Southern Cross Care (Vic.)

Effectiveness of MP3 Players to Support Carers of People Living with Dementia at Home

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1 Executive Summary

“It’s given me more hope...It’s another string to our bow that helps life to be a lot easier.”

“Now and then I’d hear him singing along, and so I knew he was very happy with it, which made me feel good.”

Background

Caring for someone with dementia can be emotionally and physically tiring. Despite the often strong desire to care for the person living with dementia in the family home, the difficulties of caring often lead to decisions to place the person into residential care. Family caregivers need strategies and support to help them cope with their caregiver role.

While music is often used in formal care settings, and there have been inspirational examples of the impact of music on the listener, no systematic consideration has been given to how music can be used by family carers as a strategy to help them cope with the stress of their caregiver role.

Southern Cross Care (Vic.) (SCC (Vic.)) aims to provide individualised care with an emphasis on healthy, positive living and independence. Founded by the Knights of the Southern Cross in 1969, SCC is renowned for providing quality care and support to older Victorians through its community and residential aged care services and retirement living options.

SCC (Vic.) provides support services to people living with dementia and is always looking for new ways to support carers. SCC began using MP3 technology in community and residential care settings in late 2010. SCC was interested to know whether the benefits they observed would be confirmed through a rigorous academic study of the program.

SCC approached the Australian Centre for Evidence Based Aged Care (ACEBAC), a specialised research centre in the Australian Institute for Primary Care & Ageing (AIPCA) at La Trobe University, to partner with them on a research project looking at the impact of using MP3 players with personalised content on the quality of life and wellbeing of carers of people living with dementia living in the community.

Method

This study involved 50 family caregivers of people living with dementia in the community setting. The SCC (Vic.) Care Manager identified and invited people to participate. Following referral, the SCC (Vic.) Dementia Consultant visited the family, and, after discussion, loaded a small personal MP3 player with music preferred by the person living with dementia—the music selected ranged from classical to André Rieu to Vera Lynn to the Beatles—and showed the carer how to use the equipment.

Carers completed a survey before they started using the MP3 player, and after using the MP3 player for four weeks. The survey included validated measures to assess the level of stress and coping among carers. Carers also kept a diary of the way they used the MP3 player. Half of the carers were interviewed by telephone about their experiences after they had used the MP3 player for four weeks.
Results

Diary data indicated that the MP3 players were used at different times of the day and night (with peaks in the middle of the day and afternoon). They were used most frequently in the home, but some caregivers used the player when waiting for appointments or during other outside activities. The average time spent listening to the MP3 player was approximately one hour, ranging from 10 minutes to several hours a day.

Individualised personal music devices are used by the program because of their hypothesised advantages, including that they are affordable and easy to operate; they are portable, which means they can be used in any setting or circumstance, and the music can be selected to suit each individual and changed by the caregiver in response to the person living with dementia. These benefits were confirmed through the study.

Caregivers described the benefits of using headphones; these included allowing the individual to listen without distractions or background noise and that the caregiver did not need to listen to the same music. In a couple of instances, caregivers said the person living with dementia did not like the headphones, and removed them; in some cases, caregivers reported they continued to use music delivered by other devices as a strategy:

“I used to put on music DVDs and other things but I found with that he’d get very tired, because he’s concentrating so much on actually looking and seeing what’s going on as well as listening, whereas this [MP3] he can just close his eyes and just listen to the music and not have to concentrate on what else is going on.”

“I’ve used the music on the iPad, but again, you’ve got to try and get that into a place where she can see it, so it’s not as convenient as the MP3 player.”

“Maybe she feels it’s more personal. It’s on her head.”

“It means he can play his sort of music and I don’t have to listen to it!”

“It gave me a break from the sound of the TV, because the TV’s been on a lot. It was great because Nick could walk around with it and he’d be more active.”

The portability of the device was confirmed as a positive quality, enabling it to be used anywhere, including around the caregiver when they were doing chores, but also meaning that the person living with dementia was able to benefit from more physical activity:

“The portability of the thing ... Being able to take the correct genre music that she liked and be portable, so you can take it anywhere!”

“I got him to put it on if he went for a walk. It’s nicer if you’re walking to have some music on your head.”

Some participants described minor difficulties using the MP3 player, but these became fewer in the later stage of the project when the instructions had been further clarified and refined. Some caregivers reported being frustrated that the person living with dementia could not operate the device themselves; it is not clear whether this is a problem related to unrealistic expectations of the caregiver, finding the optimal time for using this strategy with someone living with dementia, and/or a lack of training in using some of the functions of the device. While some caregivers were able to draw on the expertise of other family members (children or grandchildren) or friends, a number of participants withdrew from the study, citing these ‘technical’ issues as significant for them. This highlights the importance of selecting MP3 players that are ‘user friendly’ and providing sufficiently detailed instructions and training in the use of the technology for the users.
Results confirmed that the use of an MP3 player provided respite from the high level of vigilance required for caring, and improved the mental health and wellbeing of caregivers.

The quantitative data indicated there were significant improvements in mental health and wellbeing of caregivers. Specifically, the pre- and post-implementation survey data indicated that caregivers experienced a significant decrease in Psychological Distress (a measure of anxiety and depression) and a significant increase in Symptom Management Self-Efficacy (a measure of how confident the caregiver is that they will be able to manage problems that come up, and deal with the frustrations of caring).

The qualitative data collected through diaries and interviews indicated that use of the MP3 was seen by the majority of participants as a useful and positive strategy that provided some respite and relief from the day-to-day stresses associated with the caring role, while also being seen to provide a pleasurable experience for the person living with dementia.

The main themes in descriptions of benefits for carers related to the respite from the caregiving role that the use of the MP3 gave. Caregivers described having “a little bit of free time to do something I wanted to do” and having “a break”. A number of participants noted in particular that the use of the MP3 player reduced some agitated behaviours of the person living with dementia: “it’s nice to know that there’s something I can put on, and he’s quiet. And we eat in peace”. Most caregivers used the time to do household chores or other necessary tasks, rather than leisure activities, but described these tasks as being easier because of the use of the MP3 player: “I can get away and do the washing or whatever without being called up or yelled at.”

Many participants observed that the person living with dementia enjoyed the MP3 player, and this made the caregiver feel good about using it. This is an important aspect of using the MP3 player to manage behavioural and psychological symptoms, as caregivers do not always feel positive about using other interventions, particularly pharmacological ones. With the MP3 player, caregivers could see the person living with dementia enjoying the intervention or being at peace:

“Just the silence in the house, no TV, and knowing that [my husband] is happy listening to the music. Now and then I’d hear him singing along, and so I knew he was very happy with it, which made me feel good.”

“He taps away with his foot and his head wobbles around to the music and I’ve just found it marvellous.”

“It put him in another happy space. You don’t see many happy expressions on his face these days, and my daughter and grandkids came in one day and he had it on and they were all amazed at how bright and happy he looked.”

“She started to sing and/or hum more often. There’s a stimulus there that brought that back to life.”

“You can see the look on her face. She just gets relaxed.”

Conclusion

The use of MP3 players by family caregivers of people living with dementia was confirmed as a positive strategy; not only did it provide some relief from the everyday stress of caring, improving caregivers’ mental health and wellbeing, it was perceived in most cases to be an enjoyable activity for the person living with dementia.
The use of an MP3 player with a person living with dementia is an effective additional strategy that can provide respite for caregivers. The impact can be seen in the significant increase in the measure of self-efficacy to manage symptoms, and in the narratives of caregivers: “It’s just like an added sort of tool that I can use from day to day in certain circumstances.” For some caregivers, the strategy was novel and they described their surprise at its effects on the person living with dementia:

“I must say, by doing this...it’s something that’s been introduced to him that I wouldn’t have thought of. And I’m getting benefits from it now.”

“It’s something new that I wouldn’t have even thought of.”

“I never really twigged towards music—although we had hundreds of CDs and so forth, It just never really twigged—and it was out of this MP3 program that it’s developed into something far deeper now.”

“Once you know what music works, it’s just amazing.”

“It’s given me more hope...It’s another string to our bow that helps life to be a lot easier.”

“I was getting to the stage where the stress levels were becoming somewhat overwhelming...but the music from the MP3 player broke that pattern of being totally followed because she would sit down and listen to it.”

The demonstrated positive impact of the use of MP3 technology on caregivers of people living with dementia supports further research into the use of this and other contemporary technologies. The project was undertaken through a collaboration between Southern Cross Care (Vic.), as a leading provider of services in the community, and researchers from La Trobe University’s Australian Institute for Primary Care & Ageing. It provides a good example of collaboration between industry and academia, recognising practice-based expertise and building rigorous evidence to contribute to the knowledge base to guide best practice in caring for people with dementia in the community. Other research that could be undertaken through future collaborations includes:

- Understanding the impact of the use of MP3 technology on the person living with dementia, with particular attention to the effects at different stages of the progression of the disease.
- Comparing the impact of the use of an MP3 player containing spoken voice (e.g., the voice of family members; family stories); sounds of nature and preferred music content on the person living with dementia / family caregiver.
- Investigating how ‘tablet’ technology is currently being used and could be used to support people living with dementia and their caregivers.
- Investigating the impacts of the use of smart technology in the homes of people living with dementia (e.g. activity and inactivity sensors, wandering detection systems, automatic reminder systems, tele-care and tele-health).
2 Introduction

2.1 Background

2.1.1 The experience of informal care-giving

Informal caregiving is the mainstay of dementia care (Gallagher-Thompson et al., 2012; Knapp et al., 2007). Family members comprise the greater proportion of the ‘workforce’ of informal carers for people living with dementia; as a group they are unique in that, very often, they are older and can be frail themselves (Pickard, 1999). In the United States alone, 14.9 million people currently care for someone who has dementia (Family Caregiver Alliance, 2011), while the number in Australia is likely to be in the region of 200,000 (Australian Institute of Health and Welfare, 2012), with these numbers anticipated to rise as people around the world live longer into old age. This global trend has given rise to policy initiatives that seek to examine and address the needs of these people, living with dementia and cared for in the home (Department of Health, 2009; World Health Organization, 2004), and, moreover, of the support required by their informal carers (Access Economics, 2010).

Caregiving can be rewarding, but it is generally understood that caring for a person living with dementia has significant negative effects on the physical and emotional health of carers (Carr, Kimberley, & Mercieca, 2013). Accidental care-giving is an expression first applied more than ten years ago to capture the unpredictability and ongoing disruption that confronts families caring for a relative with dementia at home (Gwyther, 1998). The term characterises the steep learning curve required of informal caregivers and the ongoing challenges faced over time as the independence of the person living with dementia weakens and their self-care becomes a central feature in the familial (usually spousal) relationship (Gallagher et al., 2011). “Burden of care” is the term used to describe the adverse physical, emotional and financial impact on informal caregivers of providing care (Black & Almeida, 2004); an experience mediated further by the level of resources available to support that care, the vulnerabilities of the caregiver and level of demand (i.e. time and energy) placed upon them (Gallagher et al., 2011; Joling et al., 2010). Carers of people living with dementia experience significant adverse psychological, physical, social, and financial circumstances in maintaining support to their family member in the home (Brodaty, Green, & Koschera, 2003). They experience high levels of stress in undertaking ordinary daily routines of support and care, and the behavioural symptoms of dementia (i.e., physical aggression, physical non-aggression and verbal agitation) are the prime cause of this stress (Carr et al., 2013; Cohen-Mansfield, Marx, & Rosenthal, 1989). Social isolation and caregiver depression are commonly associated with the overwhelming burden of care, as the level of vigilance required in looking after a person living with dementia limits the caregiver’s opportunities to undertake other activities (Croog, Burleson, Sudilovsky, & Baune, 2006; Stirling et al., 2010).

Where the burden of care remains unattended to, care of the person living with dementia in the home is more likely to transition to more costly out-of-home care (Douglas, James, & Ballard, 2004; Schultz & Williamson, 1991; Carr et al., 2013). An assessment of poor quality of life is also an important precedent to transition to formal residential care (Argimon et al., 2004).
2.1.2 Interventions to address the behavioural and psychological symptoms of dementia

Pharmacological and non-pharmacological therapies that target the behavioural symptoms of the person in care are likely to have a positive impact on the caregiving relationship and thereby the quality of life of both the person living with dementia and the carer (Mohamed, Rosenheck, Lyketsos, & Schneider, 2010). Pharmacological therapies that target the agitation of the person living with dementia have been shown to be very effective; however, these have also been recognised to have long-term deleterious side-effects and have been criticised for use as first-line therapies (Lee, Gill, & Rochon, 2006; Rapoport, Mamdani, Shulman, Herrmann, & Rochon, 2005; Schneider, Pollock, & Lyness, 1990; Schneider et al., 2006). Non-pharmacological therapies (NPT), on the other hand, while demonstrating far more limited effectiveness in controlling the agitation of people living with dementia, receive strong support as the first-line therapies (Cohen-Mansfield & Mintzer, 2005). NPTs are generally inexpensive and flexible options that, while less efficacious, can be implemented to alleviate the agitation of people living with dementia in aged care settings, and when implemented in the home, have potential to support informal carers in their daily undertakings with their family member (Brodaty et al., 2003; Douglas, James, & Ballard, 2004; Hermans, Htay, & Cooley, 2009; Robinson et al., 2006).

The impact of music on mental health and wellbeing

Music is central to human experience and remains a central feature of human enjoyment, through interaction and participation, well into the more severe stages of dementia (Biley, 2000; Sixsmith & Gibson, 2007). Music triggers thought and memory in a range of ways. For example, it is widely accepted that music activates motor areas of the brain; memories of actions, tasks and movement (Barreiro, 2010). Music or music therapies have been shown to be a good non-pharmacological option to reduce agitation, aggression, wandering, restlessness, irritability, and social and emotional difficulties in people living with dementia, while also supporting improvement in nutritional intake (Hulme, Wright, Crocker, Oluboyede, & House, 2010). Music therapy can involve a number of different strategies. There is musical activity (i.e. singing or playing an instrument), listening to recorded music (i.e. acousmatic listening⁴), and engagement with live music (Vink, Bruinsma, & Scholten, 2003). As well, opportunities presented by digital technology, particularly for solitary acousmatic listening (i.e. with the use of headphones), has made the focused attention afforded by MP3 technologies widely accessible and increasingly a part of everyday life such that “any music can be taken anywhere and experienced in any context” (Clarke, 2007).

Music therapy is used widely for psychological, psychiatric and physical conditions. Listening to music is widely reported to provide both an alternative and supplementary style of management to pharmacological treatments for a range of physical and psychological needs. Studies examining the therapeutic effect of preferred music have shown that agitated behaviours reduce in people living with dementia who live in residential care homes (Sung, 2006). Emotionally sad music has been associated with improvements in autobiographic memory (García et al., 2012); pointing to close associations between the personal and episodic memory and semantic memory (Kazui, Hashimoto, Hirono, & Mori, 2003). The literature surmises on the whole that music therapies are reliable support strategies in the everyday functioning of people affected by dementia (Vasionytė, 2011), with positive effects.

⁴The term ‘acousmatic’ comes from the Pythagorean practice of public speaking from behind a screen, so that listeners were not distracted by the sight of the speaker and could concentrate entirely on the voice that they heard (Clarke, 2007).
on general functioning increasing when the music selections played were aligned to the preferences of the person living with the dementia (Trappe, 2012; Wall & Duffy, 2010).

2.1.3 Interventions to support caregivers of people living with dementia

Support to carers is crucial for maintaining home care arrangements, and strategies that alleviate the agitation of the person in care are central to the way support needs to be designed. These may include education on practical strategies applied in the care of people living with dementia, practical support solutions, or strategies that can help restore their capacity to do caregiving well (Black & Almeida, 2004). In a systematic review of interventions to support informal carers of people living with dementia, it was found that individually tailored strategies have the greatest effect to reduce caregiver burden (Beinart, Weinman, Wade, & Brady, 2012). The use of effective pharmacological treatment for the improvement and/or stabilisation of symptoms in the person living with dementia can improve caregiver burden, but the most successful strategies showed a combination of emotion-based coping with problem-focused coping (Li, Cooper, Bradley, Shulman, & Livingston, 2012). In other words, carers who believed they had more control over their caring role were less likely to suffer from the burden of their caring role (Cooke, McNally, Mulligan, Harrison, & Newman, 2001; McClendon, Smyth, & Neundorfer, 2004; O’Rourke et al., 2010).

2.1.4 Music as an intervention to support caregivers

No existing literature has been identified that considers the extent to which music could be used as a strategy to support informal and accidental carers of people living with dementia. The Dementia Consultant at SCC (Vic.) developed the hypothesis that individualised musical content delivered through portable music devices (i.e. MP3 players with headphones) may represent a novel strategy to allow carers some respite time, while the person living with dementia enjoyed the experience of listening to their preferred music. Potential advantages of using a portable music device (MP3 player) include:

- They are affordable and easy to use
- Their portability means they can be used in any setting and circumstance, so can provide support in the home or other locations
- The music can be changed easily by the carer, so the carer is able to respond to the reactions of the person living with dementia to find enjoyable music.

2.2 Project aims

The aim of this project was to:

- Determine whether the use of an MP3 player provides respite from the high level of vigilance required for caring, and the feelings of stress that can be experienced by carers.

In addition, the study aimed to:

- Assess the way carers use the MP3 with a person living with dementia
- Assess effects of the MP3 use on caregivers’ self-reported stress levels, quality of life, perceived carer burden, self-care opportunities, and confidence to manage behaviour, psychological and social difficulties.
2.3  Study design and method
A pre/post mixed methods design was used employing:

- Self-report questionnaire for carers at commencement (Time 1) and after four weeks of using the MP3 player (Time 2)
- Use of MP3 player diary
- Short semi-structured phone interview within three weeks of completion.

Participants were informal caregivers of people with old-age-onset dementia.

The SCC (Vic.) Care Managers identified carers/clients who may benefit from the MP3 intervention. The Dementia Consultant introduced the MP3 player containing content tailored to the preferences of the person living with dementia (preferred music; audio books; familiar voice).

2.3.1  Questionnaire items
Surveys included the following measures:

- ENRICHD Social Support Instrument (ESSI) (6 items) [Only asked at Time 1](Vaglio et al., 2004).
- Kessler-10 (K10) measure of Psychological Distress (10 items) (Kessler et al., 2002).  
- Family Caregiver Self-efficacy Scale (4 items) (Fortinsky, Kercher, & Burant, 2002).
- Caregiving and Stress Measure (selected items from 3 subscales)(9 items) (Pearlin et al., 1990).
- General Health Question (1 item) (Goldberg et al., 1997).
- Self-care and healthy behaviour checklist – 8 items used in psychosocial intervention evaluation and monitoring.
- Life satisfaction questions – covering 7 domains (used in several national surveys including Household Income and Labour Dynamics in Australia [HILDA] study).

2.3.2  Daily MP3 Diary
Participants were asked to complete a diary to indicate when, where and for how long they had used the MP3 device each time. These data were then summarised.

2 When determining the level of support required for carers of people living with dementia, it is accepted that constructs like ‘burden’, depression and stress are relevant indicators in the evaluation of an intervention (Schoenmakers, Buntinx, & DeLepeleire, 2010).
2.3.3 Semi-structured Interviews

A random selection of participants (aiming for approximately 50% of participants), were invited to participate in a semi-structured interview by telephone. The core questions asked during the interview were:

- How did you feel in general about using the MP3 player for the past four weeks?
  - Potential Prompts:
    - What was good about using the MP3 player? Why were these things good?
    - Where there any difficulties with using the MP3 Player? If so, what were they?
- Did you end up with a routine for using the MP3 player?
  - How did you figure out the best times and situations to use the MP3 player?
- When did you usually use the MP3 player?
  - Every day?
  - What times of day usually?
  - What kinds of situations?
- Will you continue to use the MP3 player?
  - Why? /Why not?
- Do you believe it has made any difference to [name of the person cared for]?
  - If yes, what kinds of things changed?
  - Follow-up where necessary to cover any of the following that were not mentioned.
    - Did the way you use medication change?
    - Did your sleep change?
    - Did [name of person cared for]’s sleep change?
    - Was there any change in wandering/agitation/restlessness or other behaviour experienced?
- Was [name of person cared for] happier?
  - Has the use of the MP3 player made any difference to you as a carer?
    - If yes, what has changed for you?
    - If yes, what was it about using the MP3 player that made a difference to you?

The content of the interviews was summarised; themes in responses to the different core questions were identified.
3 Results

3.1 Participant summary

Fifty-nine caregivers agreed to participate and provided baseline data commenced using the MP3 player. Of these 59, eight participants stopped using the MP3 player before the four weeks had passed. Reasons for withdrawal included: finding the device difficult to use (one respondent early in the trial) or reluctance of the person living with dementia to wear headphones (two people); a change in health status, including transfer to residential care and increasing care needs of the person living with dementia. One person declined to participate, but decided to try music as a strategy using their own CD player instead of the offered MP3 player. One carer and one person living with dementia passed away during the trial.

Fifty-one participants provided data in response to each of the surveys (at commencement and following the four-week period of usage).

Most respondents were aged over 60 (n=36, 72%) (Table 1).

Table 1: Age range distribution (Time 1)

<table>
<thead>
<tr>
<th>Age range</th>
<th>Number</th>
<th>Per cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>30–39</td>
<td>3</td>
<td>6.0</td>
</tr>
<tr>
<td>50–59</td>
<td>11</td>
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<tr>
<td>60–69</td>
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<tr>
<td>70+</td>
<td>21</td>
<td>42.0</td>
</tr>
<tr>
<td>Total</td>
<td>50*</td>
<td>100.0</td>
</tr>
</tbody>
</table>

* 1 case missing

- Most respondents were female (69%)
- The majority were married (83%); mostly to the person they were caring for (n=36, 86% of married respondents)
- 71% of respondents were caring for their spouse/partner
- 90% of respondents were not working (retired, not in paid employment)
- 94% lived in the same house as the person for whom they were caring (two respondents lived more than 10 minutes away, and one within walking distance)
- Most (94%) said they were a primary caregiver, and only slightly fewer said they were the sole caregiver (85%)
- Three people described themselves as spending less than 20 hours a week in caring activities, and five people said they cared for someone 24 hours a day; all others (84%) said they spent 20–160 hours a week caring
- Twenty-six respondents (51%) had been caring for the person for more than five years, 18 (35%) for 2–5 years, and the remaining seven respondents (14%) for less than two years.

Details of the above demographic information are provided in Appendix A.
3.2 Survey Data Results

3.2.1 Measure of Psychological Distress (Kessler 10 –K10)

Psychological distress (anxiety and depression) was measured with the K10. Each of the ten items is scored from 1 (“none of the time”) to 5 (“all of the time”). A high score indicates a greater level of psychological distress. The sum of the responses to the ten items gives a total score ranges from 10 to 50.

There was a significant decrease in psychological distress over the period ($t=4.7, df=44, p<0.001$). The mean at Time 1 was 21.6 ($SD=6.8$) and at Time 2 was 17.6 ($SD=5.8$) ($n=45$ matched cases; six participants were excluded because of missing data).

The total score on the K10 is often interpreted in relation to categories, where a score of 10–15 indicates low distress, 16–21 indicates moderate distress, 22–29 indicates high distress and 30–50 indicates very high levels of distress. People with scores in the high or very high category are assumed to require support or care for depression and/or anxiety.

| Table 2: Distribution across categories of psychological distress at Time 1 and Time 2 |
|---------------------------------|-----------------|-----------------|-----------------|-----------------|
| Category                        | Time 1          | Time 2          |                 |                 |
|                                 | Number          | Per cent        | Number          | Per cent        |
| Low distress                    | 13              | 25.5            | 19              | 42.2            |
| Moderate distress               | 11              | 21.6            | 16              | 35.6            |
| High distress                   | 20              | 39.2            | 7               | 15.6            |
| Very High distress              | 7               | 13.7            | 3               | 6.7             |
| **Total**                       | **51**          | **100.0**       | **45**          | **100.0**       |

*6 instances missing data, so total not created

For those individuals with data at both time points ($n=45$), there was a significant shift in the level of distress experienced as reflected by these categories (Wilcoxon signed ranks test; $z=-3.4, p<0.001$), with 21 respondents moving to a lower category, 19 remaining the same, and only five moving to a higher category.

Population data comparison

In 2007–08, most Australians aged 18 and over (67%) reported low levels of psychological distress. Around one-fifth (21%) reported moderate levels of distress, 8.5% reported high and 3.5% reported very high levels of psychological distress. At the national population level, women generally report higher levels of psychological distress than men, with 14% of women having high or very high levels of distress and 23% having moderate levels of distress, compared with 9.6% and 19% for men, respectively in the 2007–2008 National Health Survey.

3 A range of possible ways can be used to categorise the total scores of the K10. The ABS provides a summary of them: [http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4817.0.55.001Chapter92007-08](http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4817.0.55.001Chapter92007-08)

The 2010 Victorian Population Health Survey\(^5\) indicated the distribution across the K10 categories for females aged 55–64 was: low = 65.3%; moderate =21.0%, high = 6.2% and very high = 4.0%. For women aged 65+, the estimates were: low = 64.3%, moderate = 21%, high = 5.9% and very high = 1%.

The levels of psychological distress observed in carers taking part in the MP3 study were higher than would be expected based on these population data, reflecting the consequences of taking on a significant caring role for a person living with dementia.

3.2.2 Self-efficacy for managing dementia

Four items assessed the symptom management self-efficacy of carers.\(^6\) Respondents indicated “how certain were you right now that you can…

- Handle any problems like memory loss?
- Deal with the frustrations of caring?
- Handle problems that come up in the future?
- Do something to keep your relative independent?

Responses to the four items (on a scale where 1= “not at all certain” and 10 = “very certain”) were summed to give a total Symptom Management Self-Efficacy score.

Table 3: Self-efficacy for managing dementia at Time 1 and Time 2

<table>
<thead>
<tr>
<th>Q: How certain were you right now that you can…</th>
<th>Mean</th>
<th>SD</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>…handle any problems like memory loss</td>
<td>6.4</td>
<td>2.1</td>
<td>49</td>
<td>6.7</td>
<td>2.4</td>
<td>49</td>
</tr>
<tr>
<td>…deal with the frustrations of caring</td>
<td>5.8</td>
<td>2.0</td>
<td>48</td>
<td>6.7</td>
<td>2.2</td>
<td>48</td>
</tr>
<tr>
<td>…handle problems that come up in the future</td>
<td>5.9</td>
<td>2.0</td>
<td>48</td>
<td>6.6</td>
<td>2.3</td>
<td>48</td>
</tr>
<tr>
<td>…do something to keep your relative independent</td>
<td>5.4</td>
<td>2.4</td>
<td>48</td>
<td>7.0</td>
<td>2.3</td>
<td>48</td>
</tr>
</tbody>
</table>

There was a significant increase in Symptom Management Self-efficacy from Time 1 (prior to use of MP3 player) to Time 2 (after using the MP3 player for 4 weeks). Mean at Time 1 was 23.5 (SD=6.1) and 27.0 at Time 2 (SD=7.5) \(t=-3.1, \text{df}=47, p<0.01\).

Symptom Management Self-Efficacy was significantly negatively correlated with K10 scores \(\text{pearson } r=-.568\*, p<0.001\): the greater the level of self-efficacy for managing dementia, the less the psychological distress.

Self-reported self-efficacy for managing dementia was significantly higher for carers who were the child of the person living with dementia, than for the spouse or partner carers.


3.2.3 Caregiving stress

Nine items measure the construct of the stress associated with being a caregiver to someone with dementia. The items were taken from a longer measure and were intended to represent three different components: overload, role captivity, and loss of self. Response options were “(1) completely, (2) quite a bit, (3) somewhat and (4) not at all”.

*Overload* is measured through responses to four items introduced as follows: “Here were some statements about your energy level and the time it takes to do the things you have to do. How much does each statement describe you?”

- You were exhausted when you got to bed at night
- You have more things to do than you can handle
- You don’t have time just for yourself
- You work hard as a caregiver but never seem to make any progress.

Table 4: *Overload* at Time 1 and Time 2

<table>
<thead>
<tr>
<th>Q: How much does each statement describe you?</th>
<th>Time 1</th>
<th></th>
<th>Time 2</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean SD N</td>
<td>Mean SD N</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You were exhausted when you got to bed at night</td>
<td>2.43 .84 49</td>
<td>2.43 .96 49</td>
<td></td>
<td></td>
</tr>
<tr>
<td>You have more things to do than you can handle</td>
<td>2.56 1.11 48</td>
<td>2.60 .92 48</td>
<td></td>
<td></td>
</tr>
<tr>
<td>You don’t have time just for yourself</td>
<td>2.47 .89 49</td>
<td>2.65 .95 49</td>
<td></td>
<td></td>
</tr>
<tr>
<td>You work hard as a caregiver but never seem to make any progress</td>
<td>2.82 1.05 49</td>
<td>2.90 .96 49</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Role captivity* is measured through responses to three items introduced as follows: “Here were some thoughts and feelings that people sometimes have about themselves as caregivers. How much does each statement describe your thought about your care-giving? How much do you…”

- Wish you were free to lead a life of your own?
- Feel trapped by your relative’s illness?
- Wish you could just run away?

Table 5: *Role Captivity* at Time 1 and Time 2

<table>
<thead>
<tr>
<th>Q: How much do you...</th>
<th>Time 1</th>
<th></th>
<th>Time 2</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean SD N</td>
<td>Mean SD N</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wish you were free to lead a life of your own?</td>
<td>2.92 49 1.00</td>
<td>2.73 49 .93</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feel trapped by your relative’s illness?</td>
<td>2.78 49 .96</td>
<td>2.61 49 1.07</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wish you could just run away?</td>
<td>3.16 49 .99</td>
<td>3.22 49 .90</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

Loss of self is measured through responses to the two items introduced as follows: “Caregivers sometimes feel that they lose important things in life because of their relative’s illness. To what extent do you feel that you personally have lost the following? How much have you lost:”

- A sense of who you were?
- An important part of yourself?

There were no significant changes in the responses to each of these three sets of questions (treated as sub-scales) from Time 1 to Time 2.

**Table 6: Loss of Self at Time 1 and Time 2**

<table>
<thead>
<tr>
<th>Q: How much have you lost…</th>
<th>Time 1</th>
<th></th>
<th>Time 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>N</td>
</tr>
<tr>
<td>A sense of who you were?</td>
<td>3.13</td>
<td>.841</td>
<td>48</td>
</tr>
<tr>
<td>An important part of yourself?</td>
<td>3.15</td>
<td>.825</td>
<td>48</td>
</tr>
</tbody>
</table>

### 3.2.4 General Health

There was no change in self-rated general health observed for those respondents who provided data for both surveys (Time 1 and Time 2).

**Table 7: Self-reported general health at Time 1 and Time 2**

<table>
<thead>
<tr>
<th></th>
<th>Time 1</th>
<th></th>
<th>Time 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>Percent</td>
<td>Frequency</td>
</tr>
<tr>
<td>Excellent</td>
<td>2</td>
<td>3.9</td>
<td>2</td>
</tr>
<tr>
<td>Very good</td>
<td>15</td>
<td>29.4</td>
<td>13</td>
</tr>
<tr>
<td>Good</td>
<td>21</td>
<td>41.2</td>
<td>14</td>
</tr>
<tr>
<td>Fair</td>
<td>10</td>
<td>19.6</td>
<td>10</td>
</tr>
<tr>
<td>Poor</td>
<td>3</td>
<td>5.9</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>51</td>
<td>100.0</td>
<td>41</td>
</tr>
</tbody>
</table>

Treated as a continuous variable (where 1 indicates excellent, 2 very good, 3 good, 4 fair and 5 poor), general health was significantly correlated (p<0.05) with K10 at both Time 1 and Time 2: the poorer the respondent’s self-reported general health was, the higher the level of psychological distress.

Population data comparison

Results of the 2010 Victorian Population Health Survey\(^8\) indicated that 39.3% of people aged 65+ reported their health status to be excellent or very good, 36.9% said their health was good, and 16.7% said their health was fair or poor. Carers who took part in the MP3 study were more likely to indicate their health was fair or poor.

3.2.5  Self-care through health promoting behaviour

Respondents were asked about some key behaviours that promote health and wellbeing (described as “the things you might do to take care of yourself”). Simple “yes” or “no” responses were requested.

Table 8: Self-care through health promoting behaviour at Time 1 and Time 2

<table>
<thead>
<tr>
<th></th>
<th>Time 1</th>
<th>Time 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>Number responding</td>
</tr>
<tr>
<td>Eat a well-balanced diet</td>
<td>45</td>
<td>51</td>
</tr>
<tr>
<td>Exercise at least twice a week</td>
<td>22</td>
<td>51</td>
</tr>
<tr>
<td>Get enough relaxation, rest and sleep</td>
<td>23</td>
<td>51</td>
</tr>
<tr>
<td>Spend enjoyable time with friends and family</td>
<td>34</td>
<td>51</td>
</tr>
<tr>
<td>Have interests and hobbies</td>
<td>33</td>
<td>51</td>
</tr>
<tr>
<td>Talk to family or friends about how you feel</td>
<td>33</td>
<td>51</td>
</tr>
<tr>
<td>Use support services</td>
<td>50</td>
<td>51</td>
</tr>
<tr>
<td>Use medication to help you relax or sleep</td>
<td>9</td>
<td>51</td>
</tr>
</tbody>
</table>

When comparing responses for individuals who answered at both Time 1 and Time 2, there was a significant increase in the use of support services (significant increase in the number of people who use support services: p<0.05), but no other areas of activity.

3.2.6  Satisfaction with aspects of life

Respondents were asked to indicate on a scale of 1–11 (where 1= very dissatisfied and 11 = very satisfied) the level of their satisfaction with different aspects of life, and life in general.

Across the eleven specific domains of life, there were two in which the mean satisfaction score changed significantly, decreasing from Time 1 to Time 2: “how safe you feel” and “your relationship with your spouse or partner”. There was no change to overall life satisfaction.

The domains of life and the mean scores are described in Table 9.

Table 9: Satisfaction with domains of life at Time 1 and Time 2

<table>
<thead>
<tr>
<th>Domain</th>
<th>Time 1</th>
<th>Time 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>How safe you feel</td>
<td>8.50</td>
<td>1.81</td>
</tr>
<tr>
<td>Your current sleep pattern</td>
<td>6.02</td>
<td>2.31</td>
</tr>
<tr>
<td>The amount of free time you have</td>
<td>5.06</td>
<td>2.48</td>
</tr>
<tr>
<td>Your relationship with your spouse or partner (if applicable)</td>
<td>7.68</td>
<td>2.08</td>
</tr>
<tr>
<td>Your relationship with your children (if applicable)</td>
<td>8.14</td>
<td>1.89</td>
</tr>
</tbody>
</table>
applicable)

<table>
<thead>
<tr>
<th>Your relationship with the person for whom you care</th>
<th>7.67</th>
<th>1.30</th>
<th>12</th>
<th>7.75</th>
<th>12</th>
<th>1.82</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>6.64</td>
<td>1.81</td>
<td>47</td>
<td>6.83</td>
<td>47</td>
<td>2.33</td>
</tr>
</tbody>
</table>

For those individuals with data at both time points, the change in the mean satisfaction rating from Time 1 to Time 2 was significant for “how safe you feel” (Time 1 mean=8.5 (SD=1.8); Time 2 mean=8.1 (SD=2.0); p<0.05) and for “your relationship with your spouse or partner (Time 1 mean=7.7 (SD=2.1); Time 2 mean=6.9 (SD=2.9); p<0.04).

There was no difference between overall level of satisfaction from Time 1 to Time 2.

Population data comparison

Results of the most recent wave of data from the Household Income and Labour Dynamics in Australia (HILDA) study indicate that factors like wealth, age, health, family dynamics and employment can influence happiness. At the population level, men and women are reported to share the same satisfaction levels with their life overall, “but women are more likely to report lower levels of satisfaction than men in all relationship measures except for their relationship with their own children”. The relationship of age with life satisfaction is described as a distinct U-shape pattern, with Australians in their middle age being least satisfied, although the mean is generally around 8 (+/- 0.4).

The mean satisfaction overall and in different domains for the carers participating in this study was lower than those generally observed in the population samples used in the HILDA study. This is consistent with research which suggests that caring for sick or frail parents or partners may be detrimental to post-retirement plans and life satisfaction (e.g., Szinovacz & Davey, 2004; Vinck & Ekerdt, 1991).

3.2.7 Social Support

Six questions explore the extent of social support that respondents believe they have (perceived social support).

Responses were on a five-point scale where 1 = “none of the time” and 5 = “all of the time”. Table 10: provides a mean score for each item. A mean of 3 indicates the average response was “some of the time”, while a mean of 2 indicates the average response was “a little of the time”.

It was assumed that social support would not be affected by the use of the MP3 player, but that the extent of social support someone had may affect the impact of the use of the MP3 player on the carer.

---


Table 10: Social Support at Time 1 (n=50 responses)

<table>
<thead>
<tr>
<th></th>
<th>None of the time</th>
<th>A little</th>
<th>Some</th>
<th>Most</th>
<th>All of the time</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is there someone available to whom you can count on to listen to you when you need to talk?</td>
<td>4 (8%)</td>
<td>8 (16%)</td>
<td>14 (28%)</td>
<td>14 (28%)</td>
<td>10 (20%)</td>
<td>3.4</td>
<td>1.2</td>
</tr>
<tr>
<td>Is there someone available to you to give you good advice about a problem?</td>
<td>6 (12%)</td>
<td>7 (14%)</td>
<td>13 (26%)</td>
<td>8 (16%)</td>
<td>6 (12%)</td>
<td>3.2</td>
<td>1.2</td>
</tr>
<tr>
<td>Is there someone available to you who shows you love and affection?</td>
<td>3 (6%)</td>
<td>15 (30%)</td>
<td>12 (24%)</td>
<td>8 (16%)</td>
<td>12 (24%)</td>
<td>3.2</td>
<td>1.3</td>
</tr>
<tr>
<td>Is there someone available to help with daily chores?</td>
<td>17 (34%)</td>
<td>16 (32%)</td>
<td>6 (12%)</td>
<td>9 (18%)</td>
<td>2 (4%)</td>
<td>2.3</td>
<td>1.2</td>
</tr>
<tr>
<td>Can you count on anyone to provide you with emotional support (talking over problems or helping you make a difficult decision)?</td>
<td>5 (10%)</td>
<td>11 (22%)</td>
<td>15 (30%)</td>
<td>12 (24%)</td>
<td>7 (14%)</td>
<td>3.1</td>
<td>1.2</td>
</tr>
<tr>
<td>Do you have as much contact as you would like with someone you feel close to, someone in whom you can trust and confide in?</td>
<td>9 (18%)</td>
<td>13 (26%)</td>
<td>12 (24%)</td>
<td>12 (24%)</td>
<td>4 (8%)</td>
<td>2.8</td>
<td>1.2</td>
</tr>
</tbody>
</table>

Social support was significantly (negatively) correlated with the K10 at Time 1: the more social support reported, the lower the psychological distress.

Social support was also significantly negatively correlated with general health: the more social supported reported, the better the level of general health.

It was hypothesised that the benefits of the MP3 player may be greater for people who have access to social support; however, data from the current sample do not support this hypothesis. The relationship will be explored further in future.

### 3.3 Diaries

The 51 carers who participated in the study were asked to keep a diary around their use of the MP3 player.

#### 3.3.1 Frequency and duration of use

The total number of entries in the diary was 549. The distribution of the frequency of entries is summarised in Table 11.
Table 11: Distribution of number of diary entries

<table>
<thead>
<tr>
<th>Number of respondents</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1–9</td>
<td>20</td>
</tr>
<tr>
<td>10–19</td>
<td>13</td>
</tr>
<tr>
<td>28–29</td>
<td>10</td>
</tr>
<tr>
<td>30–39</td>
<td></td>
</tr>
<tr>
<td>40–49</td>
<td>1</td>
</tr>
</tbody>
</table>

The MP3 players were used across the day and night, with peaks in the middle of the day and afternoon (Table 12).

Table 12: Time of day MP3 player used

<table>
<thead>
<tr>
<th>Time of day</th>
<th>No. of entries</th>
<th>Proportion of all entries</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 – 8:59 am</td>
<td>18</td>
<td>3%</td>
</tr>
<tr>
<td>9 – 10:59 am</td>
<td>97</td>
<td>18%</td>
</tr>
<tr>
<td>11 am – 12:59 pm</td>
<td>93</td>
<td>17%</td>
</tr>
<tr>
<td>1 pm – 2:59 pm</td>
<td>109</td>
<td>20%</td>
</tr>
<tr>
<td>3 – 5:59 pm</td>
<td>137</td>
<td>25%</td>
</tr>
<tr>
<td>6 – 12 pm</td>
<td>40</td>
<td>7%</td>
</tr>
<tr>
<td>No time provided</td>
<td>55</td>
<td>10%</td>
</tr>
<tr>
<td>Total</td>
<td>549</td>
<td>100%</td>
</tr>
</tbody>
</table>

Most respondents provided information about the length of time of use of the MP3 for most entries.

Table 13: Average minutes MP3 player used (excluding <10 mins and >4.5 hours)

<table>
<thead>
<tr>
<th>Average time of use</th>
<th>54 minutes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Range for average</td>
<td>10 minutes to 4.5 hours</td>
</tr>
<tr>
<td>True range</td>
<td>2 minutes to 8 hours</td>
</tr>
</tbody>
</table>

3.3.2 Location of use

The MP3 player was used in the home in most cases (91%, including the garden), with only 6% of instances where it was used elsewhere. Other entries recorded they did not use the MP3 player, although they may have intended to.
Table 14: Location when using MP3 player

<table>
<thead>
<tr>
<th>No. of entries</th>
<th>Proportion of all entries</th>
</tr>
</thead>
<tbody>
<tr>
<td>In home</td>
<td>475</td>
</tr>
<tr>
<td>In garden</td>
<td>21</td>
</tr>
<tr>
<td>In the car</td>
<td>18</td>
</tr>
<tr>
<td>Doctor’s waiting room</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
<td>10</td>
</tr>
<tr>
<td>Did not use – moved to respite care or other reason</td>
<td>22</td>
</tr>
<tr>
<td>Total</td>
<td>549</td>
</tr>
</tbody>
</table>

3.3.3 How carers spent the time during MP3 use

Carers were asked “what were you able to achieve” in the time during which the person living with dementia was listening to the MP3 player. The comments related predominantly to chores, cooking, shopping, and outdoor activities (46%); relaxation, socialising and personal time accounted for approximately 29% of entries; studying or computer work accounted for 6% of entries; and 3% of entries were about eating and sleeping.

Table 15: How carers spent their time during MP3 use

<table>
<thead>
<tr>
<th>No. of entries</th>
<th>Proportion of all entries</th>
<th>No. of individuals - multiple responses possible</th>
<th>Proportion of total N=51</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chores</td>
<td>114</td>
<td>21%</td>
<td>36</td>
</tr>
<tr>
<td>Prepared meals / cooking</td>
<td>80</td>
<td>15%</td>
<td>25</td>
</tr>
<tr>
<td>Gardening / outdoor activities / shopping</td>
<td>54</td>
<td>10%</td>
<td>20</td>
</tr>
<tr>
<td>Computer work / study / research</td>
<td>31</td>
<td>6%</td>
<td>17</td>
</tr>
<tr>
<td>Relaxed / reading / TV</td>
<td>93</td>
<td>17%</td>
<td>31</td>
</tr>
<tr>
<td>Socialising</td>
<td>41</td>
<td>7%</td>
<td>18</td>
</tr>
<tr>
<td>Exercise / personal time</td>
<td>29</td>
<td>5%</td>
<td>15</td>
</tr>
<tr>
<td>Ate a meal</td>
<td>12</td>
<td>2%</td>
<td>3</td>
</tr>
<tr>
<td>Slept</td>
<td>7</td>
<td>1%</td>
<td>2</td>
</tr>
<tr>
<td>Familiarisation with MP3 player</td>
<td>5</td>
<td>1%</td>
<td>5</td>
</tr>
<tr>
<td>Other</td>
<td>9</td>
<td>2%</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>549</td>
<td>100%</td>
<td></td>
</tr>
</tbody>
</table>

3.3.4 Comments

The Diary also had a column for any other comments about each session and this was often used. All comments were classified at the broadest level as being positive or negative in nature, or neither (Table 17, over page). Using this broad classification, 65% of all comments
were classified as positive in nature; often being comments about the effects of listening to the MP3 player on the person living with dementia (see Table 16 below). Nearly all of the 51 respondents overall (84%) made at least one positive comment. Approximately 12% of all comments were negative in nature, and 51% of all respondents made at least one negative comment after a session using the MP3 player. Data in Table 16 suggest that these were most likely about minor technical issues.

Table 16: Comments about each MP3 session

<table>
<thead>
<tr>
<th>Comments</th>
<th>No. of entries</th>
<th>Proportion of all entries</th>
<th>No. of individuals - multiple responses possible</th>
<th>Proportion of total N=51</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beneficial / liked using / enjoyment</td>
<td>130</td>
<td>24%</td>
<td>32</td>
<td>63%</td>
</tr>
<tr>
<td>Relaxed / fell asleep</td>
<td>108</td>
<td>20%</td>
<td>26</td>
<td>51%</td>
</tr>
<tr>
<td>Calmed the person living with dementia</td>
<td>97</td>
<td>18%</td>
<td>26</td>
<td>51%</td>
</tr>
<tr>
<td>Less carer interruptions</td>
<td>9</td>
<td>2%</td>
<td>7</td>
<td>14%</td>
</tr>
<tr>
<td>Spare time for carer</td>
<td>5</td>
<td>1%</td>
<td>3</td>
<td>6%</td>
</tr>
<tr>
<td><strong>Total positive</strong></td>
<td><strong>349</strong></td>
<td><strong>64%</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Technical issues -- trouble operating</td>
<td>20</td>
<td>4%</td>
<td>9</td>
<td>18%</td>
</tr>
<tr>
<td>Technical issues -- headphones removed</td>
<td>17</td>
<td>3%</td>
<td>7</td>
<td>14%</td>
</tr>
<tr>
<td>Technical issues -- stopped playing</td>
<td>11</td>
<td>2%</td>
<td>7</td>
<td>14%</td>
</tr>
<tr>
<td>Technical issues -- flat battery</td>
<td>8</td>
<td>1%</td>
<td>5</td>
<td>10%</td>
</tr>
<tr>
<td><strong>Total Technical</strong></td>
<td><strong>56</strong></td>
<td><strong>10%</strong></td>
<td><strong>26</strong></td>
<td><strong>51%</strong></td>
</tr>
<tr>
<td>Not interested</td>
<td>32</td>
<td>6%</td>
<td>15</td>
<td>29%</td>
</tr>
<tr>
<td>Did not use</td>
<td>11</td>
<td>2%</td>
<td>4</td>
<td>8%</td>
</tr>
<tr>
<td>Would not settle</td>
<td>19</td>
<td>3%</td>
<td>13</td>
<td>25%</td>
</tr>
<tr>
<td>Other</td>
<td>33</td>
<td>6%</td>
<td>17</td>
<td>33%</td>
</tr>
<tr>
<td>No comments</td>
<td>49</td>
<td>9%</td>
<td>11</td>
<td>22%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>549</strong></td>
<td><strong>100%</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 17: Overall nature of comments following each session

<table>
<thead>
<tr>
<th>Comments categorised broadly into positive or negative</th>
<th>No. of entries</th>
<th>Per cent of all entries</th>
<th>No. of individuals -- multiple response</th>
<th>Per cent of all respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>General positive</td>
<td>357</td>
<td>65.0</td>
<td>43</td>
<td>84</td>
</tr>
<tr>
<td>General negative</td>
<td>68</td>
<td>12.4</td>
<td>26</td>
<td>51</td>
</tr>
<tr>
<td>Neither</td>
<td>57</td>
<td>10.4</td>
<td>23</td>
<td>45</td>
</tr>
<tr>
<td>Not used</td>
<td>17</td>
<td>3.1</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td>No comments</td>
<td>50</td>
<td>9.1</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>549</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
3.4 Participant Interviews

3.4.1 Participants’ views on the impact of the MP3 player

Twenty-five carers (half of all participants) were randomly selected following completion of the four-week period using the MP3 player and contacted by telephone to ask about their experiences.

Carers were generally very positive about the effects of the MP3 player for themselves and the person living with dementia. Most described it as a useful additional strategy to occupy or distract the person living with dementia.

Carers described themselves as feeling less worried about the person for whom they were caring, and this was related particularly to them having confidence that the person living with dementia was happily occupied and that the MP3 player was not just a distraction, but an enjoyable activity. Carers described the effects of listening to the MP3 player for the person living with dementia as relaxing and calming, or as making the person happy—observing them tapping their feet or singing along.

The MP3 was seen as a particularly valuable strategy when the person living with dementia was disruptive or restless and/or when the carer needed to get something done (e.g., do housework, make a phone call, prepare a meal).

Three major themes emerged from the interview data:

- Benefits of time and reduced stress for the carer: “It basically gives you a good break”
- Perceived benefits for the person living with dementia: “It put him in another happy space”
- Benefits, sometimes unexpected, of music as a strategy for coping with the caring role: “It’s just like an added sort of tool that I can use”.

Benefits for carers

This theme relates to carers’ perceptions of how using the MP3 player provided a sense of respite from the caring role. Carers spoke of being able to get things done without having to worry about the person living with dementia, giving them a feeling of having some free time and relief from the caring role:

“It was more short periods where it just freed me up a bit...There was only one day where there was a longer term...a couple of hours something like that. It diverted her, gave me a little bit of free time to do something I wanted to do.” (Participant 2)

“It helped calm things down and settle things down and allowed me to do other things.” (Participant 6)

“I know where she is. She’ll sit quieter. Instead of going wandering around she’ll sit there and listen to it. So I can get on with doing other things.” (Participant 36)

“I was having physio on my neck at the time and it worked out really well that the time he was waiting for me to have treatment...I found that it was really good for him to...because he doesn’t read really so to have music like that was good. It kept him occupied.” (Participant 26)

“He goes off with the music. He’s totally occupied and doesn’t need me at all. It basically gives you a good break.” (Participant 39)
This sense of respite extended to when the person living with dementia was agitated or restless:

“When you get a time of unrest or pacing around or things like that that are starting to drive you crazy, I’d just suggest ‘What about sitting down and having a listen to this?’ And it takes that attention away to something else.” (Participant 7)

“At nights he becomes very, very agitated. Eating is a big deal and things like that. Having the music quietens him down and makes it more pleasant for us.” (Participant 18)

“To have a hard day at work and then come home and have Dad going on and on and being upset and doing this, it’s nice to know that there’s something I can put on, and he’s quiet. And we eat in peace!” (Participant 18)

Carers also described themselves as feeling less stressed, because they were not being followed, questioned repeatedly, or “continually hassled”:

“It gave her something to do during that period of time rather than just following me around or asking me questions and my attention being diverted from what I was trying to do.” (Participant 2)

“I’m vacuuming at the moment and it’s keeping his mind off...because he’s full-on and he’d be sort of saying ‘When’s lunch?’, ‘When are we going here?’, ‘When are we doing this?’ Everything has to be in a routine. So it’s helping him relax to not worry about all those other things.” (Participant 3)

“He’s got frontal lobe so he has behaviour issues. It relaxes him so much that he doesn’t get up to any....nonsense.” (Participant 3)

“If I need a bit of ‘my space’ when he’s getting up my nose, I can still have him in the same room but he’s quite happy to sit in one spot.” (Participant 7)

“When she’s out in the sun here and she’s only about two metres from my location in the radio shack...she’s always buzzing, she wants a drink, turn her over, put some more suntan cream on her...constantly every ten minutes. It [the MP3] gave me a break!” (Participant 28)

“I can get away and do the washing or whatever without being called up or yelled at.” (Participant 34)

“If I’m trying to get a meal ready or that sort of thing, she stands in the doorway and sort of distracts. It was a chance to avoid that...I found relief!” (Participant 44)

Benefits for the person living with dementia
Carers were of the view that the use of the MP3 player was of benefit not only to themselves, but also to the person living with dementia. Carers indicated that listening to the MP3 player was an enjoyable activity for the person living with dementia that promoted happiness:

“He taps away with his foot and his head wobbles around to the music and I’ve just found it marvellous.” (Participant 7)

“It put him in another happy space. You don’t see many happy expressions on his face these days, and my daughter and grandkids came in one day and he had it on and they were all amazed at how bright and happy he looked.” (Participant 7)
“He seemed happy with the music. I could see him sometimes sort of nodding his head a little bit to the tempo.” (Participant 10)

“He sings when he’s got it on. He’ll sit there and he’s going ‘nanana’. You can’t hear the music of course and it sounds funny. But he’s right into it when he’s got it on.” (Participant 29)

“She’ll walk around with it on and she sings along with it.” (Participant 36)

“When he listens to music he taps his feet or hand on the chair and it nearly drives me crazy but he really loves it.” (Participant 39)

“She would certainly be singing along to it in her style.” (Participant 40)

“We put the music on and it brightened her up again.” (Participant 40)

“She started to sing and/or hum more often. There’s a stimulus there that brought that back to life.” (Participant 44)

“She taps her little feet away and tries to sing sometimes.” (Participant 53)

Carers also indicated that using the MP3 promoted relaxation in the person living with dementia:

“It was a peaceful time.” (Participant 2)

“He’s found something that he really enjoys and that’s relaxing him.” (Participant 3)

“It was the calming effect of it.” (Participant 6)

“I was amazed how much it calmed him down.” (Participant 18)

“It was relaxing for him and for us.” (Participant 18)

“A lot of the time she fell asleep with it plugged in...it was quite soothing for her.” (Participant 24)

“The music relaxes him, you know.” (Participant 26)

“Even when we go out in the car, she sits there with her eyes shut as if she’s asleep, but she’ll be listening to the music and listening to the car as well. She’s aware. She’s not really asleep. She shuts her eyes and just relaxes, pretends to be asleep.” (Participant 36)

“You can see the look on her face. She just gets relaxed.” (Participant 53)

For most participants, there were no strict routines or patterns in their use of the MP3 player; however, the choice of music was seen as important to achieving a positive effect. It appeared that the MP3 player was particularly effective for people who had a history of enjoying music:

“Patricia is a classical music fan and she was quite happy with what was on the MP3 player....” (Participant 6)

“She particularly enjoyed the piano music because her dad was a pianist and she associated that with him.” (Participant 6)

“He liked music and we generally had music.” (Participant 10)

“I’d say [music] has always been a part of our lives.” (Participant 26)
“We used to go to Bali...our routine was read a book in the morning, round lunchtime a bit of music, have some lunch, back to listen to more music, read the book again...We had a routine setup but always music involved.” (Participant 28)

“She was a state ward and they gave her a radio and she loved her little radio...She’d get up in the morning and turn the radio on. It had to be going in the background. She’s always wanted some sort of music in the background.” (Participant 36)

“She actually loved classical music and certain operas. Both of us have loved that all our married life.” (Participant 40)

“She was into music, yes. She took lessons in singing and had a wide repertoire of records she used to play.” (Participant 44)

Value of music as a strategy in caring for people living with dementia

This theme relates to how carers incorporated the use of the MP3 player into their usual activities, and the perceived value of music as a strategy in caring for a person living with dementia.

Carers indicated that the use of the MP3 player was now a valuable addition to their repertoire of interventions and complemented other activities they might utilise:

“It’s just like an added sort of tool that I can use from day to day in certain circumstances.” (Participant 5)

“She’ll read a magazine or a bit of the paper while she was listening” (Participant 5)

“We usually have the television on or a DVD when we’re home. It was mainly if we were out anywhere that I found [the MP3] more useful” (Participant 26)

“If he didn’t have the music on he would look at the telly anyway, so I’d probably be able to get things done if he was watching the telly or the music.” (Participant 29)

“Some days she prefers to...we were using the same music but we were putting it on the speaker system from the computer. I’ve got stuff loaded up on the computer and I’ve also downloaded it onto the MP3 player.” (Participant 36)

“It’s just another activity to give him. Something different. I also get the talking books from the library.” (Participant 39)

“We have either an MP3 player, with the headphones, or a television and DVD player which we setup and play many music type DVDs.” (Participant 40)

“So we keep playing Vera Lynn [on the MP3] when I want to go out somewhere. But when I’m home I play the DVDs” (Participant 53)

“It’s just another string to our bow that helps life to be a lot easier.” (Participant 59)

For some carers, using music with the person living with dementia was a novel strategy and the project introduced them to the concept of music as a therapeutic strategy. A number of carers indicated that an MP3 player was something they would never have thought of using. Several carers said they were inspired to incorporate other forms of music (CDs, music DVDs, radio) into their daily lives. This also allowed a sharing of the musical experience between the carer and the person living with dementia:

“I must say, by doing this...it’s something that’s been introduced to him that I wouldn’t have thought of. And I’m getting benefits from it now.” (Participant 3)
“It’s something new that I wouldn’t have even thought of.” (Participant 3)

“I just didn’t think of putting music on as a therapy, as something he should have.” (Participant 10)

“I didn’t think that he’d like it but he seemed to take to it quite well.” (Participant 26)

“It’s a new thing for me altogether. I know my grandchildren have had them but I haven’t taken much notice of MP3s before they told me about them. So that was a thing I hadn’t even thought about.” (Participant 26)

“I haven’t thought about using it out of the house, but that’s probably a time that it could come into its own.” (Participant 39)

“I never really twigged towards music, although we had hundreds of CDs and so forth. It just never really twigged and it was out of this MP3 program that it’s developed into something far deeper now.” (Participant 40)

“Once you know what music works, it’s just amazing.” (Participant 40)

“It opened up my eyes to what I hadn’t been taking seriously [music] but I do now.” (Participant 44)

### 3.4.2 Specific benefits and limitations of the mobile technology

Carers noted the unique benefits of using an MP3 player over other forms of musical engagement. The use of the MP3 player to deliver the music was seen by carers as being a particularly innovative, personalised and positive initiative.

Key points included:

- The headphones allow the individual to listen without distractions/background noise. The MP3 device doesn’t require the same level of concentration as watching TV/DVDs as there are no visual stimuli involved:

  “I used to put on music DVDs and other things but I found with that he’d get very tired, because he’s concentrating so much on actually looking and seeing what’s going on as well as listening, whereas this [MP3] he can just close his eyes and just listen to the music and not have to concentrate on what else is going on.” (Participant 3)

  “We have the television on, and it’s on continuously, but he doesn’t watch it and he doesn’t...I don’t even think he hears it. It’s just noise in the background. But having the music in his ear, it’s there, it’s right with him, and he hears it.” (Participant 18)

  “With the radio playing it has a similar effect but she can probably...there’s more opportunity for her to talk with the music on when it’s the radio, rather than with the MP3 player.” (Participant 22)

  “I think the fact that it’s not a huge big device. It just rested comfortably on her ears while she was lying down.” (Participant 24)

  “He’s sort of completely into the music rather than the telly. The telly you can be side-tracked with that.” (Participant 29)

  “I’ve used the music on the iPad, but again, you’ve got to try and get that into a place where she can see it, so it’s not as convenient as the MP3 player.” (Participant 40)
“It’s presented differently than watching it on telly or the radio isn’t it. You’re sitting down in a chair with an earphone in. It’s a different presentation.” (Participant 44)

“She can’t use the talking books because she falls asleep and loses her place and it’s almost impossible to find the place where she was...And she’s legally blind so the telly, although she has it on, she can’t see it. So the music was really good.” (Participant 58)

“Maybe she feels it’s more personal. It’s on her head.” (Participant 58)

“I think it’s good that she can use it with her hearing aid.” (Participant 58)

• The carer does not have to hear the music:

“It means he can play his sort of music and I don’t have to listen to it!” (Participant 39)

“It gave me a break from the sound of the TV, because the TV’s been on a lot. It was great because Nick could walk around with it and he’d be more active.” (Participant 59)

 “[The headphones were good because] I couldn’t listen to Vera Lynn all the time!” (Participant 53)

“When she’s got the earphones on, she’s the only one who can hear it, but I’m busy doing something anyway.” (Participant 53)

• Portability – the MP3 could be used in doctor’s waiting room or in the car, or while doing other jobs around the home such as watering the garden. The person living with dementia could be close to the carer without requiring constant interaction:

“I found she probably still felt a bit isolated being out of...away from me if you like. I thought we’ll try having her within eye distance it’s just that she settles at the meal table and listens [to the MP3] while I’m preparing.” (Participant 5)

“You can slip the little MP3 into the pocket of her jacket and put the earbuds in and away it went” (Participant 6)

Several respondents noted that the portability of the device also meant the person living with dementia was able to move about more and there were benefits to this physical activity:

“I got him to put it on if he went for a walk. It’s nicer if you’re walking to have some music on your head.” (Participant 29)

• The choice of music is individualised, so more likely to appeal to the listener.

“The good part about it is you get to choose what music you have on it.” (Participant 7)

“It was something special for him.” (Participant 39)
• The listener can control when the music starts and stops:

“I used to try music myself for him, but of course if it annoyed me I would go and turn it off myself but with the MP3 player he could manage with his thumbs to turn it off himself when he’d had enough....” (Participant 10)

“It was something for him to do on his own, that he could do without having to wait for me or rely on me to put another CD on.” (Participant 10)

Some of the limitations of MP3 players that were described included:

• Technical difficulties – many older carers did not know how to upload more music or troubleshoot and needed to wait for help from others. Several spoke about the assistance they obtained from younger family members, indicating the potential for inter-generational exchange around technology, which could be an additional benefit of the program:

“I thought, oh I’ll poke it in the wrong hole on the computer and blow everything up. So I left it to my two kids to [put more music on].” (Participant 7)

“I’ve got a couple of the grandchildren here. They’ll do it [put more music on] in no time!” (Participant 44)
4 Discussion

More than 200,000 people in Australia are caring for someone, usually a family member, who has dementia. While caregiving can be rewarding, there is clear evidence that caring for a person living with dementia can have negative effects on the physical and emotional health of carers. Carers of people living with dementia can experience significant adverse psychological, physical, social, and financial circumstances in maintaining support to their family member in the home. While most people express a preference for living in their own homes for as long as possible, transition to more costly out-of-home care is more likely when the burden of care remains unattended to, particularly when the behavioural and psychological symptoms of dementia become more significant.

Southern Cross Care (Vic.) (SCC (Vic.)) aims to provide individualised care with an emphasis on healthy, positive living and independence. Founded by the Knights of the Southern Cross in 1969, SCC (Vic.) is renowned for providing quality care and support to older Victorians through its community and residential aged care services and retirement living options.

Southern Cross Care (Vic.) provides support services to people living with dementia in their homes and is always looking for new ways to support carers. SCC (Vic.) began using MP3 technology in community and residential care settings in late 2010. Theoretically, music or music therapies have been shown to have a positive impact on a range of the behavioural and psychological symptoms of people living with dementia. Rather than limiting the use of music therapies to formal care settings, SCC (Vic.) hypothesised that introducing personalised content delivered via a portable digital music device (MP3 player) into the informal home care setting would have a positive impact on the quality of life and wellbeing of the carers of people living with dementia living in the community.

The current study aimed to determine whether the use of an MP3 player provides respite from the high level of vigilance required for caring, and the feelings of stress that can be experienced by carers. In addition, the study aimed to assess the way carers use the MP3 with a person living with dementia, and explore the effects of the MP3 use on caregivers’ self-reported psychological distress, quality of life, perceived carer burden, self-care opportunities and confidence to manage behaviour, psychological and social difficulties.

Method

The study used a pre–post methodology collecting quantitative and qualitative data to explore the effects of use of the MP3 player on carers. The SCC Care Managers identified and invited people to participate. Of 59 people who started using the MP3, 51 family caregivers completed the four-week study period and provided survey data.

Following referral and consent, the Dementia Consultant visited the family, and, after discussion, loaded a small personal MP3 player with music preferred by the person living with dementia—the music selected ranged from classical to André Rieu to Vera Lynn to the Beatles—and showed the caregiver how to use the equipment.

The Dementia Consultant observed that, over time, the clients being referred were more appropriate for participation in the program, with care managers recognising that it was not necessary for carers or the person living with dementia to have a prior interest in music. The health of caregivers and the stage of progression of dementia appeared to affect whether the MP3 player would be accepted and introduced successfully.

Caregivers completed a survey before they started using the MP3 player, and after using the MP3 player for four weeks. The survey included validated measures to assess the level of
stress and coping among caregivers. Caregivers also kept a diary of the way they used the MP3 player. Half of the caregivers were interviewed by telephone about their experiences after they had used the MP3 player for four weeks.

Results

Diary data indicated that the MP3 players were used at different times of the day and night (with peaks in the middle of the day and afternoon). They were used most frequently in the home, but some caregivers used the player when waiting for appointments or during other outside activities. The average time spent listening to the MP3 player was approximately one hour, ranging from 10 minutes to several hours a day.

Individualised personal music devices are used by the program because of their hypothesised advantages, including that they are affordable and easy to operate; they are portable, which means they can be used in any setting or circumstance, and the music can be selected to suit each individual and changed by the caregiver in response to the person living with dementia. These benefits were confirmed through the study.

Caregivers described the benefits of using headphones; these included allowing the individual to listen without distractions or background noise and that the caregiver did not need to listen to the same music. In a couple of instances, caregivers said that the person living with dementia did not like the headphones, and removed them; in some cases, caregivers reported they continued to use music delivered by other devices as a strategy:

“I used to put on music DVDs and other things but I found with that he’d get very tired, because he’s concentrating so much on actually looking and seeing what’s going on as well as listening, whereas this [MP3] he can just close his eyes and just listen to the music and not have to concentrate on what else is going on.”

“I’ve used the music on the iPad, but again, you’ve got to try and get that into a place where she can see it, so it’s not as convenient as the MP3 player.”

“Maybe she feels it’s more personal. It’s on her head.”

“It means he can play his sort of music and I don’t have to listen to it!”

“It gave me a break from the sound of the TV, because the TV’s been on a lot. It was great because Nick could walk around with it and he’d be more active.”

The portability of the device was confirmed as a positive quality, enabling the device to be used anywhere, including around the caregiver when they were doing chores, but also meaning that the person living with dementia was able to benefit from more physical activity.

“The portability of the thing … Being able to take the correct genre music that she liked and be portable, so you can take it anywhere!”

Some participants described minor difficulties using the MP3 player, but these were fewer in the later stage of the project when the instructions had been further clarified and refined. Some caregivers reported being frustrated that the person living with dementia could not operate the device themselves; it is not clear whether this is a problem related to unrealistic expectations of the caregiver, finding the optimal time for using for using this strategy with someone living with dementia, and/or a lack of training in using some of the functions of the device. While some caregivers were able to draw on the expertise of other family members (children or grandchildren) or friends, a number of participants withdrew from the study, citing these ‘technical’ issues as being significant for them. This highlights the importance of
selecting MP3 players which are ‘user friendly’ and providing sufficiently detailed instructions and training in the use of the technology for the users.

Results confirmed that the use of an MP3 player provided respite from the high level of vigilance required for caring, and improved the mental health and wellbeing of caregivers.

The quantitative data indicated significant improvements in mental health and wellbeing of caregivers. Specifically, the pre- and post-implementation survey data indicated that caregivers experienced a significant decrease in Psychological Distress (a measure of anxiety and depression) and a significant increase in Symptom Management Self-Efficacy (a measure of how confident the caregiver is that they will be able to manage problems that come up and deal with the frustrations of caring).

The qualitative data collected through the diaries and interviews indicated that the MP3 was seen by the majority of participants as a useful and positive strategy that provided some respite and relief from the day-to-day stresses associated with the caring role, while also being seen to provide a pleasurable experience for the person living with dementia.

The main themes in the descriptions of the benefits for carers related to the respite from the caregiving role that the use of the MP3 gave. Caregivers described having “a little bit of free time to do something I wanted to do” and having “a break”. A number of participants noted in particular that the use of the MP3 player reduced some agitated behaviours of the person living with dementia: “it’s nice to know that there’s something I can put on, and he’s quiet. And we eat in peace”. Most caregivers used the time to do household chores or other necessary tasks, rather than leisure activities, but described these tasks as being easier because of the use of the MP3 player: “I can get away and do the washing or whatever without being called up or yelled at.”

Many participants observed that the person living with dementia enjoyed the MP3 player, and this made the caregiver feel good about using it. This is an important aspect of using the MP3 player to manage behavioural and psychological symptoms, as caregivers do not always feel positive about using other interventions, particularly pharmacological ones. With the MP3 player, caregivers could see the person living with dementia enjoying the intervention or being at peace:

“Just the silence in the house, no TV, and knowing that [my husband] is happy listening to the music. Now and then I’d hear him singing along, and so I knew he was very happy with it, which made me feel good.”

“He taps away with his foot and his head wobbles around to the music and I’ve just found it marvellous.”

“It put him in another happy space. You don’t see many happy expressions on his face these days, and my daughter and grandkids came in one day and he had it on and they were all amazed at how bright and happy he looked.”

“She started to sing and/or hum more often. There’s a stimulus there that brought that back to life.”

“You can see the look on her face. She just gets relaxed.”

Conclusion

The use of MP3 players by family caregivers of people living with dementia was confirmed as a positive strategy; not only did it provide some relief from the everyday stress of caring,
improving caregivers’ mental health and wellbeing, it was perceived in most cases to be an enjoyable activity for the person living with dementia.

The use of an MP3 player with a person living with dementia is an effective additional strategy that can provide respite for caregivers. The impact can be seen in the significant increase in the measure of self-efficacy to manage symptoms, and in the narratives of caregivers: “It’s just like an added sort of tool that I can use from day to day in certain circumstances.” “It’s just another string to our bow that helps life to be a lot easier.” For some caregivers, the strategy was novel and they described their surprise at its effects on the person living with dementia:

“I must say, by doing this...it’s something that’s been introduced to him that I wouldn’t have thought of. And I’m getting benefits from it now.”

“It’s something new that I wouldn’t have even thought of.”

“I never really twigged towards music—although we had hundreds of CDs and so forth, It just never really twigged—and it was out of this MP3 program that it’s developed into something far deeper now.”

“Once you know what music works, it’s just amazing.”

“It’s given me more hope...It’s another string to our bow that helps life to be a lot easier.”

“I was getting to the stage where the stress levels were becoming somewhat overwhelming...but the music from the MP3 player broke that pattern of being totally followed because she would sit down and listen to.”

The demonstrated positive impact of the use of MP3 technology on caregivers of people living with dementia supports further research into the use of this and other contemporary technologies. The project was undertaken through a collaboration between SCC (Vic.) as a leading provider of services in the community and researchers from La Trobe University’s Australian Institute for Primary Care & Ageing. It provides a good example of collaboration between industry and academia, recognising practice-based expertise and building rigorous evidence to contribute to the knowledge base to guide best-practice in caring for people with dementia in the community. Other research that could be undertaken through future collaborations include:

- Understanding the impact of the use of MP3 technology on the person living with dementia, with particular attention to the effects at different stages of the progression of the disease.
- Comparing the impact of the use of an MP3 player containing spoken voice (e.g., the voice of family members; family stories); sounds of nature and preferred music content on the person living with dementia / family caregiver.
- Investigating how ‘tablet’ technology is currently being used and could be used to support people living with dementia and their caregivers.
- Investigating the impacts of the use of smart technology in the homes of people living with dementia (e.g., activity and inactivity sensors, wandering detection systems, automatic reminder systems, tele-care and tele-health).
5 References


6 Appendix A: Demographic information about respondents

Table 18: Marital status

<table>
<thead>
<tr>
<th>Q: Are you married?</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>9</td>
<td>17.6</td>
</tr>
<tr>
<td>Yes, to person in my care</td>
<td>36</td>
<td>70.6</td>
</tr>
<tr>
<td>Yes, to person not in my care</td>
<td>6</td>
<td>11.8</td>
</tr>
<tr>
<td>Total</td>
<td>51</td>
<td>100.0</td>
</tr>
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</table>

Table 19: Primary occupation status

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retired/ not in paid employment</td>
<td>46</td>
<td>90.2</td>
</tr>
<tr>
<td>Employed full-time in paid work</td>
<td>4</td>
<td>7.8</td>
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<tr>
<td>Employed part-time in paid work</td>
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<td>2.0</td>
</tr>
<tr>
<td>Total</td>
<td>51</td>
<td>100.0</td>
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</tbody>
</table>

Table 20: Relationship to the person in care

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse/ partner</td>
<td>36</td>
<td>70.6</td>
</tr>
<tr>
<td>Child</td>
<td>13</td>
<td>25.5</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>3.9</td>
</tr>
<tr>
<td>Total</td>
<td>51</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 21: Other relationship to the person in care

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daughter-in-law</td>
<td>1</td>
<td>50.0</td>
</tr>
<tr>
<td>Son-in-law</td>
<td>1</td>
<td>50.0</td>
</tr>
<tr>
<td>Total</td>
<td>2</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 22: Primary caregiver

<table>
<thead>
<tr>
<th>Q: Are you the primary caregiver?</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>3</td>
<td>5.9</td>
</tr>
<tr>
<td>Yes</td>
<td>48</td>
<td>94.1</td>
</tr>
<tr>
<td>Total</td>
<td>51</td>
<td>100.0</td>
</tr>
</tbody>
</table>
### Table 23: Sole caregiver

<table>
<thead>
<tr>
<th>Q: Are you the sole caregiver?</th>
<th>Frequency</th>
<th>Percent</th>
<th>Percent of those who answered</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>6</td>
<td>11.8</td>
<td>15.4</td>
</tr>
<tr>
<td>Yes</td>
<td>33</td>
<td>64.7</td>
<td>84.6</td>
</tr>
<tr>
<td>Total</td>
<td>39</td>
<td>76.5</td>
<td>100.0</td>
</tr>
<tr>
<td>No response</td>
<td>12</td>
<td>23.5</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>51</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

### Table 24: Living distance from the person in care

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live in the same dwelling</td>
<td>48</td>
<td>94.1</td>
</tr>
<tr>
<td>Walking distance/ 10min travel</td>
<td>1</td>
<td>2.0</td>
</tr>
<tr>
<td>&gt;10min travel</td>
<td>2</td>
<td>3.9</td>
</tr>
<tr>
<td>Total</td>
<td>51</td>
<td>100.0</td>
</tr>
</tbody>
</table>

### Table 25: Hours of caregiving per week

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 20 hrs</td>
<td>3</td>
<td>5.9</td>
</tr>
<tr>
<td>20–160 hrs</td>
<td>43</td>
<td>84.3</td>
</tr>
<tr>
<td>24 hrs/ day</td>
<td>5</td>
<td>9.8</td>
</tr>
<tr>
<td>Total</td>
<td>51</td>
<td>100.0</td>
</tr>
</tbody>
</table>

### Table 26: Duration of time caring for the person

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 2 yrs</td>
<td>7</td>
<td>13.7</td>
</tr>
<tr>
<td>2–5 yrs</td>
<td>18</td>
<td>35.3</td>
</tr>
<tr>
<td>&gt; 5 yrs</td>
<td>26</td>
<td>51.0</td>
</tr>
<tr>
<td>Total</td>
<td>51</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Appendix B: De-identified summaries of interviews with participants

Participant 2 Interview Summary
- Possibly saw some benefit, but not sure, not enough time to really be certain.
- Used for short periods to free carer up a bit, a temporary diversion for person living with dementia.
- No specific routine, used as appropriate (i.e., when it was a nice day or when carer needed to do something).
- Kept MP3 but has not used it since trial finished as has been busy.
- Had a bit of trouble using the MP3 player.
- Not enough variety of music on the MP3, didn’t know how to add more.

Participant 3 Interview Summary
- Had problems using the MP3 player; kept turning off.
- Not enough variety of music on the MP3, didn’t know how to add more. Daughter has since given another MP3 with 700 songs on it, and has had good benefits from it.
- Really good, enjoyable for person living with dementia, relaxing.
- Benefits to carer, she can get on with tasks without interruptions and constant questions.
- Helps with frontal lobe dementia-related behavioural issues.
- No specific routine. Some days, person living with dementia didn’t want to use. Dependant on how person living with dementia was feeling.
- Will keep using MP3, definitely.
- PWD can sit and close eyes and listen to music, no need to concentrate like with TV or DVD.

Participant 5 Interview Summary
- Additional assistance, a distraction to keep person living with dementia occupied, particularly when carer couldn’t be with her. More versatile than TV or DVD.
- Allowed carer to get on with meal preparation, tasks around the home.
- Usage times determined by carer’s needs (i.e. when he needed to do something)
- An added tool to use. Not every day or every situation.
- Sometimes person living with dementia would read magazine or newspaper while listening.
- Person living with dementia likes music, so worked well. Relaxed her.
- Continuing to use MP3, will probably add more music in future.
- Headphones were a little uncomfortable after extended periods of time (earbuds fell out of ears).
- Reduced carer stress, took some pressure off.

Participant 6 Interview Summary
• Very good, helped calm and settle the person living with dementia.
• Allowed carer to do other things.
• Used it for most of the day except for mealtimes. Person living with dementia loved the classical music and was happy to sit and listen.
• Will keep using, and add more music in future. Will also use small radio tuned to ABC classic FM.
• Kept the day a little bit less confusing and stressful. Gave carer more relaxation during the day and more time.

Participant 7 Interview Summary
• Very useful, person living with dementia is happy to sit and listen until music runs out.
• Even packed MP3 to go to respite care.
• Right choice of music very important.
• When person living with dementia driving carer crazy, pacing, asking questions etc., put on MP3 and person living with dementia settled.
• Used on a needs basis rather than strict routine. Either when person living with dementia is unsettled or when carer needed to do a specific task.
• Put person living with dementia in a ‘happy space’.
• Continuing to use MP3, children helped add another few albums on (same type of music) for more variety.

Participant 10 Interview Summary
• Very happy with MP3, as allowed person living with dementia to listen to music without annoying carer.
• PWD was able to switch off MP3 himself when he was sick of listening.
• Didn’t help with sleeping (person living with dementia), but person living with dementia seemed happy when listening.
• No routine, would use whenever person living with dementia was looking bored or restless, definitely every couple of days.
• Carer felt comfortable leaving person living with dementia alone (in a room) while listening to music so she could go to another room and do something (housework etc.).
• Reduced carer worry about whether person living with dementia is OK.
• Will continue to use MP3/music in general.
• Gave another option for therapy, had always liked music but never thought of it before.

Participant 18 Interview Summary
• Amazed how much it calmed person living with dementia down.
• Person living with dementia would often become agitated and confused in the evenings, but by putting on the music he quietened down and was much more relaxed. Made things much more pleasant for carers.
• Person living with dementia did not have a previous history of listening to music. Music wasn’t part of the person living with dementia’s life.
• Reduced carer stress, felt like there was something they could do to calm the person living with dementia down.
• TV is always on, but person living with dementia doesn’t pay attention to it or doesn’t really hear it. Whereas the MP3 is right in his ears, and other sounds were blocked out. It’s directed to him.
• Will continue to use the MP3, would like to upload more music.

Participant 22 Interview Summary
• Used the MP3 at times which fitted into person living with dementia’s timetable rather than when carer felt need for “relief” so carer was unsure of benefits to him. Didn’t really get into a routine.
• Person living with dementia mostly seemed to enjoy listening to the music.
• MP3 was used as an adjunct to other things like radio. It was helpful to have the MP3 available, although carer felt there was more “mucking about” compared to radio.
• Person living with dementia less likely to “chatter on” if listening to MP3 through the headphones compared to the radio.
• Have not used MP3 since finishing trial, although will use if needed.

Participant 24 Interview Summary
• Used MP3 on an “as needed” basis when person living with dementia was agitated, in combination with medication. Generally used in the afternoon/evenings after person living with dementia came home from activities.
• Thought MP3 was comfortable and convenient, but didn’t notice any huge benefits to person living with dementia or to self.
• Has kept MP3 and will load different music onto it.
• Person living with dementia would often fall asleep listening to MP3 as the music was soothing.
• MP3 used as an “add on” to existing methods.
• Person living with dementia wasn’t really interested in music beforehand. Carer thought it would work better for those who loved music.

Participant 26 Interview Summary
• Husband quite liked it, was happy.
• Was particularly good because could play country & western music, which husband liked but she didn’t.
• Carer was having physio and used MP3 with husband while he was waiting. Was very good, kept him occupied. Also when visiting friend in hospital. Husband waited in car or waiting room listening to MP3.
• Didn’t use it at home much because TV or DVDs were on. MP3 used mainly when they were out.
• Had a bit of trouble charging as didn’t have a computer! Bought a charger. Also didn’t know how to put more music on. Has other people to help.
• Music was always part of their lives.
• Will definitely keep using MP3.
Participant 28 Interview Summary

- When person living with dementia was in the mood to put on earphones (2–3 times/week), was good.
- Didn’t like some of the songs so carer changed them.
- Person living with dementia would doze off when listening.
- Would sit out in the sun on a warm day, just listening.
- Without MP3 person living with dementia is always buzzing (UHF radio) when out in the sun, she wants a drink, turn her over, more suntan cream, do everything...every ten minutes. The MP3 gave carer a break.
- MP3 provided a break, because person living with dementia would not go into respite; however, carer was still stressed because needed to check person living with dementia regularly to ensure she hadn’t fallen over.
- Used MP3 when person living with dementia wanted it (rather than when carer needed a break). But routine for using MP3 was same as when they used to go on yearly holidays to Bali (same time of day as they would’ve been sunbathing and reading, listening to music).

Participant 29 Interview Summary

- Person living with dementia wouldn’t think to put it on; carer had to suggest particularly when person living with dementia going for a walk.
- Person living with dementia didn’t use a lot, because carer had to suggest.
- Person living with dementia couldn’t operate himself, carer had to do it for him.
- But when person living with dementia did use it, he enjoyed the music, was “right into it”.
- If person living with dementia didn’t have MP3, would watch TV anyway, so carer could still have gotten things done.
- Just another option of something for person living with dementia to do.
- Kept MP3 and will try to use more, but at this stage hasn’t made much difference to carer.
- Person living with dementia had always loved music, but with onset of dementia has lost interest. Lacks motivation.

Participant 34 Interview Summary

- Carer thought it was quite a good idea. It worked “a couple of times”. Carer was able to go and do washing without being called up or yelled at.
- Person living with dementia got sick of it after initial benefits. Carer unsure why.
- Person living with dementia used to like listening to music, but would rather be out talking to people.
- Used mostly when person living with dementia asked to listen.

Participant 36 Interview Summary
- Person living with dementia uses it every 2–3 days.
- When person living with dementia does use it, uses it until it runs flat and really enjoys it.
- Person living with dementia occasionally lost the MP3 or the headphones, but no other disadvantages other than perhaps being a bit anti-social.
- Carer locks it so person living with dementia can’t tamper.
- Person living with dementia walks around with it, sings along, or just sits listening.
- Seems to have kept person living with dementia awake a bit more – she was sleeping a lot previously, maybe from boredom.
- Helps carer because he knows where person living with dementia is and that she’s occupied.
- MP3 shuts out everything, as opposed to music on the computer streaming through the house. Which is good when carer is busy but not ideal if wanting to engage with person living with dementia.
- Used MP3 ad hoc, as needed.
- Person living with dementia always liked music, always had it in the background.

**Participant 37 Interview Summary**

- Carer found it hard explaining over and over how to use it.
- A couple of times it was good, but person living with dementia kept forgetting and carer became frustrated.
- Person living with dementia would fiddle with MP3, even when locked.

**Participant 38 Interview Summary**

- Person living with dementia would not ask for MP3; carer would give it to him. If asked, person living with dementia would say yes.
- Person living with dementia really enjoyed music, tapped feet and hands on chair.
- It’s there and carer tries to do it every couple of days.
- Carer can go off and do something because person living with dementia is totally occupied. It gives a good break.
- For him, because he likes music, music would be a calming thing for him.
- Person living with dementia behaviour has not been particularly stressful for the carer, so no huge benefits yet, but definitely potential.
- Needs a bit of help uploading new music.
- Keen to try using MP3 in car (hadn’t thought of it!), because carer has different taste in music. Also doctor appointments (great idea!).
- Another good tool to use.

**Participant 40 Interview Summary**

- MP3 was very successful. Person living with dementia loved the music, would sing along.
- The portability was a plus, being able to take the correct genre music that person living with dementia likes. Could take it anywhere.
- Different types of music had dramatic effect on person living with dementia moods – the Beatles were upsetting to the person living with dementia, whereas Bee Gees
great. Christian music, classical and operas worked very well as was soft and calming/soothing.

- Gave person living with dementia the MP3 whenever carer needed to get things done. To occupy and relax person living with dementia.
- Used successfully at doctor’s; person living with dementia would sit there listening.
- MP3 (along with other devices) helped person living with dementia cope with carer leaving the house (when SCC (Vic) staff there). Also helped stop person living with dementia shadowing carer.
- MP3 has introduced the concept of music to carer – now using music throughout the house as therapeutic device in other forms (iPad, music DVDs, CDs) and also incorporating visuals. It’s like a pacifier for person living with dementia; takes focus off compulsive behaviours and feeling of losing dignity and intrusion.

Participant 44 Interview Summary

- It distracted person living with dementia from other things she would’ve been interfering with.
- Benefit was quite noticeable.
- Person living with dementia has started singing/humming songs that have come up on the MP3 (even when not actually listening). Family have been impressed by how PWD can recognise tunes.
- MP3 presents music differently to TV or radio, sitting down, with earphones. Format works well, fewer distractions.
- I found relief!
- Person living with dementia has always liked music, had been taught singing, played records.
- Person living with dementia had care during the day (10–3) so MP3 mostly used in afternoon/evening.
- The MP3 has instigated more music generally in the house, CDs etc.
- Will need help from grandkids to upload music – doesn’t know much about gadgets! Had a bit of trouble fast-forwarding initially.

Participant 47 Interview Summary

- Person living with dementia fell asleep listening.
- Enjoyed it some days, others not.
- Person living with dementia not very communicative, so difficult to ascertain benefits.
- Also person living with dementia behaviour wasn’t troublesome beforehand, so no huge carer benefits. Still would’ve been able to do things without MP3.
- Brought back memories of past time in the navy.
- Person living with dementia is a pipe smoker, and MP3 interfered with that a bit. Music would be better coming from an iPod dock/CD, as having the headphones wasn’t ideal.
- Person living with dementia wasn’t really into music.
Participant 49 Interview Summary

- Person living with dementia liked the music, enjoyed listening, but not for very long.
- Kept taking off headphones, probably uncomfortable and irritating to person living with dementia. Also trouble concentrating.
- Earbuds may have worked better; will try.
- Carer and person living with dementia live in small apartment, so carer is always close at hand. Doesn’t tend to worry about where person living with dementia is or what he’s doing. Therefore need for MP3 is reduced.

Participant 50 Interview Summary

- Person living with dementia has very severe dementia, would pull headphones off a lot (over head).
- Few technical issues at start, same song would play over and over.
- Person living with dementia has lost interest in music generally, not just MP3.
- Person living with dementia would fall asleep listening, which did give carer some chance to do things, but carer still needed to repeatedly check on person living with dementia.

Participant 51 Interview Summary

- Didn’t work because carer felt person living with dementia does not like being told what to do. Would say ‘no’ every time MP3 suggested. Nothing particularly bad about MP3, just unable to convince person living with dementia to sit and listen to it.
- When person living with dementia did have MP3, he quite enjoyed it.

Participant 53 Interview Summary

- [Person living with dementia] Says she really enjoyed MP3. Had a good time with it! Didn’t even leave the room. Thoroughly enjoyed it!
- Person living with dementia loved the music (Vera Lynn) and happy to listen to it over and over again. Would have driven carer mad (so headphones good) but person living with dementia loved it. Tapped feet, sang along.
- Few technical issues at start (played same song repetitively), but solved this. Has a friend across the road to help with uploading more music etc.
- MP3 gave carer time to go and do things.
- Really helped with sundowners. MP3 would help cheer the person living with dementia up. Used MP3 anytime PWD looking unhappy.
- Introduced other forms of music into the house, cassette tapes, music DVDs, radio to calm person living with dementia in the shower (MP3 can’t be used).
- Carer can go away for about an hour to do something. Person living with dementia quite happy to sit at home with door locked, listening to music, and won’t wander off. If didn’t have MP3, would have to have someone else at home.
- Person living with dementia didn’t particularly like music before but loves it now. Brought back memories of past.
- [Carer] It takes the worry away from me... It gives me time to do things which I need to do. Even the gardening...[or to] nick up to the shop and places like that.

**Participant 58 Interview Summary**

- MP3 was very good.
- Small technical issue at the start (with volume); Ben helped to fix over the phone.
- Person living with dementia can’t use talking books because falls asleep and loses place, and also legally blind so TV is pointless, so MP3 was a really good strategy.
- Person living with dementia always loved music.
- Carer knew person living with dementia was occupied in quality time (not just sitting). Alleviated need for someone to read to person living with dementia.
- Keeps person living with dementia in one place, listening and tapping her foot.
- Used it when carer needed to do something and didn’t want person living with dementia ringing her bell.
- MP3 perhaps more personal because it’s on the person living with dementia’s head (as opposed to external music).

**Participant 59 Interview Summary**

- It freed carer’s time up, reduced stress levels, slept better.
- Carer very pleased that person living with dementia learnt to operate the MP3 alone.
- Gave carer a break from the sound of the TV – the silence was wonderful.
- Person living with dementia would walk around with MP3 on, being active, watering the garden etc.
- Helped person living with dementia bond with the past.
- Used both when carer needed to do a task, and when person living with dementia wanted to use it.
- Was fantastic over Christmas period when carer was trying to prepare meals, gifts etc. but with MP3 the person living with dementia was far less demanding of attention.
- A relief to know person living with dementia was happily occupied.
- Would suggest MP3 when person living with dementia looked restless.
- Carer now feels she will have time to paint and engage in creative time for self. MP3 will facilitate this. Person living with dementia can pop into the room, carer can recognise/acknowledge, but doesn’t need to engage with person living with dementia or have a conversation.
- Like in-home respite!