



## Feature Article

# The feasibility of volunteers facilitating personalized activities for nursing home residents with dementia and agitation

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## ABSTRACT

**Background:** Nursing home residents' behavioral and psychological symptoms of dementia are often exacerbated by a lack of social contact and meaningful activity. Volunteers might assist in addressing this deficiency but they are often discouraged by staff from engaging with residents with challenging behaviors. As a result, some of the neediest residents receive the least social and psychological support.

**Aim:** This project explored the implementation of personalized, one-to-one activities by nursing home volunteers to determine if volunteers were able and willing to complete a training program and undertake activities with residents with dementia and challenging behaviors.

**Methods:** 19 nursing home volunteers in Melbourne, Australia, were trained to apply Montessori-type personalized activities with a selected resident whose dementia was complicated by a frequent, non-aggressive agitated behavior. The volunteers were asked to attend a workshop and pay six 30-min visits to the resident over a three week period. They completed knowledge and attitude rating scales before and after the intervention and were interviewed afterward regarding their experiences and perceptions.

**Results:** 16 volunteers completed the program and eight met or exceeded every study requirement. Most of them derived satisfaction from engaging residents' interest and were pleased to learn new skills. The scores on the dementia knowledge and attitude rating scale of those who completed the visits were higher at the study's outset than the scores of those who failed to make any visits.

**Conclusions:** It is certainly feasible to train volunteers to work with residents who might otherwise be isolated. It is important to demonstrate activities to volunteers at the outset and to provide them with careful, ongoing supervision and support. Notwithstanding some difficulties and challenges, volunteers represent a growing and hitherto untapped pool of support for people with dementia and complex needs.

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## Introduction

Dementia is often associated with challenging behavioral and psychological symptoms. In a population-based study in the United States, 61% of people with dementia had exhibited one or more behavioral or psychological disturbances in the past month including agitation (13%) and irritability (17%).<sup>1</sup> Rates are higher still in residential facilities. In an Australian study, for example, 53% of nursing home residents showed an "activity disturbance" and 77% behaved aggressively.<sup>2</sup>

Behavioral symptoms stemming from pain, major depression or psychosis respond to treatment with analgesics, antidepressants

and antipsychotics respectively but, in other cases, psychotropic medications have only limited efficacy. This has prompted an interest in developing, testing and implementing a wide range of non-pharmacological interventions to lift residents' mood, reduce behavioral symptoms and improve their quality of life.<sup>3</sup>

Cohen-Mansfield postulated that people with dementia behave in an agitated manner when their needs (for example for social interaction) are not correctly perceived and addressed by caregivers. These unmet needs are best remedied in her view by means of an enriched, 'person-centred' care model and, more specifically, through psychosocial interventions that are designed to elicit interest, engagement and social inclusion.<sup>4</sup>

Two recent systematic reviews concluded that psychosocial interventions including music and recreation therapy are effective in reducing agitation, particularly when tailored to participants' backgrounds, relationships, interests and skills.<sup>3,5</sup> By way of illustration, music that people had enjoyed earlier in life reduced

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agitation better than “standard” relaxing music while audiotapes of a family member’s voice worked better than a stranger’s voice.<sup>6,7</sup>

Despite a growing evidence base, truly personalized activities tend not to be offered in many aged care facilities due to constraints on staff members’ time. As an alternative resource, aged care volunteers could, if given the opportunity, work closely with individual nursing home residents to help engage them in personally-tailored activities.

Volunteering is “the voluntary giving of time and talents to deliver services or perform tasks with no direct financial compensation expected.”<sup>8</sup> It is increasingly popular with up to 36% of Australian adults engaging in recent years in some sort of volunteer activity.<sup>9</sup> According to the social exchange model, volunteers’ motives include altruism, self-development and socialization. Facilitating factors include an extroverted personality, extensive social networks and prior volunteer experience.<sup>10</sup> The consequences for volunteers are mostly beneficial. People with better than average mental and physical health are more likely to seek community service and then derive from it an even greater sense of personal well-being.<sup>8</sup>

Previous reports of volunteer programs for people with dementia were generally positive. In a study of nine volunteers in a Norwegian activity centre for people with early stage dementia, benefits for volunteers included meeting new people and working collaboratively. For those with a health care background, it was sometimes difficult though to adjust to the absence of professional colleagues and a paid role.<sup>11</sup>

Caring for people with dementia can present special challenges. For 45 North American volunteers, fear of dementia and problem behaviors emerged as one of the reasons for 38 failing to complete training as in-home respite carers.<sup>12</sup> By contrast, some of the six Portuguese in-home respite carers who received 3 h of intensive training in engaging people with dementia in meaningful activities felt disappointed that the experience was not more challenging. Most were rewarded by learning greater patience, better communication skills and emotional sensitivity.<sup>13</sup>

Residents of nursing homes are typically more cognitively and behaviorally impaired than people living in the community. In a large Canadian nursing home complex, eight volunteers were given 5 h training in dementia care, empathic communication and cultural sensitivity followed by personal mentoring. Some of them had cared for a family member with dementia and wanted to help others in the same situation. One volunteer thought that residents would be “far worse” behaviorally than proved to be the case. Most succeeded in building positive relationships, identifying congenial activities and staying “in the moment.”<sup>14</sup>

In an earlier study, we found that nursing homes welcomed volunteers’ provision of company and stimulation but tended to discourage them from engaging with residents with prominent behavioral symptoms, fearing that they would be unable to cope. As a result, the residents most in need of company, stimulation and meaningful activity were actually the least likely to receive it. The volunteers themselves reported being motivated by a wish to give something back to their community and by personal needs to remain active and form new relationships. Training was greatly valued and most reported that they would be interested in learning new approaches to working with confused, agitated residents.<sup>15</sup>

In this current study, we set out to train a small sample of nursing home volunteers in the delivery of personalized activities using an approach that has proved effective in promoting engagement and reducing agitation in nursing home residents with advanced dementia. It was not the purpose of the study to test the treatment’s effectiveness. This has been demonstrated previously.<sup>16</sup> Instead, we set out to determine volunteers’ interest in helping deliver such a program, and their capacity to persist with it despite

likely obstacles, as a guide to future practice. The question addressed by this pilot study was: Are volunteers able and willing to engage in individually-tailored activities with residents with advanced dementia and prominent behavioral symptoms?

The Montessori-type activities program employed in the study was developed for use in a readily taught, manualized fashion by professional and family caregivers with access to limited physical resources. The goals of the program were to select a range of activities that matched each resident’s former interests, skills and culture and could readily be made more or less challenging, depending on their current cognitive and physical capacities. Activity facilitators paid close attention to their posture, demeanor and speech with the goal of presenting an inviting, non-threatening presence that engaged and maintained residents’ interest. Residents were typically invited to “help” the facilitator complete a task; the activity was then modeled, and the resident was prompted to participate. Thus, a resident with moderately severe dementia and an interest in baking might be encouraged to sort pictures of baking implements by size or color; to arrange them in a sequence, or to relate a narrative of a baking task. If one task failed to capture the resident’s interest, the facilitator moved quickly to an easier or harder task as indicated. Little verbal interaction was required for people with limited language skills. A detailed description of the program is available online.<sup>17</sup>

In an earlier randomized cross-over trial involving 44 nursing home residents with frequent, persistent agitated behaviors, an identical program achieved significant reductions in agitated behavior counts and significant increases in positive effect and engagement.<sup>16</sup> The purpose of this present study was to explore the potential for the translation of individualized activities into everyday practice with volunteers acting as facilitators. Since recruiting and training volunteers in new endeavors is time-consuming and therefore expensive, it is important to check that the approach is both feasible and attractive to volunteers.

## Methods

The study was a descriptive feasibility review using largely quantitative methods to gauge: (i) volunteers’ interest in facilitating an individually-tailored activity program with a resident with advanced dementia and agitated behavior; (ii) their capacity to remain engaged in a treatment program after a period of training, and (iii) changes in their attitudes and knowledge of dementia over the course of the study. We anticipated that a greater knowledge of dementia and more positive attitudes to people with dementia at the study outset would be associated with higher retention rates.

### Sample selection

Australian aged care facilities provide accommodation and care to individuals who are no longer able to live at home. Fees are subsidized by the federal government which authorizes admission based on need and regulates standards of care.

We approached 18 aged care homes in southeast Melbourne, Australia, of which nine agreed to participate. Of the remainder, four facilities expressed interest but took no further action; volunteers at two homes chose not to be involved; one home was closing; one was undergoing accreditation, and one had no volunteers.

The nine participating homes had a total of 33 volunteers of whom 14 were unable to meet the study’s training and visitation requirements. The 19 enrolled volunteers were paired with a resident in the same home who met the following criteria: (i) a chart diagnosis of dementia; (ii) a frequent agitated but non-aggressive behavior based on staff members’ ratings on the Cohen-Mansfield

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