory-related behaviors and better affect in intervention caregivers when compared with individuals in the control condition. Also, women in intervention tended to benefit more than men did in areas of mastery and ability to manage daily caregiving tasks.

Note: ADLs = activities of daily living.

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Table 2

Descriptive Profile of the Caregivers Participating in the Interventions at the Six REACH Intervention Sites

	REACH Sites													
	Birmingham N= 140		**Boston N= 100**		**Memphis N = 245**		**Miami N = 225**		**Palo N = Alto= 257**		**Philadelphia N = 255**		**Total N = 1222**	
Characteristic	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**
Age														
Mean, *SD*	62.9	12.9	62.6	12.7	62.3	13.0	68.5	11.4	57.3	13.9	61.1	14.3	62.3	13.6
Median, range	64	28, 88	65	22, 85	63	24, 89	70	39, 92	56	23, 90	60	28,95	63	22, 95
Sex, male	30	21.4	22	22.0	53	21.6	57	25.3	0	0.0	65	25.5	227	18.6
Marital status														
Never married	9	6.5	13	13.0	18	7.4	12	5.3	32	12.5	44	17.3	128	10.5
Married/living as married	99	71.2	68	68.0	173	70.6	184	81.8	178	69.3	148	58.0	850	69.6
Widowed	11	7.9	6	6.0	22	9.0	6	2.7	8	3.1	18	7.1	71	5.8
Divorced	16	11.5	11	11.0	23	9.4	22	9.8	33	12.8	35	13.7	140	11.5
Separated	4	2.9	2	2.0	9	3.7	1	.4	6	2.3	10	3.9	32	2.6
Ethnicity														
Caucasian	80	57.1	79	79.0	143	58.6	112	49.8	147	57.2	123	48.2	684	56.0
Black	60	42.9	16	16.0	97	39.8	0	0.0	0	0.0	122	47.8	295	24.2
Hispanic	0	0.0	2	2.0	2	.8	113	50.2	110	42.8	5	2.0	232	19.0
Mexican	0	0.0	0	0.0	0	0.0	0	0.0	77	70.0	0	0.0	77	33.2
Cuban	0	0.0	0	0.0	1	50.0	113	100	2	1.8	0	0.0	116	50.0
Hispanic Other	0	0.0	2	100	1	50.0	0	0.0	31	28.2	5	100	39	16.8
Other	0	0.0	3	3.0	2	.8	0	0.0	0	0.0	5	2.0	10	.8
Income														
<$20,000	47	34.6	31	32.0	91	37.3	87	41.2	76	29.6	115	46.6	447	37.5
$20,000-$39,999	48	35.3	35	36.1	93	38.1	67	31.8	90	35.0	79	32.0	412	34.6
$40,000 or more	41	30.1	31	32.0	60	24.6	57	27.0	91	35.4	53	21.5	333	27.9
Years providing care														
Mean, SD	3.6	3.0	5.3	4.1	4.1	4.1	3.9	3.0	5.1	6.0	4.3	3.8	4.3	4.2
Median, range	3.0	0, 17	4.5	1, 26	3.0	1,32	3.0	1, 26	3.0	1,40	3.0	1,20	3	0, 40
CES-D (out of 60)														
Mean, SD	13.9	10.0	13.6	11.0	12.6	9.9	18.1	11.8	17.7	12.5	14.9	11.6	15.4	11.5
Median, range	12	0, 41	11	0, 54	11	0, 56	16	0, 49	16	0,52	13	0,54	13	0, 56
% ≥ 16	54	38.6	31	31.6	74	30.2	117	52.0	12.9	50.2	94	36.9	499	40.8

Notes: SD = standard deviation REACH = Resources for Enhancing Alzheimer's Caregiver Health CES-D = Center for Epidemiologic Studies—Depression score.

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Table 3

Descriptive Profile of Care Recipients Participating in the Interventions at the Six REACH Intervention Sites

	REACH Sites													
Characteristic	**Birmingham N=140**		**Boston N= 100**		**Memphis N = 245**		**Miami N = 225**		**Palo Alto N= 257**		**Philadelphia N = 255**		**Total *N* = 1222**	
Age														
Mean, SD	78.9	8.4	78.0	8.4	78.2	7.4	80.1	7.5	78.1	9.4	80.7	7.9	79.1	8.2
Median, range	79	51, 102	78	53, 99	78	57, 95	81	51, 95	78	44, 95	81	51, 10	80	44, 102
Sex, male (*n*, %)	54	38.6	52	52.0	109	44.5	108	48.0	133	51.8	86	33.7	542	44.4
Mini-Mental State Exam (out of 30)														
Mean, *SD*	13.0	7.3	11.2	8.6	11.1	6.8	13.6	8.2	13.7	7.7	12.2	7.0	12.6	7.5
Median, range	13.0	0, 29	10.5	0, 27	10.0	0, 28	14.0	0, 29	15.0	0, 28	13.0	0, 27	13.0	0,29
Revised Memory and Behavior Problems Checklist (out of 24)														
Mean, *SD*	11.0	3.7	8.9	4.0	10.1	4.2	10.0	4.0	11.3	4.4	9.3	3.9	10.2	4.2
Median, range	10.6	0, 22	9.0	0, 22	10.0	0,21	9.4	2, 23	11.0	1.3, 22	9.0	1, 21	10.0	0, 23
Limitations in Activities of Daily Living (out of 6)														
Mean, *SD*	3.2	2.0	3.4	2.1	3.4	2.0	2.7	2.3	3.4	2.1	3.5	1.9	3.3	2.1
Median, range	3.0	0, 6	4.0	0, 6	4.0	0, 6	3.0	0, 6	4.0	0, 6	4.0	0, 6	3.0	0, 6
Limitations in Instrumental Activities of Daily Living (out of 8)														
Mean, *SD*	7.5	.9	7.4	1.1	7.5	1.0	6.5	1.8	7.3	1.0	7.6	1.0	7.3	1.3
Median, range	8.0	3, 8	8.0	3, 8	8.0	2, 8	7.0	1, 8	8.0	2, 8	8.0	1, 8	8.0	1, 8

Notes: REACH = Resources for Enhancing Alzheimer’s Caregiver Health SD = standard deviation.