National Alzheimer's Project Act (NAPA)

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EDITORIAL

The Unforgettables: a chorus for people with dementia with their family members and friends

Summary/Abstract

Our experience evaluating a museum program for people with dementia together with their family members demonstrated benefits for all participants. We hypothesized that participation in a chorus would also have positive effects, giving them an opportunity to share a stimulating and social activity that could improve their quality of life. We inaugurated a chorus for people with dementia and their family caregivers in 2011, which rehearses and performs regularly. Each person with dementia must be accompanied by a friend or family member and must commit to attending all rehearsals and the concert that ensues. A pilot study included a structured assessment, take home questionnaires and focus groups. Analyses of pre-post scores were conducted; effect size was quantified using Cohen's d. Results showed that quality of life and communication with the other member of the dyad improved (Effect size: Cohen's d between 0.32 and 0.72) for people with dementia; quality of life, social support, communication and self-esteem improved (d between 0.29 and 0.68) for caregivers. Most participants stated that benefits included belonging to a group, having a normal activity together and learning new skills. Participants attended rehearsals in spite of harsh weather conditions. The chorus has been rehearsing and performing together for more than 6 years and contributing to its costs. Results of this pilot study suggest that people in the early to middle stage of dementia and their family members and friends can enjoy and learn from rehearsing and performing in concerts that also engage the wider community. It is essential to conduct additional larger studies of the benefits of participating in a chorus, which may include improved quality of life and social support for all, and reduced cognitive decline among people with dementia.

Introduction

Arts and culture-based activities are gradually gaining recognition as potentially effective interventions to improve the quality of life of people with dementia (Zeilig *et al.*, 2014). Less attention has been paid to interventions that are designed to also include caregivers, and the effects of these experiences on all participants. The results of our evaluation of Meet Me at MoMA, the MoMA Alzheimer's Project (Mittelman and Epstein, 2008) convinced us of the value of this kind of program and highlighted the desire of people with dementia and their family members to participate in shared experiences in the arts in which they felt welcome, rather than stigmatized because of the illness. We hypothesized that making music together, rehearsing, and giving concerts, might provide even greater benefits than a museum visit, as people with dementia and their family members could work together to create a joyful experience for themselves and for their audience. To test this hypothesis, in 2011 we founded a chorus for people with dementia and their family caregivers, and conducted a pilot study of its effects. The primary purpose of the chorus was to improve the well-being of caregivers by giving them the opportunity to learn to sing and perform in a group in which they and their relatives with dementia were all welcome.

In the past few years, evidence that music-related memories and abilities remain accessible to people with dementia has been accumulating. Research suggests that making music has a positive influence on health, mood, and cognitive function in older adults. A review of qualitative studies of choral programs for seniors concluded that music contributes to feeling competent, independent, maintaining self-esteem, and avoiding feelings of loneliness and isolation, triggers a series of cognitive, emotional and motor responses, and activates emotional and memory circuits (Särkämö *et al.*, 2012). Several other studies of choral experiences concluded that singing together fosters a sense of group support, belonging, and improved self-esteem (Clements-Cortes, 2013). Music can provide mental and physical stimulation even to those who are frail (Sorrell and Sorrell, 2008). Making music can serve as an alternative means of communication and social interaction for people with dementia and lead to a more sociable life (Ridder *et al.*, 2013). People with dementia can still be strongly moved by music, identify familiar music, recognize musical emotions, correctly perceive the pitch and melody of music, recognize the titles of familiar songs and recall familiar lyrics (Särkämö *et al.*, 2012).

Current studies in neuroscience research provide evidence that musical activities, both passive and active, have a biologic effect on the brain; music affects all lobes of the brain, involves emotional and motor responses, and can stimulate emotional memories stored in the brain (Levitin and Tirovolas, 2009). Pleasurable music has been shown to stimulate the release of neurotransmitters and endorphins among all participants, including those with dementia (Boso *et al.*, 2006). Memories associated with music, as well as the ability to sing and play an instrument, appear to be stored in such a way that they can be retrieved in dementia (Sacks, 2007). Emotional responses to music seem to be preserved in Alzheimer's disease (AD) (Drapeau *et al.*, 2009). Neuroimaging studies of people with dementia provide further support for these observations (Levitin and Tirovolas, 2009). For example, music's ability to evoke autobiographical memories and activate specific portions of the prefrontal cortex has been demonstrated with functional MRIs; the rostral prefrontal cortex, not affected until late in AD, is implicated in emotional responses to and familiarity with music (Janata, 2005).

Music making for people with dementia together with people with normal cognition

Several small studies of singing and music for people with dementia together with people with normal cognition have yielded promising results. Qualitative outcomes include reports of improvement in mood and quality of life, and strengthening of emotional bonding and social relationships through the enjoyable activity of singing (Sixsmith and Gibson, 2007). A few examples serve to illustrate these outcomes.

One example is a three-session pilot study of group singing in a non-clinical setting that included people with dementia, the family caregivers with whom they lived and some healthcare workers which reported that most participants said that they practiced the material at home and that the participants' voices got stronger over the three sessions; participants were able to learn a new song, sing in two parts, and sing a round in four parts (Bannan and Montgomery-Smith, 2008).

Another qualitative study of musical activities for people with dementia living at home concluded that music can enable people with dementia and their caregivers to enjoy the personally meaningful activity of singing together and that this activity can improve mood despite cognitive and other impairments, can serve as an important source of social cohesion and social contact, support participation in various activities both in and outside the home, and provide a degree of empowerment and control over everyday situations (Sixsmith and Gibson, 2007). A small controlled study of older adults with varying cognitive ability in a residential unit and day care center found that participation in a music therapist-led choir significantly reduced depressive symptoms, improved quality of life, and increased cognitive functioning (Ahessy, 2016).

Buddy's Glee Club included 28 participants, some of whom were cognitively normal older adults and others who were diagnosed with dementia (Clements-Cortes, 2013), all recruited from among staff and attendees at an adult day program in a Canadian metropolitan area who took part in a weekly 1-hour choral program for 16 weeks. While no statistically significant improvement was found on any of the quantitative outcomes, participants reported that the choir was a positive and enjoyable experience, that they enjoyed making friends, singing in a group with other companions, and singing familiar songs. (Clements-Cortes, 2013).

An intergenerational choir included 13 college students, six people with AD in the early stage and seven family members who met for 8 rehearsals and a concert. Qualitative data indicated that all participants enjoyed the experience, college students learned a great deal about AD and had fewer stigmatic beliefs, and the people with dementia and their family members were brought closer together, increasing social cohesion, and reducing their feelings of isolation (Harris and Caporella, 2014).

Choral singing for people with dementia with their caregivers

Recently, there have been several reports of studies of singing groups that include both people with dementia and their caregivers. In a study in the United Kingdom, 10 dyads of people with dementia and their family caregivers participated in a singing group that met for 10 weekly 90 minute sessions. While the quantitative measures failed to reveal significant improvements, qualitative data suggested both caregivers and people with dementia had positive experiences, which included a sense of social connectedness, focusing on the strengths of the person with dementia rather than the weaknesses and supporting their relationship (Camic *et al.*, 2013).

One study of a creative musical project led by the Scottish Opera included people with dementia and their caregivers who were invited to develop, write, design, rehearse, and perform a musical production along with the professional artists, singers, and choreographers of the opera company. Responses to semi-structured interviews suggested that both

caregivers and people with dementia gained greater confidence in themselves and enjoyed learning and the social interaction (McCabe *et al.*, 2015).

A randomized controlled trial of the effects of group singing on people with dementia together with their family and paid caregivers, conducted in Finland, compared singing, regular music listening and a control group. The singing group sang familiar songs, and did vocal exercises, rhythmic movements, and musical exercises at home. The researchers found that people with dementia in both the singing group and the music listening group experienced enhanced cognitive functioning and mood, but that only the active music making group improved the well-being and quality of life of caregivers and short term and working memory of the people with dementia (Särkämö *et al.*, 2014). They also noted that only the singing group had pronounced gains in the physical signs of depression, such as lack of energy and weight loss (Särkämö *et al.*, 2016).

The results of the studies done to date suggest the potential of music to contribute to the quality of life of people with dementia and their family members. These prior studies focused on the participants with dementia. Our intervention was designed to improve the well-being of caregivers by providing an opportunity for social connectedness that also included their relatives with dementia in a normative, emotionally satisfying, and productive activity.

Method

In June 2011, the NYU Center for Cognitive Neurology (NYU-CCN) inaugurated a chorus for people with dementia and their family members as a means of improving their quality of life and social connectedness, through shared participation in an enjoyable social activity. The pilot study of the chorus, approved by the NYU Institutional Review Board, was conducted in the three-month period after the chorus was founded. The goals of the pilot study were two-fold: (1) to fine-tune the intervention so that it would be enjoyable and appropriate to both the person with dementia and the caregiver, neither too difficult for the former nor to demeaning for the latter; (2) to obtain initial qualitative and quantitative data on the potential benefits of the intervention. We expected that the chorus would not only be of value in and of itself, but would also provide information that could lead to a larger, rigorous-controlled trial.

The chorus study was initiated and directed by Dr. Mary Mittelman and conducted by clinical staff of the Psychosocial Research and Support Program of the NYU-CCN, in collaboration with advisors with expertise in music therapy. Key staff included a choral conductor and assistant conductor (who also took turns being the piano accompanist), a music therapist, and a research and support team directed by Dr. Mittelman. The music therapist assisted the conductors in assuring the appropriateness of the materials, techniques, and rehearsal strategies. The research team developed specific strategies to maximize the enjoyment of participants, and test the feasibility of the program.

Participants learned about the chorus from patient and caregiver support group leaders, CaringKind (formerly the New York City Chapter of the Alzheimer's Association), the NYU AD Center and the educators at the Meet Me at MoMA program with whom we had previously collaborated. An interview to determine eligibility occurred in two parts; a prescreening interview on the telephone and a second interview in person, conducted by an NYU-CCN clinical staff member trained to ascertain stage of dementia and assess other eligibility criteria. The telephone prescreening interview was conducted to assure that prospective participants did not make an unnecessary trip if they were clearly ineligible to benefit from the chorus.

The initial members of the chorus named themselves the Unforgettables. The chorus rehearses weekly for 13 weeks before each concert. Each rehearsal lasts two hours. They rehearse 18 songs for each concert. The concerts, at Saint Peter's Church in Manhattan, are attended by family members, friends, people from the community, and the media.

At the beginning of every 13-week season, the conductors consult with participants and collect ideas and titles of songs that they are interested in singing. In the past six years, they have sung approximately 300 songs, including familiar songs, new repertoire, and canons from a variety of backgrounds and styles, including patriotic, folk, popular, Broadway, Latin, religious, American Songbook, and opera. Participants sing songs they remember from their youth and also learn new ones. The conductors strive to keep the programs interesting and make sure that all participants will enjoy and feel challenged by most of the songs in each program.

Conductors plan rehearsals and organize materials in advance. They vary the ways they teach songs and introduce difficult rhythms. The conductors regularly reevaluate their methods, to try to cater to the different hopes, expectations and needs of all the members. During rehearsals, conductors teach performance and vocal techniques, including breathing, phrasing, singing in other languages

such as Italian, Spanish, Hebrew, French, and how to prepare for concerts. During the whole process they also remind participants to be patient, understanding, and respectful of each other. Duets and small groups are fostered and created as rehearsals progress. During rehearsals, the conductors try to promote self-expression, creativity, self-esteem, a good mood, meaningful connections, sense of community, and social support.

At the beginning of each rehearsal, after greeting each couple, the conductors lead breathing exercises with the chorus for 3–5 minutes, followed by rhythm clapping patterns and solfege games with hand gestures (Solfege is a technique for the teaching of sight-singing in which each note of the score is sung to a special syllable. The seven syllables commonly used for this practice in English-speaking countries are: do, re, mi, fa, sol, la, and ti/si.). The participants then begin singing a song to get the feel, melody, and rhythm patterns. Conductors correct difficult passages using solfege, and saying the words in rhythm several times. They use rhythm to get the body moving and feeling the difficult patterns and commonly used rhythms. The conductors create patterns that are easy to follow, understand, and memorize, so that the group feels comfortable with the lyrics and can concentrate on the melody, phrasing, interpretation, and acting the part if needed.

Choral group singing involves the practice of melody, rhythm, form, and dynamics – the Unforgettables choral group involves all of these elements. Participants learn the nuance of performance, techniques of breathing and vocalization, and following the leadership of the conductor. The conductors encourage everyone to join in and to sing without fear of making a mistake or being criticized. Both the caregiver and the person with dementia are encouraged to be creative. The therapeutic benefits are inherent in participation in the chorus as it involves a normalizing activity with the use of music and helps participants feel a new sense of identity and dignity.

Warm ups are a very important part of the beginning of each rehearsal. The conductors incorporate movement along with singing, vocalizing, breathing, stretching, and exhaling to give participants an opportunity to reconnect with their breath and their body, relax, decompress from stress they may have experienced before getting to rehearsal, and release negative energy and thoughts. They are told to "breathe in positive energy, good thoughts, and to adopt good posture and get ready for a rehearsal full of enjoyable singing and rewarding experiences."

Rhythm techniques are a crucial part of the weekly rehearsals. Conductors encourage participants to feel the rhythm in their bodies by using rhythmic exercises, music games, as well as singing coupled with rhythmic movements. We use rhythm techniques to process difficult musical passages or sections with challenging lyrics and language passages. For instance, we use the natural rhythm that the text creates while clapping a steady beat, we then break down the passages and practice them using the call and response technique between the conductor and the singers. Conductors also use rhythmic group activities to maintain the attention of the participants and to add interest to the rehearsal. Rhythm techniques also help the chorus keep the momentum going, add dramatic effects when performing specific songs, and help participants stay engaged and alert.

One of the goals of the rehearsals is to provide enjoyable experiences that will give the participants with dementia and their caregivers an opportunity to share, create, express, learn, and enjoy their time together. The rehearsals are divided into two parts by a 15-minute break. Couples take turns hosting the break by bringing refreshments for everyone. The break is an important component of each rehearsal because it allows for social interactions and affords caregivers the opportunity to check in and support one another's progress or problems during the previous week. It also allows those with dementia to socialize with the conductors and the other members. It has become a tradition to end each rehearsal with a song that involves movement. Choral participants sing and dance their way to the end of the rehearsal.

Pilot study

Quantitative Assessments: The intake assessments took place no more than one-week prior to the commencement of the meetings/rehearsals in June of 2011. The follow-up assessments took place during a pre-scheduled session at the church that culminated in a celebration one week after the concert in September of 2011, to assess change in outcomes such as mood, self-esteem, and quality of life. Intake and follow-up assessments consisted of structured questionnaires that were filled out independently by the caregivers and in person by a social worker or allied health professional with the people with dementia. The forms used in the evaluation are already validated for this population. Many were used in the NYU evaluation (led by Dr. Mittelman) of the Meet Me at MoMA program, mentioned above (Mittelman and Epstein, 2008). Participants with dementia and their caregivers completed demographic questions, the Communication subscale of the Family Assessment Measure (Skinner *et al.*, 1983); and the

Rosenberg Self-esteem Scale (Rosenberg, 1965). In addition, quality of life of the person with dementia was assessed with two scales, Quality of Life-AD (QOL-AD; 13 items: Logsdon *et al.*, 2002) and the DemQoL (28 items; Chua *et al.*, 2016). In addition to the domains assessed for both members of the dyad, caregivers also completed the MOS Social Support Survey (Sherbourne and Stewart, 1991), the SF-8 measure of Health Related Quality of Life (Ware *et al.*, 2001), and the Geriatric Depression Scale (15-item version; Sheikh and Yesavage, 1986). Specific dementia diagnosis was not generally available, as participants were recruited from the community, and medical documentation was not included in eligibility requirements. Dementia severity was estimated with the Global Deterioration Scale (GDS, Reisberg *et al.*, 1982).

Qualitative assessments

The pilot study also included several types of qualitative assessments. Take-home questionnaires that included structured and open ended questions were given to participants after the last rehearsal. Two focus groups of participants were led by two NYU researchers one week after the concert for in-depth exploration of participants' reactions to the program. While resources for recording these groups for a formal qualitative analysis were not available, a staff member took notes of the discussion for later informal thematic analysis. These efforts made it possible to explore the qualitative aspects of the intervention, elaborate on the quantitative findings and elucidate additional benefits not captured by the scales.

Statistical analysis of quantitative assessments

All data were analyzed by using SPSS software (IBM SPSS Statistics version 23; SPSS, Chicago, Ill). Differences between scores at baseline (prior to the first rehearsal) and follow-up (after the first concert) were tested by using the paired sample Student *t*-test. Because of the small sample size ($n = 10$ caregivers and 10 people with dementia), we defined statistical significance as $p < 0.1$ for a two-tailed test. We estimated effect size for each outcome, using Cohen's d, as effect size emphasizes the size of the difference, and provides a more unbiased measure, not influenced by sample size, of the effectiveness of the intervention. To provide an overall impression of change, we also aggregated the data into categories to indicate whether the scores at follow-up improved, were the same, or worse than the scores at baseline.

Results

Study subjects

–Eleven dyads (pairs in which one person had dementia in the early to early middle stage and the other was an informal caregiver; $n = 22$ participants) participated in the pilot study. There were nine spouse/partner caregivers, one adult child caregiver, and one close friend. Five of the caregivers were male and six were female; seven of the persons with dementia were male and four were female. All participants were Caucasian. Among both caregivers and people with dementia, ten were non-Hispanic and one was Hispanic. The mean age of caregivers was 71.7 ($SD = 8.3$) and of the persons with dementia was 79.4 ($SD = 9.1$).

Each participant with dementia came with the same family member or close friend to all rehearsals and the culminating concert. Only one (a caregiver) had sung in public before. Ten of the 11 dyads completed both the pre- and post-evaluations. The remaining dyad was not available to complete the post-concert evaluation.

Quantitative outcomes

The results of t-tests of changes in outcome and effect sizes can be seen in Table 1. For persons with dementia, there was a significant improvement in both measures of quality of life, the QoL-AD ($t = 2.28$, $p = 0.048$, Cohen's d = 0.72) and the DemQol ($t = 1.85$, $p = 0.098$, d = 0.59), as well as in communication with the caregiver ($t = 1.97$, $p = 0.085$, d = 0.62). Self-esteem showed a small but not significant improvement, with a small to medium effect size ($t = 1.0$, $p = 0.34$, d = 0.32). For caregivers, self-esteem was the only outcome to improve significantly based on the t-test, but showed a medium large effect size ($t = 2.15$; $p = 0.060$, d = 0.68). While change in SF-8 ($t = 1.42$, NS, d = 0.45) and social support ($t = 1.32$, NS, d = 0.42) were not significant, both outcomes produced a medium effect size. Caregiver depression was very low before the intervention, and did not change with the intervention. Viewing the results as a whole, the aggregated scores show improvement in most measures for the majority of people with dementia and caregivers (Table 2), with an aggregate score for people with dementia of 22 improved, 13 the same, and 5 worse, and for caregivers of 21 improved, 12 the same, and 7 worse.

Qualitative outcomes

There were several themes that emerged from both the take-home evaluations and the focus groups. Caregivers and people with dementia said they

Table 1. Persons with dementia and caregivers; change from intake to follow-up ($n = 10$)

MEASURE	TIME 1 MEAN (SD)	TIME 2 MEAN (SD)	TEST STATISTIC, p VALUE	EFFECT SIZE COHEN'S D
Person with dementia				
QoL-AD	35.60 (5.4)	38.90 (5.4)	$t = 2.28$, $p = 0.048$	0.72
DEMQoL	93.0 (9.39)	98.1 (9.48)	$t = 1.85$, $p = 0.098$	0.59
Communication with Caregiver	39.78 (5.14)	43.89 (6.39)	$t = 1.97$, $p = 0.085$	0.62
Self-esteem	29.50 (3.50)	30.90 (4.95)	$t = 1.00$, $p = 0.34$, NS	0.32
Caregiver				
SF-8	15.10 (4.79)	13.30 (4.27)	$t = 1.42$, NS	0.45
Social Support	56.80 (12.93)	61.20 (12.99)	$t = 1.32$, NS	0.42
Depression	13.40 (1.65)	13.30 (1.89)	t=0.17, NS	0.05
Communication with person with dementia	41.50 (3.44)	41.60 (3.66)	$t = 0.93$, NS	0.29
Self-esteem	33.40 (3.31)	35.10 (3.57)	$t = 2.15$, $p = 0.060$	0.68

Table 2. Persons with dementia and caregivers. Type of change from intake to follow-up

PERSON WITH DEMENTIA			
Measure	Improved	Same	Worse
QoL-AD	5	3	2
DEMQoL	6	2	2
Communication with caregiver	5	5	0
Self-esteem	6	3	1
Total change	22	13	5
Caregiver			
Measure	Improved	Same	Worse
SF-8	6	3	1
Social support	5	3	2
Communication with person with dementia	3	4	3
Self-esteem	7	2	1
Total change	21	12	7

enjoyed sharing an experience with others like themselves, the challenge of learning new songs and singing techniques, and the pleasure in the activity itself. Many of the caregivers commented that the rehearsals had a lasting benefit on their own moods and those of the people with dementia. Participants came to rehearsals regardless of the weather.

All of the chorus members took part in the focus groups. Participants repeatedly expressed the positive outcomes that resulted from rehearsing and performing together in the concert. One spouse caregiver said, "I had given up on myself. I have now started to take care of myself again, and even to lose weight. Doing this brought me back to myself." A participant with dementia said, "Put the music on; my mouth opens up to sing." A spouse caregiver spoke about the calm that came over her frequently agitated husband when they sang together at home. Another spouse caregiver said it gave her pleasure to hear her husband singing the songs in the shower. One caregiver commented, "Rather than reaching for a pill, we sing!" Another said, "This is as good as a patch or pill, if not better. No side effects!"

Caregivers' responses to the question, "What was the best thing about the chorus?" included comments that indicated the value of the social support of the group, interacting with new people, exchanging ideas, having "an enjoyable and happy time," and sharing an experience with other caregivers and people with AD. Caregivers mentioned the group atmosphere, and the sense of community. The skill and spirit of the chorus conductors was important to caregivers, who talked about being taught by professionals who "made learning exciting and fun." "They (the leaders) encouraged and brought out the best in us," and "Tania and Dale and the whole staff made the experience positive, memorable and supportive." Many caregivers mentioned the fun of the performance and the party afterwards. Most talked about the fact that the experience had an extended effect on the person with dementia;

"He wakes up singing! He sings during the day," "L was so much happier singing and his self-esteem was so elevated by being able to sing a solo and people's response." Participants with dementia made comments like, "There is strength in numbers, we felt normal," "The best thing is the people," "Getting into the real world. I've been in a good mood all the way," "I don't see how it could be better." In summary, both the focus groups and take-home evaluations revealed that participants valued being with others in similar situations and they also found pleasure in the activity itself. Many caregivers commented on the importance of being challenged and felt they grew from the experience. People with dementia also enjoyed the opportunity to stretch their abilities and find out they could learn something new.

Over time, chorus members have learned many new songs and their singing continues to improve. Participants report that they sing these songs at home between rehearsals. Everyone sings together and there also solos and duets. We have observed that chorus members with dementia are able to sing canons, learn solos, and retain new information from one week to the next. The repertoire has included many canons (A canon is a piece of music in which two or more voices (or instrumental parts) sing or play the same music starting at different times.), as it appears that the members enjoy them, and this style of music promotes musical harmony and better listening skills. We include solo pieces in every performance, including soloists with dementia as well as caregivers; singing a solo seems to give a sense of empowerment and identity to participants and make them feel special; they appear to enjoy the attention from the rest of the chorus as well as the audience the day of the concert. Several members who never sang in public before were soloists in one or more concerts.

Initially, the chorus was intended to stop meeting after the pilot study was completed. The participants did not want the chorus to end with the pilot study, so they have continued to rehearse and perform regularly. Since the pilot study ended, operational costs for the original chorus have been covered partly by contributions of members. Of the 11 couples that initially joined the chorus, none dropped out unless there was a death or nursing home placement of one member of the dyad (although one couple was not available for follow-up assessment in the initial pilot study); several family members continued to sing with the chorus after the person with dementia could no longer participate. Many members of the chorus have become friends and meet for lunch or dinner outside of rehearsals and visit those who become sick. More than six years later, the chorus continues to perform regularly. Since the inception of the chorus, 42 dyads have participated.

The qualitative and quantitative assessments of the chorus establish the feasibility of the chorus and initial evidence of its efficacy. The information obtained by different approaches to data collection supported and enhanced the conclusions: The experience was validating and pleasurable for the couples; the conductors and staff created a nurturing and stimulating environment central to the chorus experience.

Discussion

Although public media abounds with observational and anecdotal reports on the benefits of activities involving music for people with dementia, rigorous studies in support of these observations are scarce. As was noted in a 2009 article in the Lancet Neurology (Burton, 2009), "The observational and anecdotal evidence that different types of arts-based therapies can improve the quality of life for, and even cognitive function of, patients with dementia is huge…" Creating music for others is a meaningful and worthwhile contribution to society and is a very popular activity; 18.1% of households in the USA in 2009 report at least one adult sang regularly in a chorus, or an estimated 32.5 million adults (Chorus America, 2009). Participating in a chorus is a multi-faceted experience that includes activating parts of the brain that may be relatively undamaged by AD until the latest stages, remembering songs from earlier years and learning new ones, socializing, and giving pleasure to others through performance.

To our knowledge, this is the first community chorus for people with dementia and their family members that rehearses regularly for public concerts (a similar chorus for people with Parkinson's disease and caregivers has reportedly had great success (www.trembleclefs.com). The intervention was designed as a pleasurable normative experience with a purpose. Unlike a sing-along, intended to provide pleasure in the moment, participants take seriously the fact that they are rehearsing for a concert. Singers can feel satisfaction and derive a sense of accomplishment from the enthusiastic feedback of the audience. The concerts are well publicized by the NYU Langone Medical Center and have been covered locally and nationally by newspaper, on-line, and TV reporters. Thus, the chorus not only offers an opportunity for a high quality and rewarding experience for the singers, but also can be enjoyed by the audience and educate the wider community about the possibility of shared pleasure with people with dementia. The performances and associated media attention have

provided visibility to the enormous potential of the arts to enhance the well-being of people with dementia and their family caregivers.

The conductors reported witnessing many "special moments" during rehearsals and concerts. For example, couples sometimes hold hands and look in each other's eyes as though they were first dating. They have been overheard making jokes. Often, lyrics seem to bring back memories and healthy communication. They seem to be singing from the heart, while moving to the music or spontaneously dancing together. The onlooker can feel the joy in the performers. A vignette can illustrate the atmosphere created by the chorus. At one recent concert, the program included, "New York, New York," made famous by Frank Sinatra and well known to most members of the chorus and the audience. The introduction was played by the piano several times, accompanied either by members clapping, tapping their feet, snapping their fingers or singing "na, na, na." When they began the first verse of the song, one couple spontaneously stood up and began dancing together, while singing and smiling at each other. A few bars later, another couple stood up and began dancing, too. Then, with encouragement of the conductors, members of the audience joined in singing with the chorus and clapping in time to the music. There was a sense of community, in which, at least for a time, it did not matter whether or not a participant had dementia. The chorus provides a shared activity that feels normal, and participants can enjoy the moment, rather than feeling isolated. It creates a community in which people feel supported and comfortable about having, and caring for someone with dementia.

The quantitative results suggest that the chorus had greater benefits for the people with dementia than for their caregivers. It could be that the chorus plays a larger part in the lives of people with dementia, and therefore is more likely to have an impact on global outcomes such as their quality of life. However, the qualitative outcomes suggest that both caregivers and people with dementia had consistently positive reactions. Moreover, the fact that they continue to attend the rehearsals and concerts, some even after the nursing home placement or death of the patient, suggests that they benefit from the chorus. Perhaps more weight should be put on the qualitative than the quantitative outcomes, as the sample size is so small, and the variability in measures is so large, that statistical tests can be misleading. The medium to large effect sizes estimates for many outcomes for both caregivers and people with dementia suggest that a larger sample would be likely to yield more statistically significant results.

Stigma has been identified as a major barrier to seeking a diagnostic evaluation (Koch and Iliffe, 2010; Batsch and Mittelman, 2012), and reflects an unfortunate perception in society that reinforces the isolation of people with dementia. There is a widespread assumption that people with dementia cannot partake in ordinary activities. There is also a widely held belief that they have no quality of life or capacity to contribute to society in a meaningful way. While the symptoms associated with dementia affect the way a person with dementia interacts with others, dementia should not preclude the affected person and his/her family from engaging in pleasurable and stimulating activities that have the potential to counteract the isolation that can be a consequence of the negative stereotypes associated with dementia. In addition to the evidence of positive outcomes for participants from the pilot study in New York, and perhaps at least as important, from the perspective of counteracting stigma, is the enthusiastic response of the audience at the concerts as well as the media exposure. Many who have witnessed the concerts have commented that it is very difficult to figure out who has dementia, as everyone seemed normal.

Psychosocial research on dementia care has made it clear that social engagement, environmental support, and an emphasis on the remaining capabilities and heretofore unexplored strengths of the person with dementia can do much to improve his or her quality of life, and the well-being of those who provide care. Many of the participants in the Unforgettables had never sung in a chorus before, and some discovered vocal talents of which they had been previously unaware. The chorus is an exemplar of the paradigm of social health (Vernooij-Dassen and Jeon, 2016), illustrating the potential for living well with dementia. The chorus provides participants an opportunity for both social engagement and for the pleasure of contributing to the community through its concerts, reducing the limitations imposed on people with dementia and by association, on their family caregivers, by stigma and social isolation. The capacity of participants with dementia to learn new songs challenges the belief that capabilities of people with dementia cannot be maintained or improved. This suggests that new research efforts should focus on the possibility that participation in activities such as a community chorus will not only provide enjoyment for all involved, but also slow, or perhaps even reverse some of the cognitive decline associated with dementia.

This program can serve as a prototype for others to emulate, and be a source of enjoyment and connection for participants and the concert audience. This pilot project has provided us with

the experience necessary to create a model program that will provide much-needed visibility to the enormous potential of the arts to enhance the well-being of people with dementia and their family members. We have written an initial training manual for setting up and implementing the chorus so that other groups can benefit from our experience. More widespread availability of opportunities that include rather than segregate people with dementia can do much to reduce the false beliefs and stigma that currently impede diagnosis, treatment, service delivery and the dignity, and personhood of people with dementia.

Limitations

The sample size of 10 dyads was too small for a definitive statistical analysis, and this was a pre-post, as opposed to a randomized controlled trial. It should be noted that caregivers had very few symptoms of depression, so that there was little possibility of improvement in that outcome. We did not have the resources to conduct a formal qualitative analysis, although the focus group results did reveal consistent themes related to the benefits of participation. The positive self-image reflected in responses of the people with dementia at both intake and follow-up may have resulted from sampling bias or the tendency of many people at this stage to deny their limitations.

Conclusions

Families care for the vast majority of individuals with Alzheimer's for most of the course of the illness. These caregivers have been called the "hidden victims" of AD because they too are deeply affected by the illness, and must adapt to its consequences – not only to their relative with the illness, but also to their relationship with that individual and its impact on their social lives. There is an urgent need for evidence-based management and intervention strategies to improve the quality of life for the affected individuals and their family members.

We believe it is essential to develop an evidence base not only of the psychological benefits of participation in shared pleasurable experiences for people with dementia and those who care about and for them, but also of the potential for improvement in cognitive function. We were surprised and gratified by the fact that participants with dementia were able to learn new songs. A large multi-site rigorous study of a chorus like the Unforgettables should include tests of cognitive function of the people with dementia to begin to test the hypothesis that active participation in producing music can slow or even reverse cognitive decline. Encouraging results could provide justification for more expensive studies including brain imaging to evaluate effects of choral signing on structural or functional changes.

A chorus like the Unforgettables can be provided at relatively low cost in any country where music is appreciated, providing joy to participants, reinforcing their connection to the community, and reducing the stigma of dementia. Until a drug is developed that halts or slows the progression of dementia, psychosocial interventions such as the chorus we have designed can provide pleasure to many people, has no negative side effects and may have cognitive as well as emotional benefits.

Conflict of interest

None.

Description of authors' roles

Mary Mittelman founded the chorus, formulated the research questions, designed, and supervised the study, carried out the statistical analysis and took the lead on writing the manuscript. Panayiota (Tania) Papayannopoulou has been conducting the chorus with Dale Lamb since its inception, and co-authored the manuscript.

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