Observed well-being among individuals with dementia: Memories in the Making© an art program, versus other structured activity

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Abstract

This manuscript analyzes the use of the Greater Cincinnati Chapter Well-Being Observation Tool© in observing seven domains of well-being among individuals with dementia. We observed the well-being of 12 individuals while they engaged in Memories in the Making©, an art program for persons in the early and middle stages of the disease that encourages self-expression through the visual arts. This was then compared to the observed well-being in the same individuals during participation in more traditional adult day center activities, such as current events and crafts. Results indicated that the individuals demonstrated significantly more interest, sustained attention, pleasure, self-esteem, and normalcy during participation in Memories in the Making; additionally, there were no differences in negative affect or sadness between the two types of activities. Directions for future research are also discussed.

Key words: dementia, Alzheimer's disease, observation of well-being, structured activity, art therapy

Introduction

In recent years, researchers and practitioners alike have advocated for the need to explore, understand, and foster quality of life (QOL) in individuals with dementing illnesses. QOL for the affected person was initially described as an elusive, subjective experience, which was difficult to identify and measure. Nonetheless, several researchers have begun to define QOL as a multidimensional construct that may be used to represent and measure one aspect of an individual's well-being as he/she moves through the course of the disease.[1-8]

Among conceptualizations of QOL for individuals with dementia, the work of Lawton[1,3-5] is arguably the most sophisticated. Lawton proposes that four components constitute QOL for all individuals, including those who have been diagnosed with Alzheimer's disease or related disorders. These four components are: 1) behavioral competence (i.e., leisure and other discretionary behavior), 2) environmental quality, 3) perceived QOL (i.e., an individual's subjective appraisal of the quality of his/her life), and 4) general psychological well-being. Within the realm of well-being, Lawton identifies such domains as affect state, happiness, morale, life satisfaction, and self-esteem. The first three components of QOL may be relevant to the affected individual, but may be difficult to measure because of the person's cognitive status and ability to experience competence or communicate a reliable appraisal of their QOL. Burgener and Chiverton[9] suggest that the positive and negative dimensions of affect state may be more useful indicators of psychological well-being in the cognitively impaired person, as these indicators may be reflected in behaviors that can be assessed and measured by an objective observer, whereas others[10] state that patient proxies report positive and negative affects in patients with Alzheimer's disease by observing their behaviors and facial expressions.

As we begin to define and explicate QOL for persons with dementia, we also need to identify activities that enhance a person's QOL that are cost-effective and reasonable for those who implement such activity programs. A comprehensive review of the psychosocial

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literature reveals relatively few empirical investigations that document the efficacy of activity programs on QOL and cognitive and functional status of individuals with dementia. One exception is the more recent literature on exercise programs.[11-15] Further, Marshall and Hutchinson[16] conducted an extensive literature review of major databases and found that although researchers demonstrate interest in evaluating the use of activities to promote QOL among individuals with dementia, several theoretical and methodological difficulties result in unclear findings in many of the articles. For example, they report that many of the studies did not address the reliability of the measures used to assess QOL.

One program that has the potential to promote QOL among individuals with dementia is Memories in the Making©,[17] an art program designed for persons in the early and middle stages of Alzheimer's disease that encourages self-expression through the visual arts. In this program, a person with diminished verbal and organizational skills can still communicate by drawing and painting while enjoying a sensory experience and participating in the creative process. Implemented by the Alzheimer's Association of Greater Cincinnati in 1997, Memories in the Making is offered to affected individuals who attend adult day centers (ADCs) or reside in assisted-living or long-term care facilities. Individuals meet weekly as a group to create art with an artist facilitator who is knowledgeable about Alzheimer's disease and its effect on functional abilities. The facilitator guides and supports affected individuals in thematic art activities while considering their own distinctive needs and abilities, thus ensuring that each activity provides a pleasurable, failure-free experience. The overall goals of the Memories in the Making art program are for participants to experience the following: 1) an opportunity for sensory stimulation; 2) the pleasure of being involved in the creative process; 3) a sense of well-being, if only momentarily; and 4) an increased self-esteem from having created something of value to oneself and others.

After implementation of Memories in the Making in Cincinnati, the Alzheimer's Association chapter initiated an extensive evaluation process to assess the extent to which the artist participant was achieving at least some of the aforementioned goals in the art sessions. Using Lawton's[3] conceptualization of psychological well-being as a framework, along with staff observations of affected individuals during the weekly sessions, the chapter staff 1) developed an observational tool that the activities staff used to rate objective and subjective indicators of 41 program participants' engagement, well-being, self-esteem, and expression of emotion during Memories in the Making sessions; 2) obtained site activities staff ratings of program participants' well-being, self-esteem, and expression of emotion and feelings during each session; and 3) recorded artist facilitators' and site program directors' evaluation of the Memories in the Making program.[18] Results suggested that while participating in the weekly sessions, participants experienced pleasure and satisfaction in having completed artwork, and also experienced sustained attention for periods of 30 to 45 minutes. This was particularly encouraging, given that most individuals with dementia have difficulty with attention and concentration and are unable to initiate, maintain, or complete a task without assistance and cueing.

Although promising, the reported results are not without limitations. First, multiple raters (i.e., staff assistants and facilitators) were used to collect the data, yet the instrument's reliability/inter-rater reliability was never established. Second, because of staff and facilitator commitment to the program and artist participants, their reports of participants' QOL might have been biased toward the program. Third, several of the 12 declarative statements of subjective and objective indicators of two domains of well-being, affect and self-esteem, did not have clear operational definitions, thus causing confusion for the raters. Finally, the study examined participants only during participation in Memories in the Making. As such, it was not possible to compare participants' sense of well-being during other types of activities.

The purpose of this research was to extend Rentz's pilot evaluation project[18] to provide a more methodologically rigorous evaluation of the extent to which Memories in the Making contributes to the affected person's sense of well-being. Specifically, a revised version of the tool used by Rentz, the Greater Cincinnati Chapter Well-Being Observation Tool©, was used by trained observers, rather than activities staff who assist artist facilitators in the Memories in the Making sessions. The purpose of the research was to address two specific research questions:

- To what extent do participants experience a sense of well-being as evidenced by the domains of interest, sustained attention, sense of pleasure, negative affect, sadness, enhanced self-esteem, and normalcy while they participate in Memories in the Making?

- Do individuals experience the same degree of well-being during Memories in the Making as they do while participating in different structured activities (e.g., current events/hobbies)?

Methods

Instruments used in data collection

Well-being. Well-being was assessed using an outcomes-based observation tool designed for use in this research. The operational definitions for each domain were derived from the second author's review of the literature and her clinical experience as a cofacilitator and observer of affected individuals in the Memories in the Making program for the Alzheimer's Association of Greater Cincinnati. Using Lawton's[3,19] conceptualization of well-being and borrowing from his work on assessing affect states among older adults with Alzheimer's disease, indicators were developed for each domain of well-being. Each indicator was designed specifically to capture the complete operational definition of the six domains of well-being: interest, sustained attention, pleasure, negative affect, sadness, and self-esteem. The final domain, identified as normalcy, is not a construct that has been identified or defined by Lawton and colleagues, although it has been addressed preliminarily by Gwyther[20] in her work with individuals in early stages of dementing illnesses. It is a construct that comes to mind when observing affected individuals in the art sessions. These individuals are acting "normal," and are doing "normal things" such as greeting and supporting their peers, making art, and doing so in a rational and purposeful way for a prolonged period of time, despite the imposed confusion of dementia. Therefore, normalcy was an observed phenomenon reoccurring in many sessions that needed to be acknowledged, defined, and possibly measured, even if derived out of anecdotal reports from staff and the artist participants themselves rather than the empirical literature. For the purposes of this research, normalcy was added as the seventh domain of well-being.

Initial indicators were extensively pilot tested via observations of participants during Memories in the Making sessions made by the first author and two trained research assistants, and then revised by the second author based on feedback received from those who collected the pilot data. The operational definitions for each domain and the final set of indicators are presented in Table 1.

As can be seen in Table 2, the domains of pleasure and sadness both are assessed with two indicators, whereas each of the remaining domains of well-being are assessed by three indicators. As such, the Greater Cincinnati Chapter Well-Being Observation Tool is a 19-item tool developed to assess, via direct observation, seven domains of well-being among individuals with dementia. The tool is structured so that, at 10-minute intervals, trained observers record the extent to which the individuals with dementia demonstrated each indicator of well-being during the previous 10-minute period on a scale ranging from 0 ("never demonstrates the indicator") to 4 ("always demonstrates the indicator"). Given that Memories in the Making sessions typically last less than one hour once they are underway, the data collection tool was designed so that observers could record four 10-minute intervals of behavior during each observation period. Pilot testing indicated that trained observers could record data for a maximum of three participants at one time.

Inter-rater reliability of the Greater Cincinnati Chapter Well-Being Observation Tool was evaluated by having two trained observers rate the same five individuals with dementia while they participated in three Memories in the Making sessions and three other activity sessions. The Kappa coefficient of concordance, which corrects for chance agreement, was chosen to evaluate the reliability because it provides a conservative estimate of inter-rater reliability for pairs of observational data. The Kappa coefficient could not be computed for 50 percent of the pairs of observations, owing to perfect agreement between the raters (no variability in the ratings; 34 percent of the pairs), or else only one discrepancy between the raters for the pairs (insufficient variability in the ratings; 16 percent of the pairs). For the remaining pairs of observations, the average Kappa coefficient was a respectable 0.654. No attempt was made to assess test-retest reliability of the tool due to the inherent variability in the behavior of individuals with dementia.

Cognitive status. Program directors at each ADC assessed the participants' level of impairment using the Global Deterioration Scale.[21] Individuals participating in the research ranged from level 3 (mild cognitive decline) to level 7 (very severe cognitive decline). There were no exclusion criteria based on the level of cognitive impairment.

Demographic information. Basic demographic information (i.e., gender, racial/ethnic identity) was obtained via observation and from participants' client files (i.e., age, previous work history, psychosocial history) at the ADCs where observations were conducted.

Settings and participants

Data were collected at two ADCs that serve clients with dementia. One ADC is freestanding, and the second is housed on the campus of a continuing-care retirement community. Both ADCs provide transportation, daily meals, and snacks for participants. Weekly Memories in the Making sessions are offered at each ADC as part of

Table 1. Operational definitions for the seven domains of well-being

Domain of well-being	Operational definition
Interest	Participant makes eye contact, eyes following object or person; attempts to socialize by extending hand, pat on shoulder; turning body toward or moving body toward person; chats with others (does not have to have sustained conversation or even intelligible conversation); smiles; offers and receives support from others during session.
Sustained attention	Participant is able to attend to project or activity for 10 minutes; once started on the activity, participant requires rare prompts to complete simple steps to complete the task at hand, or to return to the activity; if verbal prompts or cues required, participant returns to activity and works or pays attention until distracted; participant may engage in conversation with facilitator during the activity but returns to activity when chatting is finished.
Pleasure	Verbal expression of pleasure while participating in the actual activity; eyes crinkled, smiles, laughter, relaxed facial expression; nods positively, relaxed body language.
Negative affect	Closed body language, frown on face, angry verbal outbursts; facial grimacing, or brows furrowed; psychomotor agitation (hand tapping, moving in chair, leg jiggling, wincing); rapid breathing, eyes wide, frightened look.
Sadness	Flat affect or weeping quietly; verbalization of feeling sad over situation; eyes drooping; sighing, head in hand, eyes/head turned downward and face expressionless.
Self-esteem	Verbal expression of pride and satisfaction; nonverbal expression of pride, pleasure and satisfaction of having completed an activity (clapping, smiling, tearfulness, nodding head); expressing an internal sense of pride verbally through reminiscence in response to piece of art created by the individual (for example, client draws a picture of an apple orchard, which recalls memories of role as a farmer that he shares with the group).
Normalcy	Verbal expression of experiencing a sense of normalcy, which arises from belonging to a group and deriving enjoyment from participation in a group activity.

a comprehensive array of programming that includes, among other activities, exercise, current events, and crafts.

Twelve individuals, six from each of the two ADCs, participated in this research. Participants included five men and seven women who had diagnoses of probable Alzheimer's disease, vascular dementia, dementia pugilistica, alcohol-related dementia, and confusion. They ranged in age from 65 to 85 years, and of the 12, five were African American and seven were white. There were equal numbers of blue-collar workers and professionals. Participants included individuals who had experience with painting and others who had never painted before their enrollment in Memories in the Making.

Procedures

Before data collection, this research project was reviewed and approved by the Miami University of Ohio Institutional Review Board, with special consideration toward adhering to the guidelines for obtaining research consent for cognitively impaired adults. The project posed minimal or no risk to the cognitively impaired subjects, and could potentially offer a reasonable prospect of a direct health-related benefit such as QOL improvement. The researchers sought informed consent from family members who had the legal authority to make such decisions for the affected individual.[22] Once consent was obtained, the individuals with dementia were also asked to assent to participate in the project.

Data were collected once per week at each of the two ADCs. On each observation day, attempts were made to observe three participants and document their levels of well-being, at 10-minute intervals, while they participated in two distinct activities—Memories in the Making and the activity that followed (e.g., current events, word games, crafts, sharing)—each lasting approximately 40 minutes. As such, on each observation day, four sets of ratings were recorded at 10-minute intervals for

Table 2. Indicators for each of the domains of well-being

Domain of well-being	Indicators*
Interest	1. The participant shows interest in other participants once the activity is underway. 2. Without prompting, the participant offers support of a peer's participation in an activity by making eye contact, smiling, looking toward the person, or acknowledging the person verbally, one or all of these. 3. The participant acknowledges support from peers by eye contact, smile, verbalization, extending hand, one or all of these.
Sustained attention	1. While engaged in the activity, the participant has sustained attention for a period of 10 minutes. 2. The participant requires verbal prompting or cueing during the activity to sustain the project or activity. 3. The participant initiates and engages in conversation with peers or facilitator and then returns to activity and refocuses.
Pleasure	1. The participant has relaxed body language, smiles, and laughs during the activity. 2. The participant verbalizes a sense of pleasure with phrases such as: “this feels good,” “this is relaxing,” or in the verbal expression of unintelligible phrases such as oooh, aah, accompanied with smiles, crinkling of eyes, or relaxed facial expression.
Negative affect	1. The participant is angry during the activity. 2. The participant is agitated during the activity. 3. The participant verbalizes feeling anxious (“I feel nervous,” “I am jumpy,” “I feel funny today”).
Sadness	1. The participant is sad during the activity as evidenced by one or all of the specified indicators. 2. The participant verbalizes feeling sad at some point in the activity.
Self-esteem	1. The participant nonverbally expresses pride in participating and completing a project by smiling, nodding happily, tearfulness, clapping. 2. The participant verbally expresses satisfaction after completing a successful activity. 3. The participant verbally expresses pride through expressions of reminiscence.
Normalcy	1. The participant verbally expresses feeling good about being in a group activity, which may be expressed as “I feel normal again,” “I don't feel so alone,” or other positive statements. 2. The participant nonverbally expresses social normalcy evidenced by one or all of the following: interest in others, sustained attention to task, relaxed body language; if there is an affective reaction, that reaction does not escalate or perseverate. 3. The participant, when joining or leaving the activity, chats openly with another, shakes hands, pats back, says or nods good-bye.

*Each indicator is rated using the following scale for each 10-minute observation period: 4 = Always, 3 = Most of the time, 2 = Some of the time, 1 = Rarely, 0 = Never.

Table 3. Comparison of domains of well-being during Memories in the Making$^{©}$ and other ADC activity

Domain of well-being	Mean normalized score		*t*	*df*	*p*
	Memories	Other activity			
Interest	0.7109	0.5100	3.102	11	0.010
Sustained attention	1.2594	0.8250	4.976	11	0.000
Pleasure	1.3308	0.9897	3.184	11	0.009
Negative affect	0.0949	0.1037	–0.136	11	0.894
Sadness	0.1165	0.2287	–1.935	11	0.079
Self-esteem	0.3283	0.1679	2.534	11	0.028
Normalcy	0.4428	0.2993	2.901	11	0.014

Memories in the Making and the other activity. Although the initial data collection plan was to obtain eight observations of the seven domains of well-being during Memories in the Making and a second activity, a number of logistic obstacles prevented this from happening. For example, participants on observation days did not always attend the ADC; on certain days, field trips followed Memories in the Making rather than an activity; and, during the course of data collection, several participants stopped attending the ADC. Ultimately, there were four participants for whom five pairs of data were collected (i.e., five days of observations of Memories in the Making and the other activity; each observation included four sets of ratings for each activity), six participants for whom four pairs of data were collected, and two participants for whom only one pair of data was collected.

Results

To determine whether there were differences in the various domains of participants' well-being during Memories in the Making compared to the other structured activity, several steps were taken. Because of the relatively small number of participants and multiple (but unequal) observations for each participant in the two types of activities, the data needed to be simplified. It is important to point out that these observational data are proportional in nature. Each data point represents the proportion of time that a given participant exhibited a particular indicator of a specific domain of well-being (ranging from never to always) during the previous 10-minute interval. To simplify the data, each data point was dichotomized to reflect whether the indicator of well-being occurred at all during the previous 10-minute interval (i.e., 0 = never; 1 = occurred rarely or more frequently). Then, for each domain of well-being, the proportion of data points during which the indicator of well-being was observed for each participant was computed for the two types of activities. This resulted in a total of 14 data points for each participant (i.e., seven domains of well-being for each of the two activity types). These data points were then transformed using the square root-arc sin transformation, the standard transformation for proportional data. Paired-sample t-tests were computed on the transformed data to determine whether there were differences in participants' levels of the seven domains of well-being. The results of these t-tests are presented in Table 3.

As can be seen in Table 3, participants demonstrated significantly higher levels of interest, sustained attention, pleasure, self-esteem, and normalcy during Memories in the Making than during the other activity. Although there was relatively little negative affect and sadness observed during either activity, there was a trend for participants to report less sadness during Memories in the Making. There was no difference in negative affect during the two types of activities.

Discussion

Results from this initial use of the Greater Cincinnati

Chapter Well-Being Observation Tool suggest that the tool is a viable one for the assessment of well-being among individuals with dementia. The tool demonstrated adequate inter-rater reliability and captured differences in domains of well-being within and between the types of activities during which participants were observed.

Of the seven domains of well-being that were observed, participants demonstrated significantly more interest, sustained attention, pleasure, self-esteem, and normalcy during Memories in the Making. In contrast, there were no statistical differences in participants' observed negative affect or sadness between Memories in the Making and the other activity. Researchers and practitioners have acknowledged negative affect and sadness as important components of well-being.[1-4,9] However, relatively little negative affect and/or sadness was observed during Memories in the Making; in fact, there was a trend for more negative affect and sadness to be observed during the other activity. Also, it is important to point out that, of the seven domains of well-being included in the tool, the domain of normalcy is not a construct that has been supported in the literature. As such, operationalization of this domain must be reviewed carefully and additional empirical evidence presented to assure that normalcy is independent of the other domains of well-being. It could emerge that, as operationalized, normalcy is a higher-order construct that subsumes several of the other domains of well-being. If so, its retention in the tool warrants further consideration.

The finding that participants demonstrated higher levels of well-being in multiple domains while engaging in Memories in the Making compared to the other activity begs several questions as to why this was the case. What is it about the process that brings such pleasure and ensures such engagement? Is it the actual involvement in the art project, the immersion in the creative process that taps into brain reserves unaffected by disease process? Brod and colleagues[23] suggest that one of the subdomains of well-being is a sense of aesthetics, which is pleasure obtained from sensory awareness, appreciation of beauty, and creativity/artistic expression and appreciation. Or, is it the sense of belonging that occurs when individuals are involved in regularly scheduled failure-free activity with peers along with one-on-one attention from the artist facilitator? Kitwood and Bredin[24] argue that it is continued relationships with others that sustain and maintain our personhood, rather than the level of our cognitive status. Answers to these questions lie beyond the scope of the research reported here. Nonetheless, this is an important avenue for future research that has the potential to contribute to a growing number of appropriate and therapeutic interventions that can be implemented to promote well-being and affect QOL among individuals with dementing illnesses.

We consider the research reported here to be preliminary, and not without limitations. The major limitations derive from the relatively small sample size. Across the two data collection sites, we observed a total of 12 participants. Clearly, additional research is needed to document the applicability of Memories in the Making to other settings and other groups of individuals with dementia. Because of the small sample size, a number of strategies were used to simplify the data (i.e., data were dichotomized, proportionalized, and transformed) before analysis. As a result, this research could not make full use of the original scoring of the scale. Also, rather than comparing observations of participants in Memories in the Making with the specific "other activity" that took place on observation days (i.e., current events, word games, crafts, or sharing), because of the small sample size, observations during the other activities were aggregated. Related to this, observations of participants during Memories in the Making always preceded observations during the other activity. As such, it is possible that lower well-being scores during the other activity were a result of participant fatigue.

An additional possible limitation concerns certain aspects of the Greater Cincinnati Chapter Well-Being Observation Tool itself. The careful operational definitions and indicators of the domains of well-being make it fairly easy for observers to identify specific instances of well-being. However, a fair amount of training was necessary before we were able to accurately rate the extent to which participants demonstrated each indicator of well-being (using the 5-point scale ranging from "never demonstrates the indicator" to "always demonstrates the indicator").

Finally, although it was beyond the scope of this research, an important question is whether the increased well-being observed during Memories in the Making extends beyond the session, contributing to more generalized well-being for individuals with dementia. Should future research document such a carryover effect, this would provide additional support of the importance of providing Memories in the Making to individuals with dementia.

Despite these limitations, we are optimistic about this line of research. The Greater Cincinnati Chapter Well-Being Observation Tool offers a systematic and comprehensive way to determine if affected individuals are experiencing a sense of well-being while participating in a structured activity. Future efforts might include a larger-scale, more comprehensive effort to test this tool with a large sample of affected individuals who are participating in art programs such as Memories in the Making and other activities across a variety of settings. Only when clinicians engage in direct observation of predefined behaviors associated with QOL, rated consistently over time, can we identify appropriate QOL indicators for persons with dementia as they participate in structured and unstructured activities.[25] Such efforts will contribute to the emerging literature on this theoretically and clinically relevant area of inquiry. Dementing illnesses are incurable, with limited treatment options to ameliorate the psychological discomfort associated with these disorders. Until there is an end to this group of confounding disorders, through prevention or cure, treatment options can and must include supportive structured, nonpharmacological interventions that enhance and maintain an affected person's sense of well-being, at least for a moment in time, from beginning to end of a prolonged and often difficult disease course.

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*A copy of the Greater Cincinnati Chapter Well-Being Observation Tool is available upon request from the second author (*clarissa.rentz @alz.org).

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