


# An Intergenerational Choir Formed to Lessen Alzheimer's Disease Stigma in College Students and Decrease the Social Isolation of People With Alzheimer's Disease and Their Family Members: A Pilot Study

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## Abstract

The intergenerational choir was formed for the purpose of combating the stigma of Alzheimer's disease in college students, and in that process also lessening the social isolation of people with AD and their family members. The choir was composed of 13 college students and 13 people with AD and a family member. Data from the college students were gathered through semi-structured open-ended questions on attitudes and knowledge about AD, collected at three points in time over 8 weeks of rehearsals. Data were collected from the people with AD and their family members through a focus group and observations over 8 weeks of rehearsals. Results show a decrease in social isolation for the older choir members, and for the college students: a decrease in negative attitudes, an increase in positive attitudes and themes of - recognizing capabilities, expanded understanding of AD, reduced stigma, and reduced social discomfort.

## Keywords

Alzheimer's disease, stigma, intergenerational, music, dementia, contact theory

I have learned that music has the power to put all obstacles aside and connect you together.

(A 22-year-old college student participating in the Intergenerational Choir)

## Introduction

Once a person receives a diagnosis of Alzheimer's disease (AD), often that label then defines the person, resulting in feelings of social exclusion, "otherness," and marginalization of the person with AD as well as their family members. This experience leads to AD stigma, and though public awareness about AD is increasing, the stigma is still present. The purpose of this study is to reduce AD stigma in college students through participation in an intergenerational choir with people with AD and their family members. This is the first intergenerational choir formed whose sole purpose is to combat the stigma of AD and in that process also lessens the social isolation of people with AD and their family members.

This stigmatizing process was first proposed by Goffman<sup>1</sup> who described a process whereby social meaning with negative connotations is attached to behaviors and individuals. Stigma comes from a Greek word, which describes attributes

that indicate something out of the ordinary or bad about a person. It causes an individual to be judged by others as undesirable, "not normal," thus leading to stereotyping and rejection. As the person with the stigmatizing condition becomes more linked with that label through interactions with others, it often results in the negative consequences of lowered self-esteem and psychological well-being, decreased social support and social networks, and changed family dynamics.<sup>2-6</sup>

Aging often becomes a stigmatizing condition in our society. Thus, older adults may experience stigma from the stereotypes, myths, and misunderstanding that surround aging.<sup>7-9</sup> Butler<sup>10</sup> first coined the term ageism and related it to other

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forms bigotry such as racism and sexism. Negative stereotypes about aging are still pervasive in the United States and are harmful to older adult's psychological well-being, physical and cognitive function, and survival.<sup>8,11,12</sup> In addition, age discrimination, where people are treated less favorably because of their age, especially in the workforce, is becoming recognized as a social problem, as evidenced by a steady rise in age-related work-based discrimination claims over the last 15 years.<sup>13,14</sup>

College students, like the rest of the public, are not immune from holding ageist beliefs. Research has shown that negative stereotypes toward older adults are common in college students, most of whom have had little contact with older adults outside of family members.<sup>15-17</sup> However, students who have participated in service learning, which fostered positive interactions with older adults, have less ageist attitudes.<sup>18</sup>

Yet, there is 1 group of older adults who experience greater stigma, those diagnosed with dementia. There are also middle-aged adults (younger onset dementia) who experience this stigmatizing condition.<sup>19,20</sup> The most common form of dementia in the United States is AD. Presently it is estimated that 5.2 million Americans have AD and because of the increasing number of people aged 65 and older, it is estimated that by 2050, this number will almost triple to 13.8 million people with the disease.<sup>21</sup> Presently, worldwide more than 36 million people have dementia and by 2050 it estimated that 115 million people will be affected.<sup>22</sup> Thus, the stigma associated with dementia is a growing problem. The World Health Organization has noted that the stigma of older people with dementia has become wide spread and can have far reaching consequences.<sup>23</sup>

Husband<sup>24</sup> noted that the symptoms of dementia, cognitive decline, and memory loss, combined with societal negative responses to the diagnosis and symptoms can have profound psychological effects on well-being and quality of life. A number of people living with AD have written about their experiences with AD stigma. In a personal essay on the word dementia, Sterin<sup>25</sup> poignantly discusses the negative impact of the diagnosis on social interactions and self-concept. Taylor<sup>26</sup> in his collection of essays about his reflections of living with the disease stresses how much emphasis is placed on the negative label of AD and that the person with the diagnosis is forgotten. Finally, DeBaggio,<sup>27,28</sup> a former journalist and an herb farmer, describes his struggles with the impact of the disease on his memory and use of language, all of which helped define his sense of self and how people react to him. Also research has shown that one of the results of receiving a diagnosis of AD is that friends often withdraw, affecting the person's quality of life and well-being. There is much misunderstanding about the diagnosis; and with the communication difficulties inherent with the disease, these factors that can hinder a relationship. This withdrawal from friends adds to the diagnosed person's feelings of social isolation, depression, abandonment, and "otherness."<sup>29-31</sup> In 2007 and 2008, the Alzheimer's Association held nationwide town hall meetings with 301 people with early-stage AD or dementia and 500 caregivers and health care professionals. The impact of stigma was present in every discussion about diagnosis, recognition, and

symptoms.<sup>32</sup> There is also stigma by association experienced by family members.<sup>33-35</sup> Therefore, because of the growing concern over this stigma, the World Alzheimer's 2012 Report was completely devoted to overcoming the stigma of dementia.<sup>22</sup>

The report used survey data from over 2500 people with dementia and family members from 54 countries and also included qualitative interviews from people with dementia. The primary goal was to record individual experiences of stigma by people with dementia and family caregivers. The data showed overwhelmingly that both people with dementia and family members believed that there are negative associations for those diagnosed. In all, 75% of people with dementia responded that there was negative association, and 64% of caregivers agreed. Caregivers too are confronted by social stigma, stigma by association. Of the 4 caregivers, 1 (24%) reported that they faced negative experiences. The study concluded with 10 recommendations for overcoming stigma: (1) educate the public, (2) reduce isolation of people with dementia, (3) give people with dementia a voice, (4) recognize the rights of people with dementia and their caregivers, (5) involve people with dementia in their local communities, (6) support and educate informal and paid caregivers, (7) improve the quality of care at home and in care homes, (8) improve dementia training of primary health care physicians, (9) call on governments to create national AD plans, and (10) increase research into how to address stigma.

College students, a main focus of this study, combined with their ageist beliefs (discussed previously) have limited exposure to and knowledge of dementia.<sup>15,36</sup> Thus, they too have many misunderstandings and stereotypes about people with AD, resulting in AD stigma. Yet a service learning project with medical students to educate them about AD has had positive effects.<sup>37</sup>

### *Conceptual Underpinnings*

The conceptual framework on which this study is based is intergroup contact theory. It was first proposed by Allport<sup>38</sup> in his seminal work on the nature of prejudice. The main concepts of the theory are that contact between different groups under optimal conditions could reduce intergroup prejudice. Specifically, Allport outlined 4 important features of the groups that would need to be present for the contact to be effective: equal status among the group members, common goals, intergroup cooperation with consistent and meaningful contact, and support by authorities. Over the past 60 years, there has been extensive research based on this theory with mixed findings.<sup>39-46</sup> However, Pettigrew and Tropp<sup>47</sup> did a meta-analytic test of intergroup contact theory across 515 studies and found that intergroup contact typically does reduce intergroup prejudice and not only in regard to race and ethnicity but across a broad range of groups as well, including intergenerational groups. The meta-analysis also found that the optimal conditions are not necessarily essential to reduce prejudice, but groups that were carefully structured to meet these conditions achieved a markedly higher effect. As will be discussed in the methods' section, the intergenerational choir was structured

with these optimal conditions in mind. In addition, Pettigrew and Tropp found that intergroup contact effects were typically generalized to the larger population outside of the immediate contact context. Intergenerational research, using various forms of service learning, also confirms intergroup contact theory. Children and young adults' attitudes about older adults can be positively affected by interactions with older adults.<sup>48-50</sup>

The other concept used to guide this study can best be described as "the benefits of music." O'Connor and McFadden<sup>51</sup> suggest contact with people with dementia can produce positive attitude change, especially when these relationships occur in programs that encourage creative expression; making music is such an endeavor. Specifically, research has shown that music can add to the quality of life and well-being of older adults as well as act as a portal through which they can connect and interact with others in meaningful and positive ways.<sup>52</sup> There are a number of literature reviews that have demonstrated the potential of music therapy for people with dementia.<sup>53-56</sup> Music therapy has been used as a way to improve care, lessen agitation and behavioral disturbances, and increase engagement and communication in residents with dementia in nursing homes.<sup>57-64</sup> Most studies focus on the biomedical benefits of participating in a music therapy program. However, as Beard<sup>56</sup> points out, music as an activity program, not as a therapy, can enrich the lives of people with AD and their family members. These studies show music can be a vehicle that can foster social cohesion and contact in people with dementia and their caregivers through providing meaningful, shared, and enriching activities. Sixsmith and Gibson<sup>65</sup> examined the role of music and music-related activities in the everyday lives of people with dementia and their family members and found music was a source of social cohesion, social support, and empowerment. It affected the positive well-being of the people in the study. A full range of different types of musical activities was included in the study, including singing together and performing for others. The "Singing for the Brain" study,<sup>66</sup> a pilot study of group singing of people with AD and their caregivers, showed engagement increased, music facilitated recall, and new music could be learned. Camic et al<sup>67</sup> developed a "Singing Together Group" for people with dementia and their caregivers and found that the participation promoted well-being among the participants and engagement levels were high.

This study on AD stigma chose an intergenerational choir as the intervention through which to combat the stigma. A choir was chosen for 3 reasons: (1) because it meets many of the World Alzheimer's 2012 Report's recommendations<sup>22</sup> (stated earlier) on how to overcome stigma associated with dementia; a choir by virtue of its nature can reduce isolation, build community, give people a voice, and educate through intergroup exposure and public presentation; (2) a choir can reduce prejudice based on the psychosocial theory of intergroup contact, and (3) music has the power to bring people together and promote social contact (see research earlier) through a shared common interest and expressive blending of voices. Music cuts

across all generations and can evoke positive emotions and produce enjoyment.

In order to lessen this stigma in college students, 3 components of stigma need to be addressed: (1) knowledge (ignorance), (2) attitudes, and (3) behavior.<sup>68</sup> Thus, the 2 research questions, 1 primary and 1 secondary, which guided this study, were

1. Could participation by college students in an intergenerational choir with people with AD and their family members lessen misunderstandings about people with AD, increase knowledge about the lived experience of AD, and change the behavior of undergraduate students toward people with AD, in other words lessen stigma?
2. Could social isolation be lessened in people with AD and their family members who participated in the intergenerational choir?

## Methods

### Intervention

**Participants.** In all, 13 undergraduate college students and 13 people with early-stage dementia or mild cognitive impairment (MCI) and a family member were recruited for this study. The size of the choir (N = 26) was limited by the size of the music practice room on the college campus and the short recruitment time (3 weeks). The people with dementia (N = 6) and family members (N = 7) were recruited through the local Alzheimer's Association chapter by letters and announcements at their support group meetings. Inclusion criteria were (1) a diagnosis of early-stage dementia or MCI (diagnosis was made previous to this study by local medical centers), (2) membership in an early-stage support group run by the Association, (3) enjoyment of singing (though no previous choir experience was necessary, most people had sung previously in a choir), (4) accompaniment and participation by a family member (1 family member did not sing but came to every rehearsal and participated in the social component), and (5) commitment to attend 8 weeks of rehearsals and the concluding performance. Of the people with early-stage dementia (N = 6), 4 had a diagnosis of AD and the other 2 were diagnosed with MCI. They were equally divided between female (N = 3) and male (N = 3); the mean age at the time of the study was 72.5 years with a range from 61 to 85 years, and 5 were caucasian and 1 African American. All but 1 either attended or graduated college, and their occupations varied from housewife to artist and lawyer. Of the 7 family caregivers who participated in the choir, 5 were spouses (2 husbands and 3 wives), 1 was a son, and 1 was a granddaughter. The average age of the family members was 72.3 years, with a range from 32 to 77 years, and 5 were caucasian and 1 African American. All either graduated college or posthigh school professional training. Their occupations varied from dental hygienist to artist to businessman.

The 13 undergraduate college students were recruited from a liberal arts college in the midwest of the United States.

Announcements were made in an aging studies course, e-mails sent to students who had participated in musical events on campus, and news of the choir was spread by word of mouth by students. Any interested student had to be separately screened by the researcher and the choir director. Criteria for inclusion were (1) full-time undergraduate student, (2) prior experience singing in a choir, (3) no knowledge or experience with AD was required, (4) commitment to attend 8 weeks of rehearsals and the concluding performance, and (5) attendance at an hour orientation/information session about AD, before the choir rehearsals began. All the student choir members were female, with a mean age of 19.8 years and a range of 18 to 22 years. Of the 13 students, 4 (31%) had a family member with AD. Only 1 student had a good knowledge about the disease (assessed through self-report and researcher's assessment). In all, 3 (23%) students had some knowledge and 9 (68%) students had little knowledge. Of the 13 students, 5 (39%) were freshmen, 3 (24%) were sophomores, 1 (1%) was a junior, and 4 (32%) were seniors. Their major fields of study were also very diverse: 6 (46%) were majoring in the social sciences, 3 (24%) in the humanities, 2 (15%) in business, and 2 (15%) in the sciences.

Attrition during the 8 weeks was very low. No people with AD or their family members dropped out of the choir. Only 1 student dropped out after the fifth week of rehearsals, a freshman (a first-year student), because of academic pressures and other campus obligations.

### *Procedure and Goals*

The study was approved by the University's institutional review board committee for the Protection of Human Subjects before the recruitment started. Once the students were recruited, they attended a mandatory 1 hour orientation/information session on AD and the experience of living with AD. The researcher attended all rehearsals and was available for questions. The researcher also called the AD support group members, who were joining the choir, to answer any questions or concerns they might have. During this time, the researcher and choir director were meeting, calling, and e-mailing frequently to plan how to structure the choir to foster social interaction, to select the musical repertoire, and to discuss possible challenges that might arise and how best to handle them. It was also decided that the choir's concert would be tied to an annual AD educational event that the researcher organized on campus for the local community. In keeping with intergroup contact theory, it was important to have a shared goal (the concert) for the choir to work toward. Given that time frame, the choir met weekly for 8 weeks with rehearsals lasting for 90 minutes. Such a time-limited intervention is not unusual and has been found to be effective in the mental health field.<sup>69</sup>

The overarching goals of the choir were to reduce AD stigma and lessen social isolation. The specific objectives of the intervention were to (1) increase students' awareness of the strengths that remain in people with early-stage dementia; (2) lessen the misunderstanding students have about people with

AD and their caregivers; (3) provide opportunities for students to see how people with AD respond and handle challenges; (4) give people with AD and their family members an opportunity to interact with college students and teach them about the lived experience of AD; (5) give the person with AD and their family members an opportunity to express their felt stigma; (6) lessen social isolation of people with AD and their family members; and (7) provide an enjoyable social musical experience.

### *Structure of the Choir*

In order to meet the objectives (stated previously), it was essential to foster social interaction and contact between the college students, and people with AD and their family member. Therefore, a great deal of thought went into how best to accomplish this, keeping the principles of intergroup contact theory in mind. The following structure was used: (1) the choir, instead of usually sitting on risers in front of the choir director, sat more informally in a circle, so everyone faced each other; (2) students, starting with the first rehearsal, were "buddied up" with a person with AD and their family members, and they sat next to each other during most of the rehearsals (this was explained to the students during their orientation session and ideas for possible conversation topics were suggested); (3) at the beginning of each rehearsal, time was given (15-20 minutes) for socialization, a chance for the "buddies" and others to talk with each other; (4) after the socialization time, the researcher would take 5 minutes to update the choir, make announcements, and answer any questions. This was always done in a light, upbeat manner; and (5) the choir director, who also used an upbeat and humorous approach, had the group do a few minutes of warm-up stretching exercises that included physical contact, before starting the singing.

Crucial to the structure of the choir and social interaction, all choir members were treated as equals and called by their first names, regardless of the age difference. In addition, the setting of the tone for the choir was introduced during the first rehearsal; it was that of acceptance, being nonjudgmental, working as a team ("we are all in this together"), and having fun. Humorous ice-breaking techniques were used during the socialization period of the first rehearsal for everyone to get to know each other.

### *Music Repertoire*

The selection of the music was critical for the message to come across. It was an intergenerational choir, with a specific goal, to lessen AD stigma among college students, but also through its performance, public misunderstandings about the capabilities of people with AD could be addressed. In addition, the choice of the music for the intergenerational choir had to appeal to both generations and, if not familiar, be easy to learn. Thus, much discussion between the choir director and the researcher took place around the choice of music. The researcher was particularly interested in the "message" or text of the music. In addition to paying attention to the message, the choir was also

cognizant about how “wordy” a song would be, looking for songs with more repetition, fewer rhythmic changes, and ones that were clearly laid out on a page. It took a few trial and errors the first week to find the right songs. However, 5 songs were decided upon that ranged from the Beatles, to James Taylor, to “We shall overcome.”

### Research Design and Measures

Data collection for the college students followed a repeated measure design with a pretest (T1), a test half way through (T2), and a posttest (T3) after the concert. Since AD stigma is a relatively new area of study, there are no well-accepted scales that measure AD stigma. There are 2 scales that have been developed to measure AD stigma<sup>15,51</sup>; however, these instruments focus more on biomedical knowledge, not the lived experience, affect, and the social relationships, which was the focus of this study. Another scale has also been developed, but it examined family stigma, stigmatic perceptions of adult children caregivers, and its impact on caregiver burden.<sup>70,71</sup> Therefore, given this is a new area of inquiry, a phenomenological qualitative approach was used to gather data, primarily drawing on the writings of Holstein and Gubrium<sup>72</sup> and Schutz.<sup>73,74</sup> A qualitative phenomenological method is particularly useful when there is limited knowledge about a phenomenon. This means that this inductive approach begins with individual experiences described through their words, and the findings are located within a specific context. Thus, in the context of the reported study, the words of the students were used to explain their knowledge, attitudes, and behavior toward people with AD. The words of the people with AD and their families were used to explain their experience with AD stigma and feelings of isolation.

Using an approach to assessing college students' understanding of people with AD similar to the one used by Sabat,<sup>36</sup> at T1 and again at T3 the students were asked, “When you hear the word AD or dementia, what images come to mind? Please write down 10 words that describe those images.” They were also asked, “If your parent asked you to spend an afternoon with a family friend who has AD, would you feel comfortable doing it?” In addition, at T2 and T3, students were asked to respond to open-ended questions, such as (1) What have you learned about AD, people with AD, and their family members so far from this experience? (2) What has surprised you the most from this experience? (3) Has this experience changed your ideas/images of people with AD and their family members? If so, how? If not, why? (4) Do you feel more comfortable around people with AD?

Data collection for the people with dementia and their family members was conducted through a focus group, using an interview guide to direct the conversation and observations. They were all members of AD support groups, so they were used to participating in group discussion. One focus group was held at week 6, and all the people with AD and their family members attended. The questions in the interview guide revolved around AD stigma: (1) if they had concealed their diagnosis; ever felt discriminated due to the diagnosis, and the impact the diagnosis had on close relationships and (2) their experience of being in the

**Table 1.** Students' Attitudinal Responses.

Score	T1 (N = 13) <sup>a</sup>	T3 (N = 12) <sup>a</sup>	% Change
Negative	60% (N = 78) <sup>b</sup>	18% (N = 22) <sup>b</sup>	-42
Neutral	25% (N = 32) <sup>b</sup>	17% (N = 20) <sup>b</sup>	-8
Positive	15% (N = 20) <sup>b</sup>	65% (N = 78) <sup>b</sup>	+50

<sup>a</sup>Number of students.

<sup>b</sup>Number of responses.

choir and their interactions with the students. Observations were made over the course of the 8 weeks, as regards attendance and the quality of their interactions with the students and other couples, that is (1) Did they seem more comfortable with each other? (2) Did their conversations become more natural and animated? (3) Did they appear to look forward to seeing each other? (4) Did they come earlier to rehearsals or linger longer after rehearsals to talk with each other?

### Data Analysis

The college students had 2 sets of data: (1) the 10 descriptors of AD collected at T1 and T3 and (2) the open-ended questions asked at T2 and T3. The 10 descriptors were scored as negative, neutral, or positive attitudes/images of AD and then compared at T1 and T3 for any change. The responses to the open-ended questions were analyzed by examining common themes that emerge from the questions related to AD stigma at T2 and T3, and comparing them. In order to be considered a common theme, it had to have been mentioned by at least 50% of the participants, and quotations were then selected that captured the essence of the themes.

The focus group for people with AD and their family members was taped with permission. The tape was transcribed and then compared with field notes for accuracy. The analysis consisted of a 4-step process: (1) the entire transcript was read in its entirety; (2) the transcript was reread to develop substantive codes for the narratives; (3) the codes were grouped into themes related to the AD stigma and their experience in the choir—in order to be considered a common theme, it had to have been mentioned by at least 50% of the focus group members, and (4) quotations were selected that captured the essence of that themes.

## Results

### College Students

As was mentioned previously, 1 student dropped out after week 5. However, of the 12 remaining students, 50% attended all the rehearsals, and the other 50% only missed 1 rehearsal. Everyone attended the performance. So attendance among the students was high.

*Attitudes/images of AD.* The sample size was small. Yet, looking at the trend and direction in the change in students' attitudes toward people with AD, as indicated by the change in their descriptive words/images of people with AD, participating in

**Table 2.** Students' Attitudinal Responses by Knowledge Level of AD.

Score	Low Knowledge			Medium Knowledge			High Knowledge		
	T1 (N = 9) <sup>a</sup>	T3 (N = 9) <sup>a</sup>	% Change	T1 (N = 3) <sup>a</sup>	T3 (N = 2) <sup>a</sup>	% Change	T1 (N = 1) <sup>a</sup>	T3 (N = 1) <sup>a</sup>	% Change
Negative	67% (N = 60) <sup>b</sup>	20% (N = 18) <sup>b</sup>	-47	54% (N = 16) <sup>b</sup>	15% (N = 3) <sup>b</sup>	-39	20% (N = 2) <sup>b</sup>	10% (N = 1) <sup>b</sup>	-10
Neutral	24% (N = 22) <sup>b</sup>	17% (N = 15) <sup>b</sup>	-7	23% (N = 7) <sup>b</sup>	20% (N = 4) <sup>b</sup>	-3	30% (N = 3) <sup>b</sup>	10% (N = 1) <sup>b</sup>	-20
Positive	9% (N = 8) <sup>b</sup>	63% (N = 57) <sup>b</sup>	+54	23% (N = 7) <sup>b</sup>	65% (N = 13) <sup>b</sup>	+42	50% (N = 5) <sup>b</sup>	80% (N = 8) <sup>b</sup>	+30

Abbreviation: AD, Alzheimer's disease.

<sup>a</sup>Number of students.

<sup>b</sup>Number of responses.

the intergenerational choir appeared to have an effect (see Table 1). At T1 and T3, students were asked to describe their images of people with AD, using 10 words. These words were scored by the researcher as negative, neutral, or positive. At T1, some examples of the most common negative words chosen by the students were sadness, nursing home, sick, helplessness, memory loss, forgetfulness, depression, loss of brain function, frustration, dependency, deterioration, and confusion; examples of neutral words were elderly, senior citizens, older adults, *The Notebook*, doctors, medicine; and examples of positive words: unity, caring families, love, patience, and tolerance. At T1 (see Table 1), N = 130 responses (13 students × 10 responses), the responses were overwhelmingly negative (60%) and only 15% were positive. By T3, N = 120 (12 students × 10), 18% of the responses were negative, a change of 42%, and 65% were positive, a change of 50%.

Table 2 divides the students by their knowledge of AD before joining the choir into low, medium, and high. It appears that regardless of level of knowledge, participation in the choir changed the attitudes/images toward a more positive direction. The percentage change (see Table 2) ranged from a decrease in negative responses from 10% to 47% and an increase in positive responses from 30% to 54%, with students with the lowest level of knowledge showing the most change. In addition, at T3 the range of positive descriptors also increased to include such words as helping, joking, laughing, needing guidance but not assistance, love of life, learning, determination, hope, remaining positive, and friends. Therefore, it appears that participating in an intergenerational choir has the potential impact of changing college students' negative attitudes/images of people with AD.

**Qualitative themes.** The themes that emerged from the open-ended questions asked of the students at T2 and T3 also supports the previously discussed changes. Four major themes that emerged around AD stigma at T2: (1) expanded understanding of AD, (2) reduced stigma, (3) reduced discomfort, and (4) capabilities of people with AD.

### Themes at T2

#### 1. Expanded understanding of AD (N = 9)

By participating in the intergenerational choir, 9 students discussed how the experience had increased their awareness and

understanding about living with dementia. The following are 2 examples of the students' responses:

This experience has somewhat broadened my idea of people with AD and their families. I have experience with my grandmother's early onset AD, but have learned no two cases are alike. This has given me a broader spectrum of what the disease is like and how individuals and families respond to the diagnosis.

Alzheimer's disease is a disease that scares me and has a negative connotation in my mind. However, the families we are working with never cease to smile or crack a joke. They overlook forgetfulness and focus on the love that ties them together. I also realize how slow this disease can progress. When I imagined AD previously, I only imagined the final stages where individuals were no longer able to function. This is obviously not true for the people in the intergenerational choir.

#### 2. Reduced stigma (N = 6)

Six of the students discussed how their experience with the choir reduced the differences they thought they had with people with AD. The following are examples of responses from 2 students:

I have learned that people with AD are really no different from anyone else. I have never really encountered someone with AD or known someone that has AD. This experience has changed the way I perceive people with AD; they can be just as funny and lively as any other person. It has made me put aside the fact that they have AD and treat them equally, as any other elder.

I have learned that these people are in the early stages and therefore act much like my own grandparents. They are loving, playful and want to be treated like other individuals. I enjoy being around the choir participants and find it very easy to interact with them. They are surprisingly sharp, quick witted and humorous people.

#### 3. Reduced discomfort (N = 9)

Feeling uncomfortable around people who have AD is a common experience and very much related to the stigma of AD. Nine students remarked how singing in the choir lessened their feelings of discomfort. Following are some examples:

I feel more comfortable around people with AD after participating in this choir. Working with these people made me realize that they are no different from any of us. Like students they love to sing, laugh, make new friends, and so many things. There are times that I forget they have AD.

The woman I am paired with reminds me of my grandmother. She has been warm and friendly toward me since the start. At first I was nervous that she wouldn't remember me on the subsequent weeks of practice, and honestly I'm not sure if she does or not. However, every week she sits next to me and talks with as if I'm an old friend. And I often forget about the age gap and the disease that divides us, and I look at these people as friends.

#### 4. Capabilities of people with AD (N = 6)

One of the goals of the study was to have students gain an understanding of the strengths that remain in people with AD, instead of focusing on the negative aspects. Six students commented on various strengths that they observed and had not realized before participating in the choir. Following are 2 examples:

What has surprised me the most was how well the people with AD manage. They definitely didn't allow AD to control their lives. Though they need help at times, they try to do things for themselves. They show you a whole other view of what it is to live with AD.

Their family members have patience and I applaud them for helping, but the people with AD are very independent and are capable and enjoy speaking for themselves, even if they have trouble remembering a word.

Thus, from the previous quotations, it seems that for the students, just by participating for 4 weeks in the intergenerational choir, the experience has increased their understanding about the lived experience of AD, increased their awareness about some of the strengths that remain in people with early-stage AD, helped them focus more on the commonalities between them, rather than differences, and made them feel more comfortable interacting with people with AD and their family members. These are all signs of the lessening of AD stigma.

*Themes at T3.* At time T3, from the 12 students' responses, there was a deepening of the themes above and more students discussed them; expanded understanding (N = 12); reducing stigma (N = 8); reducing discomfort (N = 11); and capabilities of people with AD (N = 9). In addition 2 more themes emerged supportive families and enjoying the time together.

*Examples of repeated deepened themes:*

#### 1. Expanded understanding (N = 12):

I have learned that sometimes it is more difficult for a family to deal with the diagnosis than the person. The family may be

worried about how others will react. I have noticed they are all at different stages of acceptance, and they went about handling the diagnosis in different ways.

#### 2. Reducing stigma (N = 8):

Although it is sad to admit, I felt my grandma [who has AD] was not 'really there' before. Now, I see that even though she had Alzheimer's, she is still my grandma. We need to look beyond the disease and remember the person that is still there.

#### 3. Reducing discomfort (N = 11):

I do feel more comfortable. I think the reason I felt uncomfortable was simply lack of knowledge and misunderstanding. I know realize AD is not something that should make me uncomfortable. I now see no difference in interacting with people with AD than interacting with any other adult, except for their memory loss.

#### 4. Capabilities of people with AD (N = 9):

Before doing this choir I thought how difficult life is for them and that they are probably living in senior care. I usually didn't consider how people with AD try not to let the disease define who they are. They don't let the disease hold them back. Their strength and hope is something I look up to.

### *New themes*

#### 1. Supportive families (N = 11)

As the weeks went by, students become more aware of the role of the family members in assisting their diagnosed member and commented on it.

I also have learned just how dedicated their families are to them. They all try to take part in their family member's life and it makes things easier for them.

I have learned that with family members, taking care of an individual with AD is sometimes difficult, but the amount of help they provide can also make it so rewarding for them. I have a new appreciation for family members. It takes much patience and effort to help a person with AD; so I respect family members greatly.

#### 2. Enjoying the time together (N = 10)

Many of the students originally joined the intergenerational choir because they like to sing and have enjoyed service learning experiences, which is how they defined their role in the research. However, by the end of the rehearsals, their pleasure from participating in the choir far exceeded their reasons for joining. Some examples are as follows:

I originally joined the choir because I love to sing and service is very important to me. But now I look forward to coming here

every Thursday. It is the highlight of my week. We have so much fun and laugh together. These are my friends.

I really enjoyed participating in the choir. It was great to take a break from studying and spend time laughing and making music with the choir.

I had such an awesome time and am going to miss it so much! I kind of wish there was even more time to socialize during the rehearsals.

Thus, again the narratives collected at T3 after the performance show the progression of the students in their understanding about AD and the lessening of social distance, as they felt more and more comfortable interacting with people with AD. They now consider them their friends, despite the diagnosis and age difference. In addition at T3, 7 students asked whether the choir could be continued. All 12 students, when asked whether they would feel comfortable spending an afternoon with a family friend, who had AD, answered, “yes,” but at T1 only 3 students said they would feel comfortable doing so.

Therefore, from both the assessment of the attitudes/images the students held about people with AD and the qualitative analysis of the themes that emerged from the open-ended questions, there appears to be evidence to show that participation in an intergenerational choir of college students and people with AD and their family members has the potential to lessen the stigma of AD in college students.

### *People With AD and Family Members*

All 13 people with AD and their family members participated in the focus group. The analytic framework from which the focus group data were examined was organized around the person with AD and family member’s experience with AD stigma and their experience in the choir. Relating to AD stigma, 3 themes emerged: (1) perceived stigma, (2) impact of the diagnosis, and (3) managing the stigma.

#### *Alzheimer’s disease stigma*

##### 1. Perceived stigma

The experience of the focus group members, both the person with AD and the family members, was divided. All agreed that the stigma of AD was present, but some felt it more acutely, and others chose not to respond to it, not to accept the negative connotation of the label. Following is some of the dialogue that explains the 2 perspectives.

S: What’s the point of being ashamed? There is nothing to be ashamed of?

T: When I got the diagnosis, I thought I would tell everyone I know to take away the stigma. Some people might think I had too much to drink; they knew something was wrong. When I got the diagnosis of AD, a great burden was lifted off my shoulders. I knew what was wrong. People were accepting, concerned and willing to help.

J: I have not really shared it with my friends. I don’t want to be a subject of pity . . . I don’t like that. I am just not ready to tell anyone. I have only just told my children.

R: I have not told many people, I have pulled away because I am not sure how my friends would react.

Families also had different reactions to the stigma by association:

N: That word, Alzheimer’s has a stigma. I hate that word. It has negative connotations and is associated with the later stages and death. Our son did not want anyone to know about his father’s diagnosis. It was very upsetting for me.

G: We made an effort to engage friends and family . . . to inform them [about AD], to educate them, so they would feel comfortable.

##### 2. Impact

The focus group members were also divided by how they felt the stigma of the diagnosis affected them. Following are some excerpts of the focus group dialogue:

P: Fortunately, this disease is not painful, so that’s a blessing. And having a few good friends that help is so wonderful.

T: I agree. You need to attack life and still enjoy it.

F: I hear you talk about how you share it with friends and I am a little jealous of everything I hear you say. It creates a hard situation not being able to tell anyone. My husband is very private and he is not comfortable talking about it. But people see his symptoms and I don’t know what to say. I am inhibited to say anything because he has asked me not to. So we don’t have a strong support group. I feel our friends pulling away because they don’t know what is happening.

S: After the doctor called and told me the diagnosis, I didn’t tell anyone about my husband’s diagnosis for the first month, not even him. I didn’t know what to tell him.

##### 3. Managing the stigma

Again the focus group members had various ways to manage the stigma to lessen the impact on them. Here are some examples:

G: We make every effort to educate our friends and family. We feel if they have a sense of what the problem is, then they would know how to help, and they do.

T: I don’t let things bother me. For example, when I get into crowded areas, and I move slowly, like at the ball park, I can see people get frustrated with me. There is nothing I can do, so I don’t let it bother me.

C: We just need to take each day at a time and get the most out of it and try to enjoy it.

T: Public awareness is better now. All that publicity about football and head injuries, and Glen Campbell, President Reagan, and that woman basketball coach all saying they have AD is helping. We need to help educate. We are part of that process.

Thus, from the above-mentioned narratives, it appears that people with AD and their family members experience AD



stigma in a variety of ways and some have found some positive approaches to manage the impact of the stigma.

*Experience in the intergenerational choir.* There are 2 themes that emerged from the focus group narratives related to the peoples' experiences participating in the choir: (1) enjoying the time together and (2) the lessening of social isolation.

### 1. Enjoying time together

Every focus group member expressed the enjoyment they were having participating in the choir. It was a positive experience for them. Following are a few examples:

D: It's been so much fun . . . a different experience. I love meeting new people, especially young people. They have so much energy. We usually don't have a chance to be with so many young people; we meet old people.

N: It was a wonderful, wonderful idea and it should be done every year. It had been so enjoyable.

G: There is always a lot of laughing. I would keep looking over at you [to make sure things were alright] and you were always laughing and seemed to be getting everything, the words and melodies.

### 2. Lessening social isolation

One of the goals of the choir, was through participation with other choir members in an enjoyable environment, working toward a shared goal (the concert), the members would begin to feel connected to each other. Following are some examples.

E: I originally joined the choir as a way to spend some time with my grandmother. She has always been the singer in the family and that is something we liked to do together. I didn't give much thought to the rest of the group. But it has been so much fun, since the first day. There has been an instant group and bonding. It has been really nice paired with the students, I like how that was set up. There has been much more of a group feel than I expected. This has definitely been fun.

G: We have had such a wonderful experience with the young people. They have sort of an innate feeling about what to do. And it was very good watching them do this or that to help us, pointing where we are on the sheet of music if we get lost, without being prompted.

F: It was a fun time. A social time for us . . . And a wonderful experience for us on many different levels.

N: We all need each other. Listening to everyone's stories and singing together makes me feel less alone.

Thus, participating in the intergenerational choir fostered social contact and social cohesion among the people with AD, their family members, and the students. The focus group members bonded with the students and each other, resulting in feeling of less isolation. This was accomplished through participating through an enjoyable shared music making experience.

*Observations.* In addition to the above-mentioned dialogue, observations about the group's behavior were noted by the researcher and choir director over the course of the 8 weeks. This also supports the lessening of social isolation for the people with AD and their family members.

During the 8-week period, as was with the students, attendance by the people with AD and their family members was very high. Three couples missed no rehearsals and the others only one. The rehearsals went from 5:00 to 6:30 every Thursday night. However, starting with the third rehearsal, people started coming at 4:45 and staying to almost 7:00, using that time to socialize with each other, the students, the researcher, and choir director. Each week the conversations became more animated, more joking took place, and the students when they entered the music room, immediately sat down and talked with their "buddies," asking how their week had been. After the rehearsals, some of the couples (who didn't know each other before) started to have dinner together at a nearby restaurant.

The night of the concert there was an excitement among all the choir members. Everyone came early to rehearse one more time together. One of the women with AD brought a scarf, so a student could help her tie it. During the performance, the joy on their faces, as they sang together, was contagious. The audiences' response was overwhelming, with 2 standing ovations and a request for an encore. At the end of the concert, the audience (230 people) did not leave immediately. The following week, there was a "cast party," at the request of all the choir members. All the people with AD came, and only 1 family member could not, having to go out of town, but another family member came instead. Nine students came (this was 2 weeks before final exams). Everyone came in and started hugging each other, laughing, and talking about the success of the concert. The party was supposed to last from 5:00 to 6:00 but ended at 7:00. People did not want to leave. Some people exchanged e-mail addresses, and some of the couples made plans to meet for lunch a few weeks later.

Thus, based upon the focus group data and the observations of the choir members' interactions, it appears that participating in the intergenerational choir has the potential to lessen the social isolation of people with AD and their family members. But even more than that, it has the potential to "build community."

## Discussion and Conclusion

As people are living longer, the possibility of having AD increases and with that the stigma that is associated with the disease. Public education and awareness about the disease are increasing and are integral part of the US National Plan to Address AD.<sup>75</sup> One of the places to promote this education is on a college campus. This study was undertaken to see whether a unique time-limited intervention, singing in an intergenerational choir, composed of undergraduate college students, and people with early-stage AD and their family members, could reduce AD stigma in the students and in the process lessen

feelings of social isolation among people with AD and their family members.

There are many limitations to this study. It is an exploratory study, with a very small sample size and no control group. The people with AD and their family members are associated with the Alzheimer's Association and are support group members, so they may not represent the diversity among people with early-stage dementia. The college students attend a liberal arts college, where concern about issues of social justice is prevalent. With all that taken into consideration though, the overwhelming evidence presented earlier demonstrates the potential of something as common place as a choir to lessen AD stigma and build community among a very diverse population.

The specific objectives of the intervention were to (1) increase students' awareness of the strengths that remain in people with early-stage dementia; (2) lessen the misunderstanding students have about people with AD and their caregivers; (3) provide opportunities for students to see how people with AD respond and handle challenges; (4) give people with AD and their family members an opportunity to interact with college students and teach them about the lived experience of AD; (5) give the person with AD and their family members an opportunity to express their felt stigma; (6) lessen social isolation of people with AD and their family members; and (7) provide an enjoyable social musical experience. Examining the data presented previously, each of these objectives has been met on some level. Through their qualitative comments and major change in descriptor words, the students showed an increased understanding about the lived experience of AD, and the strengths, coping, and challenges for the person and the families. In addition, in that growth process, they become much more comfortable interacting and being around people with AD. Not only did they say they felt more comfortable, but there was observable behavioral change and they began to refer to the couples as "friends."

The people with AD and their family members through participation in the choir interacted in meaningful ways with the students. Through this social contact, they were able to show the students a different perspective about AD and demonstrated that one can still live a meaningful life with enjoyable times, despite the challenges of the diagnosis. In addition, in the focus group, by discussing their shared experiences about AD stigma, the couples were brought closer together, increasing social cohesion and lessening their feelings of isolation. The study also added evidence to the larger debate about the efficacies of the art therapies as possible treatment modalities for people with dementia.

Surprisingly, there were no major obstacles that occurred with the formation and development of the choir. If this choir would be replicated, more lead time for recruitment would be helpful as well as more rehearsal time. Besides a cast party, a short debriefing session to ask for suggestions and changes would be beneficial. For future research, replication of the intervention is essential to see whether its effectiveness holds true across different cohorts. This research has the potential to add to the knowledge base about reducing AD stigma, advocated by the World's Alzheimer's Report<sup>22</sup>; to support the

positive effects of intergroup contact theory,<sup>38</sup> and to demonstrate the benefits of music.<sup>56</sup>

However, what needs to be reemphasized is the vehicle that was used to bring these 2 groups together, was "the power of music," displayed through the choir. The activities of the choir, with its structured meaningful interactions and interweaving of melodic voices made beautiful music. It created the environment and conditions for change to take place, resulting in a "building of community" across generations and health conditions. For as one of the choir members said, "Music is wonderful. People respond to music in a way that they don't in conversations. It opens your heart, and it opens your mind."

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