

109 年度失智友善資源整合計畫 10 月份文獻摘譯

文章	<p>Making a University Community More Dementia Friendly Through Participation in an Intergenerational Choir.</p> <p>創造失智友善的大學社區：參與跨世代合唱團</p>
文獻出處	<p>Harris, P. B., & Caporella, C. A. (2019). Making a university community more dementia friendly through participation in an intergenerational choir. <i>Dementia</i>, 18(7-8), 2556-2575.</p>
目標	<ul style="list-style-type: none"> ● 失智友善社區應可給予相關的教育，尊重並鼓勵失智者及其家人的加入，提供支持、賦予失智者能力，並提升生活品質。 ● 此研究的參與者包含在學的大學生、失智者及其家人，呈現了跨世代合唱團的活動過程、失智友善社區的形成歷程。 ● 活動過後，大學生減少了對失智的刻板印象及誤解，轉而更能理解他們、並欣賞他們的能力。 ● 結果顯示，大學生們的態度改變、增加對失智和他們生活經驗的認識、減少對失智的汙名化，並發展出有意義的社交連結；而失智者及其家人則更加感到在社區中的歸屬感。
前言	<p>公共健康危機和失智友善社區(Public health crisis and dementia friendly communities)</p> <p>失智現在被視為全世界的公共健康危機，由於缺乏對失智的認識，產生對失智者及其家人的汙名化、難以進行診斷和有品質的照護。欲改善這個問題，我們需要以社區為單位來進行公共健康介入。設置失智友善社區的目標為：(1) 改善失智者及其家人的生活；(2) 使他們學習並有能力成為為社區貢獻的一員。</p> <p>失智的汙名化(Dementia stigma)</p> <p>學者 Goffman 於 1963 年提出汙名化的概念，失智的汙名化是一個全球關心的議題，於調查顯示，失智者及其家人都相信診斷出失智會有負面的影響，而此種汙名化卻導致延誤診斷和治療，產生了嚴重的後果。</p> <p>失智的汙名化、失智友善社區及創造性藝術(Dementia stigma, dementia friendly communities, and the creative arts)</p> <p>失智的汙名化，通常是打造失智友善社區需要突破的第一步，可能需要多種不同的介入方法來改善，例如提供教育，或是可運用小團體活動來縮小汙名化的影響。創造性藝術是一種展現心理社會(psychosocial)能力的過程。學者 Dowlen 也提出，有意義的社交互動和與音樂連結的活動，能夠使失智者擁有安全感和歸屬感。</p> <p>為了營造失智友善的大學環境，此研究將以以下三個研究問題來作探討：</p> <ol style="list-style-type: none"> 1. 藉由大學生與失智者的世代間合唱活動，是否能夠減少對失智的誤解，提升大學生對失智者生命經驗的了解，協助學生看見失智者所擁有的能力？ 2. 在合唱團成員中，是否可建立跨年齡、障礙和能力的社交連結呢？ 3. 於此研究所得的結果是否能夠複製、應用到其他族群呢？

<p>方法</p>	<p>由於失智友善社區是比較新的研究場域，此研究採用現象學的質性方法收集資料。在收集樣本的部分，於 2013、2014、2015 和 2017 年春季學期都有跨代間合唱團組成，共有四組樣本；而失智者及其家人從當地失智症協會和支持團體中得知活動訊息、而參加。</p> <p>當大學生被招募到此活動中，他們必須參加一小時的簡介/教育課程，教授他們關於失智症的知識和失智者的生活經驗。此外，研究者也參與每次的合唱練習，解答所有參與者的疑問和面對的問題。同時，研究者與合唱團團長也進行多次的會議、電話或郵件的溝通，討論如何增進活動中的社交互動、選擇曲目、過程可能遇到的困難及其解決方法等。基於族群接觸理論(intergroup contact theory)，保有一個共同目標一起努力是很重要的，因此合唱團的表演也定於失智症年度教育活動中舉行。</p> <p>為了提升合唱活動的社交互動，活動過程中的特別設計如下：</p> <ol style="list-style-type: none"> (1)團員圍坐成圓，以利可以看見每位成員； (2)將大學生與失智者及其家人配對，讓他們一起練習； (3)在練習前的 15-20 分鐘，將會預留給配對的搭檔聊天互動； (4)聊天時間之後，研究者花費約五分鐘，宣布事項或解答大家的提問； (5)合唱團團長接著進行簡單的肢體運動作為暖身。 (6)在活動過程中每位成員皆有名牌，合唱團團長以成員的名字稱呼大家，而不因年齡而改變稱呼方式。 <p>在資料蒐集的部分，共有三個階段前測(T1)、活動中(T2)、後測(T3)，詢問大學生對於失智症的想法、與他們相處的經驗和感受、與跨世代失智者之間的友誼。</p>
<p>發現</p>	<p>對失智的態度和印象改變(Changed attitudes/images of dementia)</p> <p>在前測時(T1)請學生提出與失智聯想到的字詞，大多數的答案都較於負面，例如悲傷、護理之家、生病、無助健忘、憂鬱、挫折、依賴。而在後測(T3)時發現學生的態度明顯改變，正向的描述高達 71%，包含笑容、開玩笑、需要引導但不需要協助、學習、專注、希望、保持正向等。由此可見，跨代間的合唱活動有可能可以改變大學生對失智者負面的態度/形象。</p> <p>質性資料的主題(Qualitative themes)</p> <ul style="list-style-type: none"> ● 更了解失智症和他們的生活經驗 ● 破除刻板印象來降低污名化 ● 了解失智者具有的能力 ● 發展有意義的社交連結 ● <p>由失智者及其家人的觀點(People living with dementia and family members)</p> <p>在合唱活動中，失智者及家人感受到接納、融入和被歡迎，他們也與學生們發展出友誼，確實感受到失智友善社區的精隨。</p>
<p>討論與結論</p>	<p>此研究在大學校園發揮失智友善的精神，收集了四年的資料，將大學生與失智者及其家人組成一個跨世代的合唱團。但研究中具有幾項限制：(1)缺乏對照組比較結果；(2)每一組的樣本數小；(3)失智者與家人由失智症協會所招募，可能無法代表早期失智的多樣性；(4)此學校為一人文藝術學院，可能校內對社會正義(social justice)風氣更為盛行。</p> <p>由此研究顯示學生對失智症的了解和他們的生活經驗都有更深的了解，降低了對</p>

	<p>他們的汙名化，也發現失智者所擁有的能力。在活動過程中，學生越來越了解如何互動，也慢慢與失智者及其家人成為朋友，而形成真正失智友善社區的開端。</p>
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Study	Making a University Community More Dementia Friendly Through Participation in an Intergenerational Choir.
Author	Harris, P. B., & Caporella, C. A. (2019). Making a university community more dementia friendly through participation in an intergenerational choir. <i>Dementia</i> , 18(7-8), 2556-2575.
Objectives	<ul style="list-style-type: none"> ● A dementia friendly community is one that is informed about dementia, respectful and inclusive of people with dementia and their families, provides support, promotes empowerment, and fosters quality of life. ● This study presents data from four cohorts of undergraduate college students and people with dementia and their family members, using an intergenerational choir as the process through which to begin to create a dementia friendly community. ● This was accomplished by breaking down the stereotypes and misunderstandings that young adults have about people with dementia, thus allowing their commonalities and the strengths of the people living with dementia to become more visible. ● Results across all four cohorts showed in the students: changed attitudes, increased understanding about dementia and the lived experience, reduced dementia stigma, and the development of meaningful social connections. People with dementia and their family members expressed feelings of being part of a community.
Introduction	<p>Public health crisis and dementia friendly communities</p> <p>Dementia is now being recognized worldwide as a public health crisis. This lack of knowledge about dementia results in the stigmatization of people with dementia and their family members creates barriers to diagnosis and quality care, and impacts societies socially and economically the need to mobilize on a community wide basis and take more of a public health approach is being championed at a national level. The overall goal of dementia friendly communities is to better the lives of people living with dementia and their family members, and to empower them to continue to be contributing members of society.</p> <p>Dementia stigma</p> <p>The stigmatizing process was first delineated by Goffman (1963). It was described as a process where social meaning, with negative connotations, was attached to behaviors and individuals. Dementia stigma is such a worldwide concern. The survey data showed overwhelmingly that both people with dementia and family members believed that there are negative associations for those diagnosed with dementia and their care partners. This stigma leads to serious consequences such as delayed diagnosis and treatment.</p> <p>Dementia stigma, dementia friendly communities, and the creative arts</p> <p>Dementia stigma, one of the first steps to combat in building a dementia friendly community, can be challenged through a number of different approaches and on a number of different structural levels. Addressing dementia stigma through community building can also be done on a micro level, by bringing small disparate groups of people together to work toward the common goal of lessening the stigma. The creative art is one approach that has the capability of accomplishing this psychosocial process. Dowlen</p>

	<p>et al. (2017) suggest that the meaningful social interactions and connections that musical activities enable the person with dementia to feel a sense of security and a sense of belonging.</p> <p>In order to start creating a more dementia friendly college community three components of stigma need to be addressed: (a) knowledge (ignorance), (b) attitudes, and (c) behavior. Therefore, the three research questions that guided this study were:</p> <ol style="list-style-type: none"> 1. Could participation by college students in an intergenerational choir with people with dementia and their family members: lessen misunderstandings about people with dementia, increase student’s knowledge about the lived experience of dementia, and assist students in recognizing the capabilities of people living with dementia? 2. Could meaningful social connections between the choir members be developed that would reach across the barriers of age, disabilities, and abilities? 3. Could these findings be replicated across different cohorts?
<p>Methods</p>	<p>Since dementia friendly communities is a relatively new area of inquiry, a phenomenological qualitative approach was used to gather data, primarily drawing on the writings of Holstein and Gubrium (1994) and Schutz (1967, 1970). In the context of this study, the words of the choir members were used to explain their experiences from participating in the choir. For samples, each spring term for four years (2013, 2014, 2015, and 2017) an intergenerational choir was formed, thus there were four different cohorts. The people with dementia and family members were recruited through the local Alzheimer’s Association chapter by letters and announcements at their support group meetings.</p> <p>Once the students were recruited, they attended a mandatory one-hour orientation/information session on dementia and the experience of living with dementia. Also the researcher attended all the choir rehearsals to be available for questions and handle any concerns. In addition, the researcher called the Alzheimer’s Association 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 Alzheimer’s disease educational event organized for the community. In keeping with intergroup contact theory, it was important to have a shared goal (the concert) for the choir to work toward.</p> <p>In order to build connections between the student and the people living with dementia and their family members, it was essential to foster social interaction and contact. Therefore, a great deal of thought went into how best to accomplish this. 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 dementia and their family members, and they sat next to each other during most of the rehearsals, and this was explained to the students during their orientation session, and ideas for</p>

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” to talk with each other; (4) after the socialization time, the researcher would take five 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. Name tags were used for every rehearsal. In addition, the setting of the tone for the choir was introduced during the first rehearsal; it was that of acceptance, being non-judgmental, working as a team (“we are all in this together”), and having fun.

Data for the college students were collected each year through a repeated measure design with a pre-test (T1), a test half way through (T2), and a post-test (T3) after the concert. The questions are: (1) What have you learned about dementia, people living with dementia, 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 dementia and their family members? (4) Do you feel more comfortable around people with dementia? And (5) Do you feel you have developed a connection or bond with the intergenerational choir members who have dementia?

Changed attitudes/images of dementia

Looking at the trend and direction in the change in students’ attitudes toward people with dementia across all four cohorts, participating in the intergenerational choir appeared to have an effect. At T1 and T3, students were asked to describe their images of people with dementia, using 10 words. These words were scored 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.

Aggregating all the data, totally at T3, 15% of the responses were negative, a change of 49%, and 71% were positive, a change of 55%. 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 dementia.

Qualitative themes

The themes that emerged from the open-ended questions asked of the students at T2 and T3 across all four cohorts also supports the changes discussed above. There were four common themes that emerged from the data: (1) an expanded understanding of dementia and the lived experience, (2) reduced dementia stigma by the breaking down of stereotypes, (3) recognition of the capabilities of people living with dementia, and (4) development of meaningful social connections.

Finding

	<p>People living with dementia and family members</p> <p>Across all the cohorts, by participating in the intergenerational choir the people with dementia and their family members felt accepted, included and welcomed. Some developed friendships with the students. They in essence felt part of a dementia friendly community.</p>
<p>Discussion and Conclusions</p>	<p>This study was undertaken to see if for four years with four cohorts whether a unique time-limited program, singing in an intergenerational choir composed of undergraduate college students and people with early stage dementia and their family members, could lay the foundations for a dementia friendly community on a college campus. There were many limitations to this study. It was not a randomized control group study. The sample size for each cohort was small. The people with dementia and their family members were associated with the Alzheimer’s Association and were support group members, so they may not have represented the diversity among people with early stage dementia. The college students attended a liberal arts college, where concern about issues of social justice was prevalent.</p> <p>The students through their qualitative comments and positive change in their descriptor words showed an increased understanding about the lived experience of dementia, a reduction in dementia stigma, and an increase of awareness about the capabilities of people with dementia. In that growth process, the students become much more comfortable interacting and being around people with dementia to the extent that they looked forward to their weekly rehearsals, and many students began to refer to the people with dementia and their family members as “friends.” Thus, meaningful social connections were established the start of a dementia friendly community.</p>

附件