

Evaluation of the Alzheimer Society of Toronto iPod Project

Final Report

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Executive Summary

1.0 Introduction

The *Alzheimer Society of Toronto (AST)* initiated its *Music and Memory: iPod Project* in early 2013. The *Project* provides iPod Shuffles, free of charge, as well as access to music of choice, to persons with Alzheimer’s disease and other dementias (ADOD) and their caregivers. The *Project* aims to engage a total of 10,000 participants as a way of improving communication, cognition and quality of life.

In May 2013, *AST* commissioned the *Balance of Care (BoC) Research and Evaluation Group*, based at the University of Toronto, to assess the *iPod Project’s* implementation and performance in its first year. The *iPod Project* evaluation had two key objectives:

- First, to document the implementation of the *Project* and facilitate continuous learning and improvement as it rolled out in its first year;
- Second, to demonstrate the impact of the *Project* on persons with ADOD, caregivers and other stakeholders both as a means of improving *Project* performance and as a vehicle for communicating the *Project’s* value to planners, policy-makers, funders, and potential participants.

2.0 Evaluation

To capture the dynamic nature and scope of the *Project*, we designed a multi-stage, multi-methods evaluation to make the best use of available qualitative and quantitative data, and to highlight the first-hand experiences of *Project*.

2.1 Rapid Review and Synthesis

We conducted a “rapid review” and synthesis of literature and evidence building on a preliminary review conducted by *AST* staff. We synthesized the results into a succinct 3 page “backgrounder” entitled the *Science behind the Alzheimer Society of Toronto iPod Project* which can be accessed on the website of the *Canadian Research Network for Care in the Community (CRNCC)* at <http://www.crncc.ca/knowledge/factsheets/pdf/InFocus-ScienceBehindtheASTiPodProject.pdf>.

2.2 Key Informant Perspectives

We conducted semi-structured, in-depth, qualitative interviews with “key informants” including *AST’s* senior management team, Social Workers, and *iPod Project* staff; as well as representatives of *iPod Project* partner. Key informants were asked about current practices and possible improvements in recruitment, assessment, implementation and follow-up, as well as outcomes and project performance.

2.3 Caregivers Perspectives

We conducted focus groups with participating caregivers. We asked straightforward questions:

- How do you and the person you care for use the iPod (e.g., how often, what music)?

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- How does the *iPod Project* impact on you and the person you care for (e.g., person is calmer/more engaged; caregiver is less stressed)?
- What works best? What could be improved?

2.4 Analysis of iPod Project Data

With assistance from *iPod Project* staff, we accessed and analyzed data on participants and outcomes; these data derived primarily from assessments conducted by staff at intake (Time 1) and at 3 month follow-up (Time 2).

Data measured key characteristics of persons with ADOD and caregivers (e.g., gender, ethnicity, language); as well as responses to the Caregiving Distress Scale (CDS), the Cornell Scale for Depression in Dementia (CSDD), and a single item asking caregiver confidence.

In addition to analyzing these data at the two different points in time, we looked for differences across time which might be attributed to the *iPod Project*.

3.0 Findings

3.1 Rapid Review and Synthesis

Music and music therapy appear to offer considerable potential to improve the lives of persons with ADOD and their caregivers at low cost and with little risk. Reported benefits include improved cognition, communication, and quality of life for older persons with ADOD; reduced caregiver burden and stress; an improved ability to manage behavioural and psychological symptoms of dementia (BPSD) such as depression, anxiety, agitation and aggression.

The potential appears greatest in residential LTC. While about a third of persons with ADOD in community settings exhibit levels of BPSD in the clinically significant range about 80% of those living in residential care settings are thought to do so.

Personalized music works best. Not surprisingly, music that is familiar to and resonates with the older person seems to produce the most favorable outcomes.

Music therapy has also shown positive outcomes. Music therapy “is the skillful use of music and musical elements by an accredited music therapist to promote, maintain, and restore mental, physical, emotional, and spiritual health.” Studies have found that music therapy can: reduce anxiety and depression; reduce depressive symptoms and improve cognitive function; reduce activity disturbances, aggressiveness and anxiety; Impact positively on BPSD such as delusions, agitation, anxiety, apathy, irritability, aberrant motor activity, and night-time disturbances; reduce the severity and distress of patients and caregivers; reduce frequency of agitated behaviours.

Bottom line. While music and music therapy may not work all of the for all persons with ADOD and their caregivers, there is a plausible and growing body of evidence that this low cost intervention offers a range of potential benefits with little risk of harm. This clearly distinguishes music from more costly interventions such as drug therapies and physical restraints which are widely used to manage individuals with responsive behaviours.

3.2 Key Informant Perspectives

3.2.1 AST Staff

AST key informants were strongly supportive of the *iPod Project*. They reported that:

- **The *iPod Project* benefits persons with ADOD and their caregivers.** Personalized music helps to calm persons with ADOD. Moreover, the music provides informal caregivers with opportunities to disconnect for a moment and focus on other everyday tasks such as housekeeping or meal preparation in peace and alone. The effects seem to persist: follow-up sessions with caregivers suggested that persons with ADOD continued to exhibit positive outcomes, such as reduced agitation, anxiety and fear, when listening to music.
- **The *iPod Project* benefits AST and other stakeholders.** Because it is team-based and engages partner organizations, the *Project* strengthens working relationships within AST and beyond. AST benefits by attracting new clients and raising awareness among the public and community organizations. Community organizations benefit by incorporating a low-cost, but promising tool into their toolkit. The healthcare system benefits from stronger inter-organizational partnerships, improved care coordination, and increased capacity to delay or avoid institutionalization.
- **Implementation has been relatively smooth, largely due to careful preparation and willingness to make mid-stream adjustments.** Participants were provided with initial and ongoing instruction and technical assistance by AST staff and volunteers, including help with set-up, downloading music and managing play lists.
- **There are challenges to sustaining partner engagement.** Some LTC homes reported inconsistent use of iPods because they were not always able to spare staff to help persons use their iPods. Some community agencies expressed concerns about rising workloads if the volume of participants continued to increase.
- **There are strong opportunities for scaling-up and spreading the *Project*.** Key informants asserted that the *iPod Project* can and should be scaled-up and spread by engaging new partners including adult day programs where participants are continuously monitored; memory clinics serving persons with early stage dementia; and family doctors.

3.2.2 Partner Organizations

Partner organizations observed that:

- **The *Project* is relatively easy to implement and administer.** This reflects the *Project's* simplicity and the extensive assistance and support offered by *AST*.
- **The *iPod Project* benefits persons with ADOD and their caregivers.** Partner organizations observed benefits including: increased engagement with others and an overall calming effect; more enjoyable visits because of the opportunity to share and discuss the music; easier outings (such as doctor appointments) because of the calming effect of the music; opportunities to accomplish other tasks while the person is engaged in listening to music.
- **There are some workload concerns.** Assessments took considerable time which meant that they were not always completed by staff, and sometimes handed off to caregivers who did not always complete them on their own. Assessment packages in languages other than English could promote completions.
- **Staff need to be actively involved and engaged.** There were discussions about how to incorporate the use of the iPods into programming, rather than having them as an add-on. One community organization asked staff to integrate iPods into the client's daily routine.
- **Planning has to be done to ensure safe use and storage of the iPods.** One community partner suggested labelling the iPods and putting each of them into Ziploc bags that are placed in a plastic box at the nursing station for storage.

3.3 Caregivers Perspectives

Focus groups with caregivers elaborated familiar themes:

- **Persons with ADOD benefit from the *iPod Project*.** Caregivers told us that music helped engage cared-for persons and "gave them life." Music added to personal enjoyment.
- **Caregivers also benefit.** Caregivers said that because of the music they had more time for themselves, which helped them to continue caring. Having the cared-for persons brighten up and engage in ways they otherwise wouldn't have was a huge relief.
- **Personalized music is key.** Personalized music encouraged persons with ADOD to reminisce about the past. One caregiver mentioned that when listening to her favorite music, the cared-for person talked happily about going to concerts and dancing with her spouse.
- **Caregivers reported few difficulties with the iPod technology.** Caregivers were grateful for *AST's* help in uploading music and managing music lists. Nevertheless, some caregivers experienced minor challenges with using the iPod once they brought it home.
- **The *iPod Project* should be expanded to help others.** Caregivers strongly felt that many more people can benefit. They said that the advantages of the *iPod Project* should be

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communicated to family physicians and other front-line health care providers who are the first point of access to the health care system. Caregivers emphasized that the *Project* should be expanded to more LTC residences and adult day programs.

3.4 Analysis of iPod Project Data

3.4.1 Time 1 Results

3.4.1.1 Administrative Data

Persons with ADOD. As of October 2013, 548 persons with ADOD had been enrolled in the *iPod Project*. Of these:

- The majority (60.7%) were women
- The most common diagnosis was Alzheimer's disease (59.7%) followed by other dementias (15.7%) and vascular dementia (6.9%).

Caregivers. Of participating caregivers:

- Most were female (73.9%)
- About half self-identified as Caucasian (46.2%)
- Almost all spoke English (93.4%)
- Most were adult child (59.8%) or spouses (24.4%).

Referrals. Referrals occurred through different sources including:

- The *Alzheimer Society of Toronto* (31.6%)
- Long-term care facilities (26.8%)
- Media (11.3%)
- Retirement residences (6.8%)
- Community agencies (6.6%).

3.4.1.2 Caregiver Distress Scale (CDS)

- Overall levels of caregiver stress were moderate at Time 1
- Caregivers tended to have higher scores on items related to caregiver social engagement compared to lower scores on items related to (negative) feelings for the cared-for person.

3.4.1.3 Cornell Scale for Depression in Dementia (CSDD)

- The average total score on the CSDD at Time 1 was 10.1 (out of a possible 38) suggesting low to moderate levels of depression among persons with ADOD in the *Project*
- However, 35.6% of persons with ADOD had scores greater than 10 denoting a "probably major depressive episode;" an additional 7.5% had scores greater than 18 suggesting a "definite major depressive episode."

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3.4.1.4 Caregiver Confidence

Average caregiver confidence score was 3.7 (out of a possible 5), suggesting that at Time 1 they considered themselves to be fairly confident in their ability to provide care.

3.4.2 Time 2 Results

3.4.2.1 Caregiver Distress Scale (CDS)

- The average CDS score at Time 2 was 1.9 (out of a possible 4), slightly lower than the average score recorded at Time 1
- The highest average scores at Time 2 (similar to Time 1) were on items related to social impact; the lowest scores related to negative feelings toward the cared-for person.

3.4.2.2 Cornell Scale for Depression in Dementia (CSDD)

- The total average score (standard deviation) for the CSDD at the Time 2 was 6.5 (5.7), lower than the average score of 10.1 observed at Time 1
- About a fifth (22.0%) of the sample at Time 2 had a CSDD score greater than 10 and less than or equal to 18, indicating a probably major depressive episode
- Just 4.0% of the sample at Time 2 had a CSDD score of greater than 18, indicating a definite major depressive episode, a percentage considerably lower than at Time 1.

3.4.2.3 Caregiver Confidence

- The average score was 3.9 out of 5, slightly higher than the corresponding score of 3.7 recorded at Time 1.

3.4.3 Time 1/Time 2 Comparisons

3.4.3.1 Caregiver Distress Scale (CDS)

There were two notable findings:

- Average “social impact” scores decreased from 8.3 at Time 1 to 6.7 at Time 2 (with a p value of .006) pointing to a statistically significant improvement in the ability of caregivers to engage socially
- Average “personal cost” scores decreased from 7.1 at Time 1 to 6.3 at Time 2 (with a p value of .04) pointing to a significant decline in negative impact on the caregiver’s personal life and health.

3.4.3.2 Cornell Scale for Depression in Dementia (CSDD)

- Item scores at Time 2 were identical to or lower than those observed at Time 1
- The percentage of individuals considered to have had “probably a major depressive episode” dropped from 37.5% to 25.0%; however, this difference was not statistically significant.

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3.4.3.3 Caregiver Confidence

The results show a statistically significant improvement in caregiver confidence:

- The average caregiver confidence score at Time 1 was 2.6 (out of 5); at Time 2, it increased to 3.9 (with a p value of .0004)

4.0 Summary

AST's iPod Project is a cutting-edge initiative which uses music to improve the lives of persons with ADOD and their family caregivers. In addition to benefiting from the music, *iPod Project* participants also benefit from access to one-on-one counselling, education workshops, support groups and creative therapy programs.

While still early in its stages, the *iPod Project* has already achieved considerable success. In addition to enrolling hundreds of pairs of persons with ADOD and their caregivers, it has forged stronger working relationships with community and residential LTC partners thus contributing to greater coordination and integration at a system level. It has also begun to document a range of benefits for individual participants and other stakeholders.

On the basis of these strong early returns, *AST* is already transitioning the *iPod Project* to become an ongoing and sustainable program.

The evaluation findings offer important intelligence to inform the *iPod Project's* continuing development.

First, the *Project* addresses challenges of high importance and visibility to people, providers and policy-makers. While the scientific evidence does not show that music works for all participants in all settings all of the time, it does make a convincing case that this low cost, low risk intervention can provide a wide range of benefits including better management of responsive behaviours.

Second, stakeholders already see that the *iPod Project* offers a range of important benefits to individuals, organizations and the health care system including: increased engagement and meaningful interactions and reduced agitation for persons with ADOD; reduced stress and burden for caregivers; stronger linkages with community and LTC partners that encourage joint working and build a stronger care system; recognition of *AST's* standing as the "go-to" organization not only for knowledge about the use of music, but about services and supports for persons with ADOD and their caregivers more generally.

Third, even in its early stages, the assessment data show that the *iPod Project* has generated value particularly for informal caregivers who are essential to maintaining the well-being and quality of life of persons with ADOD in community and residential LTC settings.

Fourth, expansion of the *iPod Project* will require new investment and infrastructure both within *AST* and beyond.

5.0 Recommendations

5.1 Continue to scale-up, spread and sustain the success of the iPod Project. As the number of persons with ADOD rises, as family caregivers take on an increasing burden of care along with the personal costs that entails, and as policy-makers and providers struggle to manage responsive behaviors in an era of “no new money,” music appears as a low cost, low risk intervention with an impressive range of benefits.

5.2 Use the iPod Project to build a stronger system. While policy-makers struggle to find system-level mechanisms for integrating care for persons with multiple health and social needs and their caregivers, the *iPod Project* builds stronger linkages and joint working among providers across sectors. It also confirms *AST*’s status as the “go-to” resource for knowledge and practice around ADOD.

5.3 Use the iPod Project to build partnerships. Community partners strongly supported the *iPod Project*. By providing advice and assistance to its partners, *AST* demonstrates its leading experience and knowledge around ADOD. While the *iPod Project* has been thought of as way of connecting *AST* to more people, it should also be recognized as a valuable means of connecting *AST* to other providers.

5.4 Use the iPod Project to strengthen community outreach and impact. Here the success of Alzheimer’s Cafes in the Netherlands offers an example. These “cafes” – grass-roots meetings run by volunteers in public locations – bring together older persons, caregivers, and providers to socialize, discuss shared experiences, help reduce stigma, and learn from experts about ADOD and approaches to improving the lives of people touched by the disease. The *iPod Project* seems like a strong opportunity to catalyze and sustain similar grass-roots initiatives in Toronto.

5.5 Focus on breadth versus depth. In extending its connections with people and providers, *AST* should consider strategies which shift resources away from “hands on” delivery to training and logistical support. Such strategies would see proportionately more *AST* staff time invested in “training the trainers,” organizing community events with partners, and developing print and web-based resources in different languages for use by partners and stakeholders.

5.6 Share lessons learned and best practices with local, provincial and national Alzheimer Societies. *AST* has broken new and fertile ground with its *iPod Project*; it has generated valuable intelligence about the design, implementation and outcomes of such initiatives which can inform future initiatives. Other Societies at local, provincial and national levels offer a great place to begin to share. Not only will this build the evidence base around the use of music, it can establish a national platform for scaling-up and spreading other promising local initiatives.

5.7 Continue to build the evidence base using a mix of qualitative and quantitative approaches. The findings of this initial evaluation point to a range of positive outcomes for persons with ADOD and caregivers, with caregivers significantly more confident about their ability to provide needed care, and better able to manage the potentially negative impact of

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caregiving. We think this is worth following-up; as numbers grow, clearer patterns will emerge, buttressing the case for the *iPod Project*, and for the mission and mandate of *AST*.

5.8 Engage with music professionals for support and endorsements to attract funders and raise public awareness. A major advantage of the *iPod Project* is that it is easily understood. Musicians and music industry professionals can support the *AST iPod Project* and build awareness about ADOD and *AST* among the general public. A simple Facebook endorsement or Tweet about the *AST iPod Project* could easily reach thousands of people not otherwise connected to the dementia community.

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1.0 Introduction

The *Alzheimer Society of Toronto (AST)* initiated its *Music and Memory: iPod Project* in early 2013. The *Project* provides iPod Shuffles, free of charge, to persons with Alzheimer's disease and other dementias (ADOD) and their caregivers. In addition to an iPod, participants receive a set of over-the-ear headphones, a credit and/or technical support to download music of choice from the web, and ongoing assistance. The *Project* aims to engage a total of 10,000 participants as a way of improving their communication, cognition and quality of life (Gerster, 2013).

AST's iPod Project was inspired by the ground-breaking work of *Music and Memory*, a non-profit organization based in New York, which brings "personalized music into the lives of the elderly or infirm through digital music technology, vastly improving quality of life" (Music and Memory, 2014).

This simple but profound idea is brought to life in a documentary called *Alive Inside: The Story of Music and Memory*. The documentary follows Dan Cohen, Executive Director of *Music and Memory*, on his journey to provide personalized music to residents of long-term care (LTC) facilities in the US. It looks at the lives of a number of these residents prior to and after accessing individualized music. While all respond positively, some responses are extraordinary; individuals who had been uncommunicative and withdrawn prior to accessing music now smile, express themselves and show pleasure. A short video featuring a resident called Henry has had more than 7 million views online.

AST's iPod Project goes further. While reaching out to persons with ADOD and their caregivers in residential LTC, it also engages participants in community settings including their own homes and adult day programs offered by partner agencies. It goes beyond the music; *AST's iPod Project* offers persons with ADOD and their caregivers ongoing support through scheduled follow-ups with staff at 3 months, as well as access to its extensive *Counselling Program (CP)*. In addition to benefiting from the music, *iPod Project* participants thus also benefit from the full range of services and supports offered by *AST* including one-on-one counselling; education workshops; support groups for persons with ADOD and their caregivers; and creative therapy programs.

In May 2013, *AST* commissioned the *Balance of Care (BoC) Research and Evaluation Group*, based at the University of Toronto, to assess the *iPod Project's* implementation and performance in its first year. In addition to its expertise in the area of community-based services and supports for older persons, the *Group* is very familiar with *AST's* work: between 2011 and 2013 it evaluated *AST's Caregiver Support Project* delivered in partnership with the Toronto Central Local Health Integration Network (TC LHIN), the Toronto Central Community

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Care Access Centre (TC CCAC), and 7 community agencies¹; in 2013 the *Group* conducted a formative evaluation of *AST's* flagship *Counselling Program (CP)*².

The *iPod Project* evaluation had two key objectives:

- First, to document the implementation of the *Project* and facilitate continuous learning and improvement as it rolled out in its first year;
- Second, to demonstrate the impact of the *Project* on persons with ADOD, caregivers and other stakeholders both as a means of improving *Project* performance and as a vehicle for communicating the *Project's* value to planners, policy-makers, funders, and potential participants.

In this report, we begin by detailing our evaluation approach, data and methods; we then present key findings; and subsequently offer recommendations for scaling-up, spreading and sustaining the *Project* going forward.

2.0 Evaluation

AST's iPod Project is a multi-faceted and broad-scale intervention. It connects persons with ADOD and caregivers with diverse characteristics and needs, living in residential and community settings, to personalized music. It also serves as a portal or entry-point to the wide range of valuable services and supports provided through *AST's Counselling Program (CP)*.

Moreover, the *iPod Project* is rapidly evolving and expanding. In its start-up phase, the *Project* recruited more than 60 pairs of persons with ADOD and caregivers; its ambitious goal is to recruit up to 10,000 pairs over the next three years.

To capture the dynamic nature and scope of the *Project*, we designed a multi-stage, multi-methods evaluation to make the best use of available qualitative and quantitative data, and to highlight the first-hand experiences of *Project* participants including caregivers, staff and partner agencies.

2.1 Rapid Review and Synthesis

In the evaluation's first stage, we conducted a "rapid review" and synthesis of literature and evidence around music care and music therapy for persons with ADOD. "Rapid reviews" are increasingly used by decision-makers in Ontario and elsewhere to provide insight into topics of interest as they emerge, on the grounds that systematic reviews take considerable time and

¹ Williams AP, Peckham A, Rudoler D, Tam T, Watkins J. Caregiver Support Project: Formative Evaluation Final Report. Submitted to Alzheimer Society of Toronto, April 19, 2013.

http://www.alzheimertoronto.org/documents/evaluations/csp_evaluation_report_2013.pdf

² Williams AP, Peckham A, Rudoler D, Tam T, and Watkins J. Formative Evaluation of the Alzheimer Society of Toronto Counselling Program, Final Report. April 2013.

http://www.alzheimertoronto.org/documents/evaluations/ast_cp_evaluation_report_2013.pdf

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resources, may be narrowly focused, and may not be readily accessible to non-scientific audiences.

Our review is built on a preliminary review of the literature conducted by *AST* staff. We added sources cited on the *Music & Memory* website and synthesized the results into a succinct 3 page “backgrounder” written for a general audience, entitled the *Science behind the Alzheimer Society of Toronto iPod Project*. As the title suggests, the backgrounder provides an overview of current evidence and thinking about personalized music and music therapy, and how they can improve the lives of persons with ADOD and their caregivers. The backgrounder can be publicly accessed on the website of the *Canadian Research Network for Care in the Community (CRNCC)* at <http://www.crncc.ca/knowledge/factsheets/pdf/InFocus-ScienceBehindtheASTiPodProject.pdf>. (See also Appendix 1).

2.2 Key Informant Perspectives

To document the first-hand experiences and insights of those at the “front lines” of the *iPod Project*, we conducted semi-structured, in-depth, qualitative interviews with a total of 13 “key informants.” Interviews were conducted by telephone or in-person by pairs of evaluation team members who each took detailed field notes and subsequently cross-checked them for accuracy. Interviews averaged about 45 minutes in length, with some lasting up to 90 minutes.

We interviewed:

- A total of 9 members of *AST*’s senior management team, Social Workers, and *iPod Project* staff
- A total of 4 representatives of *iPod Project* partner organizations including Humber Community Seniors’ Services, West Park Long-Term Care, Tendercare Living Centre, and Etobicoke Services for Seniors.

Key informants were asked combinations of the following questions:

- How would you describe your role (and your organization’s role) in the *iPod Project*?
- Thinking about process, what about:
 - Recruitment
 - How many of your clients are participating?
 - Who is participating?
 - How did they connect with the *Project*?
 - Is the *Project* getting to the right people?
 - Are some settings a better fit than others?
 - What, if anything, would you change?
 - Assessment
 - How well does the assessment work for participants and staff (e.g., length, format)?
 - Is it easy to administer?
 - Does it gather the right information?

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- What, if anything, would you change?
- Implementation
 - How do participants receive their iPods?
 - How do they access personalised music (e.g., download from the web)?
 - What assistance do they need? What are you able to give?
 - What, if anything, would you change?
- Follow-up
 - How many follow-up sessions have you conducted?
 - What are main lessons learned?
 - What, if anything, would participants change?
 - What, if anything, would you change?
- What do you see as the *Project's* main outcomes (both short- and long-term)
 - For persons with ADOD and caregivers?
 - For provider organizations?
 - For the health system?
- Thinking about the *iPod Project*, how would you rate its performance overall? What suggestions or recommendations do you have for improvement going forward?

We also received feedback from partner organizations about the *iPod Project* in a webinar conducted by AST in January 2014. Partners discussed strategies for enhancing staff engagement and making iPods more accessible for families; they also shared ideas about the safe use of iPods (e.g., appropriate use of ear buds).

2.3 Caregivers Perspectives

To hear the voices of those served by the *Project*, we conducted three 90 minute focus groups with participating caregivers in September 2013.

To minimize any real or perceived risk to privacy, the evaluation team was not given names or contact information for *iPod Project* participants. Instead, *Project* staff provided information about the evaluation to participants along with an invitation to join a focus group; they were asked to contact the *iPod Project* staff directly if they wished to participate.

To reassure participants that their views would remain anonymous, focus groups were not audio-recorded and participants were identified by first name only. During the focus groups, pairs of evaluation team members took detailed field notes and subsequently cross-checked them for accuracy.

To facilitate a familiar setting and easy access, focus groups were conducted at AST head offices which are readily accessible by public transit.

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We asked focus group participants straightforward questions:

- How do you and the person you care for use the iPod (e.g., how often, what music)?
- How does the *iPod Project* impact on you and the person you care for (e.g., person is calmer/more engaged; caregiver is less stressed)?
- What works best? What could be improved?

2.4 Analysis of iPod Project Data

With assistance from *iPod Project* staff, we accessed and analyzed data on participants and outcomes; these data derived primarily from assessments conducted by staff at intake (Time 1) and at 3 month follow-up (Time 2).

Intake data for a first wave of participants (Time 1) were received in October 2013. They included:

- Information about persons with ADOD:
 - Gender
 - Diagnosis.
- Information about caregivers:
 - Gender
 - Ethnicity
 - Language(s) spoken
 - Referral sources
 - Relationship to person with ADOD.

These data also included responses to:

- The Caregiving Distress Scale (CDS) (see Cousins et al., 2002). This multiple-item scale is widely used in the literature to measure aspects of family life potentially impacted by caregiving demands including relationship distress, emotional burden, care-receiver demands, social impact, and personal cost.

The CDS contains 17 items that caregivers rate using a 5-point scale where “strongly disagree” is scored 0; “disagree,” 1; “neutral,” 2; “agree,” 3; and “strongly agree,” 4. For example, items ask whether caregivers “take part in organized activities less;” “visit my family/friends less;” “take part in other social activities less;” “feel frustrated with caring for [cared-for person];” and “feel pressured between giving to [cared-for person] and others in the family.” (The full CDS is presented in Appendix 2).

- The Cornell Scale for Depression in Dementia (CSDD) (see Alexopoulos et al., 1988).

This scientifically validated and widely used scale consists of 19 items in five domains: mood-related signs; behavioral disturbance; physical signs; cyclic functions; and ideational disturbance. Each item is scored on a scale including “unable to evaluate”

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(treated as missing); “absent” (scored 0); “mild or intermittent” (1); or “severe” (2). (The full CSDD is presented in Appendix 2).

- A single item asking caregivers to rate “on a scale of 1 to 5, how confident are you in providing care at this time?” Responses range from “not confident” (scored 1) to “very confident” (scored 5). (Exact wording is presented in Appendix 2).

Time 1 data included:

- 393 responses to the multiple-item Caregiving Distress Scale (CDS)
- 277 responses to the multiple-item Cornell Scale for Depression in Dementia (CSDD)
- 206 responses to the single item measuring caregiver confidence.

As these numbers suggest, not all participants had recorded responses for all three measures (e.g., while 393 had recorded responses for the CDS, only 277 had recorded responses for the CSDD). As it turned out, there were more missing data: some individuals had not responded (or at least their responses had not been recorded) for all items in the multi-item CDS and CSDD scales, so that scale scores could not be computed. We removed incomplete responses leaving:

- 359 completions on the CDS
- 253 completions on the CSDD
- 206 completions on the measure of caregiver confidence.

Data from the 3-month follow-up assessment (Time 2) were received in December 2013. They included:

- 53 responses to the CDS
- 59 responses to the CSDD
- 26 responses to the single item on caregiver confidence.

There were missing data on the multi-item CDS and CSDD at Time 2. After excluding missing data, we analyzed:

- 42 CDS completions
- 50 CSDD completions
- 26 completions on the caregiver confidence item.

To make the most of these data, we calculated frequency distributions, average scores and standard deviations for all completed measures at Time 1 and Time 2.

Because of missing data, we were not able to match all completions at Time 1 with completions at Time 2. After eliminating individuals without matching data at Time 1 and Time 2, we analyzed differences over time for:

- 31 Time 1/Time 2 completions on the CDS
- 16 Time 1/Time 2 completions on the CSDD
- 18 Time 1/Time 2 completions on the measure of caregiver confidence.

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We assessed Time1/Time 2 differences using paired t-tests and a p value of 0.05 meaning that observed differences could have occurred by chance no more than 5% of the time. To compare categorical data, we used Fisher's exact p value test because some cell frequencies were quite low (less than 5).

Since the needs of cared-for persons are likely to be higher in residential LTC than in community settings (thus giving greater scope for change over time due to participation in the *iPod Project*), we asked *iPod Project* staff to provide "location" for each individual with matched Time 1/Time 2 data; we received this information in January 2014. We then conducted a two-way analysis of variance (ANOVA) to examine if there were any statistical differences in outcomes by location.

When considering the results of our data analysis, it is important to keep in mind the impact of the relatively small sample size. Statistical significance measures the probability that a finding could be due to chance; thus, as noted, a p-value of .05 means that an observed finding may be due to chance no more than 5% of the time. A general rule of thumb is that in smaller samples, only larger differences will reach statistical significance. In smaller samples the "null hypothesis," that is, the failure to find a statistically significant difference, is a more frequent outcome; even when you observe a finding that is interesting and makes sense, you cannot prove it. This is clearly the case for the results of this evaluation. Although, as we will see, findings almost always move in positive directions (e.g., all measures of caregiver distress decline), but differences do not always reach statistical significance.

Having said that, it is perhaps even more remarkable that a number of observed differences in the evaluation findings (such as higher levels of caregiver confidence) do reach statistical significance; thus, even in its early stages, with a relatively small pool of participants, the *Project* had already achieved measurable success.

3.0 Findings

3.1 Rapid Review and Synthesis

As described above, we conducted a rapid review and synthesis of literature and evidence around personalized music and music therapy for older persons with ADOD and their caregivers. In doing this, we built upon a preliminary review conducted by AST staff at the *Project's* inception. We added sources from the *Music and Memory* website, and then accessed articles cited by these sources.

Our findings are summarized in a short, concise "backgrounder" publicly available on the website of the *Canadian Research Network for Care in the Community* (go to <http://www.crncc.ca/knowledge/factsheets/pdf/InFocus-ScienceBehindtheASTiPodProject.pdf>) and attached to this document in Appendix 1; highlights are presented below.

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Music appears to offer considerable potential to improve the lives of persons with ADOD and their caregivers at low cost and with little risk. Reported benefits include, but are not limited to:

- Improved cognition, communication, and quality of life for older persons with ADOD
- Reduced caregiver burden and stress
- An improved ability to manage behavioural and psychological symptoms of dementia (BPSD) such as depression, anxiety, agitation and aggression.

While estimates vary, it is thought that about two-thirds of persons with dementia experience some form of BPSD at any one time (Kar, 2009). Depression has been found to be the most common BPSD (Vega et al., 2007; Lyketsos & Lee, 2004), followed by anxiety (affecting 35%-76% of persons with ADOD) (Fuh, 2006) and agitation (experienced by 55.9% of persons with ADOD) (Vega et al., 2007).

The potential appears greatest in residential LTC. While about a third of persons with ADOD in community settings exhibit levels of BPSD in the clinically significant range (Lyketsos et al., 2000), about 80% of those living in residential care settings are thought to do so (Margallo-Lana et al., 2001).

BPSD can pose risks for psychological and physical harm; particularly in residential settings when people live in close proximity. Recent media reports have documented assaults by persons experiencing BPSD on other older persons and staff in residential LTC.

Policy-makers and providers are increasingly aware of the challenges and associated costs of such behaviours. For example, *Behavioural Supports Ontario* invests \$40 million to “hire new staff-nurses, personal support workers and other health care providers, and to train them in the specialized skills necessary to provide quality care” to persons exhibiting “responsive behaviours” such as pacing and wandering, general restlessness and agitation, trying to get to a different place, grabbing onto people, complaining, repetitive sentences and questions, cursing and verbal aggression, making strange noises, and screaming (LHINs, 2013).

Music may reduce the challenges of caring for persons with such problematic behaviours. For example, one study showed that personalized music can effectively substitute for medication and restraints in the management of BPSD (Goodall & Ethers, 2005).

The evidence for using music in community settings is less developed, possibly because older persons with ADOD living in the community are not as likely to experience BPSD.

Nevertheless, even where BPSD are not present, family caregivers may still experience a heavy burden of care since they provide the bulk of the instrumental, personal and emotional support required on a day-to-day basis. Where BPSD are present, they can increase the rate of disease progression (Paulsen et al., 2000) and intensify caregiver burden (Coen et al., 1997; Matsumoto et al., 2007; Huang et al., 2012) and burnout (O'Donnell et al., 1992).

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Personalized music works best. Not surprisingly, music that is familiar to and resonates with the older person seems to produce the most favorable outcomes. For example, a study of older persons with severe cognitive impairment in residential LTC found that personalized music significantly reduced agitation compared to classical music (Gerdner, 2000). A quasi-experimental study of nursing home residents found that those who received personalized music had significantly lower anxiety scores at six weeks compared to those who did not receive music (Sung, Chang & Lee, 2010).

Similarly, an observational study of four patients with severe dementia in nursing homes found that some (but not all) patients were calmer during personalized music sessions, remained sitting longer, and stopped shouting (Ragneskog et al., 2001).

A review of research articles on the use of personalized music found evidence of reduced agitation and a lower frequency of some agitated behaviours (Sung & Chang, 2005).

Music therapy has also shown positive outcomes. Music therapy “is the skillful use of music and musical elements by an accredited music therapist to promote, maintain, and restore mental, physical, emotional, and spiritual health” (Boon, 2011; CAMT, 1994).

Studies have found that music therapy can:

- Reduce anxiety and depression (Guetin et al., 2009)
- Reduce depressive symptoms and improve cognitive function (Ashida, 2000; Chu et al., 2013)
- Reduce activity disturbances, aggressiveness and anxiety (Svansdottir & Snaedal, 2006)
- Impact positively on BPSD such as delusions, agitation, anxiety, apathy, irritability, aberrant motor activity, and night-time disturbances (Raglio et al., 2008)
- Reduce the severity and distress of patients and caregivers (Choi, Lee, Cheong & Lee, 2009)
- Reduce frequency of agitated behaviours (Zare et al., 2010).

There are a few unknowns. Of course, as in all fields of research involving complex interventions for people with widely varying needs and characteristics, the findings are not unanimous.

A meta-analytic review of 21 empirical studies showed that while the effects of music and music therapy were often significant, they varied in magnitude (Koger, Chapin & Brotons, 1999).

Another review of research between 1980 and 1997 found that while music therapy generally produced positive outcomes, there was considerable variation in interventions (e.g., types of music used, numbers of sessions, the length of exposure, populations studied, methodologies used) that made it difficult to generalize findings (Snyder & Chlan, 1999).

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A Cochrane Review on the use of music therapy for people with dementia concluded that while music therapy may have positive outcomes, there is “no substantial evidence to support nor discourage” its use in dementia care (Vink, Bruinsma & Scholten, 2011).

Bottom line. While music and music therapy may not work all of the time in all settings for all persons with ADOD and their caregivers, there is a plausible and growing body of evidence that this low cost intervention offers a range of potential benefits with little risk of harm. This clearly distinguishes music from more costly and risky interventions such as drug therapies and physical restraints, which have been widely used to manage individuals with responsive behaviours.

3.2 Key Informant Perspectives

3.2.1 AST Staff

AST key informants were strongly supportive of the *iPod Project*. They reported that:

- **The *iPod Project* benefits persons with ADOD and their caregivers.** Personalized music helps to calm persons with ADOD. The music may trigger long-term memories, improve their mood, make them happier, engage them, relieve their boredom, change their demeanor and create conversations. One key informant observed that listening to personalized music “took them on a whole other journey of emotions” and led to more meaningful engagement.

Moreover, the music provides informal caregivers with opportunities during the day to disconnect for a moment and focus on other everyday tasks such as housekeeping or meal preparation in peace and alone. Similarly, formal caregivers (such as personal support workers) can benefit because the music promotes relaxation and reduces anxiety among persons with ADOD, allowing them to perform their duties more effectively.

The effects seem to persist: follow-up sessions with caregivers suggested that persons with ADOD continued to exhibit positive outcomes, such as reduced agitation, anxiety and fear, when listening to music.

- **The *iPod Project* benefits AST and other stakeholders.** Because it is team-based and engages partner organizations, the *Project* strengthens working relationships within AST and beyond.

AST benefits by attracting new clients and raising awareness among the public and community organizations; it also raises AST’s profile as the “go-to” place for the use of “cutting edge” care for persons with ADOD and their caregivers. The *Project* positively impacts on youth engagement (through opportunities to assist with iPod set-up and download music), donor opportunities, partnerships and collaborations with community

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organizations such as retirement homes, daycare programs and LTC. Existing clients in *AST* can also be connected with the *Project*.

Community organizations benefit by incorporating a low-cost, but promising tool into their toolkit. For example, seniors' day programs can use iPods to better manage clients and improve outcomes.

The healthcare system benefits from stronger inter-organizational partnerships, improved care coordination, and increased capacity to delay or avoid institutionalization.

- **Implementation has been relatively smooth, largely due to careful preparation and willingness to make mid-stream adjustments.** Participants were provided with initial and ongoing instruction and technical assistance by *AST* staff and volunteers, including help with set-up, downloading music and managing play lists.

AST has strived to continuously improve the *Project*. For example, over-the-ear headphones were substituted for smaller ear buds following recommendation made by Dan Cohen. *AST* staff agreed with this recommendation and shared experiences of how some persons with ADOD found the smaller ear buds uncomfortable. Similarly, when some joint interviews with caregivers and persons in the early stages of dementia proved awkward, alternative approaches were arranged including telephone interviews or interviews at separate times.

- **There are challenges to sustaining partner engagement.** Some LTC homes reported inconsistent use of iPods because they were not always able to spare staff to help persons use their iPods, and there were concerns that iPods could go missing, leading to questions of liability.

Some community agencies said that they did not have the time to administer intake assessments; they also expressed concerns about rising workloads if the volume of participants continued to increase.

- **There are strong opportunities for scaling-up and spreading the *Project*.** Key informants asserted that the *iPod Project* can and should be scaled-up and spread by engaging new partners including adult day programs where participants are continuously monitored; memory clinics serving persons with early stage dementia; and family doctors, who, in addition to making quicker referrals to *AST*, could also benefit from providing music in waiting rooms to manage agitated behaviors.

3.2.2 Partner Organizations

Key informants from partner organizations were also strongly supportive of the *Project*. They observed that:

- **The *Project* is relatively easy to implement and administer.** This reflects the *Project's* simplicity and the extensive assistance and support offered by *AST*.

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- **The iPod Project benefits persons with ADOD and their caregivers.** Although the *Project* had been in operation only for a short period of time, partner organizations had already observed positive reactions from participants including:
 - Increased engagement with others and an overall calming effect
 - More enjoyable visits because of the opportunity to share and discuss the music
 - Easier outings (such as doctor appointments) because of the calming effect of the music
 - Opportunities to accomplish other tasks while the person is engaged in listening to music.
- **There are some workload concerns.** Assessments took considerable time, which meant that they were not always completed by staff, and sometimes handed off to caregivers who did not always complete them on their own. Assessment packages in languages other than English could promote completions.

It could be challenging to explain the iPod technology to caregivers and to convince them that iPods are easy to use. Older caregivers (most often spouses) expressed the most difficulty; younger caregivers (most often children) had the least difficulty.

A webinar with 10 community partners was hosted by AST in January 2014. Community partners discussed challenges and emerging best practices around the use of iPods. They observed that:

- **Staff need to be actively involved and engaged.** There were discussions about how to incorporate the use of the iPods into programming, rather than having them as an add-on. To this end, one community organization asked staff to integrate the iPods into the client's daily routine and added the iPods as a task in the "Point Click Care" process. Community partners are also providing in-services to educate staff about the use of the iPods.
- **Planning has to be done to ensure safe use and storage of the iPods.** Community partners agreed that clients with the iPods need to be monitored by either staff or students because of safety concerns such as high volume. One community partner suggested labelling the iPods and putting each of them into Ziploc bags that are placed in a plastic box at the nursing station for storage.

3.3 Caregivers Perspectives

The focus groups with caregivers elaborated familiar themes:

- **Persons with ADOD benefit from the iPod Project.** Caregivers told us that music helped engage cared-for persons and "gave them life." They described cared-for persons who were previously withdrawn, tapping or dancing to music and visibly enjoying themselves. Some caregivers told us that these effects lasted after the music finished.

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One caregiver said that the *iPod Project* had allowed the senior she cares for to stop taking antipsychotic medications; music had reduced their anxiety.

While dramatic changes in behavior were less likely among persons in the early stages of ADOD, music always added to personal enjoyment.

- **Caregivers also benefit.** Caregivers said that because of the music they had more time for themselves, which helped them to continue caring. Having the cared-for persons brighten up and engage in ways they otherwise wouldn't have was a huge relief for caregivers.

Music also allowed caregivers to accomplish activities of daily living. Examples included using the iPod during meal times; on public transportation; and during normal household tasks like vacuum cleaning which could lead persons with ADOD to become agitated.

- **Personalized music is key.** Caregivers emphasized the importance of selecting music that the care-for persons enjoyed. They listened to a wide variety of music that was familiar to them including Gregorian Chants and Ukrainian Polkas.

Personalized music encouraged persons with ADOD to reminisce about the past. One caregiver mentioned that when listening to her favorite music, the cared-for person talked happily about going to concerts and dancing with her spouse.

- **Caregivers reported few difficulties with the iPod technology.** Caregivers were grateful for AST's help in uploading music and managing music lists.

Nevertheless, some caregivers experienced minor challenges with figuring out how to use an iPod once they brought it home. They suggested having a short briefing about how to use the iPod when they picked it up.

Some caregivers mentioned having a difficult time placing the headphones on the cared-for persons; some decided to use mini-speakers instead of headphones.

- **The iPod Project should be expanded to help others.** Caregivers strongly felt that many more people can benefit. They said that the advantages of the *iPod Project* should be communicated to family physicians and other front-line health care providers who are the first point of access to the health care system. They suggested having information flyers at various places that caregivers visit like Sunnybrook Hospital's memory clinic.

Caregivers emphasized that the *Project* should be expanded to more LTC residences and adult day programs. Caregivers felt that while it takes effort to set up the music and store iPods securely when not in use, this is effort well spent if it reduced responsive behaviors and made people happier. They felt that any reluctance on the part of providers would be overcome by the benefits demonstrated by early adopters and experienced by families.

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Caregivers can play a role in the *Project's* spread. One caregiver said she would “scream it from the rooftop” to promote the *Project*. Other caregivers said they believed so strongly in the *Project* that they would promote it by word-of-mouth. Still others felt that their testimonials could be used to convince decision-makers and funders of its value.

3.4 Analysis of iPod Project Data

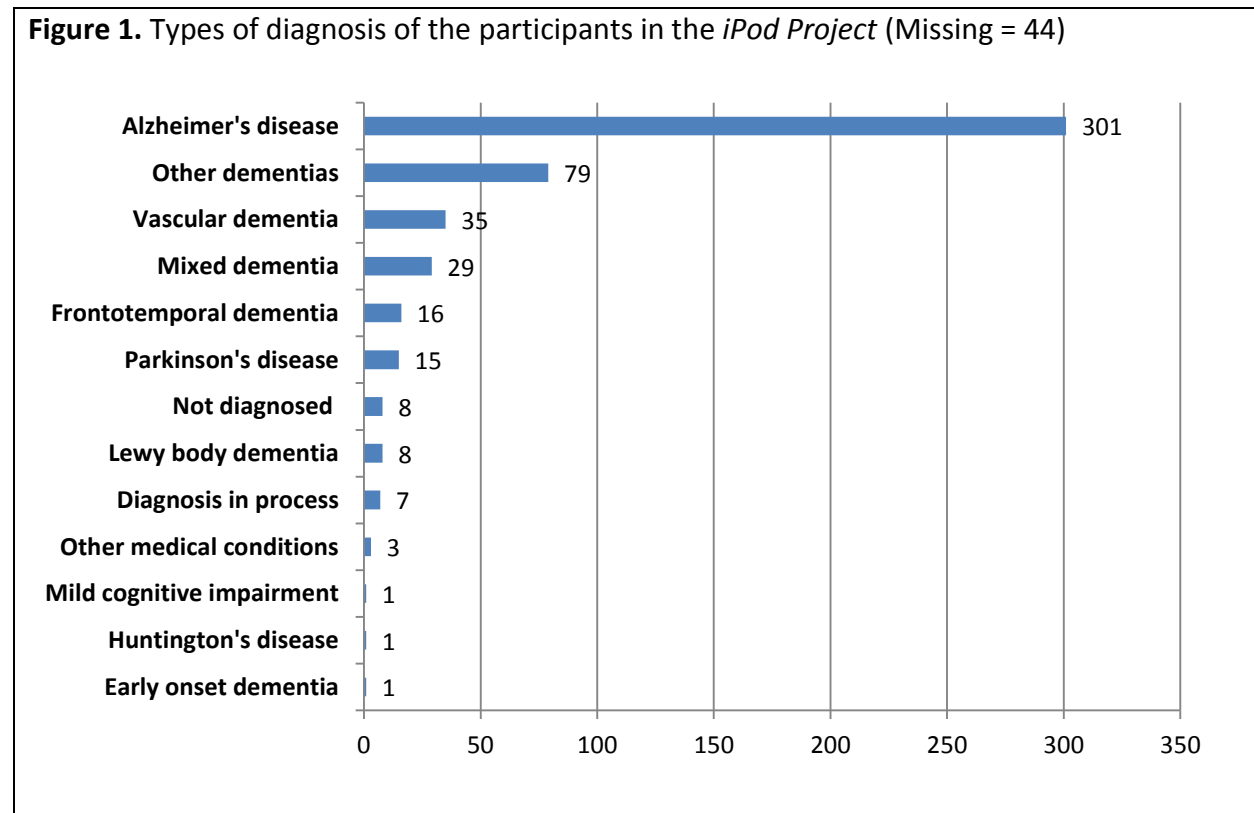
We analyzed *Project* data measuring the characteristics of caregivers and cared-for persons at intake (Time 1) and at three months (Time 2); the results are summarized below. For interested readers, more detailed findings are presented in Appendix 3.

3.4.1 Time 1 Results

3.4.1.1 Administrative Data

Persons with ADOD. As of October 2013, 548 persons with ADOD had been enrolled in the *iPod Project*. Of these:

- The majority (60.7%) were women
- The most common diagnosis was Alzheimer’s disease (59.7%) followed by other dementias (15.7%) and vascular dementia (6.9%).

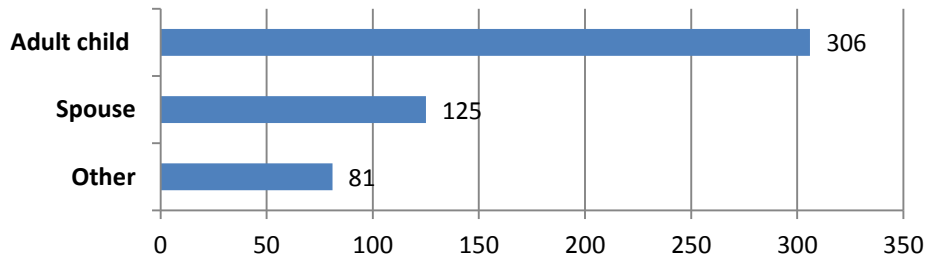


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Caregivers. Of participating caregivers:

- Most were female (73.9%)
- About half self-identified as Caucasian (46.2%)
- Almost all spoke English (93.4%)
- Most were adult child (59.8%) or spouses (24.4%).

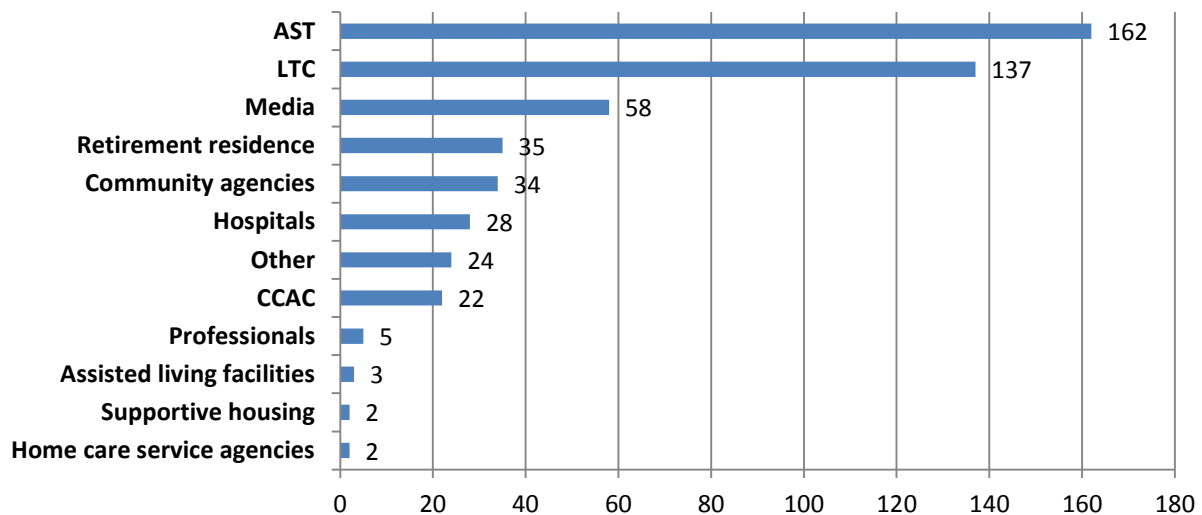
Figure 2. Types of relationships between caregivers and persons with ADOD (Missing = 36)



Referrals. The data in Figure 3 show that referrals occurred through different sources including:

- The *Alzheimer Society of Toronto* (31.6%)
- Long-term care facilities (26.8%)
- Media (11.3%)
- Retirement residences (6.8%)
- Community agencies (6.6%).

Figure 3. Referral sources (Missing = 36)



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As noted, the CDS contains 17 items addressing different aspects of life that may be affected by the demands of caregiving. For example:

- “I take part in organized activities less
- I visit my family/friends less
- I take part in other social activities less
- I feel frustrated with caring for _____
- My relationship with _____ depresses me
- I feel pressured between giving to _____ and others in the family
- My relationship with _____ is strained
- Caring for _____ has made me nervous.”

Caregivers rated each of these 17 items on a five point scale where “strongly disagree” is scored 0; “disagree,” 1; “neutral,” 2; “agree,” 3; and “strongly agree,” 4.

Detailed findings for the CDS are presented in Table 1.1, Appendix 3. In sum, these findings show that:

- Overall levels of caregiver stress were moderate at Time 1; the average score for all 17 CDS items was 2.1 (out of a possible 4).
- Caregivers tended to have higher scores on items related to caregiver social engagement including:
 - “I take part in organized activities less (2.7 out of 4)
 - I take part in other social activities less (2.7)
 - I visit my family/friends less” (2.5).
- Caregivers had lower scores on items related to (negative) feelings for the cared-for person:
 - “I feel resentful towards _____ (1.3)
 - I feel like _____ makes more requests than necessary (1.5)
 - My relationship with _____ no longer gives me pleasure” (1.6).

We also calculated scores for a number of validated CDS sub-scales measuring different dimensions of caregiver distress (for details see Table 1.2 in Appendix 3):

- The highest overall score was for “social impact” (.66 out of 1)
- The lowest overall score was for “relationship distress” (.43 out of 1).

3.4.1.3 Cornell Scale for Depression in Dementia (CSDD)

As indicated, the CSDD examines five domains of depression in persons with ADOD:

- Mood-related signs (e.g., anxiety, sadness, lack of reactivity to pleasant events, and irritability)
- Behavioral disturbance (e.g., agitation, multiple physical complaints, and loss of interests)
- Physical signs (e.g., appetite loss, weight loss, lack of energy)

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- Cyclic functions (e.g., diurnal variation in mood, difficulty falling asleep, multiple awakenings, and early-morning awakening)
- Ideational disturbance (e.g., suicide, poor self-esteem, pessimism, mood-congruent delusions).

Detailed findings are presented in Tables 1.3 and 1.4, Appendix 3. These findings show that:

- The average total score on the CSDD at Time 1 was 10.1 (out of a possible 38) suggesting low to moderate levels of depression among persons with ADOD in the *Project*.

However, as shown in the summary statistics in Table 1.4, Appendix 3:

- 35.6% of persons with ADOD had scores greater than 10 denoting a “probably major depressive episode”
- An additional 7.5% had scores greater than 18 suggesting a “definite major depressive episode.”

3.4.1.4 Caregiver Confidence

Caregivers were asked, “On a scale of 1 to 5, how confident are you in providing care at this time?” where 1 denotes “not confident,” and 5, “very confident.”

Table 1.5, Appendix 3, shows that the average caregiver confidence score was 3.7 (out of a possible 5), suggesting that at Time 1 they considered themselves to be fairly confident in their ability to provide care.

3.4.2 Time 2 Results

We analyzed data for all participants with completions at Time 2.

3.4.2.1 Caregiver Distress Scale (CDS)

Detailed results are presented in Tables 2.1 and 2.2., Appendix 3. These results show that:

- The average CDS score at Time 2 was 1.9 (out of a possible 4), slightly lower than the average score of 2.1 recorded at Time 1
- The highest average scores at Time 2 (similar to Time 1) were on items related to social impact; the lowest scores related to negative feelings toward the cared-for person.

3.4.2.2 Cornell Scale for Depression in Dementia (CSDD)

We analyzed 50 completed CSDD assessments at Time 2; details are found in Table 2.3 and 2.4, Appendix 3. Highlights show that:

- The total average score (standard deviation) for the CSDD at the Time 2 was 6.5 (5.7), lower than the average score of 10.1 observed at Time 1
- About a fifth (22.0%) of the sample at Time 2 had a CSDD score greater than 10 and less than or equal to 18, indicating a probably major depressive episode; this compares to 35.6% at Time 1, suggesting a substantial decline

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- Just 4.0% of the sample at Time 2 had a CSDD score of greater than 18, indicating a definite major depressive episode; this compares to 7.5% at Time 1, again suggesting a measurable decline.

3.4.2.3 Caregiver Confidence

At Time 2, a total of 26 caregivers responded to the question, “On a scale of 1 to 5, how confident are you in providing care at this time?” Table 2.5, Appendix 3, shows that:

- The average score was 3.9 out of 5, slightly higher than the corresponding score of 3.7 recorded at Time 1.

3.4.3 Time 1/Time 2 Comparisons

We compared corresponding scores for the same individuals at Time 1 and Time 2; these constitute stronger evidence of change.

3.4.3.1 Caregiver Distress Scale (CDS)

There were 31 caregivers with completed CDS assessments at Time 1 and Time 2.

The detailed findings in Table 3.1, Appendix 3, show that average scores were generally lower across dimensions of caregiver distress at Time 2, suggesting some improvement; however, most differences were not large enough to reach statistical significance.

There were two notable exceptions:

- Average “social impact” scores decreased from 8.3 at Time 1 to 6.7 at Time 2 (with a p value of .006) pointing to a statistically significant improvement in the ability of caregivers to engage socially
- Average “personal cost” scores decreased from 7.1 at Time 1 to 6.3 at Time 2 (with a p value of .04) pointing to a significant decline in negative impact on the caregiver’s personal life and health.

Similarly positive effects were observed in both community and residential LTC settings.

3.4.3.2 Cornell Scale for Depression in Dementia (CSDD)

We found that only 16 persons with ADOD had completed CSDD assessments at Time 1 and Time 2; all of these resided in residential LTC.

The findings in Tables 3.2 and 3.3, Appendix 3, show that:

- Item scores at Time 2 were identical to or lower than those observed at Time 1, suggesting a slight improvement. For example, the average Time 1 score on “irritability” was 1.0 (out of 2); the corresponding score at Time 2 was .8. Similarly, the average Time 1 score on “loss of interest” was 1.3; the corresponding Time 2 score was 1.1

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- The percentage of individuals considered to have had “probably a major depressive episode” dropped from 37.5% to 25.0%; however, this difference was not statistically significant.

3.4.3.3 Caregiver Confidence

A total of 18 caregivers responded to the caregiver confidence measure at both Time 1 and Time 2; detailed results are presented in Table 3.4, Appendix 3.

These results show a statistically significant improvement in caregiver confidence:

- The average caregiver confidence score at Time 1 was 2.6 (out of 5); at Time 2, it increased to 3.9 (with a p value of .0004)
- There was no statistical difference due to location; improvements in confidence were found among caregivers of persons with ADOD living in community and residential LTC.

4.0 Summary

AST's iPod Project is a cutting-edge initiative which uses music to improve the lives of persons with ADOD and their family caregivers. Building on the success of New York-based *Music and Memory*, the *Project* provides iPods, music of choice and technical assistance to participants in community and residential LTC settings. It also links participants to the extensive range of specialized services and supports offered through *AST's* proven *Counselling Program*. In addition to benefiting from the music, *iPod Project* participants thus also benefit from access to one-on-one counselling, education workshops, support groups and creative therapy programs.

While still early in its stages, the *iPod Project* has already achieved considerable success. In addition to enrolling hundreds of pairs of persons with ADOD and their caregivers, it has forged stronger working relationships with community and residential LTC partners thus contributing to greater coordination and integration at a system level. It has also begun to document a range of benefits for individual participants and other stakeholders.

On the basis of these strong early returns, *AST* is already transitioning the *iPod Project* to become an ongoing and sustainable program.

Of course, there is more to do. *AST's* ambitious target is to enrol 10,000 participant pairs in the *iPod Project*; this will require new strategies to reach out to new communities and new partners. It will also necessitate reinforcing and expanding the service infrastructure at *AST* both to manage the demands of the *Project* itself and to respond to the increased demand it will generate for *AST's* *Counselling Program*.

The evaluation findings offer important intelligence to inform the *iPod Project's* continuing development.

First, the *Project* addresses challenges of high importance and visibility to people, providers and policy-makers. While the scientific evidence does not show that music works for all participants

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in all settings all of the time, it does make a convincing case that this low cost, low risk intervention can enhance cognition, communication, and quality of life for many persons with ADOD; reduce caregiver burden and stress; and improve provider capacity to manage behavioural and psychological symptoms of dementia (BPSD) such as depression, anxiety, agitation and aggression.

Given the massive investments now being made in Ontario and other jurisdictions to manage responsive behaviours among growing numbers of persons with ADOD in community and residential LTC settings, even modest success using music constitutes a major achievement. Not only does music promise to moderate such behaviours, it promises to reduce the need for more costly and risky management approaches using drugs and physical restraints. It also promises to improve the lives of informal caregivers, who as a result, may be more able to continue to care.

Second, stakeholders already see that the *iPod Project* offers a range of important benefits to individuals, organizations and the health care system. These include:

- For persons with ADOD: increased engagement and meaningful interactions; reduced agitation, anxiety and fear; increased enjoyment and quality of life
- For caregivers: reduced stress and caregiver burden; increased ability to accomplish other tasks or have some free time; more optimistic perspectives on the future
- For other providers: more relaxed and less anxious clients; better ability to perform other tasks; more meaningful interactions with their clients
- For the health care system: stronger linkages with community and LTC partners that encourage joint working and build a stronger care system. Given the current policy push in Ontario and other jurisdictions toward greater coordination and integration of care for persons with chronic needs at the local level (e.g., through Community Health Links), this is an important benefit in and of itself
- For *AST*: recognition of *AST*'s standing as the "go-to" organization not only for knowledge about the use of music, but about services and supports for persons with ADOD and their caregivers more generally.

Such benefits build stakeholder buy-in, and strengthen the business case for *Project* expansion.

Third, even in its early stages, the assessment data show that the *iPod Project* has generated value particularly for informal caregivers who are essential to maintaining the well-being and quality of life of persons with ADOD in community and residential LTC settings. As a result of the *Project*:

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- Caregivers are better able to manage the potentially negative impact of caregiving on their social engagement and other personal costs
- Caregivers, whether cared-for persons are in community or residential settings, are more confident of being able to provide needed care.

Such outcomes promise to mitigate caregiver fatigue and burnout, encourage them to continue to care, and thus, in addition to helping cared-for persons, contribute to system sustainability by moderating demand for increasingly stretched formal care.

Fourth, expansion of the *iPod Project* will require new investment and infrastructure.

- *Within AST, Project* administration, including recruiting new participants, conducting assessments, entering data, assessing outcomes, and liaising with other partners already draw a considerable amount of staff time and energy. This draw will increase proportionately as the *Project* moves from hundreds to thousands of participants. Additional resources will also be required to sustain *AST's Counselling Program* as more *Project* participants opt to become continuing clients.
- *Beyond AST*, partner organizations will also need support. While enthusiastic about the *Project*, already stretched agencies were reluctant to commit resources, which slowed the pace of recruitment, and weakened the quality of the assessment data. These partners could see the long-term benefits of being better able to manage persons with ADOD, particularly those with responsive behaviours; nevertheless, they expressed concerns that in the short run, their efforts would be diverted from other essential tasks.

5.0 Recommendations

Based on the evaluation findings, we offer the following recommendations.

5.1 Continue to scale-up, spread and sustain the success of the iPod Project. The goal of recruiting 10,000 participating pairs of persons with ADOD and caregivers is ambitious; yet, the goal of making music a standard of care seems entirely plausible and of considerable value. As the number of persons with ADOD rises, as family caregivers take on an increasing burden of care along with the personal costs that entails, and as policy-makers and providers struggle to manage responsive behaviors in an era of “no new money,” personalized music appears to be a low cost, low risk intervention with an impressive range of benefits. Like more conventional drug therapies, music does not seem to work all of the time; yet, unlike such conventional therapies, it has few risks and low costs. Caregivers and providers told us that when music works, the benefits far outweigh the modest costs; in some cases, the outcomes are spectacular.

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5.2 Use the iPod Project to build a stronger system. The *iPod Project* has demonstrated that in addition to helping people, this low risk, low cost and accessible intervention can contribute to a stronger health care system. While policy-makers struggle to find system-level mechanisms for integrating care for persons with multiple health and social needs and their caregivers, the *iPod Project* builds stronger linkages and joint working among providers across sectors. It also confirms *AST's* status as the “go-to” resource for knowledge and practice around ADOD, and it locates *AST* at the cutting edge of “person-centred” collaborations (such as those encouraged by Ontario’s Community Health Links) which help to build local solutions to persistent health system problems “from the ground-up.”

5.3 Use the iPod Project to build partnerships. Community partners strongly supported the *iPod Project*; however, they said that in order to realize its full benefits they needed support. In our key informant interviews, partner agencies said they often struggled with routine tasks such as client intake and management of the iPods. In a Webinar attended by partner agencies, they highlighted challenges with staff buy-in and family engagement, along with issues around the safe use and storage of the iPods. These are all areas in which *AST* can bring to bear its considerable experience and knowledge, both to find solutions to short-term challenges and to cement its long-term working relationships with partners. While the *iPod Project* has been thought of as way of connecting *AST* to more people, it should also be recognized as a valuable means of connecting *AST* to other providers in an expanding “circle of care” around persons with ADOD and their caregivers.

5.4 Use the iPod Project to strengthen community outreach and impact. Here the success of Alzheimer’s Cafes in the Netherlands offers a useful example. These “cafes” – grass-roots meetings run by volunteers in public locations – bring together older persons, caregivers, and providers to socialize, discuss shared experiences, help reduce stigma, and learn from experts about ADOD and approaches to improving the lives of people touched by the disease. From a first experiment in 1997 there are now over 200 Cafes serving more than 35,000 visitors each year; evaluation results show high levels of satisfaction among participants, enhanced caregiver resilience, and greater social connectedness. The *iPod Project*, which offers people and providers access not only to music, but to the wider range of specialized resources provided by *AST*, seems like a strong opportunity to catalyze and sustain similar grass-roots initiatives.

5.5 Focus on breadth versus depth. In extending its connections with people and providers, *AST* should consider strategies which shift resources away from “hands on” delivery to training and logistical support. Such strategies would see proportionately more *AST* staff time invested in “training the trainers,” organizing community events with partners, and developing print and web-based resources in different languages for use by partners and stakeholders. In addition to extending *AST's* reach, such strategies would also begin to mitigate the substantial and probably unsustainable draw on *AST's* internal resources during the start-up phase of the *iPod Project*; now well rooted, the challenge shifts toward growing the *Project's* benefits.

5.6 Share lessons learned and best practices with local, provincial and national Alzheimer Societies. *AST* has broken new and fertile ground with its *iPod Project*; it appears to be one of a few organizations across North America that has brought personalized music to persons with ADOD and caregivers in both community and residential LTC settings, with community the clear policy direction in Ontario. In the process it has generated valuable intelligence about the design, implementation and outcomes of such initiatives which can inform future initiatives. Other Societies at local, provincial and national levels offer a great place to begin to share. Not only will this build the evidence base around the use of music, it can establish a national and international platform for scaling-up and spreading other promising local initiatives in the support of persons with ADOD and their caregivers.

5.7 Continue to build the evidence base using a mix of qualitative and quantitative approaches. The findings of this initial evaluation were constrained by relatively small numbers and limited statistical power; even so, consistent with findings in the research literature, they point to a range of positive outcomes for persons with ADOD and caregivers, with caregivers significantly more confident about their ability to provide needed care, and better able to manage the potentially negative impact of caregiving. We think this is worth following-up; as numbers grow, clearer patterns will emerge, buttressing the case for the *iPod Project*, and for the mission and mandate of *AST*.

5.8 Engage with music professionals for support and endorsements to attract funders and raise public awareness. A major advantage of the *iPod Project* is that it is easily understood. Musicians and music industry professionals can support the *AST iPod Project* and build awareness about ADOD and *AST* among the general public. A simple Facebook endorsement or Tweet about the *AST iPod Project* could easily reach thousands of people not otherwise connected to the dementia community. Musicians can be asked to organize iPod Donations Drives at concerts; auctions, raffles and giveaways on music memorabilia, such as signed shirts and guitars, can help to raise funds to sustain the *iPod Project*.

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Appendix 1: Backgrounder: Science behind the Alzheimer Society of Toronto iPod Project



CRNCC
Canadian research network for
care in the community

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Leading knowledge exchange on home and community care

The CRNCC is supported by funding from the Social Sciences and Humanities Research Council of Canada (SSHRC) and Ryerson University.

The Alzheimer Society of Toronto (AST) initiated its iPod project in 2013; the project provides personalized music to older persons in community and residential settings and is based on the work of *Music and Memory*, a US-based non-profit organization. The AST Project aims to provide iPods, free of charge, to 10,000 older persons living with Alzheimer's disease and other dementias (ADOD) as a way of improving cognition, communication, and quality of life (Gerster, 2013).

Research also suggests that personalized music can assist in the management of behavioural and psychological symptoms of dementia (BPSD) such as depression, anxiety, agitation and aggression, which can adversely impact the lives of older persons and their caregivers, and pose challenges for providers.

This backgrounder explores the science behind AST's iPod Project specifically, and the potential of personalized music more generally to improve the lives of older persons with ADOD.

What are the behavioural and psychological symptoms of dementia?

BPSD span a wide range of difficult-to-manage behavioural and psychological symptoms associated with persons with ADOD (Lawlor, 2002; Kar, 2009). Examples include depression, anxiety, apathy, agitation, aggression, delusion, hallucinations and sleep problems (Lawlor, 2002; Kar, 2009).

While estimates vary, it is thought that about two out of three persons with dementia experience some form of BPSD at any one time (Kar, 2009).

Studies have shown that among people with ADOD:

- Depression is the most common BPSD (Vega et al., 2007; Lyketsos & Lee, 2004)
- Anxiety affects 35%-76% (Fuh, 2006)
- Agitation is experienced by 55.9% (Vega et al., 2007).

BPSD are particularly challenging in residential care settings:

- About a third of persons with ADOD in community settings exhibit levels of BPSD in the clinically significant range (Lyketsos et al., 2000)
- About 80% of persons with ADOD in residential care settings show clinically significant levels of BPSD (Margallo-Lana et al., 2001).

Why is it important to manage behavioural and psychological symptoms of dementia?

BPSD can pose risks to older persons: they can increase the rate of disease progression (Paulsen et al., 2000) and erode quality of life and well-being.

BPSD can pose risks to others. The emergence of BPSD are associated with increased caregiver burden (Coen et al., 1997; Matsumoto et al., 2007; Huang et al., 2012) and burnout (O'Donnell et al., 1992).

Risks can also include psychological and physical harm. Media reports have documented assaults by persons experiencing BPSD on other older persons and staff in residential care settings. Even the possibility of such behaviour can lead to individuals being refused service.

Policy-makers and providers are well aware of such challenges. For example, Behavioural Supports Ontario promises \$40 million to “hire new staff-nurses, personal support workers and other health care providers, and to train them in the specialized skills necessary to provide quality care” to persons exhibiting “responsive behaviours” such as pacing and wandering, general restlessness and agitation, trying to get to a different place, grabbing onto people, complaining, repetitive sentences and questions, cursing and verbal aggression, making strange noises, and screaming (LHINs, 2013).

Why personalized music?

Music is a relatively low cost and low risk approach to managing BPSD. A 2005 study by Goodall & Eters showed that personalized music has can effectively substitute for medication and restraints.

Studies have found that personalized music (e.g., music familiar to and enjoyed by the older person with ADOD, also referred to as preferred music) is more effective than non-familiar music.

Personalized music has been found to:

- Reduce agitation during and following the music session (Gerdner, 2000)
- Help individuals remain calmer, sit longer and stop shouting (Ragneskog et al., 2001)
- Reduce overall Cohen-Mansfield Agitation Inventory scores (CMAI) (Sung, Chang & Abbey, 2006).

A recent quasi-experimental study on nursing home residents showed that those who received personalized music had a significantly lower anxiety score at six weeks compared to those who received the usual treatment without music (Sung, Chang & Lee, 2010).

A review of research articles on the use of personalized music found that seven out of eight articles reported significant reductions in agitation and agitated behaviours (Sung & Chang, 2005).

Other music interventions

Singing and background music have been shown to increase alert responses and communication. For example, an observational study on persons with late stage dementia living in residential care homes found that alert responses, such as head and eye movements, limb movements, changes in facial expressions, and vocalizations, were most frequent during singing sessions (Clair, 1996).

In another study, researchers found that caregiver singing and background music for patients with severe dementia decreased caregivers’ verbal instructing and narrating during their caring activities and increased the patients’ understanding of the situation both verbally and behaviourally (Gotell, Brown & Ekman, 2002). However, patients without background music exhibited cognitive and behavioural symptoms associated with dementia when communicating, and as a result, the patient and the caregiver were observed to have difficulties understanding each other (Gotell, Brown & Ekman, 2002).

Music therapy

Music therapy (directed by professionally trained and accredited music therapists (Boon, 2011)) can also produce a range of benefits. While music can be used by anyone, music therapy “is the skillful use of music and musical elements by an accredited music therapist to promote, maintain, and restore mental, physical, emotional, and spiritual health” (CAMT, 1994).

A number of studies have examined the impact of music therapy on depression and anxiety. In one study, researchers found that patients with mild to moderate Alzheimer’s disease had significant improvements in depression and anxiety; moreover, the effect lasted for up to 8 weeks (Guetin et al., 2009).

A case-control study indicated that the number of activity disturbances in participants of a music therapy group was significantly lower than non-participants over a 6-week period. Scores for aggressiveness and anxiety were also significantly lower (Svansdottir & Snaedal, 2006). Raglio and colleagues found that patients with dementia given music therapy had lower Neuropsychiatry Inventory scores than those not receiving such therapy (Raglio et al., 2008). Specific BPSD, such as delusions, agitation, anxiety, apathy, irritability, aberrant motor activity,

and night-time disturbances, all improved (Raglio et al., 2008). Other studies have found that music therapy can reduce depressive symptoms (Ashida, 2000; Chu et al., 2013) and result in improved cognitive function (Chu et al., 2013).

Another study by Raglio and colleagues found that music therapy was effective in reducing behavioural disturbances while simultaneously reducing delusions, agitation and apathy (Raglio et al., 2010). Moreover, group music intervention by certified music therapists significantly reduced agitation among patients with ADOD in a dementia day care unit (Choi, Lee, Cheong & Lee, 2009).

A study examining different forms of music therapy showed that patients with dementia in any music therapy group (listening to personalized music, group-personalized music, classical music, or singing music) had fewer agitated behaviours (Zare et al., 2010).

Systematic reviews on music therapy

Systematic reviews of research on music and music therapy for persons with ADOD also point to positive outcomes (Koger, Chapin & Brotons, 1999).

A review of nursing and non-nursing research reports on music therapy from 1980 to 1997 found positive outcomes overall (Snyder & Chlan, 1999) although with great variation in type of music selected, number of sessions, length of exposure, populations studied and methodologies used (Snyder & Chlan, 1999).

A review of recent clinical control trials and randomized controlled trials on use of music therapy found improvements in BPSD (Raglio et al., 2012).

A few qualifications

However, as in most areas of research, the findings are not unanimous.

A Cochrane Review on the use of music therapy for people with dementia concluded that there is “no substantial evidence to support nor discourage” its use in dementia care (Vink, Bruinsma & Scholten, 2011).

In fact, a small number of studies suggest that music therapy produces negative outcomes. For example, one randomized controlled study

observed that persons with dementia in residential care settings were more apt to be aggressive and express other behavioural disturbances after music sessions (Cooke et al., 2010); another study showed that Baroque music (as compared to no music at all) increased the number of behaviour disturbances (Nair et al., 2011).

Take home

In sum, the science behind the AST iPod Project suggests that in spite of some inconsistencies and qualifications, personalized music and other music interventions offer a range of potential benefits for older persons with ADOD, caregivers, and health care systems.

Moreover, personalized music and other music interventions appear to pose few risks, particularly in comparison to alternatives such as medications and physical restraints.

The AST iPod project presents an unprecedented opportunity to observe the benefits of personalized music across a large number of people; they aim to enrol 10,000 older persons in the iPod project. In addition, unlike other personalized music projects, they are targeting older persons living in both residential and community-based settings.

Evaluation of the AST iPod Project is ongoing; we will report results as they become available. Early findings suggest that in addition to achieving gains for older persons and caregivers, this project is increasing awareness of ADOD among the public, providers and policy-makers, who almost naturally see the value of personalized music as a way of improving peoples’ lives at low cost and with little risk.

For more information on the Alzheimer Society of Toronto *Music and Memory: iPod Project*, please visit: <http://www.alzheimertoronto.org/ipod.html>
The Music & Memory is a non-profit organization that incorporates personalized music into the lives of the elderly to improve their quality of life. For more information, please visit: <http://musicandmemory.org/>

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Appendix 2: iPod Project Assessment Package

Completed By:	Date (dd/mm/yyyy):
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How did you hear about the program:

New Client
 Current Client

CAREGIVER:

Last Name:	First Name:	MI:	
Phone:	Email:		
Date of Birth:	Relationship to PWD:		
Address:			
City: TORONTO	Province: ONTARIO	Postal:	Country: CANADA

CAREGIVER TECHNICAL APTITUDE:

Are you comfortable using computer technology..... Yes / No
 Are you comfortable using iPod technology?..... Yes / No

Gender:

Male Female Other _____ Refused to Respond

Ethnicity:

<input type="checkbox"/> Caucasian	<input type="checkbox"/> Korean	<input type="checkbox"/> West Asian (Iranian,Afghan,etc)
<input type="checkbox"/> African Canadian/Black	<input type="checkbox"/> Japanese	<input type="checkbox"/> Unknown
<input type="checkbox"/> Aboriginal	<input type="checkbox"/> Latin American	<input type="checkbox"/> Refused to Respond
<input type="checkbox"/> Arab	<input type="checkbox"/> South Asian (East Indian, Pakistan)	<input type="checkbox"/> Other _____
<input type="checkbox"/> Chinese	<input type="checkbox"/> Southeast Asian (Vietnamese, Cambodian, etc)	
<input type="checkbox"/> Filipino		

PERSON with DEMENTIA:

Last Name:	First Name:	MI:	
Date of Birth:			
Address:			<input type="checkbox"/> Same as Caregiver
City:	Province:	Postal:	Country:

Gender:

- Male Female Other _____ Refused to Respond

Ethnicity:

- | | | |
|---|---|--|
| <input type="checkbox"/> Caucasian | <input type="checkbox"/> Korean | <input type="checkbox"/> West Asian (Iranian, Afghan, etc) |
| <input type="checkbox"/> African Canadian/Black | <input type="checkbox"/> Japanese | <input type="checkbox"/> Unknown |
| <input type="checkbox"/> Aboriginal | <input type="checkbox"/> Latin American | <input type="checkbox"/> Refused to Respond |
| <input type="checkbox"/> Arab | <input type="checkbox"/> South Asian (East Indian, Pakistan) | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Southeast Asian (Vietnamese, Cambodian, etc) | |
| <input type="checkbox"/> Filipino | | |

Dementia Diagnosis:

- | | | |
|--|---|---|
| <input type="checkbox"/> Alzheimer's Disease | <input type="checkbox"/> Frontotemporal Dementia | <input type="checkbox"/> Wernicke-Karsaoff Syndrome |
| <input type="checkbox"/> Vascular Dementia | <input type="checkbox"/> Cruetzfeld-Jacob Disease | <input type="checkbox"/> Unspecified Dementia |
| <input type="checkbox"/> Mixed Dementia | <input type="checkbox"/> NPH | <input type="checkbox"/> Other- Indicate: _____ |
| <input type="checkbox"/> Parkinson's Disease | <input type="checkbox"/> Huntington's Disease | <input type="checkbox"/> Lewy Body Dementia |

Other Relevant Conditions:

Other Alzheimer Society Services Recommended:

- | | |
|--|---|
| <input type="checkbox"/> Counselling | <input type="checkbox"/> Creative Therapy |
| <input type="checkbox"/> Education | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Support Group | |

SERVICES REQUIRED FOR PARTICIPATION: (please check all that apply)

<input type="checkbox"/> iPod Package & music load
<input type="checkbox"/> iPod Package <u>only –client will self manage</u>
<input type="checkbox"/> Set-Up Services ONLY (client has own iPod)
<input type="checkbox"/> Dementia/caregiver related counseling
<input type="checkbox"/> Other _____

CONSENT

I [redacted] as an authorized representative for [redacted] understand that participation in the Alzheimer Society Toronto iPod program is voluntary, and agree to release Alzheimer Society Toronto and their employees, representatives and agents from any liability for injury, disability or financial cost resulting from the participation in the program.

I acknowledge receipt of the electronic device, serial # [redacted]. I agree to use the equipment as directed by the association representative, and understand that any equipment provided to me is provided for the duration of participation in the program. I agree to return provided equipment at the time of dismissal from the program.

I understand the participation requirements of the program, and agree to follow-up by phone, email, or in person as the Society deems necessary for research and participation needs related to the program. I agree to speak with an Alzheimer Society Counsellor for the regularly scheduled follow-up call at 3 months. I understand I may contact Alzheimer Society Toronto in addition to the scheduled follow-ups as I deem necessary for additional support and programming the Society may offer. I also agree to exchange any and all information provided with Society partners and volunteers for use within the program.

Caregiver Signature:
Counsellor Signature

Caregiver Name: Print

Date

ADMINISTRATIVE:

Device Used: iPod Shuffle - Blue	Serial Number:	Date Issued:
-------------------------------------	----------------	--------------

Music Upload Completed by:	Date:
Playlist Titled: _____	Created On : Client's Computer _____ AST Computer _____--_____

Education on use of iPod provided to:	Date:
---------------------------------------	-------

Caregiving Distress Scale

Instructions: Specific aspects of family life are affected by the demands of caregiving. With respect to your current situation as caregiver for _____, please indicate whether **YOU personally** disagree or agree with the following statements using the **five-point scale below**.

1. I take part in organized activities less

Strongly disagree Disagree Neutral Agree Strongly agree

2. I visit my family/friends less

Strongly disagree Disagree Neutral Agree Strongly agree

3. I take part in other social activities less

Strongly disagree Disagree Neutral Agree Strongly agree

4. I feel frustrated with caring for _____

Strongly disagree Disagree Neutral Agree Strongly agree

5. My relationship with _____ depresses me

Strongly disagree Disagree Neutral Agree Strongly agree

6. I feel pressured between giving to _____ and others in the family

Strongly disagree Disagree Neutral Agree Strongly agree

7. I feel that my own health has suffered because of _____

Strongly disagree Disagree Neutral Agree Strongly agree

8. My relationship with _____ is strained

Strongly disagree Disagree Neutral Agree Strongly agree

9. Caring for _____ has made me nervous

Strongly disagree Disagree Neutral Agree Strongly agree

10. I feel _____ can only depend on me

Strongly disagree Disagree Neutral Agree Strongly agree



11. I feel resentful towards _____

Strongly disagree Disagree Neutral Agree Strongly agree

12. I feel helpless in caring for _____

Strongly disagree Disagree Neutral Agree Strongly agree

13. My relationship with _____ no longer gives me pleasure

Strongly disagree Disagree Neutral Agree Strongly agree

14. I feel overwhelmed by caring for _____

Strongly disagree Disagree Neutral Agree Strongly agree

15. I feel like _____ makes more requests than necessary*

Strongly disagree Disagree Neutral Agree Strongly agree

16. I feel that my personal life has suffered because of _____

Strongly disagree Disagree Neutral Agree Strongly agree

SCORE: _____

**The Caregiving Distress Scale has been adapted from Cousins, et al. (2002). Assessing caregiving distress: A conceptual analysis and a brief scale. British Journal of Clinical Psychology, 41, 387–403.*

Caregiver Confidence

On a scale of 1 to 5, how confident are you in providing care at this time?

Not Confident		Very Confident		
1	2	3	4	5



Cornell Scale for Depression in Dementia

Scoring System: **a = unable to evaluate**
 0 = absent
 1 = mild or intermittent
 2 = severe

Ratings should be based on symptoms and signs occurring during the week prior to interview.
No score should be given if symptoms result from physical disability or illness.

A. Mood-Related Signs

1. Anxiety a 0 1 2
anxious expression, ruminations, worrying
2. Sadness a 0 1 2
sad expression, sad voice, tearfulness
3. Lack of reactivity to pleasant events a 0 1 2
4. Irritability a 0 1 2
easily annoyed, short-tempered

B. Behavioral Disturbance

1. Agitation a 0 1 2
restlessness, handwringing, hairpulling
2. Retardation a 0 1 2
slow movements, slow speech, slow reactions
3. Multiple physical complaints a 0 1 2
(score 0 if GI symptoms only)
4. Loss of interest a 0 1 2
less involved in usual activities
(score only if change occurred acutely, i.e., in less than 1 month)

C. Physical Signs

- | | |
|---|---------|
| 1. Appetite loss
<i>eating less than usual</i> | a 0 1 2 |
| 2. Weight loss
<i>score 2 if greater than 5 lb. in one month</i> | a 0 1 2 |
| 3. Lack of energy
<i>fatigues easily, unable to sustain activities</i>
<i>(score only if change occurred acutely, i.e., in less than 1 month)</i> | a 0 1 2 |

D. Cyclic Functions

- | | |
|---|---------|
| 1. Diurnal variation of mood
<i>symptoms worse in the morning</i> | a 0 1 2 |
| 2. Difficulty falling asleep
<i>later than usual for this individual</i> | a 0 1 2 |
| 3. Multiple awakenings during sleep | a 0 1 2 |
| 4. Early-morning awakening
<i>earlier than usual for this individual</i> | a 0 1 2 |

E. Ideational Disturbance

- | | |
|---|---------|
| 1. Suicide
<i>feels life is not worth living, has suicidal wishes or makes suicide attempt</i> | a 0 1 2 |
| 2. Poor self-esteem
<i>self-blame, self-deprecation, feelings of failure</i> | a 0 1 2 |
| 3. Pessimism
<i>anticipation of the worst</i> | a 0 1 2 |
| 4. Mood-congruent delusions
<i>delusions of poverty, illness or loss</i> | a 0 1 2 |

Continued



Scoring:

A score >10 probably major depressive episode

A score >18 definite major depressive episode

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Appendix 3: Data Analysis Detailed Findings

Table 1.1: Caregiving Distress Scale (CDS) Responses, Time 1

Table 1.1. Caregiving Distress Scale (CDS) Responses, Time 1 (N=359)						
	Strongly Disagree (Score=0)	Disagree (Score=1)	Neutral (Score=2)	Agree (Score=3)	Strongly Agree (Score=4)	Average score out of 4 (standard deviation)
1. I take part in organized activities less	3.3%	17.0%	11.1%	42.9%	25.6%	2.7 (1.1)
2. I visit my family/friends less	5.8%	19.8%	11.42%	40.7%	22.3%	2.5 (1.2)
3. I take part in other social activities less	4.2%	18.1%	9.2%	44.8%	23.7%	2.7 (1.1)
4. I feel frustrated with caring for _____	7.5%	21.7%	16.7%	41.2%	12.8%	2.3 (1.2)
5. My relationship with _____ depresses me	12.5%	22.0%	17.3%	35.1%	13.1%	2.1 (1.3)
6. I feel pressured between giving to _____ and others in the family	10.9%	23.7%	17.5%	30.1%	17.8%	2.2 (1.3)
7. I feel that my own health has suffered because of _____	11.4%	20.3%	14.8%	39.3%	14.2%	2.2 (1.3)
8. My relationship with _____ is strained	15.0%	28.7%	19.8%	27.9%	8.6%	1.9 (1.2)
9. Caring for _____ has made me nervous	10.9%	32.3%	12.3%	34.0%	10.6%	2.0 (1.2)
10. I feel _____ can only depend on me	8.9%	31.5%	11.4%	25.9%	22.3%	2.2 (1.3)
11. I feel resentful towards _____	28.1%	39.3%	14.8%	14.5%	3.3%	1.3 (1.1)
12. I feel helpless in caring for _____	14.5%	31.5%	14.5%	31.2%	8.4%	1.9 (1.2)
13. My relationship with _____ no longer gives me pleasure	16.2%	37.9%	21.2%	18.9%	5.8%	1.6 (1.1)
14. I feel overwhelmed by caring for _____	8.4%	23.7%	17.0%	39.0%	12.0%	2.2 (1.1)
15. I feel like _____	20.1%	42.6%	15.9%	13.6%	7.8%	1.5 (1.2)

makes more requests than necessary*						
16. I feel that my personal life has suffered because of	8.6%	16.4%	16.7%	44.0%	14.2%	2.4 (1.1)
Average percentage / Average score (standard deviation)	11.6%	26.7%	15.1%	32.7%	13.9%	2.1 (0.4)
Scoring: Strongly Disagree = 0; Disagree = 1; Neutral = 2; Agree = 3; Strongly Agree =4. The average score ranges from 0 to 4.						
*The Caregiving Distress Scale has been adapted from Cousins, et al. (2002). Assessing caregiving distress: A conceptual analysis and a brief scale. <i>British Journal of Clinical Psychology</i> , 41, 387–403.						

Table 1.2: Caregiving Distress Scale (CDS) Sub-Scale Scores, Time 1

Table 1.2. Caregiving Distress Scale (CDS) Sub-Scale Scores, Time 1 (N=359)		
Specific aspects of family life affected by the demands of caregiving	Average score (Standard deviation)	Normalized score out of 1 (Standard deviation)
Relationship distress (sum of scores for items 5, 8, 11, 13)	6.9 (3.7)	0.43 (0.23)
Emotional burden (sum of scores for items 4, 9, 12, 14)	8.4 (3.8)	0.53 (0.24)
Care-received demands (sum of scores for items 6, 15)	3.7 (2.0)	0.46 (0.25)
Social impact (sum of scores for items 1, 2, 3)	7.9 (3.2)	0.66 (0.26)
Personal cost (sum of scores for items 7, 10, 16)	6.8 (3.0)	0.57 (0.25)
The scoring formulas used were taken from Cousins, et al. (2002). Assessing caregiving distress: A conceptual analysis and a brief scale. <i>British Journal of Clinical Psychology</i> , 41, 387–403.		

Table 1.3: Cornell Scale for Depression in Dementia (CSDD) Responses, Time 1

Table 1.3. Cornell Scale for Depression in Dementia (CSDD) Responses, Time 1 (N=253)					
Mood-related signs					
	Unable to evaluate (Score=missing)	Absent (Score=0)	Mild or intermittent (Score=1)	Severe (Score=2)	Average score out of 2 (Standard deviation, N)
1. Anxiety (anxious expression, ruminations, worrying)	5.1%	28.9%	43.5%	22.5%	0.9 (0.7, N=240)
2. Sadness (sad expression, sad voice, tearfulness)	3.6%	39.1%	41.5%	15.8%	0.8 (0.7, N=244)
3. Lack of reactivity to pleasant events	2.4%	43.5%	37.5%	16.6%	0.7 (0.7, N=247)
4. Irritability (easily annoyed, short-tempered)	2.0%	38.7%	38.7%	20.6%	0.8 (0.8, N=248)
Behavioral disturbance					
1. Agitation (restlessness, handwringing, hairpulling)	3.6%	32.4%	44.3%	19.8%	0.9 (0.7, N=244)
2. Retardation (slow movements, slow speech, slow reactions)	5.9%	35.6%	37.2%	21.3%	0.8 (0.8, N=238)
3. Multiple physical complaints (score 0 if GI symptoms only)	7.9%	55.7%	26.5%	9.9%	0.5 (0.7, N=233)
4. Loss of interest (score only if change occurred acutely, i.e., in less than 1 month)	8.7%	28.1%	37.5%	25.7%	1.0 (0.8, N=231)
Physical signs					
1. Appetite loss (eating less than usual)	5.9%	63.6%	21.3%	9.1%	0.4 (0.7, N=238)
2. Weight loss (score 2 if greater than 5 lbs. in one month)	7.5%	68.0%	15.0%	9.5%	0.4 (0.7, N=234)
3. Lack of energy	7.1%	33.2%	41.1%	18.6%	0.8

(fatigues easily, unable to sustain activities) (score only if change occurred acutely, i.e., in less than 1 month)					(0.7, N=235)
Cyclic functions					
1. Diurnal variation of mood (symptoms worse in the morning)	17.4%	46.6%	27.3%	8.7%	0.5 (0.7, N=209)
2. Difficulty falling asleep (later than usual for this individual)	12.3%	60.9%	20.2%	6.7%	0.4 (0.6, N=222)
3. Multiple awakenings during sleep	15.8%	39.5%	30.8%	13.8%	0.7 (0.7, N=213)
4. Early-morning awakening (earlier than usual for this individual)	19.0%	55.7%	19.0%	6.3%	0.4 (0.6, N=205)
Ideational disturbance					
1. Suicide (feels life is not worth living, has suicidal wishes or makes suicide attempt)	15.0%	77.1%	6.7%	1.2%	0.1 (0.4 N=215)
2. Poor self-esteem (self-blame, self-deprecation, feelings of failure)	16.6%	62.1%	16.2%	5.1%	0.3 (0.6 N=211)
3. Pessimism (anticipation of the worst)	16.6%	61.7%	17.4%	4.3%	0.3 (0.6, N=211)
4. Mood-congruent delusions (delusions of poverty, illness or loss)	18.2%	66.8%	11.5%	3.6%	0.2 (0.5, N=207)
Scoring: Unable to evaluate = missing; Absent = 0; Mild or intermittent = 1; Severe = 2.					
The average score was calculated from the responses of "Absent", "Mild or intermittent", and "Severe" of each item in the five domains. The average score for each item ranges from 0 to 2.					

Table 1.4: Cornell Scale for Depression in Dementia (CSDD) Summary Statistics, Time 1

Table 1.4. Cornell Scale for Depression in Dementia (CSDD) Summary Statistics, Time 1 (N=253)	
Total average CSDD score (standard deviation)	10.1 (5.8)
Range of total average CSDD score (lowest to highest score)	0 to 38
Percentage of the sample with a score of >10 and ≤18 (a score of >10 probably major depressive episode)	35.6%
Percentage of the sample with a score of >18 (a score of >18 definite major depressive episode)	7.5%

Table 1.5: Caregiver Confidence, Time 1

Table 1.5. Caregiver Confidence, Time 1 (N=206)	
Caregiver confidence score (standard deviation)	3.7 (1.0)

Table 2.1: Caregiving Distress Scale (CDS) Responses, Time 2

Table 2.1. Caregiving Distress Scale (CDS) Responses, Time 2 (N=42)						
	Strongly Disagree (Score=0)	Disagree (Score=1)	Neutral (Score=2)	Agree (Score=3)	Strongly Agree (Score=4)	Average score out of 4 (standard deviation)
1. I take part in organized activities less	4.8%	28.6%	11.9%	52.4%	2.4%	2.2 (1.0)
2. I visit my family/friends less	4.8%	33.3%	19.0%	40.5%	2.4%	2.0 (1.0)
3. I take part in other social activities less	4.8%	23.8%	14.3%	50.0%	7.1%	2.3 (1.0)
4. I feel frustrated with caring for _____	0.0%	31.0%	19.0%	40.5%	9.5%	2.3 (1.0)
5. My relationship with _____ depresses me	7.1%	50.0%	14.3%	21.4%	7.1%	1.7 (1.1)
6. I feel pressured between giving to _____ and others in the family	4.8%	28.6%	23.8%	31.0%	11.9%	2.2 (1.1)
7. I feel that my own health has suffered because of _____	7.1%	33.3%	16.7%	35.7%	7.1%	2.0 (1.1)
8. My relationship with _____ is strained	7.1%	54.8%	19.0%	16.7%	2.4%	1.5 (0.9)
9. Caring for _____ has made me nervous	2.4%	57.1%	11.9%	19.0%	9.5%	1.8 (1.1)
10. I feel _____ can only depend on me	2.4%	40.5%	11.9%	35.7%	9.5%	2.1 (1.1)
11. I feel resentful towards _____	19.0%	57.1%	11.9%	11.9%	0.0%	1.2 (0.9)
12. I feel helpless in caring for _____	4.8%	61.9%	11.9%	19.0%	2.4%	1.5 (0.9)
13. My relationship with _____ no longer gives me pleasure	9.5%	57.1%	16.7%	11.9%	4.8%	1.5 (1.0)
14. I feel overwhelmed by caring for _____	2.4%	40.5%	19.0%	31.0%	7.1%	2.0 (1.1)
15. I feel like _____ makes more requests than necessary*	4.8%	61.9%	11.9%	19.0%	2.4%	1.5 (0.9)

16. I feel that my personal life has suffered because of	2.4%	35.7%	16.7%	35.7%	9.5%	2.1 (1.1)
Average percentage / Average score	5.5%	43.5%	15.6%	29.5%	6.0%	1.9 (0.3)
Scoring: Strongly Disagree = 0; Disagree = 1; Neutral = 2; Agree = 3; Strongly Agree =4. The average score ranges from 0 to 4.						
*The Caregiving Distress Scale has been adapted from Cousins, et al. (2002). Assessing caregiving distress: A conceptual analysis and a brief scale. <i>British Journal of Clinical Psychology</i> , 41, 387–403.						

Table 2.2: Caregiving Distress Scale (CDS) Sub-Scale Scores, Time 2

Table 2.2. Caregiving Distress Scale (CDS) Sub-Scale Scores, Time 2 (N=42)		
Specific aspects of family life affected by the demands of caregiving	Average score (Standard deviation)	Normalized score out of 1 (Standard deviation)
Relationship distress (sum of scores for items 5, 8, 11, 13)	5.9 (3.0)	0.37 (0.18)
Emotional burden (sum of scores for items 4, 9, 12, 14)	7.6 (3.1)	0.47 (0.20)
Care-received demands (sum of scores for items 6, 15)	3.7 (1.6)	0.46 (0.20)
Social impact (sum of scores for items 1, 2, 3)	6.5 (3.0)	0.54 (0.25)
Personal cost (sum of scores for items 7, 10, 16)	6.3 (2.7)	0.53 (0.23)
The scoring formulas used were taken from Cousins, et al. (2002). Assessing caregiving distress: A conceptual analysis and a brief scale. <i>British Journal of Clinical Psychology</i> , 41, 387–403.		

Table 2.3: Cornell Scale for Depression in Dementia (CSDD) Responses, Time 2

Table 2.3. Cornell Scale for Depression in Dementia (CSDD) Responses, Time 2 (N=50)					
Mood-related signs					
	Unable to evaluate (Score=missing)	Absent (Score=0)	Mild or intermittent (Score=1)	Severe (Score=2)	Average score out of 2 (Standard deviation, N)
1. Anxiety (anxious expression, ruminations, worrying)	4.0%	42.0%	30.0%	24.0%	0.8 (0.8, N=48)
2. Sadness (sad expression, sad voice, tearfulness)	2.0%	50.0%	32.0%	16.0%	0.6 (0.8, N=49)
3. Lack of reactivity to pleasant events	6.0%	52.0%	26.0%	16.0%	0.6 (0.8, N=47)
4. Irritability (easily annoyed, short-tempered)	8.0%	48.0%	32.0%	12.0%	0.6 (0.7, N=46)
Behavioral disturbance					
1. Agitation (restlessness, handwringing, hairpulling)	10.0%	48.0%	30.0%	12.0%	0.6 (0.7, N=45)
2. Retardation (slow movements, slow speech, slow reactions)	18.0%	50.0%	26.0%	6.0%	0.5 (0.6, N=41)
3. Multiple physical complaints (score 0 if GI symptoms only)	18.0%	58.0%	18.0%	6.0%	0.4 (0.6, N=41)
4. Loss of interest (score only if change occurred acutely, i.e., in less than 1 month)	18.0%	42.0%	26.0%	14.0%	0.7 (0.8, N=41)
Physical signs					
1. Appetite loss (eating less than usual)	24.0%	56.0%	14.0%	6.0%	0.3 (0.6, N=38)
2. Weight loss (score 2 if greater than 5 lbs. in one month)	20.0%	64.0%	14.0%	2.0%	0.2 (0.5, N=40)
3. Lack of energy	20.0%	52.0%	26.0%	2.0%	0.4

(fatigues easily, unable to sustain activities) (score only if change occurred acutely, i.e., in less than 1 month)					(0.5, N=40)
Cyclic functions					
1. Diurnal variation of mood (symptoms worse in the morning)	18.0%	64.0%	16.0%	2.0%	0.2 (0.5, N=41)
2. Difficulty falling asleep (later than usual for this individual)	24.0%	58.0%	14.0%	4.0%	0.3 (0.6, N=38)
3. Multiple awakenings during sleep	24.0%	40.0%	22.0%	14.0%	0.7 (0.8, N=38)
4. Early-morning awakening (earlier than usual for this individual)	36.0%	50.0%	10.0%	4.0%	0.3 (0.6, N=32)
Ideational disturbance					
1. Suicide (feels life is not worth living, has suicidal wishes or makes suicide attempt)	26.0%	74.0%	0.0%	0.0%	0 (0, N=37)
2. Poor self-esteem (self-blame, self-deprecation, feelings of failure)	26.0%	62.0%	10.0%	2.0%	0.2 (0.5, N=37)
3. Pessimism (anticipation of the worst)	24.0%	64.0%	10.0%	2.0%	0.2 (0.5, N=38)
4. Mood-congruent delusions (delusions of poverty, illness or loss)	26.0%	70.0%	2.0%	2.0%	0.1 (0.4, N=37)
Scoring: Unable to evaluate = missing; Absent = 0; Mild or intermittent = 1; Severe = 2.					
The average score was calculated from the responses of "Absent", "Mild or intermittent", and "Severe" of each item in the five domains. The average score for each item ranges from 0 to 2.					

Table 2.4: Cornell Scale for Depression in Dementia (CSDD) Summary Statistics, Time 2

Table 2.4. Cornell Scale for Depression in Dementia (CSDD) Summary Statistics, Time 2 (N=50)	
Total average CSDD score (standard deviation)	6.5 (5.7)
Range of the total average CSDD score (lowest to highest)	0 to 38
Percentage of the sample with a score of >10 and ≤18 (a score of >10 probably major depressive episode)	22.0%
Percentage of the sample with a score of >18 (a score of >18 definite major depressive episode)	4.0%

Table 2.5: Caregiver Confidence, Time 2

Table 2.5. Caregiver Confidence, Time 2 (N=26)	
Caregiver confidence score (standard deviation)	3.9 (1.0)

Table 3.1: Caregiving Distress Scale (CDS) Sub-Scale Scores, Time 1/Time 2 Comparisons

Table 3.1. Caregiving Distress Scale (CDS) Sub-Scale Scores, Time 1/Time 2 Comparisons (N=31)						
Specific aspects of family life affected by the demands of caregiving	Time 1		Time 2		Change in the normalized score	p value
	Average score (Standard deviation)	Normalized score out of 1 (Standard deviation)	Average score (Standard deviation)	Normalized score out of 1 (Standard deviation)		
Relationship distress (sum of scores for items 5, 8, 11, 13)	6.5 (4.0)	0.41 (0.25)	5.7 (3.0)	0.36 (0.18)	-0.05	0.3
Emotional burden (sum of scores for items 4, 9, 12, 14)	8.1 (3.6)	0.51 (0.22)	7.3 (2.6)	0.46 (0.16)	-0.05	0.2
Care-received demands (sum of scores for items 6, 15)	3.6 (1.7)	0.45(0.22)	3.7 (1.4)	0.46 (0.17)	+0.01	0.8
Social impact (sum of scores for items 1, 2, 3)	8.3 (3.6)	0.69 (0.30)	6.7 (2.9)	0.56 (0.24)	-0.13*	0.006
Personal cost (sum of scores for items 7, 10, 16)	7.1 (3.0)	0.59 (0.25)	6.3 (2.2)	0.52 (0.19)	-0.07*	0.04
The scoring formulas used were taken from Cousins, et al. (2002). Assessing caregiving distress: A conceptual analysis and a brief scale. <i>British Journal of Clinical Psychology</i> , 41, 387–403.						
Notation: * represents statistical significance (p <0.05)						

Table 3.2: Cornell Scale for Depression in Dementia (CSDD) Responses, Time 1/Time 2 Comparisons

Table 3.2. Cornell Scale for Depression in Dementia (CSDD) Responses, Time 1/Time 2 Comparisons (N=16)				
	Average score out of 2 (standard deviation, N) at Time 1	Average score out of 2 (standard deviation, N) at Time 2	Change	p value
Mood-related signs				
1. Anxiety (anxious expression, ruminations, worrying)	1.4 (0.7, N=16)	1.3 (0.8, N=16)	-0.06 (N=16)	0.3
2. Sadness (sad expression, sad voice, tearfulness)	1.4 (0.6, N=15)	1.3 (0.8, N=16)	-0.06 (N=15)	0.3
3. Lack of reactivity to pleasant events	1.3 (0.8, N=15)	1.2 (0.9, N=15)	-0.13 (N=15)	0.2
4. Irritability (easily annoyed, short-tempered)	1.0 (0.8, N=13)	0.8 (0.9, N=13)	-0.15 (N=13)	0.2
Behavioral disturbance				
1. Agitation (restlessness, handwringing, hairpulling)	1.3 (0.8, N=13)	1.3 (0.9, N=12)	-0.08 (N=12)	0.3
2. Retardation (slow movements, slow speech, slow reactions)	0.4 (0.7, N=8)	0.1 (0.4, N=8)	-0.25 (N=8)	0.4
3. Multiple physical complaints (score 0 if GI symptoms only)	0.9 (0.9, N=10)	0.6 (0.8, N=10)	-0.30 (N=10)	0.2
4. Loss of interest (score only if change occurred acutely, i.e., in less than 1 month)	1.3 (0.9, N=10)	1.1 (1.1, N=9)	-0.22 (N=9)	0.3
Physical signs				
1. Appetite loss (eating less than usual)	0.5 (0.8, N=10)	0.3 (0.7, N=10)	-0.20 (N=10)	0.3
2. Weight loss (score 2 if greater than 5 lbs. in one month)	0.3 (0.5, N=11)	0.1 (0.3, N=11)	-0.18 (N=11)	0.2
3. Lack of energy			-0.22	

(fatigues easily, unable to sustain activities) (score only if change occurred acutely, i.e., in less than 1 month)	0.5 (0.7, N=10)	0.2 (0.4, N=9)	(N=9)	0.3
Cyclic functions				
1. Diurnal variation of mood (symptoms worse in the morning)	0.5 (0.5, N=11)	0.4 (0.5, N=10)	0 (N=10)	n/a
2. Difficulty falling asleep (later than usual for this individual)	0.7 (0.8, N=13)	0.7 (0.8, N=13)	0 (N=13)	n/a
3. Multiple awakenings during sleep	1.4 (0.7, N=16)	1.2 (0.8, N=16)	-0.23 (N=16)	0.2
4. Early-morning awakening (earlier than usual for this individual)	0.3 (0.7, N=9)	0.2 (0.7, N=9)	-0.11 (N=9)	0.3
Ideational disturbance				
1. Suicide (feels life is not worth living, has suicidal wishes or makes suicide attempt)	0 (0, N=6)	0 (0, N=6)	0 (N=6)	n/a
2. Poor self-esteem (self-blame, self-deprecation, feelings of failure)	0.5 (0.8, N=6)	0.5 (0.8, N=6)	0 (N=6)	n/a
3. Pessimism (anticipation of the worst)	0.1 (0.2, N=7)	0.1 (0.2, N=7)	0 (N=7)	n/a
4. Mood-congruent delusions (delusions of poverty, illness or loss)	0 (0, N=6)	0 (0, N=6)	0 (N=6)	n/a

Scoring: Unable to evaluate = missing; Absent = 0; Mild or intermittent = 1; Severe = 2.

The average score was calculated from the responses of “Absent”, “Mild or intermittent”, and “Severe” of each item in the five domains. The average score for each item ranges from 0 to 2. The change of the average score was calculated from the difference between the intake average score and the follow-up average score.

For the p values, “n/a” = not applicable because p values cannot be computed from paired t-tests when the difference between intake and follow-up for every respondent is the same.

Table 3.3: Cornell Scale for Depression in Dementia (CSDD) Summary Statistics, Time 1/Time 2 Comparisons

Table 3.3. Cornell Scale for Depression in Dementia (CSDD) Summary Statistics, Time 1/Time 2 Comparisons (N=16)			
	Time 1	Time 2	Change (p-value)
Total CSDD score (standard deviation)	10.7 (5.8)	8.9 (6.2)	-1.8 (p=0.2)
Percentage of the sample with a score of >10 and ≤18 (a score of >10 probably major depressive episode)	37.5%	25.0%	-12.5% (p=0.7)
Percentage of the sample with a score of >18 (a score of >18 definite major depressive episode)	6.3%	6.3%	0 (p=1.0)

Table 3.4: Caregiver Confidence, Time 1/Time 2 Comparisons

Table 3.4: Caregiver Confidence, Time 1/Time 2 Comparisons (N=18)				
	Time 1	Time 2	Change	p value
Caregiver confidence score (standard deviation)	2.6 (1.1)	3.9 (0.9)	+1.3*	0.0004
Notation: * represents statistical significance (p <0.05)				