# Time to invest in prevention and better care of behaviours and psychological symptoms associated with dementia

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**Conflicts of interest**

The authors have no conflicts of interest to declare.

**Summary**

Our review is the first to summarise studies showing the overall costs of individual BPSD and studies demonstrating the cost–effectiveness of nonpharmacological interventions for reducing BPSD (mainly agitation). The few studies that have built cost–effectiveness analyses into the design indicate the economic feasibility of adopting non–pharmacological approaches such as person–centred care and staff training into everyday practice.

While dementia is defined as cognitive decline leading to functional impairment, behaviours and psychological symptoms (BPSD; also referred to as 'neuropsychiatric symptoms', 'changed behaviours', 'behavioural and psychological symptoms of dementia', 'responsive behaviours'; see Cunningham and colleagues)[1] which become almost universal as dementia becomes more severe, often cause more distress to people with dementia and their families and account for much of the cost (see Lancet commission).[2] Symptoms comprise aggression, agitation, anxiety, apathy, depression, disinhibited behaviours, nocturnal disruption, psychotic symptoms, vocally disruptive behaviours, and wandering.

Behaviours and psychological symptoms are a key driver of the rapidly escalating social and economic costs of dementia globally. This paper poses the question: Do the economic benefits of non–pharmacological approaches in preventing and managing BPSD outweigh the costs?

The rising prevalence of dementia (currently 50 million people worldwide, estimated to reach 82 million by 2030 and 152 million by 2050; www.alz.co.uk/research/statistics) leads to rapidly increasing costs (currently over US $1 trillion, estimated to reach $2 trillion by 2030,[3] to which BPSD have been shown to contribute over 25% of total indirect and 35% of total direct annual costs (i.e., $2,665 and $1,450 respectively in an individual patient) of care in an Israeli community setting.[4] This may not be surprising as BPSD are ubiquitous, affecting up to 90% of people during the course of dementia and strongly correlate with functional and cognitive impairment.[5,6] They also cause family and carer partner distress, which predicts loss of independence,[7] early care home admission,[8,9,10] higher use of emergency department[11] and other health facilities;[12] as well as requiring direct care[4,13] in care facilities and the community.[14]

The contribution of agitation to dementia costs has been reported to increase informal care costs in a homecare setting[15] by 17% and increase overall costs[16,17] by 22%. In care homes agitation accounts for 44% of excess costs on top of the costs of the home itself;[18–20] indicating that calculated costs depend on the setting and increase in a dose–dependent manner with symptom severity (i.e., higher scores on the neuropsychiatric inventory (NPI); see also Herrmann[21] and Gustavsson[14] and colleagues).

Evidence is accumulating that nonpharmacological (also known as psychosocial) interventions and person–centred care can reduce agitation and other behaviours.[2,22] Yet there are difficulties in sustaining implementation and change in practice beyond the period of the intervention.[18] This is perhaps because implementing change takes time, practice and additional support as these approaches are not built into the care environment. There may also be concerns about cost and staff time, driven by insufficient awareness of studies that have focused specifically on cost analysis of BPSD and demonstrated the potential savings that can be made by investing in treatments that are symptom targeted and individualised (i.e., person–centred). Without a strong case for intervention– and cost–effectiveness, resistance to implementing change remains high, from managers and care workers at the local level, to policy makers, political leaders and societies at the macro–level.

We reasoned that demonstration of cost–effectiveness could further incentivise governments, funders and service providers to invest in practice change and the implementation of effective person–centred approaches. We reviewed the literature to calculate monetary costs of individual BPSD and their management, in order to determine whether there was evidence of financial benefits to convince policy makers and service providers to change practices to reduce BPSD.

## Nonpharmacological interventions for BPSD

Nonpharmacological interventions, including well powered randomised controlled trials (RCTs), shown to be effective in reducing BPSD include: person–centred care,[23–26] reminiscence–based approaches,[27,28] aerobic and resistance exercise,[29] music,[30,31] use of a robotic or soft seal,[32,33] humour therapy,[34,35] and educational training.[36,37] Specifically, person–centred care led to improvements in agitation revealed with the Cohen–Mansfield Agitation Inventory (CMAI) or Neuropsychiatric Inventory (NPI), reminiscence therapy improved apathy and depression measured using the Apathy Evaluation Scale (AES) and the Cornell Scale for Depression in Dementia (CSDD), and physical activity improved depression (determined with CSDD) and other BPSD (see Livingston and colleagues[2]).

Barriers to adoption of these practices include the heterogeneity of interventions, the lack of rigour in their evaluation and concerns surrounding cost, resources and staff time. Cost–effectiveness analyses can illustrate how an outcome may (or may not) be desirable, despite what may otherwise be perceived as involving high costs. Simplistically this involves identifying the associated benefits of the intervention as well as the associated costs and subtracting the costs from the benefits. This approach is crucial (rather than focusing only on cost savings) given that to care effectively for people living with dementia and BPSD, competent and confident trained healthcare workers and adequate staff numbers are essential.

## Costing BPSD

Cross–sectional, prospective and longitudinal studies have investigated costs of BPSD (usually agitation) and have used either group comparison approaches (i.e. based on dementia severity) or linear regression approaches to determine costs per unit increase on an individual symptom measure (see Table 1 for summary). Caution should be taken when interpreting findings from cross–sectional studies due to unclear causal mechanisms. We have focused primarily on prospective and longitudinal studies. Costs of BPSD differ between community, clinic, hospital and residential settings in line with differences in dependency levels and costs of care.[38] Costs are generally calculated using used a general linear mixed model including relevant covariates to estimate main predictors of costs.

In a 1–year prospective study of resource utilisation, a 1–point increase in agitation determined by the NPI resulted in an increase in costs of US$30 per month,[21] where total cost of care was calculated to be US $1,298 per month. Other studies have reported between 1·6 – 17% increase in costs per 1–point increase on the total NPI in a community setting.[15,39–41] Some studies have considered variability and used standard deviations to compute costs where an increase of one standard deviation in NPI severity translated into a 6% and 8·8% increase in costs.[14,38] While studies tend to focus on agitation, one study found apathy and hallucinations were the biggest contributors and significantly increased costs ($p$=0·0016 and $p$<0·0001 respectively).[38]

Several intervention studies have calculated cost–effectiveness analyses in this area. In these, they calculated an incremental cost–effectiveness ratio (ICER). The ICER is calculated as the difference in total cost between two intervention groups, divided by the difference in outcome measures (e.g., agitation measured using CMAI or NPI) between the two intervention groups (see Table 2 for summary).[25,32,42,43] 'Willingness to pay' for additional units of outcome has also been included in calculations to plot cost–effectiveness acceptability curves (CEACs)[44] and determine if, from a societal perspective, an intervention is effective by leading to a clinically meaningful improvement in BPSD. For example, D'Amico and colleagues' study calculated a clinically meaningful reduction in NPI (i.e., three points) to cost £1,263 and calculated a willingness to pay £500 per increment improvement (i.e., per 1–point decrease in NPI score) would mean the probability of exercise being cost–effective would be higher than 80 percent.[45,46]

In a systematic review of worldwide studies costing individual BPSD[18] the cost of 30 interventions that had a significant impact on agitation was calculated, 11 of which used the CMAI. In total, health and social care costs in people without clinically significant symptoms in NPI agitation over three months were calculated to be around £7,000 compared to £15,000 for those with the most severe levels of agitation. The incremental cost per unit reduction in CMAI score following therapeutic activities was reported to be £162 for Montessori–based activities[47] and £3,480 for a highly structured programme of sensorimotor activities.[48] The cost per unit were calculated for music therapy[49] at £4 and sensory interventions using acupressure[50,47] at £24 and £143 respectively. Training paid caregivers in person–centred care or communication skills[25,51,52] was costed at £6, £42 and £62 respectively per unit reduction in CMAI.

The main health outcome measure used by the National Institute for Health and Clinical Excellence (NICE) and many other national reimbursement authorities is the quality–adjusted life–year (QALY). A QALY is a unit that combines both quantity (length) of life and health–related quality of life into a single measure of health gain (NICE guidelines 2008,[53] page 17). Cost–effectiveness is also often calculated considering improvements in quality of life. An RCT of an intervention to consider and address needs of residents with agitation and improve communication did not improve agitation but was cost–effective in improving quality of life.[19] Livingston and

colleagues[18] measured cost–effectiveness as the mean QALYs gained per patient accrued to the intervention multiplied by the decision–makers' maximum willingness to pay for a QALY, minus the mean incremental cost per patient for the intervention (termed net monetary benefits (NMBs)). This model converts the gain or loss in outcomes associated with the intervention into monetary units and subtracts the associated cost of the intervention to determine cost–effectiveness (NMB>0 represents good value for money). A willingness to pay £20,000 for a QALY (see UK NICE guidelines,[53] page 18) equated to an 82 percent probability of being cost–effective.[18] QALYs are frequently used to access health outcomes and are used in calculating ICER, though have several limitations in the field of dementia research and the clinical relevance of quality of life measures (i.e., QALYs) has been questioned.

Methodological inconsistencies and the techniques used to value informal care[39] make it difficult to compare findings across studies. Despite the variability in calculations and reporting approaches of symptom costs, all studies demonstrate that BPSD contribute significantly to the overall costs of dementia care. There is a general focus on agitation; costing of other symptoms is lacking apart from one study on apathy[21] even though other symptoms such as apathy, anxiety and depression can cause significant distress,[10] which would likely impact on costs. Other studies using person–centred and staff training approaches[23,26,55] have reported cost–effectiveness though have not costed symptoms separately.[26,54,56] A UK study found significant improvements in quality of life and BPSD in people living with dementia following the intervention.[23,54] However, improvements in BPSD were not observed in people with young-onset dementia in a Dutch study; possibly due to overlap between the intervention and specialised methods of care already in use for treatment as usual.[55]

## Time for action

Barriers to achieving better value for money in dementia care include reluctance to implement evidence, poor coordination of health and social care provision and financing[57] Evidence is presented of monetary costs of BPSD and of benefits of interventions. The few studies that have built cost–effectiveness analyses into their design indicate the economic feasibility of adopting non–pharmacological approaches

such as person–centred care into everyday practice. This will require change in attitudes and care practice.

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Table 1: Studies that have costed individual BPSD in different parts or the world.

| Authors, year, country | Setting, study type, number of participants (N) | BPSD, measure | BPSD cost ($ per unit or predictor %) |
|---|---|---|---|
| Herrmann et al., 2006, USA[21] | Community setting.1–year prospective study, N=500 | Agitation, NPI | 1–point change associated with 2·3% increase in total costs. (1–point increase = $30 per month (95% CI: $19–$41) |
| Jönsson et al., 2006, Sweden, Finland and Denmark[39] | Community setting. N=272 (Costs analysis, N= 208) | Agitation, NPI | 1–point change associated with 8% increase in total costs |
| Gustavsson et al., 2011, Sweden[14] | Community and residential setting. N=1,222 | Agitation, NPI | 1–SD increase translated to 8% increase in costs (community setting) |
| Lacey et al., 2013, ADNI study, Ireland & USA[40] | Community setting. Longitudinal observation study, N=138 | Agitation, NPI | 1–point change associated with 1·62% increase in total costs |
| Rattinger et al., 2015, USA[41] | Community setting. Longitudinal prospective study, N=287 | Agitation, NPI | 1–point change associated with 2% increase in informal costs |
| Wübker et al., 2015, Spain, Germany & France[38] | Community and residential setting (community group 'at risk'). Prospective cohort study, N=2,014 (Community, N=1,048) | Agitation, apathy & hallucinations, NPI | 1–SD increase translated to 8·8% increase in costs (community setting) |
| Costa et al., 2018, 8 European countries[15] | Community (homecare) and residential care (institutional long–term care) setting. Cross–sectional study, N=1,997 (Community, N=1,217) | Agitation, NPI | 17% increase in informal care costs (community setting) |

*Abbreviations: NPI, neuropsychiatric inventory; SD, standard deviation.*

Table 2: Intervention studies that have costed individual BPSD.

| Authors, year, country | Setting, study type, number of participants (N) | BPSD, measure | BPSD cost analysis |
|---|---|---|---|
| Mintzer et al., 1997, USA[42] | Residential setting, 2 conditions: 21–day Inpatient Programme (IP) & Continuum of Care (CC) (21– vs. 7–days hospitalisation). N=178 (N=68 & 110 respectively) | Agitation, CMAI | Change in CMAI score per US $1,000: CC: 0·89, IP: 0·27 (CC was more than three times more cost–effective) |
| Chenoweth et al., 2009, Australia[25] | Residential setting, 3 conditions: Person–Centred Care (PCC), Dementia Care Mapping (DCM) and usual care. Cluster RCT, N=289 (N=95, 77 and 64 respectively) | Agitation, CMAI | Incremental cost per 1–point decrease on CMAI scale. PCC: AU $8 AU, $6 at follow–up. DCC: AU $49, AU$ 47 at follow–up |
| D'Amico et al., 2016, United Kingdom[45] | Community setting, 2 conditions: exercise and treatment as usual. RCT, N=52 (N=30 and 22 respectively) | Agitation, NPI | Intervention cost: £284 (range: £190–£320). CEAC: willingness to pay £500 per increment improvement, cost effective with a probability greater than 80% |
| Mervin et al., 2018, Australia[32] | Residential setting, 3 conditions: Therapeutic robotic seal (PARO), soft seal, usual care. Cluster RCT, N=415 (N=138, 140 and 137 respectively) | Agitation, CMAI | AU $13 incremental cost per 1–point decrease on CMAI scale |

*Abbreviations: CEAC, cost–effectiveness acceptability curve; CMAI, Cohen Mansfield agitation inventory; NPI, neuropsychiatric inventory.*