Behavioral & Psychological Symptoms of Dementia:

The Elephant in the Room?

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Reactive Approach to Service Provision

Family Circus

“Would you like me to check your knee-flexes?”
BPSD present in all patients with Dementia


<table>
<thead>
<tr>
<th>Neuropsychiatric Inventory Item</th>
<th>Participants With Dementia (N=329)^b</th>
<th>Participants Without Dementia (N=673)^b</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Item Absent</td>
<td>Item Present</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Protection</td>
<td>259</td>
<td>78.7</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>276</td>
<td>83.9</td>
</tr>
<tr>
<td>Depression</td>
<td>249</td>
<td>75.7</td>
</tr>
<tr>
<td>Anxiety</td>
<td>266</td>
<td>80.9</td>
</tr>
<tr>
<td>Apathy</td>
<td>235</td>
<td>71.4</td>
</tr>
<tr>
<td>Irritability</td>
<td>258</td>
<td>78.4</td>
</tr>
<tr>
<td>Elation</td>
<td>325</td>
<td>98.8</td>
</tr>
<tr>
<td>Agitation/aggression</td>
<td>245</td>
<td>74.5</td>
</tr>
<tr>
<td>Disinhibition</td>
<td>294</td>
<td>89.4</td>
</tr>
<tr>
<td>Aberrant motor behavior</td>
<td>275</td>
<td>83.6</td>
</tr>
<tr>
<td>Total</td>
<td>116</td>
<td>35.3</td>
</tr>
</tbody>
</table>

^a Significant differences (p<0.01) between participants with and without dementia in all proportions of participants with the disturbance (linear regression) and all mean domain and total scores (logistic regression).

^b Numbers across columns do not add up to total N and percents do not add up to 100% in some cases because of missing data.
## Prevalence in UK & US Population Studies

* Savva G et al Br J Psychiatry 2009  
** Lyketsos CG et al Am J Psychiatry 2000

<table>
<thead>
<tr>
<th></th>
<th>UK Study *</th>
<th>US Study **</th>
</tr>
</thead>
<tbody>
<tr>
<td>DEMENTIA</td>
<td>-</td>
<td>+</td>
</tr>
<tr>
<td>Irritability</td>
<td>13</td>
<td>29</td>
</tr>
<tr>
<td>Delusions</td>
<td>8</td>
<td>25</td>
</tr>
<tr>
<td>Depression</td>
<td>9</td>
<td>21</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>4</td>
<td>15</td>
</tr>
<tr>
<td>Agitation</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Apathy</td>
<td>12</td>
<td>50</td>
</tr>
</tbody>
</table>
Dementia: Not a “Memory Disease”

Cognitive:
- Attention
- Language
- Visuospatial
- Executive

Neuropsychiatric Signs & Symptoms

Function:
- ADL’s
- iADL’s
- iADL’s

“One of the first disease symptoms of a 51-year-old woman was a strong feeling of jealousy towards her husband. Very soon she showed rapidly increasing memory impairments; she could not find her way about her home, she dragged objects to and fro, hid herself, or sometimes thought that people were out to kill her, then she would start to scream loudly.”
Behavioral Clusters

Aggression
- Withdrawn
- Lack of interest
- Amotivated
- Sad
- Tearful
- Hopeless
- Anxious
- Physical Aggression
- Verbal Aggression

Resistance to Care
- Walking aimlessly
- Pacing
- Restlessness
- Repetitive Actions
- Undressing
- Sleep Disturbance

Hallucinations
- Delusions
- Misidentification

Apathy
- Depression

Agitation
- Walking aimlessly
- Pacing
- Restlessness
- Repetitive Actions
- Undressing
- Sleep Disturbance

Psychosis
- Agitiation
Optimising treatment and care for people with behavioural and psychological symptoms of dementia

A best practice guide for health and social care professionals

The toolkit follows a basic stepped care model based on a colour-coded traffic light system. The traffic light colours represent:

<table>
<thead>
<tr>
<th>Colour</th>
<th>Description</th>
<th>Stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Green</td>
<td>No symptoms. Simple preventative measures</td>
<td>Prevention</td>
</tr>
<tr>
<td>Amber</td>
<td>Mild or moderate symptoms. Low intensity, general interventions</td>
<td>Watchful waiting</td>
</tr>
<tr>
<td>Red</td>
<td>Severe symptoms. Specific interventions and guidance for antipsychotic use</td>
<td>Specific interventions Antipsychotic prescription</td>
</tr>
</tbody>
</table>
6-D’s

Discover
Describe
Decode
Devise
Determine
Devote

Gitlin, Kales & Lyketsos 2012
A Case of Peer Pressure..?
Do we treat these little fellows with 2mg Haloperidol?
Non-Pharmacological Approaches

- Individualized Behavioral Management Techniques
- Caregiver Psycho-education (Individualized?)
- Music Therapy (Personalized?) (for agitation)
- Staff Education (agitation, dep, AP use)
Non-Pharmacological Approaches

- Pleasant Activities with or without Social Interaction (for agitation)
- Exercise (for depression in DAT)
- Reminiscence (for depression in DAT)
- Addressing Pain
### Evidence-Based Training Manuals

<table>
<thead>
<tr>
<th>Paper</th>
<th>Study</th>
<th>Intervention</th>
<th>Training</th>
<th>Effect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Buettner &amp; Ferraro 1998</td>
<td>RCT in LTCH’s N=60</td>
<td>30 week</td>
<td>10 week staff training program</td>
<td>Significant improvement in agitation and Depression</td>
</tr>
<tr>
<td>Fossey et al 2006</td>
<td>RCT 12 LTCH’s N=349</td>
<td>10 months</td>
<td>Training of LTCH staff over 10 months</td>
<td>20 % Reduction in AP use</td>
</tr>
<tr>
<td>Buettner et al 1999</td>
<td>X-over design in 2 40-bed LTCH</td>
<td>6 months</td>
<td>Training of Volunteer Groups with 30 minute educ program</td>
<td>Improvement in agitation</td>
</tr>
<tr>
<td>Goyder et al 2012</td>
<td>2 LTCH’s 25 staff 32 residents</td>
<td>8 weeks</td>
<td>2 workshops + 4 x 30 min supervision sessions</td>
<td>Reduction in depression, anxiety, and behavior</td>
</tr>
</tbody>
</table>
Why are Non-Pharm Interventions Not Widely Used First Line?
Challenge of Translating Knowledge to Practice: Myths & Realities

- Time: Yet countless hours wasted on dealing with behavioral crises due to unavailable resources, training, and prevention

- Funding: Investing in BPSD should decrease Costs

- Guidelines: Good guidelines available

- Strategy: Need Proactive Approaches
Economic Costs of Dementia

**FIG 2.6** Distribution of total societal costs (%) by World Bank Income level
Economic Cost of Dementia: Impact of BPSD

- Europe: Cost €10,000 - €30,000 / year / patient (Institutional Care > 40%)
- Informal Caregiving accounts for 25% of total costs (higher in LMIC countries)
- Cost is directly related to Disease Severity
- Medical Costs not related to Disease Severity
- BPSD increases with disease severity
- BPSD is associated with increased cost of informal care and direct social care
## Contribution of BPSD to Dementia Cost

Herrmann N et al Int J Geriatr Psychiatry 2006

<table>
<thead>
<tr>
<th>Monthly Cost</th>
<th>No BPSD ($CAN)</th>
<th>BPSD ($CAN)</th>
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<tbody>
<tr>
<td>Total Direct Medical Excluding Medication</td>
<td>45</td>
<td>99</td>
</tr>
<tr>
<td>Cost of Medication</td>
<td>111</td>
<td>113</td>
</tr>
<tr>
<td>Total Direct Non-Medical</td>
<td>59</td>
<td>157</td>
</tr>
<tr>
<td>Indirect (Opportunity Cost)</td>
<td>399</td>
<td>1028</td>
</tr>
<tr>
<td><strong>TOTAL COST</strong></td>
<td><strong>615</strong></td>
<td><strong>1398</strong></td>
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“I'm right there in the room, and no one even acknowledges me.”
Economic Significance of BPSD

BPSD → Caregiver Stress

Opportunity Cost to Carer → LTCH Cost

Direct Non-Medical Cost to Carer

Disease Severity → Decline in ADL's
Economic Significance of BPSD

- BPSD
- Caregiver Stress
- Opportunity Cost to Carer
- LTCH Cost
- Direct Non-Medical Cost to Carer
- Decline in ADL’s
- Disease Severity
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<tr>
<th>Location</th>
<th>Pre-Diagnosis</th>
<th>At Diagnosis</th>
<th>Post-Diagnosis</th>
<th>Co-ordination and Care Mgmt</th>
<th>Community Services</th>
<th>Continuous Care</th>
<th>End-of-Life Care</th>
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<tr>
<td>Location</td>
<td>Clinic PH</td>
<td>Clinic</td>
<td>Clinic Outreach</td>
<td>Outreach Clinic</td>
<td>Outreach LTCH</td>
<td>Outreach LTCH</td>
<td>Outreach LTCH</td>
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<tr>
<td>Focus</td>
<td>CVS Mood</td>
<td>Mood</td>
<td>Interpersonal Mood</td>
<td>“Latency Stage” BPSD +</td>
<td>iADL’s BPSD ++ Caregiver Capacity</td>
<td>ADL’s BPSD +++ Caregiver Capacity</td>
<td>Ethics Medico-legal Palliative</td>
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Implications for Service Delivery: Pre-diagnosis

1. New Mood & Anxiety Presentation in Late Life: Screen for Cognitive Decline

2. Education on Normal Cognitive Ageing

3. Counsel & Screen High Risk Relatives

4. Close Liaison with other care providers

5. “Geriatric” services must start to provide a “family-oriented” approach rather than adopted a “fixed age cut-off” for service provision
Implications for Service Delivery: Peri- and Post-Diagnosis

1. Comorbidity is the norm: *Mental Health Service within Ger Medicine setting*

2. Stigma: *Avoid usual “psychiatric setting”*; regular re-assessments

3. Education: Resources – printed, CD, courses, groups, coordination

4. **Family/Partner/Caregiver:** Old interpersonal conflicts re-appear – must be able to counsel/manage within same setting and not refer out

5. **Role Transition:** Work with Psychologist to address Grief (patient and family), Education, Interpersonal Therapy, Marital Therapy.
Implications for Service Delivery: Coordination and Care Management

1. "Latency" in terms of behavior – an opportunity for prevention!
2. Planning & Advance Directives if not done earlier
3. Counsel & Education of Caregivers to Prevent Burnout
4. Explore social support structure and plan services needed
5. Introduce Community Resources / Coordinator
Implications for Service Delivery: Continuous Care

1. **Intensify outreach** and support of caregivers

2. **Education** remains crucial

3. Continuity of Care: *Community Resource Coordinator*

4. Coordinate Hospital Services

5. Coordinate Respite
Implications for Service Delivery: End-of-life Care

1. Intensify outreach and support of caregivers

2. *Education* remains crucial

1. **Re-visit issues of advance directives** in anticipation of needs – e.g. tube feeding, admission to acute care hospitals, etc.

2. Coordinate Medical and Social Support Services: *Ensure Comfort*

3. **Grief Counseling with Caregivers/Family**
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**Pre-Diagnosis**
- Clinic PH

**At Diagnosis**
- Clinic

**Post-Diagnosis**
- Clinic

**Co-ordination and Care Mgmt**
- Clinic Outreach

**Community Services**
- Outreach Clinic

**Continuous Care**
- Outreach LTCH

**End-of-Life Care**
- Outreach LTCH
Conclusions

- Behavioral & Psychological Symptoms sine qua non of Dementia & a major contributor to Total Dementia Cost

- Prevention & Management Tools Available: Structure and Resources to Implement often not a priority (a case of false economy?)

- Geriatric Mental Health service delivery models must allow for flexibility in location of care delivery, share care with other medical colleagues, and include a well-coordinated community outreach service.

- Social and Health Policy needs to include BPSD Management & Prevention as an integral part in it’s Pathway to Care in Dementia

- Research on economic modeling of innovative community-based pathways to care in dementia are urgently needed
Thank you!
Discussion