

Appendix Table 3. Caregiving*

Author, Year (Reference); Country	Funding Source	Study Design and Quality	Population†	Sampling Approach and Setting	Intervention Description	Control Description	Time Point for Outcome Analysis	Outcomes	Description of Results
Baker et al, 2000 (136, 137); USA	Robert Wood Johnson Foundation	CCT/Prospective cohort	Number approached: Not reported	Patients at high risk of death hospitalized at five U.S. teaching hospitals, randomized within physician specialty status group	Delivery of prognostic estimates for survival, function, pain, and treatment preferences to attending physicians by nurses trained to facilitate communication among providers, patients, and family. Patient counseling on prognosis and treatment options.	Usual care	Baseline hospitalization to after death	8 item caregiver satisfaction with end-of-life care scale including a comfort score and communication score	This study described caregiver outcomes for the cohort, although it also evaluated the intervention effect differences and found none overall. However, if the death occurred after discharge, satisfaction was greater among those assigned to the intervention (OR, 1.98 [95% CI, 1.21–3.24]).
		Jadad: NA	Number enrolled: Not reported Number included in analysis of results: 767/983 (those with after death interviews among all deaths) Age: median years 65.5 Gender: male 57% Race/ethnicity: white 57% Disease: COPD, CHF, ESLD, coma, metastatic colorectal cancer, stage III or IV lung cancer, multiple system organ failure with cancer or sepsis Severity: Hospitalized						
Bucher et al., 2001 (144); USA	Not reported	Design: Uncontrolled pre–post	Number approached: Not reported	Convenience sample of family caregivers of patients receiving care at an oncology center	Single 90-minute problem solving–oriented instructional session using the <i>Home Care Guide for Cancer</i>	NA	Baseline and 2 months	(Pre–post) Community resource information and problem solving ability	Participants reported being more informed about community resources and better problem solving ability two months after a single educational session.
		Jadad: NA	Number enrolled: 54 family caregivers of 49 patients Number included in analysis of results: 17 family caregivers of 14 patients Age: patients (51 years), caregivers (48 years) Gender: patients 57% male, caregivers 26% male Race/ethnicity: Not reported Disease and stage of illness: Stage III or IV advanced cancer						
Burgio et al., 2003 (145); USA	National Institute of Nursing Research	Design: RCT	Number approached: 289 dyads	AD, caregiver dyads recruited from various dementia home and specialty clinics in	Training in caregiver skills including behavioral modification of the demented patient with intensive home based training	Periodic brief telephone calls focused on active listening	Baseline and 6 months	Patient problem behaviors, caregiver social support and activity, wellbeing	This REACH study found no differences in any outcome at 6 months.

		Jadad: 2	Number enrolled: 140 dyads Number included in analysis of results: 118 dyads Age: intervention mean caregiver 62 years vs. 64 control Gender: intervention 47/61 female vs. 45/57 control Race/ethnicity: intervention African-American 25/61 vs. 23/57 control Disease: AD Severity: Participants had to have 1 ADL or 2 IADL limitations	Birmingham					
Burns et al., 2003 (146; USA)	National Institute on Aging, National Institute of Nursing Research	Design: RCT	Number approached: 433 caregivers	Caregivers in Memphis, Tennessee, recruited from 14 county-wide practice sites serving 19 physicians	Enhanced care: focused on improving the caregiver's well-being in response to behavioral problems	Behavior care: focused on improving caregiver management of behavioral problems	Baseline to 24 months	Depression, upset or burden associated with behavioral problems, satisfaction with social support, ADL/IADL impairment	This REACH study found a higher risk for burden among behavior, but not enhanced, care recipients. Depression was greater among behavior care recipients (at all times), and problem behaviors improved in both groups.
		Jadad score: 3	Number enrolled: 167 caregiver-patient dyads Number included in analysis of results: 120 Age: mean years 81 control and 79 intervention Gender: male 40% Behavior vs. 49% Enhanced Race/ethnicity: African-American 38% Behavior and 46.2% Enhanced Disease: AD Severity: Participants had to have 1 ADL or 2 IADL limitations						
Cameron et al., 2004 (150); Canada	University Health Network Mental Health Research Program	Design: Uncontrolled pre-post	Number approached: 112 patients, 105 of whom had family caregivers	Convenience sample of family caregivers of patients receiving care at a hospital-based oncology center	Single 60 minute problem solving-oriented instructional session using the <i>Home Care Guide for Cancer</i>	NA	Baseline, 4 weeks	Caregiver emotional wellbeing, problem solving capability	Improvements in emotional tension ($P < 0.03$) and nonsignificant improvement in confidence and problem solving orientation were noted.
		Jadad score: NA	Number enrolled: 58 caregivers Number included in analysis of results: 47 caregivers Age: mean, 64 years Gender: 58% male						

			Race/ethnicity: Not reported Disease: Cancer Severity: Advanced						
Eisdorfer et al., 2003 (147); USA	National Institute on Aging, National Institute of Nursing Research	Design: 3 arm RCT Jadad score: 2	Number approached: Not reported Number enrolled: 225 caregivers Number included in analysis of results: 147 caregivers Age: caregiver mean years 66–73 across all conditions Gender: 42/147 caregivers were male Race/ethnicity: 76/147 caregivers were Cuban Americans Disease: AD Severity: Participants had to have 1 ADL or 2 IADL limitations	Caregivers and patients recruited from memory disorder and primary care clinics, social service agencies through community outreach.	Structural ecosystems theory (SET)–based therapist sessions with family, SET + telephone/computer support	Periodic brief telephone calls focused on active listening	Baseline, 6, 12, 18 months	Depression, upset or burden associated with behavioral problems, satisfaction with social support, ADL/IADL impairment	This REACH study found that depressive symptoms were lower at 6 months in the combined family therapy, telephone/computer support intervention. At 18 months, improvement was sustained in Cuban-American, but not white, caregivers.
Gitlin et al., 2003 (142); USA	National Institute on Aging, National Institute of Nursing Research	Design: Jadad score: 2	Number approached: 413 caregivers Number enrolled: 255 caregivers Number included in analysis of results: 188 caregivers Age: mean caregiver 60 years intervention vs. 61 controls Gender: 75% female intervention vs. 77% control Race/ethnicity: 54% African-American intervention vs. 52% control Disease: AD Severity: Participants had to have 1 ADL or 2 IADL limitations	Caregivers recruited from the Philadelphia Corporation for Aging and media announcements	Environmental skill building program using 6 in home occupational therapist visits	Usual care	Baseline, 6 months	Depression, upset or burden associated with behavioral problems, satisfaction with social support, ADL/IADL impairment	In this REACH study, intervention caregivers reported less upset with memory-related behaviors, less need for assistance, and better affect.
Gitlin et al., 2003 (141); USA	National Institute on Aging,	Design: Pooled RCTs	Number approached: Not reported	Caregivers of patients with dementia in	9 active conditions tested at 6 sites (skills training, telephone-linked computer, environmental	6 control conditions used	Baseline to 6 month	Common measures used at all sites—depression, upset	Pre-planned pooled analysis of REACH interventions at 6 months demonstrated that interventions (pooled) vs. controls benefited

	National Institute of Nursing Research			community sites including clinical, social services, and health agency settings	skills building, behavioral and enhanced care, family-based multisystem in-home intervention and combined with computer telephone integration, caregiver classes and enhanced support group	including limited versions of interventions, usual care		or burden associated with behavioral problems, satisfaction with social support, ADL/IADL impairment	burden ($P = 0.022$). For depressive symptoms, family therapy and a computer-technology intervention were beneficial ($P = 0.034$). Multicomponent, tailored interventions tended to be more effective.
		Jadad score: NA	Number enrolled: 1202 (780 intervention, 442 control) Number included in analysis of results: 1202 Age: Gender: Race/ethnicity: Disease: AD Severity: 1 ADL or 2 IADL limitations						
Hanks et al., 2002 (135); UK	NHS Cancer R&D Program	RCT	Number approached: 684	Inpatient palliative care referrals	In person palliative care consultation	Telephonic palliative care advice	1 week	Symptom control and HR-QOL, global satisfaction, utilization	No differences noted
		Jadad: 3	Number enrolled: 261 Number in analysis of results: 109–191 Age: mean years 68 both groups Gender : male intervention 54% vs. 53% control Race/ethnicity: Not reported Disease: cancer 93% intervention vs. 88% control Severity: advanced						
Hughes et al., 2000 (134); USA	Department of Veterans Affairs	RCT	Number approached: Not reported	Hospitalized veterans who were being discharged to a 35 mile catchment area served by a home based primary care team, with 2 or more ADL impairments, or terminal illness, or homebound with CHF or COPD	Team-managed, home-based primary care including screening and targeting high-risk patients, 24-hour contact, team manager, prior approval of scheduled hospitalization, and team inclusion in discharge planning	Usual care	1,6, and 12 months	Functional status, health-related quality of life (HR-QOL), satisfaction, and cost/utilization	Function did not differ, but improvements in most patient and caregiver HR-QOL scales were observed. Caregivers reported reduced burden ($P = 0.008$) Costs were higher in the intervention group (12.1% at 12 months, $P = 0.005$) and may reflect shift of inpatient to nursing home and home care costs.
		Jadad: 3	Number enrolled: 1966 patients and 1883 caregivers randomized Number in analysis of results: 667 completed trial (80% of dropouts due to death or loss of cognitive function)						

			Age: 70 years patients, 62 years caregivers Gender: 97% male patients, 17% male caregivers Race/ethnicity: 63% white, 30% black, 8% other Disease: 21% terminally ill, 55% with COPD or CHF Severity: 75% severely disabled						
Mahoney et al., 2003 (148); USA	National Institute on Aging, National Institute of Nursing Research	Design: RCT	Number approached: 143 caregivers	Southern New England community and clinical sites	Automated tele-care that allowed dial-in to mailbox, bulletin board, automated respite/distraction conversations, interactive voice-response caregiver conversation with coaching	Usual care	Baseline, 6, 12, and 18 months	Depression, upset or burden associated with behavioral problems, satisfaction with social support, ADL/IADL impairment	Although there was no overall effect, as hypothesized, intervention participants with baseline mid-low mastery improved on behavioral problem, depression, and anxiety.
		Jadad: 2 score:	Number enrolled: 100 caregivers Number included in analysis of results: 82–45 (outcome dependent) Age: mean years intervention 61 vs. 64 control Gender: female 40/49 intervention vs. 38/51 control Race/ethnicity: white 38/49 intervention vs. 41/51 control Disease: AD Severity: 1 ADL or 2 IADL limitations						
Molloy et al., 2000 (149); Canada	Agency for Healthcare Research and Quality	Design: CCT	Number approached; 215 nursing homes surveyed; 1292 residents at 6 randomized nursing homes	Nursing homes in Ontario with >100 residents, selected as pairs similar in regard to annual hospitalization, level of care, hospital deaths	Quality improvement using Let Me Decide advance directives; training nurses as health care facilitators for implementation, chart flagging	Usual care	Baseline, 6, 12, and 18 months	Directive completion, satisfaction with care and involvement in decision making, utilization and costs	In intervention homes, 49% of competent and 78% of incompetent residents completed directives. Satisfaction and mortality were similar between intervention and control homes, although hospitalization per resident (0.27 vs. 0.48, $P = 0.001$) and costs (Can \$3490 vs. \$5239, $P = 0.01$) were lower.
		Jadad score: NA	Number enrolled: 6 nursing homes; 1133 residents Number included in analysis of results: 6 nursing homes; 818 residents Age: mean years 79–85 among homes Gender: mean female 63–82% among homes Race/ethnicity: mean white 94–100% among homes						

			Disease: Diverse Severity: unable to consent due to cognitive impairment 36–94% among homes						
Ringdal et al., 2002 (138); Norway	Norwegian Cancer Society; Swedish Cancer Society, Norwegian Medical Association Fund for Quality Improvement	Design: CCT	Number approached: 426 family members of 434 patients	Community healthcare districts in the Trondheim, Norway University Hospital service area	Coordination, education among hospital-based palliative care staff, community practitioners, and family	Usual care	After death survey	Family satisfaction with care (FAMCARE)	Intervention vs. control family members were more satisfied with care (+7.7, $P < 0.016$). Spouses were more satisfied (+12.5, $P < 0.015$) than children.
		Jadad score: NA	Number enrolled: 312						
			Number included in analysis of results: 183						
			Age: mean years 58 intervention vs. 54 control						
			Gender: intervention mean male 32% vs. 31% control						
			Race/ethnicity: Not reported						
			Disease: Cancer						
			Severity: Advanced						
Ringdal et al., 2004 (139); Norway	Norwegian Cancer Society, Swedish Cancer Society, Norwegian Fund for Quality Improvement	CCT (Norway)/nonrandomized, controlled (Swedish)	Number approached: Not reported; family members of 434 cancer patients	Norway—patients in health districts served by the palliative care unit Trondheim; Sweden—patients living in Malme receiving hospital-based palliative services while residing in the community	Palliative care programs coordinated with the community	Usual home based care	Baseline and every other month while patient alive, then 1, 3, 6, and 13 months after death	HR-QOL	This analysis pooled results from two studies conducted with different designs, but similar measures. Role limitation due to emotional problems and mental health worsened or stayed the same in control, but improved in intervention groups.
			Number enrolled: 314 family members of patients (Norway) 204 family members of patients (Sweden); 731 patients (354 intervention, 377 control)						
			Number included in analysis of results: 517 caregivers completed at least one questionnaire						
			Age: caregiver mean years 58–65 across groups/sites						

			Gender: caregiver mean male 29–42% across groups/sites Race/ethnicity: Not reported Disease: Cancer Severity: Incurable with predicted survival of 2–9 months						
Schneiderman et al., 2000 (104); USA	Agency for Healthcare Policy and Research	RCT	Number approached: Not reported	Consecutive ICU patients at 1 U.S. hospital referred by nurses who identified patients with potential value laden conflicts	Ethics consultations by individuals with advanced training or experience in bioethics	Usual care	Following death or discharge (2–4 weeks)	Hospital and ICU days, use of life sustaining treatments, perceptions of experiences with care and consultation from providers and family	No difference in mortality, but reduced hospital and ICU days and lower use of life sustaining treatment. Most providers and patients found the experience helpful.
		Jadad: 2	Number enrolled: 74 Number in analysis of results: 70 Age: Mean years, intervention 46 vs. control 52 Gender Race/ethnicity: intervention white 40% vs. control 43% Disease: Diverse Severity: Advanced (60% of patients in both groups died in hospital)						
Schneiderman et al., 2003 (103); USA	Agency for Healthcare Research and Quality	RCT	Number approached: 551	Consecutive ICU patients at 7 U.S. hospitals referred by nurses who identified patients with potential value laden conflicts	Ethics consultations by individuals with advanced training or experience in bioethics	Usual care	Following death or discharge (1–2 weeks)	Hospital and ICU days, use of life sustaining treatments, perceptions of experiences with care and consultation from providers and family	No difference in mortality, but reduced hospital (–2.95, <i>P</i> = 0.01) and ICU (–1.44, <i>P</i> = 0.03) days and ventilatory support (–1.7 days, <i>P</i> = 0.03) 87% of providers and surrogates agreed consultation was helpful in addressing conflicts.
		Jadad: 3	Number enrolled: 551 Number in analysis of results: 546 Age: mean years intervention 68 vs. control 68 Gender Race/ethnicity: intervention white 63% vs. control 63% Disease: Diverse Severity: Advanced (63% of intervention and 58% of control patients died in hospital)						
Smeenk et al., 1998 (143); Netherlands	National Committee of Chronic Disease in	Design: Controlled pre–post	Number approached: Not reported	Terminally ill cancer patients and their caregivers discharged from	Specialist nurse coordinator, 24 hour telephone link to home care, home care case file, and care protocols	Usual care	One week before patient discharge, 1 and 4 weeks after, and after death	Caregiver quality of life	Caregiver quality of life was higher in intervention than control at 1 week following discharge and 3 months after death.

	the Netherlands		Jadad score:	Number enrolled: 116 Number included in analysis of results: 45 Age: mean years 55 intervention vs. 61 control Gender: male intervention 29% vs. 36% control Race/ethnicity: Not reported Disease: Cancer Severity: Terminal	hospital in Eindhoven					
Walsh and Schmidt, 2003 (140); USA	University of Miami School of Nursing Dean's Award	Design: Uncontrolled pre-post	Jadad score: NA	Number approached: 14 Number enrolled: 6 Number included in analysis of results: 5 Age: mean years 66 Gender: 3 men, 3 women Race/ethnicity: 5/6 white Disease: Mixed Severity: Hospice patients	Caregivers of hospice patients thought to live 6 weeks or more referred by hospice staff	One home visit followed by 4 weeks of tele-care counseling from nurse interventionist using materials structured to help caregivers address psychosocial, practical personal needs	NA	Burden, depression, social support	Baseline, 4 weeks	Lower depression, despair, and disorganization were reported over time, although burden increased.

* AD = Alzheimer disease; ADL = activity of daily living; CCT = clinical controlled trial; CHF = congestive heart failure; COPD = chronic obstructive pulmonary disease; ESLD = end-stage liver disease; HR-QOL = health-related quality of life; IADL = independent activity of daily living; ICU = intensive care unit; NA = not available; OR = odds ratio; RCT = randomized, controlled trial; REACH = Resources Enhancing Alzheimer's Caregiver Health Project; UK = United Kingdom; USA = United States of America.

† All descriptions of the population are for the intervention group (if overall is not described), and differences with the control are indicated where appropriate.