Personal message cards: an evaluation of an alternative method of delivering Simulated Presence therapy

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Abstract

Simulated Presence Therapy (SPT) is a technique which utilises a familiar recorded voice to calm and reassure people with dementia who are agitated or anxious. Although SPT has shown potential benefits in small scale studies, practical limitations in making and playing the recordings have restricted its use. An alternative method of delivering a message from an attachment figure is through a Personal Message Card. This was one of seven products used within the Bath Memory Technology Library which were made available free of charge to people affected by dementia and their carers. This paper provides an evaluation of the Personal Message cards. Although feedback was received on only 10 of the 24 cards that were distributed, for nine people there was evidence that the cards met the goals that had been set either fully or in part, and that people affected by even quite severe levels of dementia could benefit from them.
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Background

Anxiety and agitation are relatively common amongst people with dementia, with prevalence estimates for anxiety symptoms ranging from 8 to 71 per cent (Seignourel et al, 2008). Anxiety is associated with lower levels of quality of life, limitations in activities of daily living and increased risk of future nursing home placement (Gibbons, Teri and Logsdon, 2002; Seignourel et al, 2008). Best practice guidelines suggest that the management of such anxious behaviours should be non-pharmacological, at least in the first instance (Department of Health, 2011). However, as yet few psychosocial interventions exist which reduce levels of agitation and distress whilst being relatively easy to implement.

Simulated Presence Therapy, or SPT, involves playing a recording of a familiar voice to a person with dementia, typically with the aim of reducing anxiety or agitation (Woods and Ashley, 1995; Camberg, et al, 1999). A series of studies have found encouraging results (Byatt and Cheston, 1999; Protheroe, 1999; Miller et al, 2001; Peak and Cheston, 2002; Cheston et al, 2007; Garland et al, 2007), and a trial of a video version of SPT using an n=1 ABA methodology has also described (O’Connor et al, 2011). In clinical terms, SPT can be seen as meeting the attachment needs of the person with dementia when they are separated from their primary attachment figures, thus acting as a transitional phenomena (Miesen, 1999; Osborne, Stokes and Simpson, 2010; Browne and Shlosberg, 2005). In this way its use has similarities with the use of transitional objects such as dolls (Mackenzie, Wood-Mitchell & James, 2006; Stephens, Cheston and Gleeson, 2013).

However, while there is evidence for the impact of SPT on levels of agitation SPT with people with moderate to severe levels of dementia who are verbally and physically agitated (Bayles et al, 2006), many studies are of mixed quality and the case for SPT is not conclusive (Zetteler, 2008). Moreover, practical difficulties in recording and playing a message from a carer have restricted the use of SPT.
Consequently, further research to develop and evaluate more effective methods of delivery is necessary.

**Personal message cards**

The first Personal Messages card was made by the son of a woman who was affected by dementia, utilising a commercially available talking greetings card, with a facility to record a short recorded audio message\(^1\). The message is replayed each time the card is opened, and the card can also be personalised with photographs adding to its potential impact as a transitional object.

**Memory Technology Library.**

The Bath Memory Technology Library was funded by the NHS South of England Dementia Challenge Fund. The Library was managed by a community health provider (Sirona Care & Health) with support from a Health Technology provider (Designability - Bath Institute of Medical Engineering). The primary aim of the library was to provide seven low-tech and relatively simple products (including the Personal Message Card) that could make life easier for people living with memory loss ([www.memorytechnologylibrary.co.uk](http://www.memorytechnologylibrary.co.uk)). “Libraries” were established within both statutory and voluntary settings including carers’ centres, a memory clinic, hospital wards and nursing homes. Where a product proved successful, it did not need to be returned. Librarians were appointed in each centre, all of whom had a clinical role (such as a nurse, social worker or therapist), and were familiar with the problems faced by their client group. Regular meetings for the librarians led by the project team enabled them to share information about the therapeutic potential of the products and good practice. The process by which products were distributed was designed to be suitable for a staff from different professional backgrounds who were working for a wide range of organisations:

1. Librarians discussed the issues that were faced within care with the person affected by dementia and either someone who cared for or worked with them, and identified one or more of the items within the library as having a potential use. Where the person with

\(^1\) A guide to recording a Personal Message card is available from the authors on request
dementia was judged to have capacity, then they completed a consent form. Where they lacked capacity, then their carer provided consent.

2. Using the Goal Attainment Scaling (GAS) (Kiresuk and Sherman, 1968; Kiresuk and Lund, 1979), up to two goals were set for the person affected by dementia, as well as one carer-related goal. The GAS has been widely used as a clinical evaluation tool in older adult settings and allows for collaborative goal setting between the researcher, people with dementia and their carers (Rockwood, Joyce and Stolee, 1997; Rockwood, Stolee and Fox, 1993).

3. Librarians rated the level of cognitive ability of the person with dementia, using a tick box table that was based on the Clinical Dementia Rating Scale (Morris, 1993). They rated the person affected by dementia on a five point scale from 0 ("no difficulty") to 4 "severe difficulty") across six domains (short term memory, orientation, ability to use judgement, ability to function in a work and / or social setting, ability to participate in home life and hobbies, and personal care) which were combined to give a maximum total score of 24. A score between 6 and 12 was defined as showing a mild impairment, from 13 to 18 a moderate level of impairment, and of 19 or above were represented as a severe impairment.

4. The product was then issued to the person affected by dementia and their carers by the librarian, who also provided instructions about its use.

5. After a four week period, the librarian contacted the carer to assess whether the product had been of use, and completed a review form.

Aims
The purpose of this exploratory study was to collect key information about the way in which Personal Message cards were used, including the goals that were set for them and the extent to which they would be perceived as being successful in meeting these goals.
Results

Use of the cards. In all, 24 Personal message cards were issued by the library, with recipients having an average age of 85.5 years (range 79-93). However, only 10 reviews (42 per cent) were completed by the librarians. The level of cognitive impairment was scored for 23 subjects, with 6 being rated as having a mild impairment, 9 moderate and 8 as having a severe level of impairment. Thirteen cards were used in nursing homes, with the rest being almost equally divided between people living at home on their own (five) or with others (six).

Goals set for the cards. The goals that were set reflected three key themes: for reassurance; as a link between families and the person affected by dementia; and as a way of helping the person affected by dementia to remember people and events.

Significance of the goals. Librarians asked carers to rate both how difficult and how important the problem was to them, ranging from 1 (not very) to 4 (very difficult/important). The mean difficulty for the Personal message cards where a review was completed was 2.87, with an average importance rating of 3. For those cards where a review was not completed, the mean scores were both higher (3.4 and 3.63 respectively). A two tailed T-test indicated these differences were not significant.

Were the goals met? The ten participants who received a card and provided feedback at 4 weeks, set 17 goals between them (described in Table 1). Eleven of these goals were rated as being fully met, with five being rated as being partially met. In one case the card had not been used. Nine of the ten carers who provided feedback said that they would continue to use the Personal Message cards (at which point the cards were provided for them permanently) and that they would consider purchasing a Personal Message Card in the future.

Case Study - Val and Fred. The way in which the cards were used was described by an Art Therapist who had worked with Val, whose husband Fred was in a Nursing Home. Val wanted to use the cards
to let Fred know that she would see him soon, as she worried that when she wasn’t with him Fred felt that she was never coming back. As Fred was a keen artist, Val put pictures of herself and Fred’s paintings on the card. She also incorporated a brief extract of Fred’s favourite piano music in the message. In her feedback, Val described the impact of the card “I played a piece on the piano and he enjoys it. He opens it and he understands it. There is a photo of me on the front.” Val described the reaction of Fred “his eyes light up ... maybe it’s the music, but that’s what it’s about ... I am not sure that he recognises me, but when he looked at the painting he looked for a very long time”

Discussion

Good practice guidelines consistently stress the importance of non-pharmacological interventions as the first form of intervention for challenging behaviour. However, the evidence base for these interventions is limited, and there is an urgent clinical need to develop a greater repertoire of evidence-based, practical interventions. Although there is evidence that Simulated Presence Therapy can reduce levels of distress amongst people who are affected by even quite severe levels of dementia, its impact as a clinical intervention has been limited. Personal Messages cards may be one way of making SPT more accessible.

For nine of the ten people for whom we received feedback, their original goals were either partially or fully met. Although our study did not look at longer term use, the results suggests that carers intended to continue to use the cards. The low rate of feedback was common across all of the Library products and probably reflects both the difficulty of maintaining engagement across a range of community settings and structural difficulties in the way products were made available (for instance, librarians often had only relatively little contact with participants after a device had been issued). As the project progressed, and librarians became more used to the process so return rates for all products improved.

The Personal Messages card seemed to have a number of advantages over the method of recording and delivering SPT used in other studies that typically involve somewhat cumbersome equipment.
Personal Message cards are simple to play, whilst recording involves an intuitive system with a message that can be easily altered, thereby maintaining the interest of the person with dementia. In attachment terms, the physical nature of the cards may also reinforce their effectiveness as a transitional phenomena, as they can be held, touched and played with. Thus in our initial use of the cards, RC (a Clinical Psychologist in the NHS) provided a card to a female resident of a Nursing Home who was almost continually distressed when her daughter was absent. The card greatly reduced her distress, and she spoke about it at length and held it tightly to her chest before going to sleep. The principle disadvantage of the Personal Message cards is that the battery life of the cards is limited, as is the volume and length of the recording.

The purpose of this exploratory study was to collect information about the way in which Personal Message cards were used and the goals that were set for them. The study did not set out to test the efficacy of the cards as an intervention for separation anxiety or agitation. While there are clear weaknesses to the study (e.g. in the collection of data including outcome measures), it nevertheless met its original goals and provides tentative testimony that under some circumstances Personal Message cards may be a viable method of reducing distress amongst people affected with moderate and severe levels of dementia. However, further trialling using more robust methodology is required before more definitive conclusions can be drawn.

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