# IDENTIFYING THE CREATIVE-EXPRESSIVE ABILITIES OF PEOPLE WITH DEMENTIA



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By

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In this article, Dalia Gottlieb-Tanaka and Hilary Lee introduce the Creative Expressive Abilities Assessment (CEAA) tool, the first comprehensive observational tool specifically designed to assess and show changes in the creative expressive abilities of people with dementia and assist in evaluating the effectiveness of creative activity programs such as art, music, dancing, singing, reminiscence and storytelling.

This article describes the development and research behind the Creative-Expressive Abilities Assessment (CEAA) tool, which is designed to obtain in-depth information about the creative-expressive abilities of older people with dementia. The tool is successful in showing changes in abilities when seniors participate in meaningful activity programs. In this article, we describe the need for such a tool, its development, with brief references to its validation and reliability studies, and provide feedback from creative arts practitioners who have used the tool.

## Why Was This Tool Needed?

Engaging in creative arts activities can contribute to the quality of life at every stage in human development (*Runco, Ebersole, & Mraz, 1990; Runco & Richards, 1997*). In recent years there has been a global expansion in the use of the creative arts in dementia care. Prominent among the programs designed to enhance quality of life for older people are the creative expression programs, which harness and build on seniors' remaining abilities by engaging them in creative thinking and spiritual contemplation in order to reaffirm their dignity and self-worth (Lee 2007).

These programs focus on creative arts such as painting, listening to and making music, dancing, singing, reminiscing, storytelling, and life review. Their specific aim is to foster a positive psychological health, promote well-being, encourage and elicit abilities in a meaningful and possibly novel way by stimulating curiosity, self-reflection and the expression of emotions.

However, as the number of people living with dementia increases dramatically, along with the cost of their care, there is a risk that psychosocial care will be undervalued while the focus of care may turn to physical needs only.

The authors were convinced that one vital reason why the value of creative expression programs continues to be underappreciated stems from the lack of an easy-to-use instrument for collecting solid quantitative evidence concerning the possible positive effects these programs provide. We wanted to find a way to demonstrate the value of these programs, to identify and track changes over time and also to justify the existence of these programs when resources are scarce.

#### The Creative-Expressive Abilities Assessment Tool

The idea for the CEAA tool was conceived by Dalia Gottlieb-Tanaka during her graduate studies and was brought to fruition after meeting Hilary Lee in 2006 at a Creative Expression, Communication and Dementia conference at the University of British Columbia, sponsored by the Society for the Arts in Dementia Care. The two agreed that new tools were needed for assessing and documenting the benefits of creative arts activities and related programs, but no such tool existed. We then decided to build a practical and comprehensive tool to assess the creative abilities of people with dementia.

In conjunction with Dr. Peter Graf, Professor of Psychology at the University of British Columbia, the authors developed the Creative-Expressive Abilities Assessment (CEAA) tool to answer specific and practical questions that were based on a systematic collection of data (quality data) such as:

- Are some creative arts activity programs more effective than others for enhancing the expressive abilities and quality of life of seniors with dementia?
- What are the specific benefits of these programs for people with dementia?
- Can specific abilities such as memory, language or reasoning be tracked over time?

The CEAA Tool is a unique and comprehensive observational tool specifically designed for people with dementia to identify their creative expressive abilities. It was developed using standard psychometric techniques. It reflects in descriptive language, as well as a quantitative score, how people with dementia can creatively express (for example through language, dance, music, art and humour) their emotions, thoughts and experiences, when offered creative arts programs as a catalyst for communication.

The tool is easy to use and is intended for health professionals, activity and lifestyle leaders, artists and anyone who facilitates innovative and meaningful therapeutic programs in the fields of dementia and aged care and older adult mental health. It assists therapists to evaluate, describe and quantify results of their creative arts programs, fine-tune these programs, justify funding for such programs and support accreditation documentation in their care facilities.

The CEAA tool consists of 25 core items, plus two optional items that involve some form of writing that are related to the following seven ability domains: memory, attention, language, psychosocial skills, reasoning/problem solving skills, emotions and culture. While clients participate in creative arts programs, their responses are recorded and rated by an observer trained on the CEAA tool. Each item is scored on a five-point scale: 0=the program did not provide any opportunity for the participant to exhibit the expressive ability; 1=never; 2=rarely; 3=sometimes; 4= (nearly) always. The domains then are aggregated into a total creative-expressive ability score.

# **Developing the CEAA Tool**

There were two important aspects to the development of the tool. These were processes relating to ensuring that the tool was both reliable and valid.

# Reliability of the CEAA Tool

The first part of the tool's development was based on qualitative inquiry. It described the specific creative responses to social and arts programs which would be suitable for quantification (applying a numerical score). This segment included:

- A detailed review of the literature to ensure no such tool already existed
- The authors' personal first-hand experience with creative arts programs
- Discussions with creative expression facilitators
- Identifying seven overarching domains of creative expression
- Describing a list of items of creative-expressive responses for each of the seven domains
- Testing version 1 of the tool and refining it with feedback from facilitators using focus groups in Canada and in Australia
- Removing core items that showed floor or ceiling effects (where variations in scores could not be identified)

The first version of the tool was used in Western Australia by eight different observers over nearly six months to assess people with dementia participating in two different creative arts activity programs. Based on the insights, experiences and data from this phase, we drafted a second version of the tool, which was then used in Vancouver, Canada by four observers assessing people with dementia in 17 different creative arts activity programs. We then combined these results with feedback from two focus groups in Canada (six participants) and Australia (ten participants) and activity programs directors who might use the tool. The last steps resulted in a third version of the tool.

## Validation of the CEAA Tool

In 2015, the authors arranged an independent analysis to test the validity of the CEAA tool whether it measured the abilities it was intended to measure: the creative expressive abilities of people with dementia. The validity analysis was based on previous data that was collected during the reliability testing conducted by Dr. Elizabeth Lokon and her students at the Miami University in Ohio, during the Cedar Village Creative Arts in Ageing program described later in this article. The validity analysis was conducted by Dr. Ruth Childs and her graduate students, Tian Tang, Jinli Yang and Saira Mall, at the University of Toronto. The analysis supported the validity of some of the domains of the CEAA tool to assess the creative expressive abilities of seniors with dementia. Ratings on the CEAA tool were moderately and significantly correlated

(degree of association) with two instruments that measured some aspects of creative abilities: the Oshkosh Social Behaviour Checklist and the Measurable Assessment in Recreation for Resident-Centred Care. In addition, four of the domains were strongly internally consistent (these were memory, language, reasoning and culture).

The validation analysis by Dr. Childs and her students indicated that the CEAA tool could make reliable and trustworthy observations on creative-expressive abilities of people with dementia. The term trustworthy was described by Shenton (2004) as dependable, credible, transferable and confirmable.

# How to Use the Tool

Assigned observers, or the program facilitators, can choose between using pencil and paper for scoring or enter the scoring directly into digital forms provided with the CEAA tool's guidebook on a USB stick. The observations can be conducted as often as the creative arts activities sessions occur. The observations can take place before any program is implemented to get baseline data. Additional observations can then be implemented as often as desired. This method of collecting data is known as a 'Before and After' approach to assessment.

We would like to clarify that the CEAA is an observation tool and does not include personal interviews with the participants. The results do not explain why changes occurred, rather they identify what kind of changes occurred and it is up to the researcher or staff members to reflect and look for the reasons as to why changes took place.

# Benefits of Using the CEAA Tool

Program facilitators can observe clients' creative abilities in a systematic way and monitor any changes over time. The tool provides valuable and insightful information with specific details for reporting in meetings with colleagues, administration and families. The tool is helpful in assessing the abilities of new clients. Facilitators can use the CEAA tool to monitor sessions and evaluate their effectiveness. It also serves as a guide in planning activities that are meaningful for each client.

Also:

- Administrators of care facilities can use the CEAA tool to compare the impact and effectiveness of various programs
- The tool could serve as a complementary information source to medical reports
- The tool can be used in planning budgets for effective and meaningful social programs that are run by skilled facilitators
- The CEAA tool could assist in finding the right facilitator for a specific program

A User Guide to the CEAA tool is available for first-time and experienced users alike. Users have reported the guidebook was a valuable resource for training facilitators. More information is available at the Dementia Activities website (http://www.dementia-activities.com/index. html).

#### International Use of the CEAA Tool

#### The Spark of Life Culture Enrichment Program

The CEAA tool is used to evaluate the *Spark of Life* Club Program, as part of the *Spark of Life* Culture Enrichment Program in Australia, Denmark, New Zealand, Singapore, the US and Africa. Dementia Care Australia provides the CEAA tool with its International *Spark of Life* Master Practitioner Course for residential and community care leaders. The tool was chosen for its ability to measure the strengths and abilities of clients in a non-intrusive way. It is person-centered in a way that gives staff important reporting skills (format and language) to describe in detail what is being observed and, consequently, its results.

For more details about Spark of Life please visit: www.dementiacareaustralia.com

## The Creative Arts in Ageing Program, Cedar Village, US

In 2012, the CEAA tool was used to evaluate art and music activities for people with dementia as part of the Creative Arts in Ageing Program at Cedar Village in Ohio. The evaluation was conducted by Scripps Gerontology Centre at Miami University. A total of 63 people were observed, with a total of 122 observations. It did not include residents in more advanced stages of dementia. The use of the CEAA tool to observe residents participating in the Creative Arts in Ageing Program and in more traditional activities enabled the observation team to find the differences between the two programs. The results of the observations showed that music and art therapy programs provided residents with significantly more opportunities for creative expression than did traditional activities.

More details on this study can be found in the Wolf Report: http://www. dementia-activities.com/PDF/WOLF\_Report\_July2012.pdf)

#### Seniors Centre, West Vancouver, Canada

In 2015, the CEAA tool was successfully implemented at this Seniors Centre in West Vancouver, British Columbia, which provides programs for people with dementia who still live in the community. The Centre provides programs for seniors of healthy cognition too. The dementia program is based on the Creative Expression Activities Program developed by Dalia Gottlieb-Tanaka (2006). The Centre's staff were trained over a period of several months using the CEAA tool as a guide. Staff learned to interact with their clients and gain important personal information that resulted in adapting their program to each person.

#### Summary

The CEAA tool represents a practical assessment instrument that enables the evaluation of people with dementia when engaged in meaningful creative-expression programs. The results of the assessment not only enable facilitators, therapists and administrators to evaluate their programs, but also identify specific changes in seven creative-expression domains. It is a trustworthy tool that describes and quantifies the creative-expression abilities of people with dementia and assists in developing better therapeutic social and arts programs for them.

#### **Important Note:**

To demonstrate the use of the CEAA tool, we included three case scenarios. Two of them took place in academic institutions in Australia, where two graduate students working on their PhDs used the CEAA tool to defend their dissertations. A third case was used in practice at a seniors' day-care centre in West Vancouver, Canada. Each case demonstrates the CEAA tool being used for different arts programs. All were unrelated. However, the tool was sensitive enough to pick up changes over time and helped successfully in the data collection stage which in turn led to successful graduations. The third case in practice, the data collection and its analysis led to more funding for the program and to a BC Provincial Award for Excellence in 2016.

For more information about the CEAA tool please visit: www.dementiaactivities.com or email the authors.



#### Dr. Dalia Gottlieb-Tanaka

Dr. Dalia Gottlieb-Tanaka is a graduate of the Bezalel Academy of Arts and Design in Jerusalem, has a Master of Architecture degree and PhD from the University of British Columbia; she founded the Society for the Arts in Dementia Care.

Dalia continues to do research and deliver presentations and workshops internationally on the use of visual and performing arts in health services for people with dementia.

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#### Hilary Lee, OTR, MSc

Hilary has a background in occupational therapy as well as qualitative research, having undertaken a Masters in Science at Curtin University of Technology, Perth, Western Australia. She has 30 years of diverse experience in dementia care. She established and chaired a chapter of the Society for the Arts in Dementia Care in Australia between 2006 and 2016. Hilary is President of *Spark of Life* with Dementia Care, Australia.

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This self-published Article can be found on: www.dementia-activities.com www.cecd-society.com

ArtScience Press #205 - 3609 30th Avenue Vernon, British Columbia, Canada V1T 2E6 www.dementia-activities.com

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# International Use of the CEAA Tool: Testimonials

# The CEAA Tool and Dramatherapy - by Joanna Janniste, PhD

In 2011 I used the CEAA tool to assess possible creative expression improvement in six people with dementia participating in 16 sessions of dramatherapy. This was undertaken as part of my PhD research project investigating possible quality of life (QoL) improvement through dramatherapy (Jaaniste et al 2015).

All sessions were videotaped. The seven domains of the CEAA scale: language, memory, attention, sociability, problem-solving, feelings and cultural/spiritual aspects, are all important areas of investigation for any serious attempt to improve the QoL of people with dementia. As a quantitative measurement that was designed along qualitative lines, the tool is based on a mixed method of observation, and is tested, reliable and valid (Gottlieb-Tanaka, 2016). In my study, three health professionals and two art therapy students used the tool to observe and record what actually changed and where change may have occurred. In almost all cases, except for the section on cultural attributes, there was an overall average improvement in the group.

#### Method

Each week after the 90-minute session, consensus scores for each of the above domains were averaged for the group and transferred from the assessment pro-forma to an Excel spreadsheet. The week's scores for each item were then averaged for the group and graphs were made from the scores at the end of the program. From the graphs we were able to obtain a visual average tally for each session and also the linear progress or decline over time. In each case but one, the group's ability to express through creativity (in this case, drama and some visual art) improved in both areas. In some cases, the improvement was surprising, especially in the cases of memory and attention.

Ninety minutes was a long time for these participants to concentrate and yet their attention skills improved over the period, with no break or 'time out'. Improved evidence of memory came through in the role play and reflection on improvisation and story-making and was occasionally worked with therapeutically; on some occasions improvements in short-term memory were also observed.

The other four domains of language, sociability, emotion and problem solving also improved, but not as substantially. In the culture/spirituality domain, the scores diminished. The reason for this reduction is unknown, but may be due to the similar Anglo-Celtic background of all the participants.

# Conclusion

The study as a whole demonstrated that the CEAA tool was a robust measurement. It showed unusual improvements in people with dementia and justified the extra time spent by health professionals. We saw a surprising cross-fertilisation of interests and a depth of immersion in art works and drama that showed what could be achieved if participants continued with this work. The CEAA tool illustrated elements of quality of life that showed improvements in participants' sociability, problem-solving skills, use of language and expression of feeling over the time, as well as attention and memory.

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#### Joanna Jaaniste, PhD, AthR (Drama)

Joanna is a registered dramatherapist and an Adjunct Fellow of Western Sydney University where she also tutors and lectures on the Master of Art Therapy course. She is principal of The Dramatherapy Centre, Sydney, NSW where she teaches introductory and advanced dramatherapy courses and is the Australian representative for the 2017 European Consortium for Arts Therapies Education (ECArTE) Conference.

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# The CEAA Tool and the Creative-Expression Activities Program - by Carly Graham

The Creative Expression Activities Program was implemented at the West Vancouver Senior's Activity Centre in Canada on September 25th 2015, after several months of training by Dr. Dalia Gottlieb-Tanaka. We began using the CEAA tool in October that year to assess four of the participants in the program. We looked for what was and wasn't working in the lesson planning, what the participants responded well to and how to plan for future lessons. Assessing all the participants was not feasible time-wise.

The number of participants in the program varied from seven to ten including one caregiver. Some of the seniors were diagnosed with Alzheimer's disease, while the others were considered to be at risk of developing dementia due to loneliness and being isolated. Each week we had a different theme for the program's activities. I categorized the various activities into keywords. For example: audio/visual, painting, show and tell, crayon and pencils/pastels. At the end of the term I looked at which themes the participants achieved high scores. I also analyzed the common keywords for those themes and used that as the basis for my activity planning. Using the CEAA tool allowed me to identify the items in the domains the participants responded well to, such as:

- Audio/visual stimulation
- Unusual topics
- Tactile and hands-on activities
- Sharing likes and dislikes regarding the topic
- Show and tell activity (bringing something from home)

I found participants engaged with the topic when they had an opportunity to bring a related object to the activity. They demonstrated a sense of pride, shared stories and were able to reminisce. I found that audio-visual presentations stimulated their creative responses. For example, in our topic on graffiti we showed a video clip about grandmothers in Berlin doing graffiti. The participants enjoyed seeing someone similar to them doing such a young 'thing' and talked about how it might feel to paint on walls without inhibitions. In this session participants scored high in the attention and the language domain, producing complete sentences when speaking and providing elaborate descriptions of objects, actions or events.

The CEAA tool allowed me to follow their responses and document them in an organized fashion. The participants also scored high in tactile and hands-on activities. They scored high in language, attention and the reason/problem solving domains. While making a collage out of sea shells and driftwood using a hot glue gun (with supervision), participants showed insight into problem solving in relation to plans, design and space. They worked out where the wood would go, what piece would fit where and what would be aesthetically pleasing.

Some participants had low scores, perhaps due to a variety of reasons: not being fully awake due to a poor night's sleep, uncomfortable wheelchairs and/or high anxiety. One participant relaxed over time and settled in comfortably with the group. His assessment results reflected this.

The assessment tool helped us understand how successful our program was and whether or not we were meeting the needs of our participants. It kept us on track and made us accountable for the work we were doing. At one point I realized we had not done an activity that would allow the participants the opportunity to demonstrate a writing ability in the language ability domain, therefore I made a note to incorporate this the following week. The most important thing I learned from my interactions with our clients was that each participant is unique in their likes, dislikes, and memory ability. By using the CEAA tool's Client Observation Form I was able to get a sense of the types of activities that produced the highest scores in the seven domains of abilities. With this knowledge I was better equipped to provide suitable activities for the participants in order to achieve maximum engagement, allowing them to enjoy the moment and encourage memory recall.



#### Carly Graham

Carly is a student of gerontology at the Simon Fraser University, Vancouver, British Columbia, Canada and a facilitator at the West Vancouver Senior's Activity Centre.

## The CEAA Tool and the MacArt Program - by Julie Cross McAdam, PhD

The challenge any researcher faces when attempting to research dementia-specific creative expressive art activity is to find an assessment tool that is sensitive enough to do a research question justice.

Between 2008 and 2011, I conducted a phenomenological (lived experience) PhD research study. My aim was to document the relationship between art and dementia and well-being in people living with dementia whilst they engaged in an art activity. My task was to find a research tool that would provide valid and reliable outcomes.

The concept of well-being can be elusive because it generally means different things to different people. After examining a number of methodologies, I settled on the Creative Expressive Abilities Assessment (CEAA) tool because of its sensitive ability to catch creative expressions responses of people living with dementia and its easy-to-use scoring system. The CEAA is designed to assess seven recognised domains of creative expression abilities, six of which I have used in my dissertation. The CEAA tool allows detailed observations of a wide range of different skills and abilities.

I used the CEAA to assess 'what' people living with dementia did and experienced during a one-on-one art activity. Three different scorers independently scored participants in the study. One scorer observed and scored the live art activity. Then later, in a single sitting, post activity assessment, a staff employee, and myself as the principle researcher, scored the activity whilst watching a videotape replay. Three independent sets of data gathered during the same activity yielded remarkably similar scores for every participant.

The CEAA provided me with an opportunity to closely observe creative engagement and more accurately identify a variety of innate skills and subtle responses. The selected six domains of creative expression abilities enabled me to gain valuable insights into each participant's lived experience. More importantly, the results indicated that creative expressive

art activity is capable of stimulating a novel and varied experience for people with dementia that can now be reliably assessed and documented. In the future, a steady accumulation of such data could be adapted to develop new and much needed psychosocial activities for facilitation by arts and activity practitioners.

The research methodology fulfilled a strict performance criteria set by the Victoria University, Melbourne, for its PhD degree award. The research findings have been widely distributed both in Australia and internationally, including in the following peer-reviewed journal: http://www.education.unimelb.edu.au/UNESCO/ejournal/ejournal\_vol3iss3. html



#### Dr. Julie Gross McAdam

Dr. Julie Gross McAdam is an executive member on the board of The Society for the Arts in Dementia Care (North America). Julie is also the Founder of the MacArt Program in Melbourne, Victoria, Australia