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Sundance: A Novel Community-based Pilot Program for Later-stage Dementia Care

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School of Occupational Therapy

Doctoral Capstone Manuscript

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Abstract

This article provides background, philosophy, and program development strategies used for Sundance, a community-based dementia care program in Portland, Oregon. The program is an innovative extension of existing adult day services. It is designed to serve individuals with later-stage dementia who demonstrate challenging behaviors and live in the community with a family caregiver. Programming includes evidence informed person-centered care using nonpharmacologic strategies and sensory-based interventions.

Sundance: A Novel Community-based Pilot Program for Later-stage Dementia Care

Tucked away among tall fir trees in a low-income neighborhood in Portland is an A-frame building. This converted church is the home of Lambert House Adult Day Services, and it recently became the home of a new program, Sundance. Every Tuesday and Thursday afternoon, Lambert House transforms into Sundance, an innovative program which serves a unique population of individuals with moderate to later-stage dementia who demonstrate challenging behaviors and are living in the community with a family caregiver. As participants of Lambert House make their way home, the 15 Sundance participants are dropped off by their spouses or grown children. Soon the space fill with positive energy for another afternoon together, which often begins with a round of balloon volleyball followed by a reminiscing activity; topics focus on personal interests of the participants, ranging from the Oregon Coast to the music of the Rat Pack.

Volunteers of America Oregon has been successfully operating two adult day service (ADS) programs in the Portland, Oregon metro area for 15 years. Lambert House and its sister site offer structured therapeutic, social, and health services to seniors and adults with disabilities living in the community. In 2014, approximately 45% of clients served had a diagnosis of dementia. The need for a bridge program arose as the program director, forced by the demands of efficient programming, had to reverse enrollment for a number of clients who required a higher level of care due to advancing dementia. Families, who were left with no viable alternative for respite or the engagement provided by ADS attendance, reacted with anger, sadness, and disappointment. This gap in services led Volunteers of America to establish Sundance, a pilot program designed for higher level dementia care. The purpose of this article is to describe program development and sustainability of Sundance.

Sundance

Challenging behaviors, including delusions, hallucinations, and aggression are more common as dementia progresses, creating a greater challenge for caregivers (Lykestos et al., 2011). The Sundance program provides a much needed opportunity for community-based engagement and interventions to address behavioral symptoms for individuals in the later stages of dementia who live with a family caregiver. Sundance is grant-funded by the state of Oregon and it is the only program of its kind in the state. The name *Sundance* evokes the positive potential surrounding the experience of dementia, in contrast to the negative stigma attached to sundowning syndrome, an escalation in neuropsychiatric symptoms which cause challenging behaviors (Cipriani et al., 2015). Sundance operates from 3 p.m. to 8 p.m. twice a week. This afternoon timeframe offers the benefit of cost-effectiveness, in that the space for the program is shared with Lambert House, and addresses a challenging time of day for dementia behaviors, afternoon and evening.

Philosophy

Person-centered care and a dementia-capable staff serve as the cornerstones of program development. Person-centered care incorporates the whole person: life history, values, personal preferences, and routines of the individual; an emphasis on remaining abilities rather than losses; and an understanding of the person and their identity within social and cultural context. Personalized intake forms developed for Sundance allow family caregivers to share information about function as well as personal history and values of the individual with dementia (IWD). Program development took into account that specialized staff-training is identified as a key element to improve dementia care, and caregiver/staff training is essential to implementing successful activity intervention (Gould & Reed, 2009; Padilla, 2011). Enhanced staff training in dementia, communication, safety, and activity engagement were designed using the philosophy

and strategies outlined by Gitlin and colleagues for nonpharmacologic management of dementia behaviors (Gitlin, Kales, & Lykestos, 2012). A ratio of 1:3 staff to participants allows for one-on-one interactions and appropriate individualized attention and assistance for participants.

Sundance enhanced innovative programming through partnership with an occupational therapy doctoral candidate who added a perspective regarding the transactional relationship of persons with dementia (including physical and mental capacity, valuable roles, and beliefs), their physical and social environments, and engagement in occupation (Law et al., 1996). Although cognitive and functional impairments make it challenging to engage IWD in activities, finding the best fit of person, environment, and occupation can maximize the engagement and participation of the IWD and facilitate his or her use of existing capacities, increasing physical and mental stimulation; ideally this will decrease challenging behaviors as the need for engagement and stimulation is being met and optimized. Activities tailored to meet individual interests and abilities, as well as customized adaptations of the environment, including tailored communication, are shown to have the best results for engaging IWD, and are incorporated as an integral part of this program (Trahan, Kuo, Carlson, & Gitlin, 2014).

Programming

Sundance uses structured and unstructured activities designed to maximize engagement of participants. Daily activities include therapeutic groups, dinner, reminiscing, arts and crafts, physical games, and stations and boards designed to tap into interests, habits, and routines. Sundance also implements evidence-informed sensory-based interventions. A multi-sensory environment (MSE) was built to be used for creating a pleasant and stimulating experience led by interaction with the senses rather than cognitive demands, as well as provide an intervention that can decrease agitated behaviors (Staal et al., 2007). Rather than invest in expensive fiber-optic components often used in the MSE model, the program developers aim to create a more natural

environment in order to elicit a calming effect and appeal to the older adult population (Goto, Kamal, Puzio, Kobylarz, & Harrup, 2014). Programmers invested in a projector for images of nature, ambient lighting, nature sounds, aromatherapy, tactile stimuli, and a gliding sofa. When participants are in need of a calm environment staff uses the MSE, which provides opportunity for a one-on-one interaction with the attending staff member. Staff monitors behavior and facilitates use of sensory stimulation which has proven effective for each individual, such as a hand massage with scented lotion. Group music therapy, which has been shown to alleviate agitated behaviors in IWD (Lin et al., 2011), is provided every afternoon. The music therapist uses techniques for sensory stimulation and reminiscence; participants express themselves through song, rhythm, and laughter. Horticultural therapy, shown to increase positive mood in IWD (Gigliotti & Jarrott, 2005), is provided once a week. Participants explore the textures and smells of plant life, find satisfaction in completed group projects, and take walks in the garden to harvest radishes or release lady bugs.

Lived Experience

The following story demonstrates the efficacy of the Sundance model: person centered care, enhanced staff training, and sensory-based interventions. Gwen is 88 years old and lives with her son David; she is in the later stages of Alzheimer's disease (both names have been changed). Gwen arrives to each session in a purple hat, and she laughs and says "*thank you*" when she is told how beautiful she looks. The direct care staff knows that when Gwen is calling out for her son that she responds very well to being given a direct answer. She can barely see, but she responds to voices, movement, and shadows. She will sing along to *You Are My Sunshine* and laugh in response to a rhyming poem. She loves Frank Sinatra. Gwen needs assistance with feeding and might bite a finger if it gets too close to her mouth. Care staff also knows that Gwen worked as an accountant, and she likes to know how much something is going to cost her,

especially her dinner. When she is agitated, she responds well to the MSE, where she calms down immediately with the scent of geranium, enjoying a laugh with the attending staff member. Gwen has more behaviors on evenings when she is tired. David tells us that since the program started five months ago, Gwen is much calmer during their time together at home, she sleeps better at night, and even the neighbors have noticed that she yells out less frequently. David says Sundance has provided Gwen with a community again.

Future Directions and Outcomes

Sundance provides a unique and necessary care option to a greatly underserved population. There is magic in the joy and community shared as individuals interact, express themselves, demonstrate caring behavior toward one another, and engage in activities. To overcome funding challenges, Sundance plans to use a fee for service model and seek further grant funding. The pilot program runs for one year and anticipated outcomes are a reduction in challenging behaviors and decreased caregiver burden. Data is collected regularly from staff and family caregivers, and the outcomes are being evaluated by researchers at Portland State University, which is also providing family caregiver focus groups to collect qualitative data. As the program moves forward, goals for change based on lessons learned include: increased care coordination and family caregiver education, a ratio of 1:4 staff to participants, and a lead direct care staff /activities director. Development of effective, non-pharmacologic and community-based care solutions is a public health priority as the population with dementia increases. Sundance is breaking new ground to support the future of community-based dementia care.

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