

Evaluating the “Sundance” Program for Late-Stage Dementia: The Family Caregivers’ Perspective



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Background

The Sundance program, designed and run by the Volunteers of America Oregon and funded by the Oregon Department of Human Services, was a non-pharmacological, community-based pilot intervention providing person-centered care to individuals with moderate to late-stage dementia.

Outcome objectives included:

- **Decreasing behavioral expressions (e.g., aggression) among program participants**
- **Decreasing their family caregivers’ perceived stress**

The longer-term goal of the program was to enable individuals with dementia to remain in their homes and to participate in community-based activities as long as possible.

This poster summarizes the findings from the qualitative assessments with family caregivers as part of the evaluation of the Sundance program.

Data Collection

Over the course of the 9-month program, 3 focus groups (1.5h each) were conducted with family caregivers. Questions addressed changes observed in both program participants and themselves, perceived benefits of and difficulties with the program, and suggestions for program improvement.

Focus Group 1 (week 7)	11 caregivers of 9 program participants <ul style="list-style-type: none"> • 5 spouses • 4 adult children (+2 accompanying partners)
Focus Group 2 (week 20)	13 caregivers of 12 program participants <ul style="list-style-type: none"> • 7 spouses • 5 adult children (+1 accompanying partner)
Focus Group 3 (week 33)	8 caregivers of 8 program participants <ul style="list-style-type: none"> • 2 spouses • 6 adult children

The Sundance Intervention



Sundance participants engaging in an indoors horticulture project with seasonal material during the fall.

Program Logistics

- Time frame: March–December 2015
- Location: an established, fully equipped adult day center with a fenced garden area in Portland, OR
- Operation: twice a week from 3–8pm to include the hours during which sundowning-associated behaviors typically occur
- Group meal: dinner was provided within nutritional and dietary constraints, including ethnic choices
- Direct care staff to participant ratio: approx. 1:3
- Staff training: 3 initial trainings (3h each) and several additional trainings on various topics (e.g., safety, dementia, person-centered care, communication)

Person-Centered Program Components

Weekly therapeutic interventions (1h each) in a group setting, led by experienced therapists:

- Individualized music therapy
- Horticultural therapy

Additional components and activities:

- Multisensory elements (e.g., aromatherapy, multisensory room, touch)
- Various group activities to enhance positive communication and group connection
- Various options for activities tailored to the participants’ individual abilities and preferences



Sundance participants singing, relaxing, and playing instruments during a music therapy session.

Results

Program components perceived as particularly beneficial:

- Staff (highly competent and caring)
- Activities offered (multisensory approach)
- Person-centered approach

Observed positive program effects on the program participants:

- Social inclusion and sense of belonging
- Activation and stimulation
- Increased communication and contact-seeking
- Lasting positive memories of the program
- Positive changes in mood and behavior

Observed positive program effects on the family caregivers themselves:

- Respite and relief
- Peace of mind

Perceived challenges:

- Adjusting to program (initial reluctance)
- Assessment instruments (bothersome)
- Logistics (long commute, blocked driveway)

Suggestions:

- Increase program availability
- Offer a caregiver support group
- Facilitate regular information exchange with staff
- Include culturally-specific program elements

Conclusions

The qualitative data provided a powerful account of the lived caregiving experience and complemented the traditional quantitative measures in this study.

Family caregivers perceived the Sundance program as beneficial for both their family members and themselves. Funding is currently being sought for continuation and expansion of the program.