The International Journal of Reminiscence and Life Review
2024, Volume 10, Issue 1, pp. 34-37
https://journals.radford.edu/index.php/IJRLR

Social Engagement of Individuals Living With Dementia Through Shared Stories: A Program Evaluation

Steven M Hoover
Central Minnesota Council on Aging

The use of Guided Autobiography (GAB) as a promising practice for individuals living with dementia was utilized with two groups of six individuals along with care providers over two, eight-week sessions. A qualitative program evaluation was conducted to determine the feasibility of offering the GAB class for program evaluation for individuals living with dementia. The evaluation was guided by a theoretical foundation utilizing Self-Determination Theory.

Key words: guided autobiography; dementia; self-determination theory

Individuals living with dementia and their care partners run the risk of becoming socially isolated and lonely. Social isolation and loneliness have come to the forefront of public attention during the recent pandemic; however, the health problems of a lack of social engagement and loneliness have been evident and growing for some time. While social isolation and loneliness are an issue across the lifespan, studies indicate that there are two major times when these issues are most prevalent: adolescence through early adulthood, and among seniors. The issue for the latter group was especially evident during the pandemic when seniors were no longer able to make contact with family or others, especially those in long-term care facilities and those living alone. It was to address this issue that the Central Minnesota Council on Aging, along with the St. Cloud Whitney Senior Center began offering Guided Autobiography classes virtually. As the effectiveness of these classes became evident, a retired family physician contacted the author to explore the feasibility of offering Guided Autobiography classes to individuals that had been diagnosed with dementia. This article offers a brief report on the first two pilot classes offered to individuals living with dementia, and it highlights how the program was modified to meet the needs of those who participated, identifies the theoretical rationale for the modifications, and outlines the qualitative feedback obtained from the first two programs.

Guided Autobiography

Guided Autobiography (GAB) was developed in the 1970's by James Birren as a structured life review process (Birren & Cochran, 2001; Birren & Deutchamn,1991; Campbell & Svensson, 2015; The Birren Center for Autobiographical Studies). The class consists of eight, weekly, 90-minute sessions led by a facilitator trained to offer the GAB program. Each week the six (maximum enrollment) participants are introduced to a theme through activities and discussions, along with a set of "sensitizing questions" designed to prompt memories and spark interest in writing on the theme. Weekly themes include:

- Branching Points in Our Lives
- Family Relations
- Role of Money in Our Lives
- Major Life Work or Career
- Health and Body
- Spiritual Life and Values
- Goals and Aspirations.

Over the years additional themes have been added for those who may choose to enroll in additional GAB classes. Once the theme for the week has been introduced and discussed, each participant has the opportunity to read his/her story based on the theme from the previous week. Stories are limited to approximately 2 – 2 ½ typed pages to allow for everyone to have the opportunity to read. Following each story participants share comments, similar experiences, and supportive feedback. Individuals are encouraged to make positive, supportive comments and reflections as the emphasis is not on how to write, but to share stories with one another. Over the 8 weeks the group comes to develop deep bonds along with the confidence to share stories such that individuals often are willing to relate challenging as well as uplifting episodes from their lives.

Dementia Community Action Network (DCAN) of St. Cloud, MN

Founded in 2019 by retired family physician Dr. Pat Zook, DCAN was designed to offer diagnosis and support for individuals and families living with dementia. DCAN offers in-depth assessments, often lasting for up to three

***Author Note**:*

Steven M. Hoover, Central Minnesota Council on Aging

Correspondence should be addressed to Steven M. Hoover, Central Minnesota Council on Aging, 250 Riverside Ave., N., Suite 300, Sartell, MN 56377. E-mail: Steve.Hoover@cmcoa.org

No known conflicts of interest to disclose.

hours, along with referrals for further testing and opportunities for on-going support and development. Realizing that long-term memories remained intact among his patients, Dr. Zook recognized the potential benefits of offering the Guided Autobiography program to his patients. He reached out in 2020 to the author to explore how the traditional GAB class might be modified to meet the needs and abilities of his patients. Based on these discussions, it was determined that there was a need to provide a guiding theoretical rationale for modifying the traditional Guided Autobiography class as well as pragmatic issues around screening and support.

Theoretical Rationale for Modified Guided Autobiography: Self-Determination Theory

Based on a review of theories of human functioning and flourishing, it was decided to base the modification and evaluation of the Guided Autobiography program on the Theory of Self-Determination developed by Deci and Ryan (2017). While *self-determination theory* (SDT) is an organismic theory of human development and personality that differentiates levels of motivation, it has as its basis a central concern with wellness and human flourishing. In particular, it is concerned with the social conditions that either hinder or facilitate human flourishing and has among its premises the concept that humans are more likely to flourish and achieve their potentialities when they are in conditions that facilitate *competence, autonomy, and relatedness*. It was these three basic human needs that are likely to be at risk for individuals living with dementia. It was hypothesized that by engaging individuals with the opportunity to utilize their existing long-term memory stores, writing about these memories, and then sharing their stories in a group setting that was supportive, these core human functions would be effective. Therefore, the manner in which the Guided Autobiography class was modified was structured around 1) how best to assist in maintaining competence in memory selection and the writing process, 2) allowing for the autonomy of story selection and the purposes underlying the desire to capture their life stories, and 3) small-group facilitation strategies that would promote a sense of relatedness.

Screening and Participant Selection

Every individual and his/her family members that were involved as patients in DCAN were provided a handout explaining the Guided Autobiography class and asked to contact the author via email or phone if they were interested in learning more. The class is normally limited to six individuals to allow time to cover class activities and time for the reading and commenting on stories. Prior to enrolling in the class, the author interviewed, as appropriate, each participant and his/her care provider. The interviews were less about selection but centered on what modifications and support might be needed for them to participate. Specifically, the following broad areas of motivation, product to be developed, issues with capturing the stories, and how the stories will be shared in class were explored. Comments that follow each of these questions provide the basis for modifications that were made to the class. Actual responses are not included here as the intent is to demonstrate how the set of responses were used to modify the class. Many of the responses in the selection process were also incorporated into the qualitative assessments done weekly.

1. What is the motivation to participate in the Guided Autobiography class?

It was evident that there were two major reasons for participating in the program. First, there was a desire to capture life stories while they were still alive and to share them with family and relatives. This was particularly true as a motivation to write each week – to be held accountable for getting their stories done. Second, there was a need to engage in a group setting that was of interest and "not about their disease" that would allow them to have a positive social relatedness. This motivation was often expressed by the care provider (spouse, child, or social worker) and was subsequently by the participants as well. These points were evident among the individuals to maintain a sense of autonomy and competence in the creation and sharing of the stories. While some participants needed technical assistance in capturing their stories, the care providers were careful to be certain that the stories were authentically those of the participants.

2. Is there a product to be created, i.e., a book or manuscript for family or friends?

This was true for a few people, especially one person in the first pilot class who wanted to create a book similar to what a great uncle had created. His goal was to have it for his sons once he was gone. Others simply wanted the opportunity to reflect and share stories. For those who were interested in a book of some type, the author/instructor provided local resources and online resources on how to self-publish a memoir.

3. How will the story be captured each week?

This was an important question and one that was of concern to several of the participants and their care providers. Two individuals were challenged in being able to craft a story of 2 – 2 ½ pages. One was living with Parkinson's and was not able to write or type his stories. In this case his social worker met with him during the week and wrote out the story for him. He also struggled with being able to maintain the theme for the full set of pages. Fortunately, the author/instructor had recently come across the concept of "micro-memoirs." These are short stories, sometimes less than 100 words, that capture a very brief moment in time. They are similar to those shared stories we experience during family gatherings that are often begun with, "Do you remember when… ." The

instructor/author provided some personal examples during the first class as well as reading a few from the short book, *Heating and Cooling: 52 Micro Memoirs* (Fennelly, 2017). The micro memoir was utilized by two of the participants in the initial pilot class.

In another situation, one gentleman, normally a "stoic" individual, was reluctant to share, even with his wife, a lengthy story. Therefore, she found that if she prompted him with one of the sensitizing questions, he would briefly reminisce while she captured his thoughts on paper, then read them back to him, which prompted additional memories and details to add to the story. This iterative process would occur several times during the week until he felt that he had captured all he wanted to share.

4. How will the story be shared in class?

Once the stories had been written, the individuals were able to read them in class, with two exceptions. In one case, a 92-year-old participant was not able to see her story well enough, so her daughter, who had written it for her, read it aloud, and her mother added some details during the sharing. In another case, a spouse would occasionally use her finger to keep her husband on track when he lost his place. Several of the individuals were also dealing with not being able to hear the stories being read aloud, so the instructor/author asked that participants email the stories in advance and copies were provided for those needing them.

5. Are there pictures, memory books, or other items available to spark memories and that can be shared with the group during the reading of stories?

While not superficially a modification for this group, it turned out to be an important point for many of the participants. Photos and songs/music served as memory prompts and were shared each week as the stories were read. One gentleman even sang a portion of his story.

6. What concerns are there regarding participating in the program?

As the first class was offered shortly after the "shut down" in Minnesota was being gradually lifted, there was some reluctance among participants with regard to the transmission of the COVID-19 virus. Therefore, it was decided that in order to participate, individuals, care providers and the instructor/author would provide evidence of full vaccination. Further, since the class was held at the DCAN offices, which were housed in a medical facility, there was a mask requirement in place. The wearing of the masks became problematic, however, in that it became difficult for individuals to hear one another when the stories were being read. In consultation with the medical director, and with the support of the participants, it was decided that individuals could lower their masks as they read their stories and shared comments. Additional issues of transportation and the scheduling of support personnel, such as social workers, also need to be addressed.

Finally, the daughter of the 92-year-old participant was concerned that her mother might not be able to attend all sessions due to impending health concerns. It turned out that after 5 weeks, the decision had to be made to have her enter hospice, and the participant did not return to class. However, her daughter found that her mother so enjoyed the weekly sensitizing questions as a way to reminisce with her that she requested all of them and spent the final weeks of life sharing memories with her mother.

Material and Additional Modifications

Each participant was provided a binder that included a name tent to be displayed weekly and contact information for the instructor/author. Each week the new theme and activity prompts were provided to be added to the binder, rather than giving out all the materials the first week as was done with the regular GAB class. It was decided that by focusing on one week at a time it might be less confusing to the participants.

Additionally, the normal sequence of the class was to initially do a writing check-in to see how it went during the week and to address any questions and share processes. This was followed by the new theme, along with activities before the stories were read. This process was modified by having the stories read after the check-in, then, finally, the new theme for the next writing assignment was introduced. It was believed that this would make for a smoother sequence that was easier to comprehend. The issue this raises is to be certain there is sufficient time following the reading of the stories to allow for the introduction of the next theme.

Qualitative Evaluation of the Pilot Classes

As this was a pilot project, a formative evaluation was conducted with the intent to modify the classes based on feedback from the participants. Therefore, much of the assessment of the effectiveness of the classes was evident on a weekly basis in the reading and sharing of the stories, and in the aforementioned comments with regard to the pre-class interviews and the ensuing modifications. Each week, all participants and care providers were actively engaged in sharing anecdotes, making relevant comments, and discussing the stories and memories prompted by others. The instructor/author made notes each week at check-in time in response to three questions:

1. How did the writing process go this week? Were there any challenges or problems?
2. What is working best for you in creating and capturing your stories?
3. Are there any questions you have for the instructor or for the group?

The major challenges for everyone, just as there is in the regular GAB classes, is how to choose just one story to share. It was common for the participants to struggle with having to write only one story, or to keep it to the time limit. For the one person living with Parkinson's, it was necessary for him to schedule time with his social worker for the writing of his story. He arranged prior to their meeting to voice record his story on his phone. When he shared this in class, a couple of others decided to also try this method. After the first couple of weeks, the participants settled into routines with their care providers that worked around one anothers' schedules. As mentioned previously, one wife worked over several days with her husband to get his full story written.

Many of the participants used photos and mementos as memory prompts for the writing and then brought them in to share while reading the story. These became a highlight of each week and, as expected, prompted more sharing of memories. Participants, including care providers, often asked for additional details of the person's life based on the photographs shared. These discussions and sharing provided an additional personal element to the classes.

At the final class, a brief, open-ended questionnaire was given to the participants and the care providers for them to take home, read together, and complete within one week. The questions were very general and addressed what they found most beneficial about the class and what changes or recommendations they would suggest for future offerings. Comments included:

> *It was nice to have a group that wasn't about our dementia.*
>
> *There was an emphasis on what we can do rather than a focus on what we no longer are able to do.*

One spouse said it sparked a full day of remembrances for her husband, even sharing the story of his first job as a babysitter, which she never knew. This same couple was using a marriage and family therapist who is trained as a "Dementia Friend" (part of the offerings of DCAN), who indicated that the class had become an effective part of their "therapy."

One participant shared the book (120 pages) he wrote, along with a quiz he created to make sure his two sons would actually read it (he shared this one day in class, but wasn't certain they would even take the quiz, when one member quipped "that he should tie their inheritance to their scores on the quiz"). This became an on-going joke in the class.

One person who was a care provider asked if it would be possible in the second round to have the spouse care partners also participate in writing and sharing stories. This was included very successfully in the second pilot offering, and it was something we found very effective for the couples who participated.

Discussion

The purpose of this evaluation was to determine the feasibility of offering Guided Autobiography for individuals living with dementia. From the perspective of Self-Determination Theory's foundational concepts of human needs of autonomy, competence, and relatedness, it was clear that the Guided Autobiography pilot project with persons living with dementia was instrumental in furthering their personal self-determination. The stories were genuinely those of the participants, and there was a clear sense of pride in sharing the stories, they truly "owned" them. The biggest modification related to self-determination was one of competence, but not in the sense of recalling events, but in the ability to adequately capture the stories. In this area, the care providers were essential, and this represented the largest modification. In some cases, the care providers wrote down the stories, read them back and then added details coming from the participants. This modification allowed participants to maintain their "train of thought" which sometimes waned. One of the most positive aspects was the sense of relatedness that emerged from sharing and commenting on stories. Care providers shared personally that this class was often the highlight of the week for those with whom they cared and evidenced an increase in positive mood following the class each week.

Limitations

While the size of the classes makes it difficult to collect quantitative data beyond satisfaction ratings, the qualitative assessment supports the feasibility of offering the Guided Autobiography class for this population. Future efforts will include capturing data on life satisfaction and specifically elements of Self-Determination Theory now that the pilot has been deemed successful.

Overall, the Guided Autobiography class was an extremely positive experience for all involved, including the participants, care providers, and the instructor. It was determined that no further changes would be needed to offer future sessions.

References

Birren, J. E. & Cochran, K. N. (2001). *Telling the stories of our lives through guided autobiography groups*. Johns Hopkins University Press.

Birren, J. E. & Deutchman, D. E., (1991*). Guided autobiography groups for older adults: Exploring the fabric of life*. Johns Hopkins University Press. https://doi.org/10.1353/book.3469

Campbell, R. & Svensson, C. (2015). *Writing your legacy: The step-by-step guide to crafting your life story*. Writer's Digest Books.

Fennelly, B. A. (2017). *Heating and cooling: 52 micro-memoirs*. W.W. Norton.

Ryan, R. M. & Deci, E. L. (2017). *Self-determination Theory: Basic psychological needs in motivation, development and wellness*. Guilford Press. https://doi.org/10.1521/978.14625/28806