

Music and Memories iPod Eau Claire Community Project Results
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Although 25 participants started the program, only 22 participants finished. One was sent to a nursing home facility out of the area, one moved out of the area with a different caregiver, and they did not return e-mails, and the third one was because they chose not to participate in the post-evaluations since the person did not ever use the iPod.

15 participants had moderate/middle-stage dementia
5 participants had mild/early-stage dementia
3 participants had moderate/middle stage-advanced/late-stage dementia
1 participant had mild/early stage-moderate/middle-stage dementia
1 participant had advanced/late-stage dementia
17 of the participants were cared for by their wife
5 of the participants were cared for by their daughter
3 of the participants were cared for by their husband

The Caregiver Distress Scale has 17 questions, with a total score range from 0-68.

The Caregiver Distress Scale (CDS) used this scale:
0-strongly disagree 1-disagree 2-neutral 3-agree 4-strongly agree

There were subscales for emotional burden, relationship distress, care-receiver demands, social impact, and social cost.

p values are displayed to 3 decimal points; all other scores were rounded to 2 decimal points

Results are the difference of scores from time 1 (before iPod use) to time 2 (after ~ 3 months of iPod use)

The mean overall score on the CDS decreased by 6.45 ($p=.006$), from 29.19 to 22.74, which is a 22.10% decrease

The mean score for the subscale emotional burden decreased by 3.36 ($p=.000$), from 6.70 to 3.34, which is a 50.12% decrease

The mean score for the subscale relationship distress decreased by 2.20 ($p=.002$), from 5.07 to 2.86, which is a 43.41% decrease

There was no statistical significance for difference in scores in the subscales for care-receiver demands, social impact, and social cost

CDS Question #4: "I feel frustrated with caring for ____" decreased by 1.05 ($p=.001$), from 1.93 to .89, which is a 54.40 % decrease

CDS Question #5: "My relationship with ____ depresses me" decreased .77 (p=.004), from 1.43 to .66, which is a 53.85% decrease
CDS Question #8: "My relationship with ____ is strained" decreased by .67 (p=.023), from 1.26 to .62, which is a 53.17% decrease
CDS Question #9: "Caring for ____ has made me nervous" decreased by .75 (p=.003), from 1.57 to .82, which is a 38.85% decrease
CDS Question #12: "I feel helpless in caring for ____" decreased by 1.00 (p=.001), from 1.30 to .30, which is a 76.92% decrease
CDS Question #13: "My relationship with _____ no longer gives me pleasure" decreased by .61 (p=.005), from 1.25 to .64, which is a 60.00% decrease

For the other 11 questions on the CDS, there was no statistical significance in different scores.

Overall, caregivers believed that personalized music brought more pleasure to their loved ones and also helped them care for their loved ones. The music intervention not only helped people with dementia, but also helped support their caregivers and reduced caregiver stress.

19 stated that the music positively impacted the quality of life of the person with dementia and also the quality of life of the caregiver.

6 stated that it was effective to help the person with dementia sleep at night.

No noticeable effect on pain.

9 stated that it helped decrease anxiety in the person with dementia.

7 noticed a positive effect on verbal and/or physical behaviors

6 noticed a decrease in depression in their loved ones; 1 noticed a decrease in depression for herself (caregiver)

3 participants noted that the iPod was too small and the buttons were too small

5 noted that the iPod decreased stress for the caregiver

12 noted that the iPod helped the patient be more relaxed and more calm

5 noted that the patients were livelier, happier, more engaged, sing

The was a wide variety of how often and when they used the music.

Quotes:

"Good idea for anyone."

"We are really enjoying it."

"For such a small thing it does give a respite for both of us."

"Music and Memory is definitely a positive program. I appreciate we are a part of it."

"Motivation, dancing to music, less depression."

"Music is big part of life."

"It's nice to see him doing something he enjoys."

"Gives something to do, keeps mind occupied."

"Likes dancing around and singing."

"Helps both caregiver and receiver to interact with a better attitude."

"It helps me. I'm able to do things while he listens to the iPod."

"One time we danced to it. The day care facility found it helpful as well."

“I actually noticed he was directing the band one day!”
 “I love to watch him with the iPod on. It was pleasant to know he was listening to music he liked and enjoyed and that he still had those memories.”
 “We enjoy music with the iPod concept that provides pleasure for many hours.”
 “It gave him joy and made his life better when he used it.”
 “Improved his mood at times.”
 “It has allowed her to reconnect with songs and that area of her life.”
 “It makes him happy to listen to music.”

The community project results show that the personalized music intervention decreased overall caregiver distress, including emotional burden, relationship distress, and feelings of helplessness. Overall, caregivers believed that personalized music supported them in caring for their loved one and also brought more pleasure to their loved ones

Next time, I would get external speakers for all participants and I would also get bigger iPods for them.

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.

- | | | | | |
|-------------------|----------|---------|-------|----------------|
| 0 | 1 | 2 | 3 | 4 |
| Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
- _____ 1. I take part in organized activities less
 - _____ 2. I visit my family/friends less
 - _____ 3. I take part in other social activities less
 - _____ 4. I feel frustrated with caring for _____
 - _____ 5. My relationship with _____ depresses me
 - _____ 6. I feel pressured between giving to _____ and others in the family
 - _____ 7. I feel that my own health has suffered because of _____
 - _____ 8. My relationship with _____ is strained
 - _____ 9. Caring for _____ has made me nervous
 - _____ 10. I feel _____ can only depend on me
 - _____ 11. I feel resentful towards _____
 - _____ 12. I feel helpless in caring for _____
 - _____ 13. My relationship with _____ no longer gives me pleasure
 - _____ 14. _____ tries to manipulate me
 - _____ 15. I feel overwhelmed by caring for _____
 - _____ 16. _____ makes more requests than necessary
 - _____ 17. I feel that my personal life has suffered because of _____

Cousins, R., Davies, A.D.M., Turnbull, C.J., Playfer JR. (2002). Assessing caregiving distress: A conceptual analysis and a brief scale. *British Journal of Clinical Psychology*, 41(4), 387-403.

Subscale Scoring

Relationship distress – sum of items 5, 8, 11, 13 (0-16 points)

Emotional burden – sum of items 4, 9, 12, 15 (0-16 points)

Care-receiver demands – sum of items 6, 14, 16 (0-12 points)

Social impact – sum of items 1, 2, 3 (0-12 points)

Personal cost – sum of items 7, 10, 17 (0-12 points)