|  **Supplementary Table 1**. **Characteristics of included studies** |
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| **Author, date & QA** | **Population &recruitment source.** | **Diagnosis, & Sample *n*,**  | **Measure of behaviour (validity/ reliability)**  | **Measure of caregiver wellbeing (validity/ reliability)**  | **Main findings** |
| Aarsland et al. (2007) High, 75%. | NorwayResearch centres. | Parkinson’s Disease537 | 10-item NPI (Cummings et al., 1994). | 10-item NPI (Cummings et al., 1994). | Depression, anxiety and apathy were associated with the most distress. Euphoria was the least distressing. |
| Allegri et al. (2006). High, 75%. | ArgentinaUniversity and memory clinic. | Alzheimer’s disease.82  | Spanish version of the 12-item NPI (Cummings et al., 1994). | Zarit’s Burden Interview (Zarit et al 1985). | Delusions, hallucinations, agitation, anxiety, disinhibition, aberrant motor behaviours, sleep related behaviours, and appetite and eating disorders were significantly correlated to burden. |
| Baiyewu et al. (2003). Medium, 71%. | Nigeria.Door to door screening of the Ibadan area identified through census. | Dementia.40  | Nigerian version of the 12-item NPI (Cummings et al., 1994). | Nigerian version of the Caregiver distress index (Kaufer et al., 1998). | Mean distress associated with the mean total score of the behaviour was reported. The top 5 most distressing were: depression; irritability; sleep related behaviours; anxiety; and agitation. The least distressing was euphoria. |
| Baiyewu et al. (2012). High, 92%. | NigeriaTotal population survey in the Idikan area and the adjacent area of Ibadan | Dementia34 | 12-item NPI (Cummings et al., 1994). | 12-item NPI (Cummings et al., 1994). | Depression, irritability and apathy were associated with the most distress. Euphoria was the least distressing. |
| Balieiro et al. (2010). Medium, 73%. | BrazilBehavioural Neurology Outpatient Clinic | Alzheimer’s disease.50  | 12-item NPI (Cummings et al., 1994). | Caregiver distress index of the NPI-D (Kaufer et al., 1998). | Mean distress associated with the mean total score of the behaviour was reported. The top 5 most distressing were: delusions; depression; agitation; and irritability. The least distressing was euphoria. Delusions, hallucinations, depression, indifference, irritability, aberrant motor behaviour, appetite and eating disorders were significantly correlated to distress. |
| Berger et al. (2005). Medium, 69%. | GermanyMemory clinic. | Dementia45 | Behavioural Pathology in Alzheimer’s Disease Rating Scale (BEHAVE-AD)(Reisberg et al., 1987), valid & reliableNurses Observation Scale for Geriatric Patients (NOSGER)(Spiegel et al., 1991) | Zarit’s Burden Interview (Zarit et al 1985), valid & reliable.Geriatric Depression Scale (GDS)(Yesavage et al., 1982)Beck Depression Inventory (BDI)(Beck et al., 1961) | Memory, mood and social behaviours were significantly correlated with caregiver burden, but only memory significantly correlated with depression. |
| Chappell et al. (1996). High, 100%. | CanadaRandomly chosen from medicare lists across 9 provinces. | Dementia327 | Dementia BehaviourDisturbance (DBD) scale (Baumgarten et al*.* 1990), valid & reliable. | Zarit’s Burden Interview (Zarit et al., 1987, 1983), valid & reliable, proxy. Center for Epidemiological StudiesDepression Scale (CES-D) (Radloff 1977), valid & reliable. | Aimlessness, aggressiveness, forgetfulness, restlessness and apathy significantly predicted increased burden. |
| Conde-Sala et al. (2010). High, 77%. | SpainOutpatient memory and dementia assessment unit. | Alzheimer’s disease.251  | The Spanish adaptation(Vilalta-Franch et al., 1999) of the 12-itemNPI (Cummings et al., 1994).  | CBI (Zarit et al., 1986),validated for the Spanish population by Martin-Carrasco al. (1996), valid & reliable. | Apathy, irritability and appetite and eating changes positively predicted burden in spousal caregivers. Apathy, disinhibition, and irritability positively predicted burden in adult-spouse caregivers. |
| Covinsky et al. (2003). Medium, 66%. | USAPhysician and self-referral | Dementia5627 | Used their own list of behaviours. | Geriatric Depression Scale (GDS)(Yesavage et al., 1982) | Anger and aggressive behaviour, dangerous to self and waking the caregiver up at night were all significantly correlated to caregiver depression. |
| Crellin et al. (2014). High, 91%. | UKMemory clinics, voluntary sector, local advertising. | Dementia245 | 12-item NPI (Cummings et al., 1994), valid & reliable. | 12-item NPI (Cummings et al., 1994), valid & reliable. | Delusions, agitation and depression were associated with the most distress. Euphoria was the least distressing. |
| Davidsdottir et al. (2012). Medium, 58%. | IcelandMemory clinic. | Alzheimer’s disease (AD) and vascular dementia (VaD).38 | Behavioural Pathology in Alzheimer’s Disease Rating Scale (BEHAVE-AD)(Reisberg et al., 1987), valid & reliable | Caregiver distress index of the NPI-D (Kaufer et al., 1998), valid & reliable.Relative Stress Scale (RSS)(Greene et al., 1982)Screen for Caregiver Burden (SCB)(Vitaliano et al., 1991)Geriatric Depression Scale (GDS)(Yesavage et al., 1982) | All behaviours on the NPI were significantly correlated with distress other than hallucinations and euphoria.  |
| Davis et al. (2007). Medium, 69% | USACommunity and memory clinics. | Dementia72 | Frontal Systems Behaviour Scale (FrSBe)(Grace et al., 200q) | Zarit’s Burden Interview (Zarit et al., 1987, 1983), valid & reliableGeriatric Depression Scale (GDS)(Yesavage et al., 1982) | Executive dysfunction and disinhibition were predictors of caregiver burden. |
| Donaldson et al (1998). High, 84%. | UKOld age psychiatry outreach services. | Alzheimer’s disease.100  | Cornell Scale for Depression inDementia (CSDD;Alexopoulos etal., 1988) valid & reliable. MOUSEPAD(Allen et al.,1996), valid & reliable.  | Gilleard’s Strain Scale (1984) (GSS) was used to provide an index of subjective burden, valid & reliable, IA.General Health questionnaire (Goldberg, 1978) measured distress, valid & reliable. | Depression, mood-related signs, behaviour changes, cyclic functions, behaviour disturbances, sleep, psychotic symptoms, delusions, hallucinations and reduplication were significantly associated with distress. |
| Fauth & Gibbons. (2014)Medium, 69%. | USACarers who were listed as contacting dementia services. | Dementia177 | 12-item NPI (Cummings et al., 1994), valid & reliable.Revised Memory and Behavioural Problem Checklist (RMBPC)(Teri et al., 1992),valid and reliable. | Geriatric Depression Scale (GDS)(Brink et al., 1982),valid and reliable.12-item NPI (Cummings et al., 1994), valid & reliable. | Symptoms revealed as “most problematic” varied by measurement criterion. Common or frequent symptoms are not necessarily the most distressing or most predictive of caregiver depression. |
| Fuh et al. (2001). High, 77% | TaiwanMemory clinic | Alzheimer’s disease.95 | Chinese version of the 12-item NPI (Cummings et al., 1994). | Chinese version of the 12-item NPI (Cummings et al., 1994). | Aberrant motor behaviour, anxiety and delusions were associated with the most caregiver distress. Euphoria was associated with the least distress. Euphoria was the only behaviour on the NPI which was significantly correlated with burden. |
| Haley et al. (1987). Medium, 54%. | USAMailing listof a local Alzheimer's society, physician & community agencyreferral, and announcements on radio & in newspapers. | Dementia.40 | Revised version of theMemory and Behavior Problems Checklist (MBPC; Zarit & Zarit,1982), valid & reliable. | Rated their perception of the stressfulness of the problem, on a 0-3 scale (0 = not at all, to 3 =extremely), not stated. | The top 5 behaviours rated as most stressful were: dangerous to self; hiding things, dangerous to others; agitation, not completing tasks; and embarrassing behaviour (last 2 behaviours had identical score). The least stressful behaviour was being disoriented to day.  |
| Hasegawa et al. (2014). Medium, 69%. | JapanMemory clinics. | Dementia135 | 10-item NPI (Cummings et al., 1994). | Center for Epidemiological StudiesDepression Scale (CES-D) (Radloff 1977), valid & reliable.NPI-D (Kaufer et al., 1998). | Depressive state in caregivers was independent of the decline in cognitive function in patients with dementia but was associated with severity of delusions. |
| Hishikawa et al. (2012). Medium, 53% | JapanNot stated | Alzheimer’s disease.3 | Japanese version of the NPI-Q caregiver distress scale NPI-D (Kaufer et al., 1998). | Japanese version of the NPI-Q caregiver distress scale NPI-D (Kaufer et al., 1998). | Agitation, depression and anxiety were the most distressing behaviours. |
| Huang et al. (2012). High, 75%. | TaiwanMemory clinic | Dementia88 | 12-item NPI (Cummings et al., 1994), valid & reliable. | NPI-D (Kaufer et al., 1998), valid & reliable.Center for Epidemiological StudiesDepression Scale (CES-D) (Radloff 1977), valid & reliable. | Delusions, agitation and anxiety were associated with the most distress. |
| Huang et al. (2015). Medium, 69%. | TaiwanMemory clinic | Dementia57 | Revised Memory and Behavior Problems Checklist (RMBPC)(Teri et al., 1992) | The Chinese version of the Caregiver Burden Inventory(Novak and Guest, 1989), valid and reliable. | Each subscale of the RMPBC was significantly correlated with caregiver burden. |
| Johnson et al. (2012). Medium, 50% | USAClients were referred primarily by Area Agency on Aging staff. | Dementia129 | The 12-item NPI-Q (Cummings et al., 1994). | Geriatric Depression Scale (GDS)(Yesavage et al., 1982) | Anxiety, agitation and depression were associated with the most distress. Euphoria was the only behaviour not associated with any distress. |
| Kaufer et al. (1998). Medium, 67%.  | USAMemory disorder clinic. | Alzheimer’s disease.85 | 10-item NPI (Cummings et al., 1994). | NPI-D (Kaufer et al., 1998). | Mean distress associated with the mean total score of the behaviour was reported. The top 5 most distressing were: depression; aberrant motor behaviour; agitation; anxiety; and indifference. The least distressing was euphoria. |
| Khoo et al. (2014). High, 75%. | SingaporeMemory clinic | Dementia667 | Chinese version of the 12-item NPI-Q (Cummings et al., 1994). | Chinese version of the 12-item NPI-Q (Cummings et al., 1994). | The severity of euphoria, disinhibition and depression were the largest predictors of caregiver distress. |
| Lee et al. (2013). Medium, 69%. | UKMemory clinic. | Dementia121 | NPI-D (Kaufer et al., 1998). | NPI-D (Kaufer et al., 1998). | Anxiety, apathy and delusions significantly predicted caregiver distress. |
| Matsumoto et al. (2007). Medium, 64%. | JapanAll persons aged 65 yearsand older residing at home in Nakayama town on theprevalence day (January 1, 1997). | Dementia67 | 10-item NPI (Cummings et al., 1994). | NPI-D (Kaufer et al., 1998). | Mean distress associated with the mean total score of the behaviour was reported. The top 5 most distressing were: agitation; delusion; disinhibition; irritability; and aberrant motor behaviour. The least distressing was euphoria.Delusions, agitation, indifference, irritability, and appetite and eating changes were significantly correlated to distress. |
| Merrilees et al. (2014). High, 75%. | USANot stated. | Frontotemporal Dementia22 | 12-item NPI (Cummings et al., 1994). | 12-item NPI (Cummings et al., 1994).Pittsburgh Sleep Quality Index (PSQI)(Buysse et al., 1989) | Sleep disturbance in behavioural variant Frontotemporal dementia was associated with more distress than for carers of participants with semantic dementia. |
| Mourik et al. (2004). High, 100% | The NetherlandsNeurologic and psychogeriatric outpatient clinics. | Frontotemporal Dementia63 | Dutch version of the NPI.  | NPI-D (Kaufer et al., 1998). | Euphoria, aberrant motor behaviour predicted caregiver burden but apathy did not. |
| Muangpaisan et al. (2010). High, 83%. | ThailandParticipants who attended “Caregiver Day” organized bythe Department of Preventive and Social Medicine | Dementia72 | Used their own list of behaviours. | Dementia Caregiver burden inventory (Novak and Guest, 1989), valid and reliable. | Top 5 most burdensome behaviours were: not remembering; repeating questions; insomnia; impaired activities of daily leaving; and irritability. Crying and inappropriate behaviour were the least burdensome.  |
| Nagarantnam et al. (1998). High, 83%. | AustraliaReferred to the Blacktown Aged Care AssessmentTeam. | Dementia77  | Used their own list of behaviours. | Most disturbing but not a formal scale. | Top 5 most disturbing behaviours were: verbal aggression; wandering; theft/suspiciousness; incontinence; persecutory and delusions. Sexual disinhibition was the least disturbing.  |
| Nogales-Gonzales (2015). High, 77% | SpainSocial welfare and health centres in Madrid, Spain | Dementia231 | The Spanish version of the RMPBC (Teri et al., 1992; Nogales-Gonzalez et al., 2014)  | The Spanish version of the RMPBC (Teri et al., 1992; Nogales-Gonzalez et al., 2014) | Depressive and disruptive behaviours significantly predict caregiver distress. |
| Nygaard et al. (1988). High, 75%. | NorwayRandomly drawn frompatients registered at a home nursecenter. | Dementia46  | Rabins et al., (1982), problem checklist, not stated. | Rabins et al., (1982), problem checklist also measured strain, not stated. | The top 5 behaviours which caused the most serious problems were: memory disturbance; apathy; urinary incontinence ; critical behaviour; faecal incontinence; and careless with heat (last 2 behaviours had identical score). The least serious behaviour was hitting. |
| Quayhagen et al.(1988). High, 57%. | USAAlzheimer's Disease and RelatedDisorders Association (ADRDA) supportGroups and Five external referrals.. | Alzheimer’s disease58 | Memory and behaviour problems checklist (Zarit et al., 1980), valid & reliable | Stress measured by Memory and behaviour problems checklist (Zarit et al., 1980), valid & reliable. | The top 5 behaviours identified as moderately to severely stressful were: repetitive questions; difficulty handling money; embarrassing things; difficulty bathing; and difficulty cooking. Least stressful was incontinent behaviour. |
| Rinaldi et al.(2005). High, 76%.  | ItalyOutpatients from 15 Geriatric Clinics | Dementia419 | Brief Symptom Inventory (BSI-d and BSI-a)(Derogatis and Melisaratos, 1983), not stated, IA.12-item NPI (Cummings et al., 1994). | Dementia Caregiver burden inventory (Novak and Guest, 1989), valid and reliable.NPI-D (Kaufer et al., 1998). | Mean distress associated with the mean total score of the behaviour was reported. The top 5 most distressing were: indifference; agitation; depression; hallucinations; and irritability. The least distressing was euphoria. |
| Robinson et al. (2001). Medium, 69% | USAConvenience sample of family ADRD cases | Alzheimer’s Disiease and Related Dementia30 | The Revised Memory and Behaviour Problem Checklist (RMBPC)(Teri et al., 1992) | Cost of Care Index (CCI)(Kosberg and Cairl, 1986) and RMPBC | Caregivers’ reactions to depressive and disruptive behaviours may put them at risk for problems of declining physical and emotional health, and loss of economic resources. |
| Savorani et al.(1998). Medium, 55%. | ItalyGeriatric day hospital & AD support group. | Dementia.140 | The questionnaire of the Association for Research and Assistance for Dementia (ARAD), not stated. | Ranked the most stressing behaviours, not stated. | The top 5 were: sleep rhythm disorders; delusions; physical or verbal aggression; agitation; and incontinence. Hallucinations were the least burdensome.  |
| Slachevsky et al. (2013). High, 77%. | ChileConvenience sampling, which aimed to include the urban community of caregivers from different settings. | Dementia291 | Neuropsychiatric Inventory Questionnaire (NPI-Q)(Cummings et al., 1994).Global Deterioration Scale(GDS)(Reisberg et al., 1982) | Chilean version of the Zarit Burden Interview (ZBI)(Breinbauer et al., 2009)12-item General Health Questionnaire (GHQ-12)(Goldberg et al., 1997) | Agitation and anxiety were the only behaviours which significantly predicted burden. |
| Tan et al. (2005) High, 92%. | SingaporePatients newly diagnosed in outpatient clinics & acute psychogeriatric wards. | Dementia85 | Chinese version of the 12-item NPI-Q (Cummings et al., 1994). | Chinese version of the NPI-Q caregiver distress scale NPI-D (Kaufer et al., 1998). | Mean distress associated with the mean total score of the behaviour was reported. The top 5 most distressing were: agitation; delusions; disinhibition; aberrant motor behaviour; and irritability. The least distressing was euphoria. |
| de Vugt et al. (2006) High, 92%. | The NetherlandsConsecutively referred patients to the memory clinic | Alzheimer’s disease and frontotemporal dementia.74 | 10-item NPI (Cummings et al., 1994). | NPI-D (Kaufer et al., 1998). | Mean distress associated with the mean total score of the behaviour was reported. The top 5 most distressing were: anxiety; depression; apathy; irritability; and aberrant motor behaviour. The least distressing was euphoria. |
| Wang et al. (2015). High, 84%. | ChinaMemory clinic. | Dementia 152 | Chinese version of the 12-item NPI-Q (Cummings et al., 1994). | Chinese version of the 12-item NPI-Q (Cummings et al., 1994). | Delusions, hallucinations and apathy/indifference were rated as the most distressing to caregivers. Delusions, hallucinations, anxiety and irritable behaviours significantly predicted distress. |
| Chiu et al (2013). Medium, 69%. | TaiwanMemory clinic. | Dementia180 | Chinese neuropsychiatric inventory (CNPI) (Leung et al., 2001). | Chinese Center for Epidemiological Studies Depression Scale (CESD-10) (Boey, 1999)Chinese neuropsychiatric inventory (CNPI) (Leung et al., 2001).18-item Visual Analogue for Fatigue Scale (VAS-F) – Chinese version (Lee et al., 1991; Lee at al., 2007).28-item Chinese General Sleep Disturbance Scale (GSDS)(Lee, 1992, 2007). | Anxiety, depression, and delusions were the most strongly associated with caregiver sleep disturbance. |
| QA % = quality appraisal percentage. Only Savorani et al. (1998) asked participants to complete the questionnaire independently the other studies administered their questionnaires by researchers. All versions of the NPI were valid and reliable. |

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