**Online Supplementary Table.** Characteristics of studies included in the review.

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **First author (Year), country** | **Population** | **Sample size** | **Design** | **Patients dementia stage**  | **Outcome measures**  | **Process measures** | **Quality assessment**  |
| Bonner (2014), USA (Bonner et al., 2014) | African-American (AA) caregivers whose relatives were enrolled in adult day care centers located in AA urban communities in Chicago | N=68 (Intervention: n=35; control: n=33) | Pre/post intervention  | Mixed, Self-reported | Carer:Increase in carer decision making self-efficacy 26.4 vs. 30.6 (P 0.02) | Carers:More accurate knowledge of effectiveness of CPR (p <.001)No change in carer knowledge of dementia (P 0.21)Reduction in SDM intention to use CPR 367% change vs. 38% control, MV 100% change vs. – 6% control, TF 240% change vs. 30% control  | Fair  |
| Hilgeman (2014), USA (Hilgeman et al., 2014) | Individuals with mild dementia; MildClinical dementia rating (CDR) .5 or 1 | N=18 (Intervention: n=10; control: n=8)  | RCT 2 group comparison with blocked randomisation | Mild, clinical dementia rating (CDR) .5 or 1 | PWD; Reduction in depression F (1, 15) = 5.51 ( n2p 0.27), Reduction in dependence in mobility F (1, 15) = 2.72 ( n2p 0.15), Increased quality of life F (1, 15) = 1.13n2p = 0:07, improved coping F (1, 16) = 3.35 ( n2p 0.17),, Caring rating of PWD:Increased QOL F ( (1, 14) =5.41 n2p 0.28), Reduction in depression F (1, 14) = 1.72 n2p 0.11),No change in anxiety, meaning, social engagement and emotional support  | Reduction in decisional conflict (F (1, 14) = 3.74 ( n2p 0.21) | Good  |
| Lewis (2015), Australia (Lewis, Rand, Mullaly, Mellor, & Macfarlane, 2015) | Clients and their carers diagnosed with MCI or dementia | N=189 (Clients: n=97; Carers: n=92) | Cross-sectional survey | Recently diagnosed (53%) or MCI  | NR | PWD:53% were interested in ACP seminar, 61.8% aware of Medical EPOA and 64.7% aware of financial EPOA.Carers:62% were interested in ACP seminar75% aware of Medical EPOA and 72.9% aware of financial EPOA 2/48 (4%) carers and 3/34 (8.8%) clients completed an ACP 23% completed an Medical EPOA | Fair |
| Logsdon (2007), USA (Logsdon, McCurry, & Teri, 2007) | Individuals and carers with early stage dementia | N=39 dyads (Intervention: n=25; control: n=14) | RCT | Early, MMSE >18 | PWD:No significant changes in QOL or depression PWDCarer: Increase in QOL (p < .05)Reduction in conflict (p < .05) | In carers and PWD90% rated program as valuable95% would recommend to others | Fair  |
| Moorhouse (2012), Canada (Moorhouse & Mallery, 2012) | Frail adults aged 65 and older with advanced or progressive illness (including dementia [68%]); multiple emergency department visits or hospital admissions within thelast 6 months; or a progressive decline in mobility, function, or cognition in the last 12 months.  | N=150 | Chart audit and cross-sectional survey | Mild, mean MMSE 19.3 |  NR | 93% completed an ACD 75% of scheduled procedures were cancelled People with more advanced dementia (OR = 1.66, 95% CI = 1.06–2.65) or increased frailty (OR) = 3.41, 95% (CI) = 1.39–8.38) were more likely to decline surgeryReferral source (primary care 21%, specialist 61% geriatrician 9%)Location of assessment (Outpatient clinic 47%, Inpatient 49% in home 4%)63% found conversation emotional charged or upsetting 96% found information useful, 100% found it useful for decision making  | Poor  |
| Pratt (1989), USA (Pratt, Nay, Ladd, & Heagerty, 1989) | Elderly patients and carers; including 46% with Alzheimer's Disease and 15%multi-infarct dementia (15%). Other diagnoses included Parkinson's Disease, stroke, Amyotropic Lateral Sclerosis (ALS), and other neurological disorders.  | N=68 | Post program survey | Mixed, self-reported; 59% diagnosed within the past 4 years. | NR  | Carers:91% completed 1 or more financial planning actions Increase in POA (33% pre, 55% post)Increase in health care proxy (16% pre 33% post)85% found program helpful | Poor  |
| Roberts (2009), USA (Roberts & Silverio, 2009) | Individuals and care partners with early dementia | N=71 (37 PWD; 37 Care partners) | Pre post intervention  | Mild, mean MMSE 23.8 | PWD:Increased supportive behaviour and attitudes, (physical activity, driving, nutrition and involvement in support group) (p ¸.05)No change in coping self-efficacy (p .10)No change in knowledge of dementia Carer: No change in coping self-efficacy, carer strain, or knowledge of dementia | Carers and PWD:Increased intention to complete ACP 44 – 66% (p < .05)Increase in intention to complete financial planning 31 – 66% (p < .05) 97% found program helpful, 86% found information easy to understand  | Fair  |
| Samus (2014), USA (Samus et al., 2014) | Community dwelling elders with cognitive disorders, including 87% with dementia | N=303 (Intervention: n=110; control: n=193) | 18-month prospective, single-blind, parallel group randomized pilot trial design comparing the MIND care coordination intervention with augmented usual care | Mild – moderate, MMSE 19.1 SD 7.8 | PWD:Increase in self-reported QOL 1.91 (p .027) No change in NPSD or depressionNo change in mortality | PWD:Reduction in proportion of unmet needs in Safety & Legal/ACP 17.9 – 6.4 (p= .015)Delay in transfer to nursing home 41.8% vs. 53.4% 948 days in home vs. 660 ( p 0.043 25% of contacts (excluding messages) were by phone, 5.5% in person, 12.8% by email/mail/fax | Good  |
| Silverstein (2010), USA (Silverstein & Sherman, 2010) | People with early stage Alzheimer’s disease and there care partners | 140 dyads - 73 respondents including 33 persons with dementia, 40 care partners representing 31 dyads, 1 triad and 1 person with dementia without care partner and 7 care partners without a person with dementia | Mailed survey | Mild | NR | PWD:No change in comfort with sharing diagnosis, 75% of respondents made changes recommended in training Carers and PWD:20% increase in ACP increasing to ACD (80%), POA (90%) health care proxy (90%), or wills (91%)90% satisfaction topics surveyed were considered relevant by between 56 – 95% of respondents  | Poor  |
| Ahronheim (2000), USA (Ahronheim, Morrison, Morris, Baskin, & Meier, 2000) | Patients with advanced dementia that had been hospitalized for acute illness | N=99 (Intervention: n=48; control: n=51) | RCT - randomised at level of patient | Advanced, > 6d on FAST | PWD:No change in mortality (24.5 vs. 25%) | Increased palliative care plans (p .008) but 9/10 not adopted until discharge. No diff in DNR (Mean 66%)No change in rehospitalisation or mean LOS, Intervention did not stop use of non-palliative interventions. Inconsistent information to determine adherence to wishes | Good  |
| Campbell (2004), USA (Campbell & Guzman, 2004) | Patients with advanced-stage dementia admitted to medical ICU | N=52 (Intervention: n=26; control: n=26) | Retrospective chart analysis | Advanced, > 6d on FAST | PWD:No change in mortality (14 vs. 17) | Increase in DNR (73% vs. 100%) Increased in CMO 16% vs. 62% (p>.001)Reduction in Hospital LOS 7.4 vs. 12.1 days (p .007)Reduction in MICU LOS 3.5 vs. 6.8 days (p.004) No change in time between DNR to discharge No change in discharge destination | Fair  |
| Catic (2013), USA (Catic et al., 2013) | Individuals admitted with advanced dementia | N=29 (Intervention: n=5; control: n=24)  | Pilot study. case-control/ longitudinal | Advanced, 7 on GDS | PWD:No change in mortality (24 vs. 25%)No change in symptom management (28.5 vs. 28.5)Carer:Increase in satisfaction EOL care (29.9 vs. 30.8) | Increase GOC discussions (71% vs. 100%)Increase DNR (75% vs.80%) Increase in LOS (4.1 vs. 6.6) Increase in hospice referral (12.5 % vs. 20%)Reduction in ED visits (0% vs. 33%) and rehospitalisation (0% vs.29.2%)No decrease in burdensome interventionsNo change in number of feeding tubes (10% vs. 12.5%) Increase in quality of communication (84.3 vs. 88.6%) Increase in knowledge of health in dementia (54.2 vs. 80.0%)  | Fair  |
| Sampson (2011), UK (Sampson et al., 2011) | Patients aged 70 years or over with advanced primary degenerative dementia | N=33 (Intervention: n=22; control: n=11) | Pilot study ; a two-arm feasibility cluster randomized controlled trial | Advanced, > 6d on FAST | PWD:No change pain or distress Carer:Increase in satisfaction with EOL care (23 vs. 27No change in health or QOLIncrease in decisional conflict in intervention group (18.8 vs. 30.9) | Increased ACP (0% vs. 32%)  | Fair  |
| Bekelman (2005), USA (Bekelman, Black, Shore, Kasper, & Rabins, 2005) | Patients above 70 years old with dementia (80%) or MCI within last year of life | N=81 (Hospice patients: n=24; non-hospice patients: n=57)  | Prospective observational cohort study | Mixed | PWD:65% more likely to be free of psychiatric symptoms (OR 5 0.35; 95% CI 0.13--0.96Reduction in proxy reports of pain 41.7% vs. 61.4%, (p 0.085), Carer:Non sig change in carer satisfaction | No significant Increase in ACD 64.8 % vs. 79.2% (p .205), Living will 49.1% vs. 54.2% (P 0.510), POA for health care 54.4% vs. 75.0% (p 0.169)  | Fair  |
| Caplan (2006), Australia (Caplan, Meller, Squires, Chan, & Willett, 2006) | Nursing home residents with dementia | N=1344 | Mixed, retrospective and prospective data collection | Mixed | PWD: No change in mortality except for 3rd year when sig higher in control 30.3 vs. 41.6 per 100 beds (p >.05) | 8 ACP documents completed. 30 ACP discussions Reduction in hospital admission 0.865 versus 1.254 (*P*<0.0001) Decreased bed days by NH residents 5.734 vs. 12.755 *P*<0.0001) Reduction in ambulance usage 1% vs. 21% (p .0019)100% died in preferred place  | Poor  |
| Cassarett (2005), USA (Casarett et al., 2005) | RACF residents in last 6 months of life, including 62% with dementia, and surrogate decision makers | N=205 (Intervention: n=107; control: n=98)  | RCT - randomised at patient level | Mixed | PWD: Mortality rates were similar (15/107 (14%) vs. 8/98 (8%); p .18) Increased SDM ratings of quality of care 2.2 vs. 4.3 (p = .01) | Increase in hospice use 6/98 (6%) vs. 27/ 107 (25%) (P< .001)Reduction in acute care admissions mean: 0.49 vs. 0.28 (P .04) Reduction in LOS 2.99 vs. 1.17 (p .03)  | Good |
| Delagarza (2001), USA (DeLaGarza, Andersen, Mach, & Bennett, 2001) | Long-stay nursing home residents, 70% with dementia, and/or their responsiblefamily members or guardians | Participants were 4,248 enrollees in a managed medicare program in 1996, and 6,598 enrollees in 1997, in Georgia, Maryland, Massachusetts, Minnesota,Arizona, and Florida. | Pre post intervention | NR | NR  | Increase in ACP discussions 73% vs. 85% post intervention (p< .001)Reduction in desire for hospitalization (65% versus 62%, (p 0.001).Reduction in desire for CPR in some states (p 0.001) | Poor  |
| Einterz (2014), USA (Einterz, Gilliam, Lin, McBride, & Hanson, 2014) | Surrogate Decision-Makers (SDMs) of Nursing Home residents with dementia | N=18 | Pilot study; Pre-post intervention | Moderate - Severe, 5,6,7 on GDS | PWD:No change in QOL, Improved symptom management 8.8 vs. 14.7 (p .013) Carer:No Sig change in satisfaction | Increase in GOC discussion with NP 11% vs. 72% (p .001)Increase in palliative care domains at 3 months 1.8 vs. 4.3 (p< .001)33% had a documented discussion of GOC, while 67% of SDM remembered being asked about GOC.Increase in SDM and staff concordance in GOC 50% vs. 78% (p .003)Increase in in quality of communication at EOL 3.3 vs. 4.7 (p .006) Increased knowledge 12.5 vs. 14.2 (p < 001) | Poor  |
| Ersek (2014), USA (Ersek et al., 2014) | Dyads of nursing home residents with advanced dementia and their surrogate decision-makers | N=256 dyads | Cluster RCT | Advanced, 6 – 7 on GDS | NR | Intervention group decreased decisional conflict score −0.08 vs. −.47 (p .008) and −0.30 v. −.0.68 (p .014) respectively  | Fair |
| Garden (2016), UK (Garden, Green, Pieniak, & Gladman, 2016) | Residents with dementia in a care home | N=4,248 in 1996 and N=6,598 in 1997 | Pre/post intervention  | Mixed | PWD: 67/68 PWD died in preferred placeHealthcare system: Decreased estimates of health care costs | 102 ACP completed 4/102 wished to die in hospital Decrease in hospital admissions 202 vs. 91 (55%) High satisfaction - 92% carers rated ACP service >9/10 | Fair  |
| Hanson (2005), USA (Hanson, Reynolds, Henderson, & Pickard, 2005) | Nursing home residents with advanced dementia | N=458 (Intervention: n=345; control: n=113) | Pre/post intervention | Advanced, 6 – 7 on GDS | NR | Increase in ACP discussions 4 - 17% (p< .001)Increase in DNR orders 58% to 65%, (P .04) No change in living will and POA Increase in hospice enrolment 4 – 6.8% (p .01)Increase in pain assessment 18%-60% (p< .001) Increase in non-pharmacological pain management 15%-35% (P.001)Increase in referral to hospice (P.01) | Fair  |
| Hanson (2011), USA (Hanson et al., 2011) | Residents 65 years and older with advanced dementia and feeding problems and their surrogates | N=256 surrogate dyads (Intervention: n=127; control: n=129) | Cluster RCT | Mixed | PWD: Reduction in weight loss in intervention 6% vs. 16% (P.01)No change in mortality (p .58)  | Increased carer knowledge 16.8 vs. 15.1 (P < .001) Carers expected fewer benefits from tube feeding 2.3 vs. 2.6 (P = .001) Increased not to tube feed orders. (Pooled result over 9 months % not provided)Increase in feeding tube discussion with HC provider 33% - 46% (P. 04) Increase in dysphagia diet 89 vs. 76% (P.04) | Fair  |
| Hanson (2016), USA (Hanson et al., 2016) | Residents with advanced dementia and their carers | N=22 (Intervention: n=11; control: n=11)  | Cluster RCT  | Advanced, 5,6,7 on GDS | NR | 90% of SDM involved in GOC discussion 69% of GOC discussion were within 3 months, 84% within 6 months 92% - 99% of discussions reviewed all content areas100% compliance with review of decision aid.  | Good |
| Hockley (2010), UK (Hockley, Watson, Oxenham, & Murray, 2010) | Nursing home residents, 60% with dementia  | N=228 | Retrospective chart review, and post implementation; staff audit  | NR | NR | Increase in DNR instruction 15% vs. 72% (p<0.001)Increase in ACP conversations 4% vs. 53% (p<0.001).In hospital death decreased from 8% to 15%. 38% decrease in hospital bed-days Increased use of Liverpool care pathway from 3% to 30% (p<0.001) | Fair  |
| Livingston (2013), UK (Livingston et al., 2013)  | People with dementia living in a care home, their family members, and staff from the same care home | N=112 (Pre: n=69; post: n=52) | Mixed method - Pre post intervention design Qualitative interviews with care staff. Review of resident records for evidence of ACP and if wishes were followed, post death interview with family | Severe, Mean MMSE 5 | PWD:No change in QOL or pain controlCarer:No change in anxiety and depression Increased concordance with EOL wishes71% vs. 100% (p .04) | Increase in EOL discussions 13% to 46%, (p < 0.001) Increase in DNR orders (p<.001) (14% - 73%)Increase in dying in care home compared with hospital 76% vs. 47% (p < .02) Reduction in hospital mean LOS 4 vs. 1.25Families satisfaction with input into care planning 69% vs. 100% | Fair  |
| Molloy (2000), Canada (Molloy et al., 2000) | Nursing home residents | N=527 | RCT - Randomised at level of nursing home | Mixed, Mean Short form MMSE 23 | PWD: No change in mortality 24% vs. 28% (p = .02) No change in satisfaction Carer:No changes in satisfaction Healthcare system: Health care cost plus intervention costs were lower in control than in intervention $3490 vs. $5239 (p .01) | Increase in ACD completed in intervention homes 57% vs. 70%. ACD were more likely to be "Let me decide" (89%) while in control home most were DNR (71%). Reduction in rate of hospitalisation (P .001) Reduction in bed days 2.61 vs. 5.86 (p .01) | Good  |
| Morrison (2005), USA (Morrison et al., 2005) | Nursing home residents (93% in intervention with dementia and 67% with dementia in control) and their surrogate decision makers | N=205 (Intervention: n=107; control: n=98)  | RCT - Randomised at level of social worker | Mixed | PWD: Increase in concordance with stated wishes 5% vs. 18% (P .04) | Increase in documentation of; preference for CPR 20% vs 40%. (P.005), IV Abs 9% vs. 44% (P <. 001), hospitalisation 16% vs. 49% (P< .001) and artificial nutrition and hydration 9% vs. 47% (P <. 001) No change in ACD rates although competent residents were few | Fair  |
| Reinhardt (2014), USA (Reinhardt, Chichin, Posner, & Kassabian, 2014) | Family members (surrogates) of current residents with advanced dementia | N=87 (Intervention: n=47; control: n=40) | Longitudinal, 6-month, prospective, randomized trial | Advanced, CPS 4,5,6 | PWD:No difference in care satisfaction or symptom controlNo difference in symptom controlCarer:Increase in care rating at 6 months 7.3 vs. 8.2 (p<.05) No difference at other time points. No change in depression or life satisfaction of carer | Increase in MOLST 78% - 100% (p<.01), DNR 72% - 94% (p<.01), DNI 57% - 83% (p<.001), DNH 11 – 30% (p<.01), No feeding tube 36% - 57% (p<.01), and Comfort care 9 – 19% (p<.1)No change in preference for IV Abs and Antibiotics  | Fair  |
| Van der steen (2012), Canada, The Netherlands, and Italy (van der Steen et al., 2012) | Family of Nursing home residents with advanced dementia post death  | N=138 | Mailed survey  | Carer of people who had died from dementia | NR | Participant from all countries found the info useful and acceptable (94- 100%). 93 - 96% of families felt they should have had the information sooner. Italian families wanted more information, Italians preferred to receive book from physician, Canadians from a nurse. | Fair  |
| Volicer (1986), USA | Nursing home male residents with advanced dementia in an intermediate medical ward | N=47 | Prospective chart audit and cross-sectional survey | Severe, Time from diagnosis | PWD: Mortality 32% | No difference in Hospice LOS 43 months (t= 0.43)Staff and carer rating of treatment intensity before family conferences did not correlate r+-.051 (P =.377). Staff rating correlated with severity of dementia r -.540 (p<.001) | Fair  |

**Legend:** ACP: Advance Care Planning; ACD:Advanced Care Directive; C: Control Group; CMO: Comfort Measures Only; CPS: Cognitive Performance Scale; CPR: Cardiopulmonary Resuscitation; DNI: Do Not Intubate; DNH: Do Not Hospitalise; DNR: Do Not Resuscitate; EOL: End of life; EOPA: Enduring Power of Attorney; FAST: Functional Assessment Staging Tool; GDS: Global Deterioration Scale; GOC: Goals of Care; I: Intervention Group; ICU: Intensive Care Unit; IV abs: Intravenous Antibiotics; LOS: Length of Stay; MICU: Medical Intensive Care Unit; MCI: Mild Cognitive Impairment; MMSE: Mini Mental State; MOLST: Medical Orders for Life Sustaining Treatment; MV: Mechanical Ventilation; NP: Nurse Practitioner; NPSD: Neurological and Psychological Symptoms of Dementia; NR: Not Reported; OR: Odds Ratio; PWD: Person With Dementia; QOL: Quality of Life; RCF: Residential Care Facility; RCT: Randomised Controlled Trial; SDM: Substitute Decision Maker; TF: Tube Feeding ; TISS: Therapeutic Intervention Scoring System; \* indicates physician assistant

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