

Invited Commentary for International Psychogeriatrics: Time to invest in better dementia care

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

1,770~~34~~ words, 57~~5~~ references, 2 tables

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### **Keywords**

Behaviours and psychological symptoms associated with dementia (BPSD), care, cost-effectiveness, cognitive therapy, dementia, psychosocial, physical activity, nonpharmacological, therapeutic activities

### **Conflicts of interest**

The authors have no conflicts of interest to declare.

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

10  
11 ~~These behaviours and symptoms impose a large financial burden, as they cause~~  
12 ~~family and carer partner distress, which also predicts early care home admission,<sup>3,4</sup>~~  
13 ~~higher use of emergency department<sup>5</sup> and other health facilities,<sup>6</sup> as well as requiring~~  
14 ~~direct care<sup>7-9</sup> in care facilities and the community.<sup>9</sup>~~

15  
16 Behaviours and psychological symptoms are a key driver of the rapidly escalating  
17 social and economic costs of dementia globally. This paper poses the question: Do  
18 the economic benefits of non-pharmacological approaches in preventing and  
19 managing BPSD outweigh the costs?

20  
21 The rising prevalence of dementia (currently 50 million people worldwide, estimated  
22 to reach 82 million by 2030 and 152 million by 2050; [www.alz.co.uk/research/statistics](http://www.alz.co.uk/research/statistics))  
23 leads to rapidly increasing costs (currently over US \$1 trillion, estimated to reach \$2  
24 trillion by 2030,<sup>3</sup> to which BPSD have been shown to contribute over 25% of total  
25 indirect and 35% of total direct annual costs (i.e., \$2,665 and \$1,450 respectively in  
26 an individual patient) of care in an Israeli community setting.<sup>4</sup> This may not be  
27 surprising as BPSD are ubiquitous, affecting ≤ up to 90% of people during the course  
28 of dementia and strongly correlate with functional and cognitive impairment.<sup>5,6</sup> They  
29 also cause family and carer partner distress, which predicts loss of independence.<sup>7</sup>  
30 early care home admission,<sup>8,9,10</sup> higher use of emergency department<sup>11</sup> and other  
31 health facilities;<sup>12</sup> as well as requiring direct care<sup>4,13</sup> in care facilities and the  
32 community.<sup>14</sup>

33 ~~loss of independence,<sup>13</sup> and care home admission.<sup>4,14</sup>~~

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

8  
9 Evidence is accumulating that nonpharmacological (also known as psychosocial)  
10 interventions and person-centred care can reduce agitation and other behaviours.<sup>2,22</sup>  
11 Yet there are difficulties in sustaining implementation and change in practice beyond  
12 the period of the intervention.<sup>18</sup> This is perhaps because implementing change takes  
13 practice and time, practice to bed in and additional support as these approaches are  
14 not built into the care environment. There may also be concerns about cost and staff  
15 time, driven by insufficient awareness of studies that have focused specifically on cost  
16 analysis of ag BPSD and demonstrated the potential savings that can be made by  
17 investing in treatments that are symptom targeted and individualised (i.e., person-  
18 centred). Without a strong case for intervention- and cost-effectiveness, resistance  
19 to implementing change remains high, from managers and care workers at the local  
20 level, to policy makers, political leaders and societies at the macro-level.

21  
22 We reasoned that demonstration of cost-effectiveness could further incentivise  
23 governments, funders and service providers to invest in practice change and the  
24 implementation of effective person-centred approaches. We scoped-reviewed the  
25 literature to calculate monetary costs of individual BPSD and their management, in  
26 order to determine whether there was evidence of financial benefits to convince policy  
27 makers and service providers to change practices to reduce BPSD.

### 28 29 **Nonpharmacological interventions for BPSD**

30  
31 Nonpharmacological interventions, including well powered randomised controlled  
32 trials (RCTs), shown to be effective in reducing BPSD include: person-centred  
33 care,<sup>23–26</sup> reminiscence-based approaches,<sup>27,28</sup> aerobic and resistance exercise,<sup>29</sup>  
34 music,<sup>30,31</sup> use of a robotic or soft seal,<sup>32,33</sup> humour therapy,<sup>34,35</sup> and educational

1 training.<sup>36,37</sup> Specifically, person-centred care led to improvements in agitation  
2 revealed with the Cohen–Mansfield Agitation Inventory (CMAI) or Neuropsychiatric  
3 Inventory (NPI), reminiscence therapy improved apathy and depression measured  
4 using the Apathy Evaluation Scale (AES) and the Cornell Scale for Depression in  
5 Dementia (CSDD), and physical activity improved depression (determined with  
6 CSDD) and other BPSD (see Livingston and colleagues<sup>2</sup>).

7  
8 Barriers to adoption of these practices include the heterogeneity of interventions, the  
9 lack of rigour in their evaluation and concerns surrounding cost, resources and staff  
10 time. Cost-effectiveness analyses can illustrate how an outcome may (or may not) be  
11 desirable, despite what may otherwise be perceived as involving high costs.  
12 Simplistically this involves identifying the associated benefits of the intervention as well  
13 as the associated costs and subtracting the costs from the benefits. This approach is  
14 crucial (rather than focusing only on cost savings) given that to care effectively for  
15 people living with dementia and BPSD, competent and confident trained healthcare  
16 workers and adequate staff numbers are essential.

17

### 18 **Costing BPSD**

19

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

30

31 In a 1-year prospective study of resource utilisation, a 1-point increase in agitation  
32 determined by the NPI resulted in an increase in costs of US\$30 per month,<sup>21</sup> where  
33 total cost of care was calculated to be US \$1,298 per month. Other studies have  
34 reported between 1.6 – 17% increase in costs per 1-point increase on the total NPI in

1 a community setting.<sup>15,39–41</sup> Some studies have considered variability and used  
2 standard deviations to compute costs where an increase of one standard deviation in  
3 NPI severity translated into a 6% and 8·8% increase in costs.<sup>14,38</sup> While studies tend  
4 to focus on agitation, one study found apathy and hallucinations were the biggest  
5 contributors and significantly increased costs ( $p=0\cdot0016$  and  $p<0\cdot0001$  respectively).<sup>38</sup>

6  
7 Several intervention studies have calculated cost–effectiveness analyses in this area.  
8 In these, they calculated an incremental cost–effectiveness ratio (ICER). The ICER is  
9 calculated as the difference in total cost between two intervention groups, divided by  
10 the difference in outcome measures (e.g., agitation measured using CMAI or NPI)  
11 between the two intervention groups (see Table 2 for summary).<sup>25,32,42,43</sup> ‘Willingness  
12 to pay’ for additional units of outcome has also been included in calculations to plot  
13 cost–effectiveness acceptability curves (CEACs)<sup>44</sup> and determine if, from a societal  
14 perspective, an intervention is effective by leading to a clinically meaningful  
15 improvement in BPSD. For example, D’Amico and colleagues’ study calculated a  
16 clinically meaningful reduction in NPI (i.e., three points) to cost £1,263 and calculated  
17 a willingness to pay £500 per increment improvement (i.e., per 1–point decrease in  
18 NPI score) would mean the probability of exercise being cost–effective would be  
19 higher than 80 percent.<sup>45,46</sup>

20  
21 In a systematic review of worldwide studies costing individual BPSD<sup>18</sup> the cost of 30  
22 interventions that had a significant impact on agitation was calculated, 11 of which  
23 used the CMAI. In total, health and social care costs in people without clinically  
24 significant symptoms in NPI agitation over three months were calculated to be around  
25 £7,000 compared to £15,000 for those with the most severe levels of agitation. The  
26 incremental cost per unit reduction in CMAI score following therapeutic activities was  
27 reported to be £162 for Montessori–based activities<sup>47</sup> and £3,480 for a highly  
28 structured programme of sensorimotor activities.<sup>48</sup> The cost per unit were calculated  
29 for music therapy<sup>49</sup> at £4 and sensory interventions using acupressure<sup>50,47</sup> at £24 and  
30 £143 respectively. Training paid caregivers in person–centred care or communication  
31 skills<sup>25,51,52</sup> was costed at £6, £42 and £62 respectively per unit reduction in CMAI.

32  
33 The main health outcome measure used by the National Institute for Health and  
34 Clinical Excellence (NICE) and many other national reimbursement authorities is the

1 quality-adjusted life-year (QALY). A QALY is a unit that combines both quantity  
2 (length) of life and health-related quality of life into a single measure of health gain  
3 (NICE guidelines 2008,<sup>53</sup> page 17). Cost-effectiveness is also often calculated  
4 considering improvements in quality of life. An RCT of an intervention to consider and  
5 address needs of residents with agitation and improve communication did not improve  
6 agitation but was cost-effective in improving quality of life.<sup>19</sup> Livingston and  
7 colleagues<sup>18</sup> measured cost-effectiveness as the mean QALYs gained per patient  
8 accrued to the intervention multiplied by the decision-makers' maximum willingness  
9 to pay for a QALY, minus the mean incremental cost per patient for the intervention  
10 (termed net monetary benefits (NMBs)). This model converts the gain or loss in  
11 outcomes associated with the intervention into monetary units and subtracts the  
12 associated cost of the intervention to determine cost-effectiveness (NMB>0  
13 represents good value for money). A willingness to pay £20,000 for a QALY (see UK  
14 NICE guidelines,<sup>53</sup> page 18) equated to an 82 percent probability of being cost-  
15 effective.<sup>18</sup> QALYs are frequently used to assess health outcomes and are used in  
16 calculating ICER, though have several limitations in the field of dementia research and  
17 the clinical relevance of quality of life measures (i.e., QALYs) has been questioned.

18  
19 Methodological inconsistencies and the techniques used to value informal care<sup>39</sup>  
20 make it difficult to compare findings across studies. Despite the variability in  
21 calculations and reporting approaches of symptom costs, all studies demonstrate  
22 that BPSD contribute significantly to the overall costs of dementia care. There is a  
23 general focus on agitation; costing of other symptoms is lacking apart from one study  
24 on apathy<sup>21</sup> even though other symptoms such as apathy, anxiety and depression  
25 can cause significant distress,<sup>10</sup> which would likely impact on costs. Several Other  
26 cost-effectiveness studies using person-centred and staff training approaches<sup>23,26</sup>  
27 <sup>55</sup> have reported cost-effectiveness though have not costed symptoms  
28 separately.<sup>26,54,56</sup> also A UK study found significant improvements in quality of life  
29 and BPSD in response to people living with dementia following the intervention.  
30 person-centred approaches<sup>236,54</sup> However, improvements in BPSD were not  
31 observed in people with young-onset dementia in a Dutch study; possibly due to  
32 overlap between the intervention and specialised methods of care already in use for  
33 treatment as usual.<sup>55</sup> though these have not costed symptoms separately.  
34  
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Commented [HB1]: Claire, my reading of the Dutch paper is that they just report costs. I read it quickly but did not see any results for QOL or BPSD

Commented [CB2R1]: I've added the paper that reports BPSD outcomes though unfortunately there were no significant improvements (reference 55) Sorry, I think this was incorrect before. Hopefully it's clear now? I've tried not to end on a negative note.

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1 **Time for action**

2  
3 Barriers to achieving better value for money in dementia care include reluctance to  
4 implement evidence, poor coordination of health and social care provision and  
5 financing.<sup>5657</sup> Evidence is presented of monetary costs of BPSD and of benefits of  
6 interventions. The few studies that have built cost-effectiveness analyses into their  
7 design indicate the economic feasibility of adopting non-pharmacological approaches  
8 such as person-centred care into everyday practice. This will require change in  
9 attitudes and care practice.

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Invited Commentary for International Psychogeriatrics: Time to invest in better dementia care

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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 <sup>21</sup>	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 <sup>39</sup>	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 <sup>14</sup>	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 <sup>40</sup>	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 <sup>41</sup>	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 <sup>38</sup>	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 <sup>15</sup>	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 <sup>42</sup>	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 <sup>25</sup>	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 <sup>45</sup>	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 <sup>32</sup>	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.