

# Personal message cards: An evaluation of an alternative method of delivering simulated presence therapy

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### Abstract

Simulated presence therapy is a technique which utilises a familiar recorded voice to calm and reassure people with dementia who are agitated or anxious. Although simulated presence therapy 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 was 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.

### Keywords

Alzheimer's disease, dementia, anxiety, challenging behaviour, psychosocial interventions, technology, simulated presence therapy

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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% (Seignourel, Kunik, Snow, Wilson, & Stanley, 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, & 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 (Camberg et al., 1999; Woods & Ashley, 1995). 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 transitional phenomena (Browne & Shlosberg, 2005; Miesen, 1999; Osborne, Stokes, & Simpson, 2010). In this way its use has similarities with the use of transitional objects such as dolls (Mackenzie, Wood-Mitchell, & James, 2006; Stephens, Cheston, & Gleeson, 2013).

However, while there is evidence for the impact of SPT on levels of agitation 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.<sup>1</sup> 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 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 & Lund, 1979; Kiresuk & Sherman, 1968), 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, & Stolee, 1997; Rockwood, Stolee & 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%) were completed by the librarians. The level of cognitive impairment was scored for 23 subjects, with six being rated as having a mild impairment, nine moderate and eight 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 10 participants who received a card and provided feedback at four 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 10 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 was not 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 SPT can reduce levels of distress amongst people who are affected by even

**Table 1.** One: use of personal messages cards.

Gender	Age	Living context	Diagnosis	Level of cognitive impairment	Main presenting difficulty (ratings out of 4 of difficulty and importance)	Goal(s)	Degree that goals were met	Comments
F	Not given	Nursing Home	Not known	Mild	Keeping in touch with family (1 difficulty/1 importance)	X will call the person by names (when remembered) and share how they are related	Fully	It was an engagement with the person owning the card to talk to and know him and his life before going into the care home
F	88	Living at home on her own	Alzheimer's disease	Moderate	In between carer visits and during the night, gets very anxious. The card may help with reassurance and reduce phone calls. To stop ringing daughter constantly between 4-6 pm at night time (-/-)	To reassure X between 4.00 to 8.00 pm that carer is coming, thus reducing phone calls and anxiety levels Reassure daughter that Mum is okay and knows what is happening at these periods To encourage X to communicate and encourage memory	Not known	
F	91	Nursing Home	Normal pressure hydrocephalus	Severe	Gets frustrated (3/3)		Not known	
F	Not given	At home with others	Not known	Moderate	Constant demands to contact family (3/3)	Reduce distress at separation	Partially	
M	83	At home with family	Alzheimer's disease	Severe	The family would like to get the grandchildren to make a card and	To let X know his grandchildren are thinking of him To give some joy to X	Not known	

(continued)

Table 1. Continued.

Gender	Age	Living context	Diagnosis	Level of cognitive impairment	Main presenting difficulty (ratings out of 4 of difficulty and importance)	Goal(s)	Degree that goals were met	Comments
F	81	Nursing Home	Not known	Moderate	record a message to send to X (-/4) Disorientation, knowing where she is and that is where she is living now (3/3)	X will be reminded that she is loved, shown by talking to staff about family X says that it was helpful	Fully	
F	83	Nursing home	Alzheimer's disease	Severe	No specific difficulties (4/4)	For X to have happy moments and to have a contented and happy aura around her. Be happy when she has 1-2-1 time To reassure and calm X down and help her to be less anxious To help X to settle after her move into the Dementia Unit	Fully	It had such a positive effect on Mum, she enjoyed it and was happy when she used it
F	89	Nursing Home	Alzheimer's disease	Moderate	Needs reassurance (3/4)	To reassure and calm X down and help her to be less anxious To help X to settle after her move into the Dementia Unit	Partially	Helped the first time, but X has deteriorated since card was first recorded, and updating the message to fit X's questions more often may have helped.
M	87	At home with family	Non-cerebral haemorrhage	Moderate	Calling out at night, becoming anxious in the day (4/4)	To reduce anxiety To reduce distress for carer	Not known	
M	79	Nursing Home	Vascular dementia	Severe		Reduce his anxiety	Not known	

(continued)

Table 1. Continued.

Gender	Age	Living context	Diagnosis	Level of cognitive impairment	Main presenting difficulty (ratings out of 4 of difficulty and importance)	Goal(s)	Degree that goals were met	Comments
					Anxiety caused by disorientation and confusion. Desire to call his wife regularly – he is confused and disorientated (4/4)	Help orientate him as to when he will speak to his wife	Not known	
F		Nursing Home	Dementia	Severe	Poor short term memory due to Dementia (4/4)	To help X to remember her first grandchild, and her eldest daughter	Not known	
						To help X to recall people in her family and act as a stimuli to talk about them	Not known	
F	91	Nursing Home	Dementia	Moderate	Help to calm X down as she becomes agitated (4/4)	To calm X and reduce agitation	Not known	
F	83	Nursing Home	Alzheimer's disease	Severe	Listening and voice recognition. Keeping her brain active. Reassuring X. (3/3)	Keep her memory going Keep her active and improve socialisation	Not known	
M	81	Nursing Home	Alzheimer's disease	Moderate	Memory of loved ones and past events (3/4)	Help X to remember the past Maintain memory of loved ones	Fully Fully	It is very useful. The card has helped [his wife] to be more confident leaving her husband and going home.

(continued)

Table 1. Continued.

Gender	Age	Living context	Diagnosis	Level of cognitive impairment	Main presenting difficulty (ratings out of 4 of difficulty and importance)	Goal(s)	Degree that goals were met	Comments
F	81	Nursing Home	Not known	Mild	Keeping in touch and hearing from loved ones (3/3)	To keep in touch with Mum and remind her she has things to look forward to. Shown when she tells me it has and that she likes it. To give a link between her family and carers	Fully	X likes to listen to the message, and says that she loves to hear her daughter's voice. She is friendlier towards the carers and has something to talk to them about
M	88	At home alone	Not known	Mild	Not given	Reduce telephone calls and anxiety	Not known	
M	84	At home with family	Dementia	Moderate	The main difficulty is retaining information about what we have planned to do on each day of the week (3/3)	To reassure x of his wife's whereabouts in the house, garden or neighbourhood	Not known	
F	93	At home alone	Alzheimer's disease	Mild	To give her daily recognition of new important people in her life (4/4)	Rather than wake X from a nap to tell him where I'm going, I will leave the card without disturbing him. X lives in the moment	Not known	
						huge pleasure if she remembers people. Reduce feeling of loneliness. A card that will be available all the	Not known	

(continued)



Table 1. Continued.

Gender	Age	Living context	Diagnosis	Level of cognitive impairment	Main presenting difficulty (ratings out of 4 of difficulty and importance)	Goal(s)	Degree that goals were met	Comments
F	93	At home alone	Alzheimer's disease	Mild	To make connection with twin sister who also is diagnosed with Dementia (4/4)	time to help her to recognise and give her pleasure Pleasure - a means of connecting as they do not see each other as twin is in residential care	Not known	
						Reminds of times past - card acts as a prompt	Not known	
						Reassure X with a visual cue and voice of his wife and son	Not known	
						To help X know what it planned for the day.	Not known	
M	81	Nursing Home	Vascular dementia	Severe	X does not communicate verbally and is very withdrawn and placid. Difficult to know what his thoughts and feelings are (4/4)	To reassure X that his wife will be in to visit soon When his wife is not with him, he can hear her voice To help X know what is planned for the day.	Partially	I leave it on the table so he can open and hear the messages. To record your own is an asset, especially if someone is away in a Nursing Home. It gives reassurance. The card was not used
F	79	At home with family	Vascular dementia	Mild	Short-term memory loss means X forgets daily events and activities (2/3)	To help X feel more relaxed	Not met	

(continued)

Table 1. Continued.

Gender	Age	Living context	Diagnosis	Level of cognitive impairment	Main presenting difficulty (ratings out of 4 of difficulty and importance)	Goal(s)	Degree that goals were met	Comments
M	86	At home with family	Mixed dementia	Moderate	Recognition to stimulate his memory (2/3)	To help X know what it planned for the day. His wife to feel more comfortable to leave x for short periods Support X to feel less concerned about his wife popping out.	Not known	
M	84	Residential Home	Not known	Severe	He is mixed up and confused and agitated as a result of ongoing disorientation to time and place. Just about remembers close family members and their names (4/4)	To help him to know where he is To reassure him and reduce anxiety	Not known	
F	Not known	At home alone	Not known	Not given	Not given	A daughter used it to keep in touch with her family who are abroad	Fully	Liked that she could record messages from her grandchildren and took to Barbados and gave to the grandmother

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 10 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 suggest 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, 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 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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## Note

1. A guide to recording a personal message card is available from the authors on request.

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