| **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%. | Norway  Research centres. | Parkinson’s Disease  537 | 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%. | Argentina  University 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%. | Nigeria  Total population survey in the Idikan area and the adjacent area of Ibadan | Dementia  34 | 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%. | Brazil  Behavioural 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%. | Germany  Memory clinic. | Dementia  45 | Behavioural Pathology in Alzheimer’s Disease Rating Scale (BEHAVE-AD)  (Reisberg et al., 1987), valid & reliable  Nurses 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%. | Canada  Randomly chosen from medicare lists across 9 provinces. | Dementia  327 | Dementia Behaviour  Disturbance (DBD) scale (Baumgarten et al*.* 1990), valid & reliable. | Zarit’s Burden Interview (Zarit et al., 1987, 1983), valid & reliable, proxy. Center for Epidemiological Studies  Depression Scale (CES-D) (Radloff 1977), valid & reliable. | Aimlessness, aggressiveness, forgetfulness, restlessness and apathy significantly predicted increased burden. |
| Conde-Sala et al. (2010). High, 77%. | Spain  Outpatient memory and dementia assessment unit. | Alzheimer’s disease.  251 | The Spanish adaptation  (Vilalta-Franch et al., 1999) of the 12-item  NPI (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%. | USA  Physician and self-referral | Dementia  5627 | 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%. | UK  Memory clinics, voluntary sector, local advertising. | Dementia  245 | 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%. | Iceland  Memory 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% | USA  Community and memory clinics. | Dementia  72 | Frontal Systems Behaviour Scale (FrSBe)  (Grace et al., 200q) | Zarit’s Burden Interview (Zarit et al., 1987, 1983), valid & reliable  Geriatric Depression Scale (GDS)  (Yesavage et al., 1982) | Executive dysfunction and disinhibition were predictors of caregiver burden. |
| Donaldson et al (1998). High, 84%. | UK  Old age psychiatry outreach services. | Alzheimer’s disease.  100 | Cornell Scale for Depression in  Dementia (CSDD;  Alexopoulos et  al., 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%. | USA  Carers who were listed as contacting dementia services. | Dementia  177 | 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% | Taiwan  Memory 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%. | USA  Mailing list  of a local Alzheimer's society, physician & community agency  referral, and announcements on radio & in newspapers. | Dementia.  40 | Revised version of the  Memory 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%. | Japan  Memory clinics. | Dementia  135 | 10-item NPI (Cummings et al., 1994). | Center for Epidemiological Studies  Depression 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% | Japan  Not 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%. | Taiwan  Memory clinic | Dementia  88 | 12-item NPI (Cummings et al., 1994), valid & reliable. | NPI-D (Kaufer et al., 1998), valid & reliable.  Center for Epidemiological Studies  Depression Scale (CES-D) (Radloff 1977), valid & reliable. | Delusions, agitation and anxiety were associated with the most distress. |
| Huang et al. (2015). Medium, 69%. | Taiwan  Memory clinic | Dementia  57 | 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% | USA  Clients were referred primarily by Area Agency on Aging staff. | Dementia  129 | 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%. | USA  Memory 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%. | Singapore  Memory clinic | Dementia  667 | 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%. | UK  Memory clinic. | Dementia  121 | 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%. | Japan  All persons aged 65 years  and older residing at home in Nakayama town on the  prevalence day (January 1, 1997). | Dementia  67 | 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%. | USA  Not stated. | Frontotemporal Dementia  22 | 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 Netherlands  Neurologic and psychogeriatric outpatient clinics. | Frontotemporal Dementia  63 | 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%. | Thailand  Participants who attended “Caregiver Day” organized by  the Department of Preventive and Social Medicine | Dementia  72 | 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%. | Australia  Referred to the Blacktown Aged Care Assessment  Team. | Dementia  77 | 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% | Spain  Social welfare and health centres in Madrid, Spain | Dementia  231 | 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%. | Norway  Randomly drawn from  patients registered at a home nurse  center. | Dementia  46 | 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%. | USA  Alzheimer's Disease and Related  Disorders Association (ADRDA) support  Groups and Five external referrals.  . | Alzheimer’s disease  58 | 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%. | Italy  Outpatients from 15 Geriatric Clinics | Dementia  419 | 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% | USA  Convenience sample of family ADRD cases | Alzheimer’s Disiease and Related Dementia  30 | 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%. | Italy  Geriatric 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%. | Chile  Convenience sampling, which aimed to include the urban community of caregivers from different settings. | Dementia  291 | 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%. | Singapore  Patients newly diagnosed in outpatient clinics & acute psychogeriatric wards. | Dementia  85 | 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 Netherlands  Consecutively 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%. | China  Memory 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%. | Taiwan  Memory clinic. | Dementia  180 | 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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