

“We Were Good, Weren’t We?” The Discover Your Story Museum Tour for Visitors with
Memory Loss

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Abstract

In 2010 the Minneapolis Institute of Arts, a fine-arts museum in Minneapolis, Minnesota, conducted an evaluation of a guided tour program called “Discover Your Story,” designed for persons with memory loss and their care partners, family and professional. This evaluation examined the perspective of 19 community care providers (paid staff or volunteers from local assisted-living facilities, adult day programs, or similar community agencies) prior to and following participation in Discover Your Story tours. The online surveys collected empirical and open-ended information on community care providers’ perceptions of the various benefits of the Discover Your Story tour for persons with memory loss whom they accompanied to the museum as well as for themselves. The findings of the study illustrate the success of the tour program on a range of participant outcomes, including alleviating their concerns about visiting the museum, meeting and exceeding their expectations, and yielding numerous benefits to participants’ lives well beyond the tours themselves.

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“It was refreshing to be able to see their responses to the tour. It made me feel rejuvenated and excited about my job all over again. I loved to see them be goofy and giggle, knowing that it was because the guide validated everything that they said, even if it was the most off-the-wall answer that could have been given.”

—*Professional care provider commenting on a recent art-museum tour experience with individuals with memory loss*

As the search for non-pharmacological treatments of Alzheimer’s disease and related forms of dementia continues, increased attention has focused on alternative approaches that allow persons with memory loss (PWMLs) and family care partners, such as spouses, to manage the emotional,

social, and psychological challenges of dementia. Engagement with art appears to be a potentially cost-effective strategy with multifaceted benefits. Anecdotal accounts, and to a lesser extent, research evidence, suggest that a variety of artistic experiences, such as dance, music, theater, and similar creative expressions may help to improve mood and quality of life of persons with dementia (Basting, 2006; Burton, 2009; Smith, 2010). However, there are few evaluations of the benefits of art in helping PWMLs or individuals involved in their care manage the challenges of dementia.

In 2010, the Minneapolis Institute of Arts in Minneapolis, Minnesota, conducted a research study of a guided-tour program, called “Discover Your Story” (DYS), designed specifically for people with Alzheimer’s disease and related dementias and their care partners, both family and professional. The DYS program’s overarching goal is to foster creative, meaningful interaction among PWMLs and their care partners, families, and friends, one another and art in a safe and welcoming environment. Tours are designed to provide PWMLs opportunities to connect to the present by reconnecting with their own memories through facilitated discussions of original art works. The power of these discussions and art works to spark observations, interpretations, and storytelling, and to draw out PWMLs was immediately evident to museum staff. What also became apparent was the impact of these museum tours on the professional care providers who accompanied many of the PWMLs to the museum. In conversation and in informal written evaluations the care providers eagerly shared their own stories about the museum experience and their observations about how the tours were affecting the lives of those they cared for.

These responses inspired museum staff to study the DYS tours from the perspective of the community care providers (CCPs—paid staff or volunteers from local assisted-living facilities, adult day programs, or similar community agencies that attend DYS tours with older participants). Among the DYS program’s main objectives regarding CCPs are to alleviate concerns about what might happen on a tour, achieve expectations regarding the impact of the tour on participants, increase their knowledge of participants, and provide positive benefits.

The Discover Your Story Tour

In 2008, the Minneapolis Institute of Arts’ Department of Museum Guide Programs, with support from the Alzheimer’s Association Minnesota—North Dakota, developed the DYS tour program for PWMLs. Hour-long tours facilitated by volunteer tour guides engage individuals in the early and middle stages of Alzheimer’s or related dementias as well as their family, friends or care partners in discussions focused on themes related to artworks in the museum’s galleries. Conversations encourage participants to discover themselves while reminiscing about, reflecting upon, or comparing their own life stories to the stories in works of art. The program aims to provide participants with a meaningful experience discussing art and socializing in the welcoming environment of the Minneapolis Institute of Arts’ galleries. Programs at other museums including New York’s Museum of Modern Art (Mittelman & Epstein, 2009), the Museum of Fine Arts, Boston, and the Walker Art Center in Minneapolis (Gaugler et al., 2010) have demonstrated that viewing art is an enjoyable experience that promotes discussion and memory.

The conversation-based format is similar to other tours at the Minneapolis Institute of Arts, but tailored to the specific needs of PWMLs. Attendance is limited, allowing for a personal, relaxed experience. The docents who facilitate these tours are specially trained by Alzheimer's Association and museum staff to understand and work with this audience. Additional Minneapolis Institute of Arts volunteers accompany tours as needed to support participants as friends and assistants. The docents ask many open-ended and directed questions, and listen actively to what participants express about the artworks and to the stories they share about their own lives. Docents also regularly incorporate touchable props, music, and scents into the tours to engage many senses. Some tours include a creative storytelling activity that encourages participants to imagine stories based on select artworks. At the time of this study, each tour participant left with a postcard of an artwork he or she discussed as a memento of the experience and as a prompt for further discussions.

With careful consideration of time and gallery usage, seating, and accessibility, including the provision of wheelchairs and assisted-listening devices, DYS tours take place when the museum is open to the general public, thus providing truly equal access to everything the museum has to offer. These tours are made available in two ways: groups can reserve spaces in advance according to their schedules, or a PWML and a care partner can register in advance for a regularly scheduled DYS tour, offered twice a month. All tours are free.

The Discover Your Story Evaluation Goals

The main goal of the Discover Your Story tour evaluation was to examine whether CCPs' perceptions improved following participation in the DYS tour at the Minneapolis Institute of Arts.

Utilizing a single group pre-tour/post-tour evaluation design, the research questions were:

- 1) What were community care providers' concerns prior to and after the DYS tours?
- 2) What were community care providers' expectations prior to the DYS tours and were those expectations met?
- 3) Did community care providers' knowledge of tour participants significantly increase ($p < .05$) following participation in DYS tours?
- 4) What were community care providers' perceptions of the benefits, hassles, and surprises of the DYS tours?
- 5) What were community care providers' satisfaction ratings of the DYS tours?

The majority of current research on arts-related programs and memory loss focuses on persons with dementia and, to a lesser extent, on their family members. Not heretofore studied was whether the implementation of a specialized arts-education program in a museum setting enhances perceptions of and relationships with PWMLs for non-family, professional care providers who accompany these individuals on such tours. Most arts programs focusing on older persons take place in residential settings; the emphasis on providing a beneficial, normalizing experience for professional care providers as well as PWMLs in a museum setting (such as on DYS tours) is unique when considering the larger literature on artistic activity and memory loss.

Methods

The Study

Community care providers from local residential memory-loss settings or adult day programs were eligible to participate. A total of 25 individuals participated and 19 completed both pre- and post-DYS tour assessments. The pre-tour and post-tour assessments (conducted 70

days apart, on average) were administered online by Minneapolis Institute of Arts staff to assess CCPs' backgrounds, concerns, expectations, knowledge of tour participants' lives, benefits, surprises, and hassles of DYS tours, and CCP satisfaction. The post-DYS tour assessment occurred following participation in at least one DYS tour. Community care providers consented to release unidentified data from the pre- and post-DYS tour information they provided for the purposes of evaluation (University of Minnesota IRB# 1005S81875).

Due to the lack of standardized measures gauging the effects of arts programs on PWMLs, numerous scales were created or modified by the evaluator (Dr. Gaugler) and reviewed by participating Minneapolis Institute of Arts staff (Sheila McGuire, Jane Tygesson, and Stacey Thompson) to assess the potential influence of DYS tours on professional care providers' perceptions.

Measures

Participating CCPs during the pre-DYS tour survey provided background and socio-demographic information. They were also asked to consider their degree of concern (1 = not concerned at all, to 10 = extremely concerned) regarding a series of issues that could arise during DYS tours (e.g., participant confusion, wandering) in the pre-DYS tour survey. Community care providers were then provided the same list of concerns post-DYS tours, and were asked if these concerns remained now that the CCPs had completed the tours. Another measure determined whether CCPs' expectations of the DYS tours were met. Community care providers were asked if they strongly agreed, agreed, felt neutral, disagreed, or strongly disagreed with a series of expectations prior to the DYS tour, such as feeling closer to participants following the DYS tour. At the post-DYS tour assessment, CCPs were provided the same list of expectations and were

asked the degree to which the DYS tour met their expectations (using the same set of item responses used during the pre-DYS tour assessment). Relying on behaviors listed in the Neuropsychiatric Inventory (Cummings et al., 1994), CCPs were also asked to indicate which specific behavioral disturbances the DYS tour positively influenced. In addition, CCPs were asked a series of open-ended questions related to two of the post-DYS assessment items regarding expectations to expand on how a given expectation was met. Kane's measure of staff knowledge (Kane et al., 1997) was administered at the pre- and post-DYS tour assessment to ascertain whether CCPs reported improvements in knowledge about tour participants' lives and former occupations, families, tastes and interests, and their medical conditions. Item responses included "very well," "well," "somewhat," and "not at all."

The post-DYS tour assessment asked CCPs to list, in open-ended fashion, the three greatest benefits of the DYS tour for participants or CCPs themselves. After each benefit, CCPs were asked to rank each benefit from 1 = no benefit at all to 10 = maximum benefit. An identical format was used for CCPs to identify hassles or surprises related to the DYS tours. Community care providers were also asked an open-ended question about the "ride home" after the DYS tours ("In your own words, please describe what the ride home was like after you completed one of the Discover Your Story tours"). Similar to the benefits, hassles, and surprises items, CCPs were asked to rate how stimulating the conversation was on the ride home, from 1 = not stimulating at all to 10 = very stimulating. Community care providers were also asked an open-ended question during the post-DYS tour assessment: "Please tell us, in your own words, how the Discover Your Story tour has influenced your attitude toward your job and the tour participants." Two closed-ended items were administered to the CCPs during the post-DYS tour

survey to determine CCPs' satisfaction with the program. Community care providers were asked to rate their overall DYS tour experience (item responses included "very good," "good," "neutral," "poor," and "very poor"). In addition, they were asked whether they would recommend DYS tours to someone else in a similar situation (item responses included "definitely," "probably," "not sure," "probably not," and "definitely not").

Analysis

Paired T-tests were conducted to compare statistically significant ($p < .05$) changes on pre-DYS and post-DYS tour measures for the domains assessed above. These domains included concerns, expectations, and knowledge measures. Descriptive, univariate statistics were used to summarize benefits, hassles, surprises, the ride home, and satisfaction items related to DYS tour participation administered during the post-DYS tour assessment. For narrative responses generated from the open-ended survey questions collected during the post-DYS tour surveys, responses were examined and analyzed to identify common issues or perceptions that captured the CCPs' experience of the DYS tour.

Results and Discussion

Community Care Providers

Six CCPs did not complete the DYS tour evaluation protocol because of changes in employment or volunteer positions. Over 3/4 of CCPs were women, 2/3 were married or living with a partner, and all were Caucasian, and well-educated (over 80% had a bachelor's degree or higher). Community care providers were, on average, 46 years of age with a range from 21 to 75 years. Approximately half of CCPs were affiliated with a live-in memory-care facility and over 80% were paid employees of their organizations. On average, CCPs worked or volunteered at

their organizations for a little over five years at over 30 hours per week. Almost all CCPs had attended a museum previously, and approximately 3/4 had attended the Minneapolis Institute of Arts in the past. During the course of the evaluation, CCPs participated in slightly over two tours on average (with a range from one to nine tours). Each DYS tour lasted an hour on average. The average length of time from the pre- to post-DYS tour assessments was approximately 73 days.

Outcome Analysis

Question 1: What were community care providers' concerns prior to and after the DYS tours? Community care providers' overall level of concern prior to the DYS tours was 2.64 (ranging from 1 = no concern at all to 10 = highest level of concern). The greatest concern noted by CCPs was "That one or more of the tour participants will become confused during the tour" ($M = 3.28$). During the post-DYS tour assessment, CCPs' overall level of concern was 1.75. A paired T-Test was conducted to determine if degree of concern changed from the pre- to post-DYS tour assessments. Average perception of concern on the part of CCPs was significantly reduced ($p = .006$).

It appeared that the effective management and administration of the guided tour on the part of the Minneapolis Institute of Arts, as well as the ability of the museum staff (includes volunteers) to engage PWMLs to prevent potential behavioral disturbances or memory problems, helped to allay CCPs' concerns during the course of the evaluation. It is also possible the contemplation of art on the tour itself, as well as the discussions among PWMLs, CCPS, and the Minneapolis Institute of Arts staff, stimulated cognition of PWMLs and prevented additional mood issues during DYS tours.

Question 2. What were community care providers' expectations prior to the DYS tour and were those expectations met? On average, CCPs had high expectations prior to the DYS

tours ($M = 4.20$) and indicated that following participation in DYS their expectations were met to a considerable degree ($M = 4.16$). Significant statistical change was not expected in the analysis of expectations; instead, it was anticipated that CCPs' expectations would be high at both the pre- and post-DYS tour assessments. The post-tour assessment also included several open-ended probes. For example, on the item "The Discover Your Story Tours helped me feel closer to tour participants," CCPs were asked, "If you agree or strongly agree on this item, in what ways do you feel closer to tour participants?" Select responses include:

- "I have a chance to get close to them one-on-one. Being able to be with them in this environment is a change they enjoy. I see them delight in new things, and that is priceless. It is great to sit next to them and watch and listen. It is so rewarding."
- "I love the way that your staff really gets them to open up and share things about themselves that I would never have known without this program. And I love the way the participants get when telling their story. They just open up, smiling the whole time."
- "It was amazing to see how a few participants opened up when prompted by the sensory stimulation and just the atmosphere in general. It was laid back, no right or wrong answers, and everything was validated, which in turn, made the participants feel at ease and open up more. I have begun something similar to this program in our own facility with pictures and sensory stim [sic] objects that go along with what we're looking at."

These responses suggest the benefits of facilitated DYS tours in the art museum to enhance communication and interactions among CCPs and tour participants, improve the emotional affect of tour participants due to interaction with Minneapolis Institute of Arts staff, stimulate DYS tour participants via the viewing and discussion of art, and engage tour participants well after the conclusion of the tours.

On the item "The Discover Your Story Tour helped me learn something new about tour participants," CCPs were also asked to provide their thoughts on the follow-up probe, "If you agree or strongly agree on this item, what did you learn that was new?" They offered some of the following responses:

- “I have learned from them via the stories that come out while they are looking at art. Great things that would not be included in ‘Social History.’ We have had great laughs, stories, and memories come out that we just had not heard before.”
- “That some of them can talk!!! I have one gentleman who is usually rather crabby and doesn't want to be social with anyone. To sit and listen to him tell his story really almost had me in tears. Since then my relationship has changed with him because I continue to feed off that one time of him telling his story. Also found out that my folks have a good sense of humor.”
- “I saw a sense of humor I hadn't realized existed. I saw the desire to be helpful, aka polite, during the tour.”

The opportunity to take part in DYS tours resulted in participants sharing stories that provided insights that went far beyond what CCPs already knew about tour participants. The opportunity to view art allowed CCPs a venue to learn about the more personal sides of participants. The sharing process also allowed tour participants to overcome potentially negative moods and engage in more positive fashion with those around them. The DYS tour experience led to participants revealing dimensions of their personalities and histories that were not previously apparent to many CCPs.

Another expectation item administered at the post-DYS tour assessment (“The Discover Your Story Tour positively influenced the behavior of tour participants”) was followed by the query, “Which of the following behaviors were positively influenced?” Among the most common behaviors identified as improved included apathy/indifference, agitation/aggression, depression, and anxiety. This provides additional evidence that the stimulation offered by DYS tours positively influenced PWMLs’ behavior and moods following participation in the tours.

Question 3. Did community care providers’ knowledge of tour participants significantly increase ($p < .05$) following participation in DYS tours? Change in knowledge was not statistically significant and only demonstrated a slight increase, on average ($M = 2.81$ pre-DYS; $M = 3.00$ post-DYS). While the DYS tour offered considerable stimulation and engagement for

participants, even to the point that PWMLs shared personal interests and stories, it did not appear these activities influenced CCPs' knowledge to a significant extent during the course of the evaluation. In fact, CCPs' knowledge of PWMLs remained fairly moderate from the pre- to post-DYS tour assessment.

Question 4. What were community care providers' perceptions of the benefits, hassles, and surprises of the DYS tours? During the post-DYS tour assessment, CCPs were asked to identify the benefits, hassles, and surprises of the DYS tours. They rated the benefits of DYS tours as considerable ($M = 8.46$); the main benefits indicated by CCPs included enjoyment of art itself, change in the daily/routine environment of PWMLs, the stimulation offered by engaging with art and others, and effective engagement by Minneapolis Institute of Arts staff. Alternatively, CCPs reported that hassles associated with the DYS tours were fairly low ($M = 3.66$). The specific hassles reported by CCPs largely focused on logistical issues such as transportation arrangements, parking locations, finding exhibits within the museum, and keeping the groups together during the DYS tours. Finally, CCPs reported considerable surprise at some of the outcomes of the DYS tours ($M = 7.49$). While CCPs' expectations were high (see above), they were surprised by the expertise and engagement of the Minneapolis Institute of Arts tour staff, the extensive stimulation that occurred during the DYS tours, and the high quality of art at the Minneapolis Institute of Arts.

Some of the main benefits consistently highlighted by CCPs included the following:

- Enjoyment of art itself: “awareness of the art and the people in the art”/“reminding them that they are still a person who can appreciate art and culture”/“seeing a variety of artwork”/“seeing beautiful art;”
- Stimulation: “cognitive stimulation that we cannot provide at our facility (re: art, historical references)”/“mental stimulation”/“social stimulation”/“memory stimulation”/“mental stim [sic]”/“memory/sensory stimulation;”

- Enhanced interaction: “interaction among themselves, fueling a sense of ‘we’re community’”/ “interactions with group”/“Sense of Community”/“an activity in a large group setting”/“one-on-one interactions;” and
- Effective engagement of staff: “private tour with volunteers helping”/“the kindness of the helpers at the facility, helps the clients with being secure to view the art”/“Conversation”/ “knowledgeable and courteous staff.”

The surprises mentioned by CCPs at the post-DYS tour survey generally fell into five categories:

- Care and expertise of museum staff managing the tours: “docents knowledge of the pieces that were visited”/“care of docents”/“pleasantly surprised how gentle volunteers were, unruffled, able to affirm any answer”/“the organization by staff”/“how [docent] used multiple senses to draw in the attention of the participants, i.e., gave them lilacs for the ride home, had them hold seashells”/“staff was amazing!!!”/“the helpfulness of the staff;”
- Participant attitude and involvement: “eagerness of participants”/“Degree of involvement of participants”/“the level of participation, even from those who are generally withdrawn”/“energy of clients;”
- Cognitive stimulation exhibited during the tours: “extent of memory”/“discussion”/“that they remembered what they saw. Sometimes.”/ “the sensory stimulation of things to smell, touch”/“depth of memories shared by one particular resident”/“level of reminiscing;”
- Program take-aways: “the flowers and postcards”/“that the helpers gave out flowers to the clients!”/“the gift of the flowers”/“flowers for all;” and
- The art itself: “how clients were able to see a cat in an abstract painting”/ “the variety of the artwork.”

Question 5. What were community care providers’ satisfaction ratings of the DYS tours?

Community care providers were asked to rate their overall DYS tour experience. Their satisfaction was high. On a 5-point scale, CCPs had an average of 4.74; similarly, almost all CCPs responded “definitely” to recommending the DYS to others in similar situations. The DYS tours appeared to provide a unique opportunity for CCPs to engage with tour participants and for CCPs to learn more about the personalities and lives of tour participants. The DYS experience also allowed tour participants to engage among themselves.

Similarly, CCPs noted that the ride home following the DYS tour was fairly stimulating.

Community care providers were asked to describe, in their own words, what the ride home was like following the DYS tour. Below are several of the responses:

- “Nice! They are quiet on their own, but I encouraged our caregiver to ask about each group and ask what they liked best. They do share and enjoy hearing others. The ‘gifts’ given as a souvenir is always talked about. When they get a flower, we put them in a vase on the table for lunch, they love that!”
- “The ride home was very calm and quiet...often on some outing, one or more resident has become confused about the destination. That was not the case in this instance. Each resident had either a staff member, family member, or volunteer to converse with on the ride home, which may have contributed to the relaxed nature of the ride as well.”
- “A resident, who was silent on ride there, said ‘oh look, that’s a really old building’[and a] couple residents shared a chuckle about ‘we were good, weren’t we?’”
- “This varied so much depending on the group. Some were tired and some wanted to have a chance to view more art and were anxious to return”

Some of the highlights of the ride home focused on participants’ enjoyment of the flowers they received and how these gifts helped to brighten the facility/adult day program these participants attended, appreciation of the Minneapolis Institute of Arts staff, reduction in confusion and a sense of relaxation on the ride home, humor on the part of participants, and tour participants’ excitement to return to the Minneapolis Institute of Arts.

On an open-ended item, CCPs were also asked to reflect on how the DYS tour changed CCPs’ attitudes toward their jobs or the tour participants themselves. Open-ended responses included the following:

- “I am a firm believer in a place for the arts in dementia care. I absolutely love these tours and have great respect for the care that has gone into designing them. The docents are superb. The storytelling experience worked very well for our group, and will encourage me to try using real works of art when I do TimeSlips© storytelling as an activity. ...Anything that reminds people with dementia of their humanity, their normalcy, and their right to experience whatever they are experiencing is a wonderful thing and so necessary. Opportunities like this help me do my job more effectively and make me love my work even more.”

- “I would highly recommend the program. I loved spending what I would call quality time with my folks. Not always are you able to [do so]. I loved to watch them open up and to be so willing to share things about themselves like they did. The staff made it a relaxing time for me, which was awesome, and I so appreciate that they do that. I then can fully enjoy this adventure with my folks.”
- “It was nice to break the habit of reminiscing in our facility about the ‘usual’ topics such as work and family life, holidays, seasons, etc.... It made me feel rejuvenated and excited about my job all over again. I loved to see them be goofy and giggle, knowing that it was because the guide validated everything that they said, even if it was the most off-the-wall answer that could have been given. That is one thing that I have really taken away from this experience. And to genuinely listen. Too many times we hurry to get groups to wherever we are going, to move the group along, etc. But we have to realize that we need to slow down to their speed. Silence shouldn’t be awkward, it should be embraced. We have to let them think about what they are seeing, smelling, feeling, and the memories that come back will flow.”

These open-ended responses reinforced the high ratings of CCP satisfaction.

Conclusion

The study confirmed what Minneapolis Institute of Arts staff and volunteers had observed anecdotally. Community care providers’ concerns decreased significantly following their tour experiences at the museum. They noted that their high expectations of Discover Your Story tours were met or exceeded following participation in at least two tours at the museum. Although these care providers did not report a significant change in their knowledge of tour participants, their comments suggested the knowledge they gained was meaningful. They noted a number of benefits and a high level of satisfaction related to participating in the tours. These benefits included stimulation, superb Minneapolis Institute of Arts staff and volunteer guidance, engagement with art, and interaction with others in new and interesting ways. They observed that the specialized tours resulted in a proactive approach to living with memory loss that involved increased engagement, stimulation and sharing of personal stories. Furthermore, the experience offered the opportunity to “normalize” the enjoyment and contemplation of art for people with memory loss by providing an individualized tour experience within museum open hours.

The findings of the DYS tour study illustrate the success of the DYS tour program on a range of professional care provider and tour participant outcomes. The collection of outcomes from CCPs contributes to the understanding of this and other arts programs for PWMLs and offers a novel perspective. Moreover, both empirical and open-ended data were collected and compared to provide a fuller picture of how DYS tours influenced CCPs' positive perceptions of the program. The guided art tour and discussion had strong, positive benefits in alleviating CCPs' concerns (a statistically significant change), met or exceeded all CCP expectations, and yielded a number of benefits and positive surprises for CCPs. The Discover Your Story museum tours offered stimulation within a calm and peaceful environment along with caring tour staff to provide an experience that carried benefits to participants' lives well beyond the tours themselves.

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