"Sundance" – Evaluation of an Innovative Program for Individuals with Late-Stage Dementia
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Background
Individuals with moderate or late-stage dementia are often excluded from community-based activities because providers of adult day and similar services do not have the capacity to provide individualized care to respond to what is commonly referred to as “behavioral expressions associated with dementia.”

To better serve people with progressed dementia, the Volunteers of America Oregon (VOAOR) designed the Sundance program – an intervention that follows a person-centered approach in an adult day service setting. The 9-month-long pilot phase was funded by the Oregon Department of Human Services and evaluated by Portland State University’s Institute on Aging.

Main program goals:
• Reduce behavioral expressions (e.g., aggression) among program participants
• Reduce family caregivers’ perceived stress

Intervention
• 19 program participants, 6 trained direct care staff
• Meeting twice a week at adult care center from 3-8pm (= time of day when sundowning-associated behavior typically occurs)
• Individualized music and horticultural therapy
• Various group and individualized activities
• Multisensory elements

Process & Outcome Evaluation
• Is the program implemented according to plan?
• Are structural or procedural adjustments needed?
• Does the program have the intended effect on participants’ behavior and the family caregivers’ perceived stress?
• Are other changes observed by families and staff?

Method
Quantitative component:
• Neuropsychiatric Inventory Questionnaire (NPI-Q), completed weekly by family caregivers and twice a week by staff
• Perceived Stress Scale (PSS-10), completed weekly by family caregivers

Group averages were calculated for each observation point to examine changes in prevalence and severity of the participants’ behavioral expressions and changes in family caregivers’ perceived stress (both in relation to the behaviors and in general).

R² values from simple regression analysis were used to report trends in the observed changes over time.

Qualitative component:
• Focus groups after 7, 20, and 33 weeks, conducted separately with family caregivers and staff

Results
Reported changes over time (R² values) in (a) the severity of participants’ behavioral expressions and (b) the behaviors’ impact on family caregivers:

<table>
<thead>
<tr>
<th>Behavior</th>
<th>(a) Staff</th>
<th>(a) Caregiver</th>
<th>(b) Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delusions</td>
<td>(+) 0.04</td>
<td>(-) 0.02</td>
<td>(-) 0.45</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>(+) 0.05</td>
<td>(-) 0.09</td>
<td>(-) 0.38</td>
</tr>
<tr>
<td>Agitation/Aggression</td>
<td>(-) 0.03</td>
<td>(-) 0.06</td>
<td>(-) 0.09</td>
</tr>
<tr>
<td>Depression/Dysphoria</td>
<td>0.00</td>
<td>(-) 0.06</td>
<td>(-) 0.06</td>
</tr>
<tr>
<td>Anxiety</td>
<td>0.00</td>
<td>(+) 0.06</td>
<td>(-) 0.28</td>
</tr>
<tr>
<td>Elation/Euphoria</td>
<td>(+) 0.06</td>
<td>(-) 0.25</td>
<td>(-) 0.33</td>
</tr>
<tr>
<td>Apathy/Indifference</td>
<td>(-) 0.06*</td>
<td>(-) 0.03</td>
<td>(-) 0.24</td>
</tr>
<tr>
<td>Disinhibition</td>
<td>0.00</td>
<td>(-) 0.04</td>
<td>(-) 0.27</td>
</tr>
<tr>
<td>Irritability/Lability</td>
<td>(+) 0.01</td>
<td>0.00</td>
<td>(-) 0.16</td>
</tr>
<tr>
<td>Motor Disturbance</td>
<td>(-) 0.02</td>
<td>(-) 0.15</td>
<td>(+) 0.02</td>
</tr>
<tr>
<td>Night-time Behavior</td>
<td>(not asked)</td>
<td>(-) 0.03</td>
<td>(+) 0.01</td>
</tr>
<tr>
<td>Appetite/Eating</td>
<td>(+) 0.01</td>
<td>(-) 0.01</td>
<td>(+) 0.03</td>
</tr>
</tbody>
</table>

*(Statistically significant (p<0.05))

Over time, family caregivers experienced an overall reduction in perceived general stress levels.

In the focus groups, caregivers and staff reported, among others, high program acceptance, positive changes in the participants’ mood and behavior, increased social interaction and group cohesion, and caregiver respite and relief.

Conclusions
Despite the small sample size, the results point toward an important contribution of the Sundance program in reducing dementia-related behavioral expressions and perceived caregiver stress.