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Two Professionally Led Choir Programs: Empowering People with Dementia and Their Care Partners

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Case Study

Two Professionally Led Choir Programs: Empowering People with Dementia and Their Care Partners

by Helen Kivnick, PhD, LP, LICSW and Debra Sheets, PhD, MSN, RN



Educational Objectives

Identify the benefits of participation in a community-based choir for persons with dementia (PwD) and their care partners.

1. Describe the work of the choirs to show the potential of living well with dementia.
2. Identify the ways in which the choirs address stigma and social isolation.
3. Highlight lessons learned and future directions from this social movement.

Background

In 2019, the estimated number of people with Alzheimer's disease and related dementias (ADRD) was more than six million in North America, with dementia rates projected to nearly double by 2031 because of the large boomer population and increases

in longevity. No medical cure is expected anytime soon. Most of us have had personal experience with dementia and know the significant medical, financial and emotional impacts it has on families. There is an urgency to develop low cost and effective community-based programs that support people with dementia and their care partners.

Stigma represents one of the biggest barriers to living with dignity following diagnosis. Many older adults with dementia fear stigmatization and would not want others to know they have dementia. It is, therefore, all too common for those with dementia to become socially isolated, a condition that poses health risks comparable to being sedentary, smoking 15 cigarettes a day, or being obese (Holt-Lunstad, et al., 2015). It is also a strong predictor of mortality (Holt-Lunstad, et al., 2010).

How can we address the deleterious effects of stigma and social isolation associated with dementia? Arts-based approaches are unique in shifting attention from disease-related declines and losses toward innovation and creative action. Among such interventions, community choirs have garnered increased interest as a result of promising findings from several pilot studies (Bannan & Montgomery-Smith, 2008; Camic, et al, 2011; Unadkat, et al., 2016). For example, Bannan & Montgomery Smith (2008) found that persons with dementia (PwD) involved in group

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singing had increased engagement, better recall, and were able to learn new music. In another pilot study, Camic et al., (2011) found that even as PwD choir participants deteriorated, quality of life for them and their caregiver remained stable.

Singing in a choir is also associated with positive outcomes that include improved mood, increased energy, reduced stress, and higher self-esteem and confidence (Johnson, et al., 2015; Johnson, et al., 2013). Recently completed research on a community choir intervention to promote well-being among diverse older adults (N=390), although none with cognitive impairment, found that participants experienced significant improvements in loneliness and interest in life, compared to controls (Johnson et al., 2020).

Similarly, choral participation for PwD and care partners has been shown to facilitate stronger relationships within dyads (Dingle, et al., 2012; Han & Radel, 2016), to promote positive affect in care partners (Han & Radel, 2016), and to foster improved general health and well-being for the “duets,” that is, PwD and their care partners (Dingle, et al., 2012; Holt-Lunstad et al., 2010).

Raising Our Voices for Those with Dementia

We write as representatives of two non-profit organizations, one in the USA and one in Canada, that offer community-based choirs for people with mild to moderate dementia, also called ADRD, and care partners. *Giving Voice*, based in Minneapolis, MN, directly sponsors five choirs in the Twin Cities, and has provided inspiration, a toolkit, and ongoing support for over 42 additional choirs in the USA and internationally. *Voices in Motion*, based in Victoria, British Columbia, directly sponsors six choirs and has provided support for at least three other choirs in Canada.

Giving Voice was co-founded in 2014 by two women with high-level experience in administration, Alzheimer’s disease, and radio production. In addition to being long-time friends, both women had lost a parent to Alzheimer’s disease; they were eager to create something positive from their personal loss that would benefit PwD, their families, and communities experiencing ADRD stigma. They established *Giving*

Voice in collaboration with the Minneapolis MacPhail Center for Music’s “Music for Life” program.

Voices in Motion (ViM) was inspired by *Giving Voice* and launched in 2018 by an interdisciplinary research team (i.e., music, nursing, psychology, and sociology) at the University of Victoria in British Columbia. Research funding came from the Alzheimer’s Society Research Program (ASRP) and the Pacific Alzheimer’s Research Foundation (PARF). The research involved two community-based *ViM* choirs conducted over 18 months. The *ViM* study investigated the impact of participation in a professionally directed community choir for ADRD on measures of stigma, social connections, and well-being for PwD and their care partners.

Our Choir Programs

Although our choruses are “therapeutic,” we have deliberately not organized them as music therapy or linked them to medical treatment. They are intended as arts-based, high-quality music participation programs that are “healing,” making one whole (Kivnick & Erikson, 1983; Cohen, et al., 2006). Both *Giving Voice* and *Voices in Motion* choruses spring from the conviction that older adults with chronic disabling conditions are also people who retain skills, abilities, competencies, and have the potential to contribute to the lives around them. They remain people who, like all of us, need to be needed, want to be useful, and are capable of experiencing joy. *Giving Voice* and *Voices in Motion* provide these opportunities

Participants in both *Giving Voice* and *Voices in Motion* rehearse weekly, for up to two hours. We do not require a background in music. Each choir consists of 50+ singers, including people with mild to moderate stage ADRD, care partners, and volunteers. Care partners include spouses, siblings, friends, children, and grandchildren. Volunteers include community members with interests and expertise in music, music teaching, gerontology, ADRD, and other related areas. Increasingly, volunteers also include care partners of chorus singers who have died or moved into residential facilities. *ViM* is an intergenerational choir; 20 students from a local high school volunteer in order to get community service credit. Volunteers primarily assist ADRD singers whose care part-

ners sing in other sections. They also help prepare member music resources and organize the social time snacks described below.

These year-round programs include a fall season and spring season (each 12 to 14 weeks). *Giving Voice* offers an eight-week summer season. *ViM* will offer a bi-weekly “Music in the Garden” drop-in choir for choristers across all three choirs for the first time this summer to ensure opportunities to get together and sing. Rehearsals are run by a professional Choral Director/Vocalist who is “equal parts music director and cheerleader.” *Giving Voice* uses a professional accompanist; the *ViM* Director accompanies herself. All participants wear name tags.

Musical repertoire is chosen to facilitate social connection and to stimulate memories and emotions. Repertoire explicitly includes songs from the past, songs in different languages, songs that require movement, and contemporary songs with which participants may be unfamiliar. Each member receives a notebook each season, with the season’s repertoire in both sheet music and lyrics-only format. Members also receive practice CDs for each season, to support practicing between rehearsals. In addition to working on three to five songs, each rehearsal includes 10-15 minutes of directed physical movement to live music, and at least one “Music and Me” presentation, in which a member describes their personal history with music. Good. Bad. Funny. Who knew how much history we all shared? Weekly sessions also include social time where members mingle informally, enjoy snacks and beverages, and, over time, come to know each other across choir sections. In addition to invited performances, each season ends with a public performance followed, the next week, by a debriefing session.

The Choir as Intervention

ViM’s mixed methods research design involved participants from two choirs over an 18 month period. Sample size for the two choirs was 64: 32 care partners (usually spouses or adult children) and 32 PwD. (Data gathered from the high school students is not reported here.) IRB approval was obtained from the University of Victoria, BC, Canada. Over the course of the choir season, participants underwent compre-

hensive assessments every four to six weeks as part of an intensive repeated measure design. PwD and their care partners took identical assessments. Standardized measures were used to gather data during face-to face interviews using an assessment battery that included neuropsychological assessment, cognitive testing, physical assessments, gait mapping, and a quality of life survey. Care partners and PwD also completed a questionnaire to gather self-report data on physical health, medications, activities of daily living (ADL), social networks, caregiver burden, affect, depressive symptoms, quality of life, and more. Finally, choir participants engaged in a semi-structured, in-home interview lasting about one hour.

Research findings indicate that *ViM* is having significant impacts on care partners, PwD, and students; findings are summarized below.

Care partners. Analyses show that levels of care partner distress significantly decline ($p < .05$) over the choir season, and that distress increases again during the choir break over the summer. Levels of distress decline again upon resuming the following choir, supporting a conclusion that the choir is causing this effect. Care partners also experienced a significant cognitive boost with increases in episodic memory, i.e. word recall, ($pp < .05$) and reduced depressive symptoms ($p < .05$).

PwD. Surprisingly, cognition improved significantly ((i.e., Mini-Mental State Exam (MMSE)) ($p < .05$) for choir participants with dementia. We suspect that this is not because the disease process changed but rather it suggests how the stigma of dementia prevents people from functioning at their optimal level. In a welcoming place like the choir, PwD are able to function at their best. Similarly, scores on episodic memory significantly increased, indicating improvement in ability to recall a list of 30 words provided earlier in the assessment. In short, the choir offers a boost in PwD’s cognition by reducing stress. Depressive symptoms were significantly reduced from minimal to no symptoms.

Students. Qualitative findings indicate that the intergenerational component added value to all participants’ experiences of the choir. Focus groups with students found shifts towards more positive views of

aging and of dementia. One student stated: “When you hear people just talking about people suffering from memory loss, you just assume that they’re very old and near death. But I think this choir solidifies the whole concept of human dignity and . . .how these people are still very much here and they’re very present and they still have these personalities that are just incredible. And I think the stigma surrounding something like memory loss is just so, so stupid.” One older singer said: “I just love seeing the kids here. We live in a senior complex with too many old people. All our friends are old, my husband is old. I’m just so . . . sick of old people.” Music was a catalyst for the formation of an intergenerational community that resulted in new friendships and social connections.

Qualitative Research Findings

Both choirs have conducted qualitative research based on open-ended interviews with members and staff, and on ongoing participant-observation during rehearsals and performances. Thematic analyses of chorus benefits by participant group are summarized in Table 1.

Case Study #1: Voices in Motion

Virginia is an 85-year-old widow who has always sung in community choirs. A few years ago, dementia terminated her participation. She could not follow the music and the choir was not able to accommodate her need for support. Carolyn, Virginia’s daughter, moved in with her about 18 months ago when her business failed. About the same time, it became clear that Virginia needed additional support to continue to live in her home as her dementia progressed. However, in the last year, Carolyn has experienced increasing stress as Virginia’s dementia progresses. Virginia has no close friends, for most have died. Both Carolyn and Virginia are increasingly isolated. Social activities centered around trips to the store or going out to eat together. No other family members live nearby. Carolyn has never belonged to a choir before. She didn’t think she could sing and viewed bringing her mom to the choir as one more “task” to do.

During the first season, Carolyn’s resentment at additional strain imposed by attending and participating in the choir rehearsals gradually evaporated. She met other care partners she felt she could “vent to” be-

Table 1. Summary of Choir Participant Benefits by Group

<p><u>PwD</u> Affective (Individual) Joy (singing; good mood) Energy / relaxation Identity other than Alzheimer’s Increased self-esteem, confidence Misc. emotions (laugh/smile; tears; light-in-eyes) Social Health Belonging; Being welcome Shared experience Egalitarian participation; Ownership See/help others New friends; Ordinary friendship Moving / Hugging Transcendent Hope; Purpose Spirituality Healing “Rejoin human community” Choir-Audience Reciprocity Change attitudes Admiration / Respect</p>	<p><u>Care Partners</u> Enjoyment / Heartwarming New friends Relief from Caregiver burden Rediscovery Personal growth</p> <p><u>Couples</u> Changing roles “Breathes oxygen into the relationship” Togetherness/family outside rehearsal</p> <p><u>High School Volunteers</u> (Where applicable) Meaningful contact/communication with older adults Recognition of human dignity in “these people” Enjoyment New friends Helping others</p>
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cause they understood her situation. She enjoyed the respite of being in a different section from her mom and simply focusing on learning her part in the choir. It was wonderful to see her mom smiling and singing across the room with a high school student who was becoming a close friend. Over time Carolyn became even more committed to *ViM* than her mother, as she discovered their relationship deepening as they regularly sing together with the practice CD.

Case Study #2: Giving Voice



75-year-old Rob was diagnosed with Alzheimer's after losing a second job for poor performance. After

retiring, he occupied himself with long-time hobbies that included listening to long-beloved opera recordings, woodworking, and reading. But he gradually stopped being able to concentrate on anything. Rob and his wife Kate had joined an Alzheimer's Association Memory Club, where they learned about the disease and its progression, and shared stories and survival strategies with other couples. Their group provided peer support for one another. They commiserated about being dropped (sometimes not so gently) from groups in which they had participated for decades. Over lunches and dinners, they shared coping strategies and funny stories. But as Alzheimer's progressed among the peer support group, some members stopped being able to socialize, some entered memory care, all became increasingly fragile, and the group disintegrated.

Although Kate was eager to serve as a volunteer, she was adamant that "For us, this chorus has to be something we share. Something for both of us. I'm happy to help a soprano with Alzheimer's, but I refuse to be Rob's caretaker in here." So Kate buddied up with a soprano with Alzheimer's, and volunteers vied for the privilege of helping Rob follow his lyric sheets. Within the first several weeks of rehearsals, Rob established himself as jokester-in-chief. He began telling the Music Director, "In here, I feel like myself again." At each rehearsal, a different member shared their personal singing history. Surprisingly quickly, this gathering of "lovers of singing, with personal Alzheimer's connections" became a com-

munity whose members looked forward to being together each week and part of a chorus where they all belonged. One day Rob asked the Music Director, "Are the men singing a quarter note or an eighth note at Letter 'E'?" Flabbergasted, she replied, "Rob, you use the lyrics. How can you be asking that question?" Rob was nonchalant. "I remembered how to read music." Over with the sopranos, Kate beamed.

These stories illustrate specific benefits of choir participation. In Case #1, we see how both care partner and PwD benefit from new social connections and a shared activity that strengthens their mutual relationship. Case #2 shows how the choir helped restore a PwD's sense of self and supported his optimal performance despite memory loss.

Lessons Learned

A number of lessons can be drawn from both programs. First, the personality of the professional choir director is crucial; she/he must be able to make the choir fun, challenging, and achievable. The choir director is also social facilitator; so she/he must be comfortable helping people to get to know one another through all choir activities. Second, choirs need administrative support to help with recruitment, concert planning, photocopying, collating music notebooks, coordinating volunteers, organizing refreshments, and more. Third, a carefully selected Board of Directors is critical to the long-term sustainability of these choirs and to reflecting participant preferences in decision-making. Fourth, well-chosen partnerships (e.g., high schools, Alzheimer's Associations, caregiver organizations, churches) can enrich and support these choir programs. Fifth, a few passionate people can make programs like ours happen in their own communities. These programs are socially compelling and their positive impact on health and well-being, as well as overall community vitality, is supported by a growing body of research, not only for PwD but also for all participants and audience members. Moreover, an energetic network of dementia choir programs is helping this social movement and its new programs to grow. In broader psychosocial terms, we are seeing choir programs like these promoting the vital involvement that Erikson and colleagues (Erikson et al., 1986; Kivnick & Wells, 2014) have defined as meaningful, reciprocal

engagement between self and outside environment; these scholars have identified vital involvement as the fundamental dynamic for creating and maintaining psychosocial health.

Primer

Giving Voice has created a Toolkit (downloaded from <https://givingvoicechorus.org/>) that addresses the elements and FAQs of planning and running a high-quality chorus for PwD and care partners.

Giving Voice also sponsors a National Collective Leadership Gathering in Rochester, MN, in July. For two days, continent-wide staff, administrators, board members, and researchers of existing choruses and those still in planning share experiences and information, tell stories, brainstorm problems, report research, participate in exercises, and otherwise celebrate the potential of people with dementia.

Voices in Motion is currently developing an online “Train the Trainer” program to supplement an initial weeklong in-person training program on how to develop a community choir for PwD. The training program will launch in 2021.

Conclusion

Participants in all of our choirs are consistently impressed with the psychosocial benefits of involvement, whether as PwD, care partners, staff, volunteers, audience members, or guest composers. PwDs emphasize the importance of individual experiences of personhood, identity, competence, joy, purpose, hope, and friendship; they increasingly find themselves without such experiences as their disease progresses. To these benefits, care partners add welcome relief from burden, pride in their partner, regained intimacy, new relationships, and personal growth.

As important as these internal, personal experiences are, all participants express overwhelming feelings at being part of a wonderful group. Major health risks associated with loneliness and social isolation are increasingly recognized by practitioners and researchers of ADRD, in particular, and of aging, in general. Chorus participation counters pernicious disconnectedness with the belonging, cooperation, sharing,

and ownership that are natural parts of meaningful, regular social engagement. A newly arrived choir member recently told his choir, “I’ve only been here for these first two rehearsals. But this is a *real* choir. It belongs to all of you, you all belong to it, and you all belong to each other. That comes through so powerfully in the way you all sing together.”

Equally important is the dismantling of society-wide negative attitudes and stigma around ADRD. Audience members routinely find themselves wondering who among the singers onstage has dementia and who does not. Wrote one concert attendee, “[You] inspire all not only to have a better understanding of dementia, but also to advocate for those who are walking through this journey.” A volunteer contributed to a concert debriefing session, “A little boy was wriggling in his mother’s lap in the front row of the audience. I saw him point at the man who was comedically introducing the next song, and ask her ‘Is that Grandpa? He never does anything but sit with his eyes closed!’”

Study Questions

1. Explain two key benefits of participation in the dementia choir program on the health and well-being of: 1) a PwD and 2) their care partners.
2. Identify two ways in which these choirs can address dementia stigma and social isolation.
3. How can student participation in choirs contribute to a change in society-wide attitudes about dementia and aging?

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Drs. Kivnick and Sheets are equal co-authors of this piece.