Volunteer-facilitated implementation of personalised one-to-one activities with people with dementia and agitated behaviour

Investigators: Dr Eva van der Ploeg and Prof Daniel O'Connor

(i) Aims of the project

This knowledge transfer pilot project aims to explore the implementation by volunteers of personalised one-to-one activities as a treatment of agitation associated with dementia. Our research questions are:

- (i) Is participation in a personalized activity program feasible and acceptable to volunteers?
- (ii) Does their participation result in changes in their knowledge about, and attitudes towards, people with dementia?

(ii) Background and significance

Advanced dementia is often associated with behavioural symptoms, including pacing, calling out and aggression. Pharmacological treatments can bring relief but in recent years research has broadened to address non-pharmacological strategies. Some psychosocial interventions, and especially those tailored to individuals' skills and interests, have proved effective in reducing agitation and improving mood (O'Connor *et al.*, 2009a, 2009b; Gerdner, 2000; Garland *et al.*, 2007; Lin *et al.*, 2009). However, despite a growing evidence base, personalised activities are not often implemented in aged care facilities. Preparation and implementation are time-consuming, there are too few available staff members, and staff lack training.

Nursing home volunteers might represent a large, untapped pool of activity facilitators. In a recent survey, one third of the Australian adult population (Australian Bureau of Statistics, 2006) had volunteered in some capacity in the previous year, contributing 713 million hours annually. The four most popular areas for volunteering were sport and physical recreation, education and training, community welfare and religion. Approximately 4% had volunteered in the health sector (ABS, 2006).

With respect to nursing homes, volunteer programs are common (Damianakis *et al.* (2007) but there is a tendency for volunteers to spend most time with cognitively intact residents and to avoid those with marked cognitive impairment, perhaps through fear of dementia and its associated symptoms (Robinson and Clemons, 1999).

In a recent study of local aged residential facilities, we questioned 17 facility managers and diversional therapists and 39 volunteers about recruitment, induction, activities, benefits, difficulties and the volunteers' willingness to learn new methods of interacting with residents. Facilities were well able to find and keep volunteers, but the latter either assisted with the current activities program or pursued their own interests (e.g. pet therapy), with the result that few of their activities were directed to individual residents' needs and preferences. Furthermore, individuals with more advanced dementia and associated behavioural symptoms (i.e. the ones most likely to benefit from one-to-one, individually tailored interactions) often missed out. However, almost all the volunteers were

open to learning new approaches to engaging in a meaningful way with confused residents.

In summary, current aged care volunteers are available and willing to work therapeutically with agitated residents. With appropriate training and ongoing supervision, they are a potential resource to overcome structural barriers to delivering better care to some of the neediest residents within aged care facilities. The proposed study will explore the feasibility and acceptability of implementation by volunteers of a non-pharmacological treatment of behavioural symptoms of dementia.

(iii) Research strategy

Study design

We will conduct a pre-post study to explore volunteers' capacity to engage in Montessoritype activities and changes in their knowledge and attitudes towards people with dementia.

Subjects and sites

This pilot study will include 20 volunteers across five aged care facilities in south-eastern Melbourne, Victoria.

Inclusion and exclusion criteria

Volunteers should visit the facility at least twice a week and be willing to follow study procedures. They must be sufficiently fluent in English to understand the activities workshop and to complete questionnaires.

They will each be paired with a resident in their usual facility. The resident must have lived in the facility for over 3 months; have a chart diagnosis of dementia, and display a high frequency agitated but non-aggressive behavioural symptom (e.g. pacing).

Study procedure

Once volunteers are recruited and paired with a suitable resident, we will seek consent for the resident's participation in the study from the next of kin or legal guardian.

A researcher will develop a personalized program of about 10 appropriate activities in consultation with the family member who is most familiar the resident's background, interests and skills.

Volunteers will receive 3 hours of one-on-one training. The training session will include tuition in Montessori methodology and its application to people with dementia; the activities selected for the resident; role-playing of activities, and finally interaction with the matched resident. They will be asked to deliver 6 activity sessions of 30 minutes duration over the next 3 weeks, keeping a log book for each session. The researcher will telephone them after 1 week to check on their progress and to resolve any issues or questions. We can be contacted at all other times by telephone, email and personal contact to offer support.

Measures

Volunteers will record in their log books the date and duration of each activity session; the number of activities employed; ratings of the resident's engagement in the activities, and any problems that arose.

Once the sessions have finished, volunteers will be asked to participate in a semistructured interview concerning the feasibility and acceptability of the activities from their own perspective; the most and least appealing aspects of the sessions; their perception of residents' behaviour, affect and engagement during the activities; their reasons for withdrawing from the activities (where applicable) and their willingness to continue with them once the study ends (this will be checked again by telephone 3 months later).

In addition, we will administer the Knowledge and Attitude subscales of the Tool for Understanding Residents' Needs as Individual Persons (TURNIP, Edvardsson *et al.*, 2011). Examples of items include: "Challenging behaviours are inevitable with dementia" (knowledge) and "People with dementia have ways to communicating what they want and don't want" (attitudes). All items are answered on a five-point Likert scale.

Statistical rationale and analysis

Transcribed copies of final interviews will be read separately by two researchers to identify themes, categories and issues important to volunteers. Items with divergent scores will be discussed to reach a consensus rating. TURNIP sub-scale scores will be analysed using paired-sample t-tests to explore volunteers' changes in knowledge and attitudes regarding people with dementia.

(iv) References

Australian Bureau of Statistics. (2006). *Voluntary Work Australia*. Canberra, Australia: Australian Bureau of Statistics.

Damianakis T, Wagner LM, Bernstein S, Marziali E. (2007). Volunteers' experiences visiting the cognitively impaired in nursing homes: a friendly visiting program. *Canadian Journal on Aging* 26, 343-356.

Edvardsson D, Fetherstonhaugh D, Nay R. (2011) The Tool for Understanding Residents' Needs as Individual Persons (TURNIP): construction and initial testing. *Journal of Clinical Nursing*, 2011 Apr 7. doi: 10.1111/j.1365-2702.2011.03706.x.

Garland K, Beer E, Eppingstall B, O'Connor DW. (2007). A comparison of two treatments of agitated behavior in nursing home residents with behaviour: simulated family presence and preferred music. *American Journal of Geriatric Psychiatry* 15, 514-521.

Gerdner LA. (2000). Effects of individualized versus classical "relaxation" music on the frequency of agitation in elderly persons with Alzheimer's disease and related disorders. *International Psychogeriatrics* 12, 49-65.

Lin LC, Yang MH, Kao CC, Wu SC, Tang SH, Lin JG. (2009). Using acupressure and Montessori-based activities to decrease agitation for residents in dementia: a cross-over trial. *Journal of the American Geriatric Society* 57, 1022-1029.

O'Connor DW, Ames D, Gardner B, King M. (2009a). Psychosocial treatments of behavior symptoms in dementia: a systematic review of reports meeting quality standards. *International Psychogeriatrics* 21, 225-240.

O'Connor DW, Ames D, Gardner B, King M. (2009b). Psychosocial treatments of psychological symptoms in dementia: a systematic review of reports meeting quality standards. *International Psychogeriatrics* 21, 241-251.

Robinson KM, Clemons JW. (1999). Respite care: volunteers as providers. *Journal of Psychosocial Nursing and Mental Health Services* 37, 30-35.