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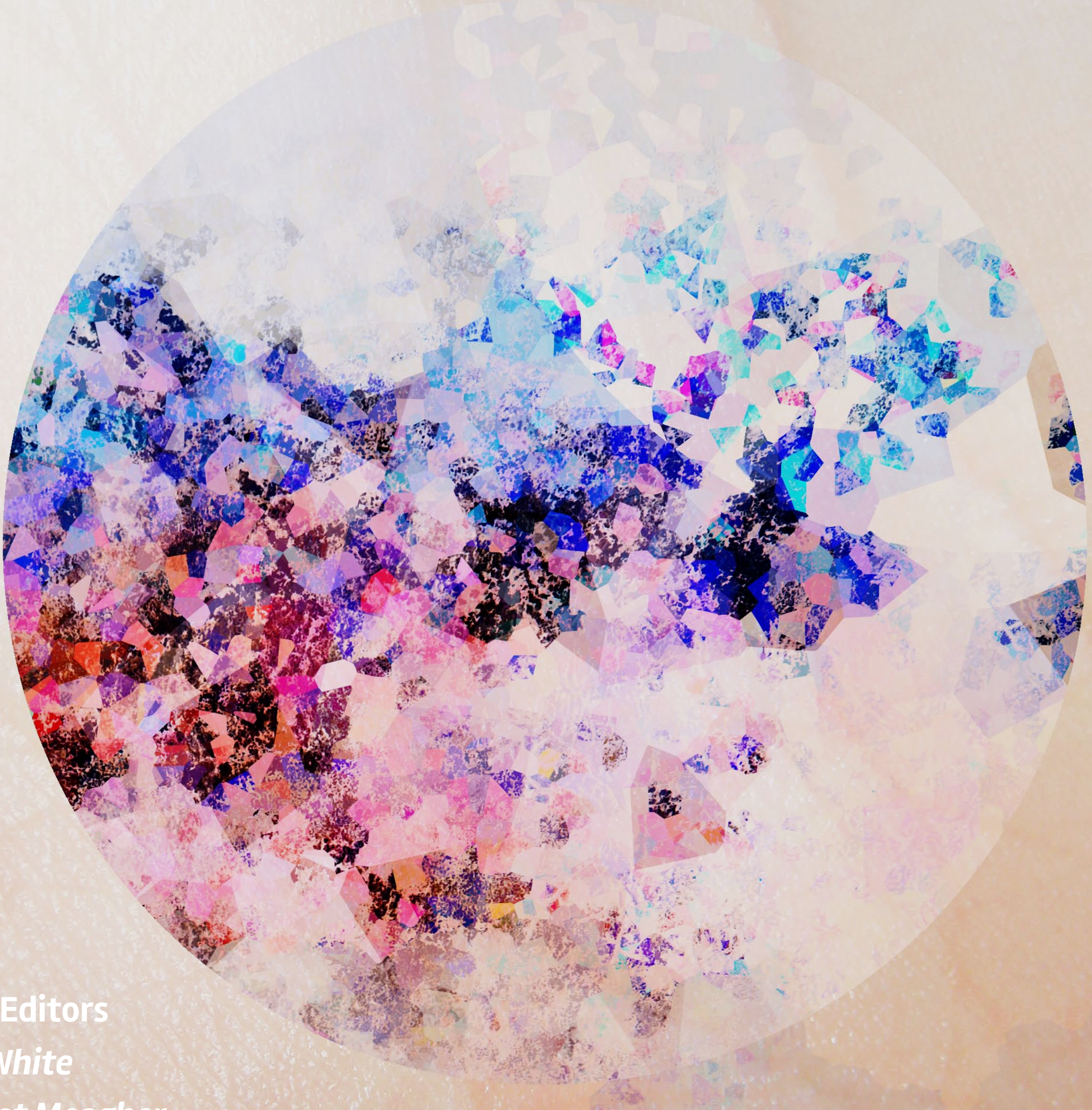
# UNESCO Observatory Multi-Disciplinary Journal in the Arts



Guest Editors
*Mike White*
*Margret Meagher*
*Dr. Sarah Atkinson*

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## International perspectives on the development of research-guided practice in community-based arts in health

# UNESCO Observatory Multi-Disciplinary Journal in the Arts

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## ABOUT THE E-JOURNAL

*The UNESCO Observatory refereed e-journal is based within the Graduate School of Education at The University of Melbourne, Australia. The journal promotes multi-disciplinary research in the Arts and Education and arose out of a recognised need for knowledge sharing in the field. The publication of diverse arts and cultural experiences within a multi-disciplinary context informs the development of future initiatives in this expanding field. There are many instances where the arts work successfully in collaboration with formerly non-traditional partners such as the sciences and health care, and this peer-reviewed journal aims to publish examples of excellence.*

*Valuable contributions from international researchers are providing evidence of the impact of the arts on individuals, groups and organisations across all sectors of society. The UNESCO Observatory refereed e-journal is a clearing house of research which can be used to support advocacy processes; to improve practice; influence policy making, and benefit the integration of the arts in formal and non-formal educational systems across communities, regions and countries.*

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# International perspectives on the development of research-guided practice in community-based arts in health

**Guest Editors**
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## THEME

Health has become a recurrent topic in discussion of the role of the arts in society, fuelled by a growing body of research into links between culture and flourishing. In community arts in particular there has been a widespread development of projects addressing health issues. This is a distinct area of activity operating mainly outside of acute healthcare settings and is characterised by the use of participatory arts to promote health. There are indications that this work is developing in response to health needs of communities in differing cultures and healthcare systems around the world, but so far there is little mutual knowledge or connection of the work at an international level.

This issue aims to draw together well-researched case studies of community-based arts in health projects from different parts of the globe. Each case study should explain the motivation for the work undertaken and its sensitivity to context and cultural diversity, the partnership structures and ethos developed in its delivery, and the research methodologies used. Submissions are particularly invited that reflect multidisciplinary knowledge of the application of arts development to health and flourishing communities from the perspectives of applied arts, public health, anthropology, social geography, education and other disciplines.

# Conducting art-based research in dementia-specific healthcare in Australia.

**Dr. Julie Gross McAdam**
*MAC.ART Program Director*

## ABSTRACT

This paper describes an art-based research project and is intended to inform researchers in the healthcare field of the outcomes of a four-year Australian community art-based research project that investigated the relationship between art and wellbeing for those living with dementia.

With the intention of furthering research-guided practice in community-based arts in healthcare, this paper explains the project design, research methodology, assessment tools and outcomes. It also puts in context some of the pitfalls of conducting research in dementia-specific healthcare and makes recommendation to further art-based research in the future.

## KEYWORDS

*Dementia, biomedical model, psychosocial interventions, person-centred care model, Alzheimer's disease, Kitwoodian theory.*

## INTRODUCTION

The paper begins with a glossary of terms and then describes dementia. It sets out the author's motivational impetus and relates why the investigation took a phenomenological approach in closely examining the lived experience of a group of residents with dementia in an Australian aged care hostel. It then explains how the dementia-specific assessment tools were used by the principle researcher, initially to observe 'what' individuals experienced during an art activity, and then, to analyse 'how' participants responded to that phenomenon.

To place the research project within established theoretical terms of reference, a brief outline of the dementia-specific, person-centred approach, developed by the late Thomas Kitwood (1937-1998) at Britain's Bradford University in the 1980s and 90s, is provided. Finally a select list of research outcomes pertaining to the inherent skills of those living with dementia is highlighted to demonstrate the effectiveness of the research methodology, and some recommendations are provided to further art-based research in the future.

### GLOSSARY OF KEYWORDS:

The dementia-specific art activity referred to in this text falls under a psychosocial interventions umbrella. These interventions include a widening stream of creative arts therapies and dementia-specific programs designed especially for those living in aged and healthcare settings. The following glossary of terms briefly explains keywords used in dementia-specific healthcare.

**Alzheimer's disease**: The most common form of dementia 'discovered' by Alois Alzheimer in 1906.

**Biomedical model**: An arguably reductionist approach to healthcare that tends to place the treatment of the disease, rather than the person, at the centre of the care equation.

**Creative expressive arts therapies**: A term used to describe a group of therapies that may include, but not limited to art, music, poetry, reminiscence, dance and movement.

**Dementia**: An umbrella term to describe the eighty or more diseases or syndromes that result in progressive cognitive impairment.

**Kitwoodian theory**: The theoretical/philosophical ideas that are based on the dementia-specific writings and model of care designed by the late Professor Thomas Kitwood (1937-1998), an English academic specialist in dementia care.

**Kitwood's primary psychological 'needs'**: Tom Kitwood identified five primary psychological needs: comfort, attachment, inclusion, occupation, identity plus unconditional love. These needs must be met to sustain dementia-specific wellbeing.

**Living with dementia**: A dementia/disability term that has since the 1990s increasingly replaced the widely used biomedical term 'suffering from dementia'.

**McAdam Aged Care Art Recreation Therapy (MAC.ART)**: An original art as recreation therapy program designed by Julie Gross McAdam in 2001. www.macart.com.au The program was written to meet the requirements of Australian aged care legislation. Legislation requires aged care facilities, to provide purposeful activities and recreational opportunities for all residents, as part of their accreditation responsibility.

**Person-centred care and model**: A model of care designed by Tom Kitwood that places the person and their needs at the centre of the care equation.

**Positive person work tenets**: Tom Kitwood formulated twelve positive work practices for the workplace aimed at promoting the wellbeing needs of those living with dementia.

**Psychosocial interventions**: A term to describe a group of psychological and social (psychosocial) non-drug interventions, such as art, music, dance and movement, pet and horticultural therapy used in aged care to promote wellbeing and advance the quality of the lived experience of individuals with dementia. Psychosocial interventions are often times described in biomedical literature as 'non-pharmacological interventions'.

## WHAT IS DEMENTIA?

Dementia is an umbrella term that describes as many as eighty different diseases and syndromes that result in progressive and irreversible memory loss and cognitive impairment. Dementia is a mounting international healthcare issue that knows no boundaries (Alzheimer's Australia: 2003; Greenfield: 2011). It currently costs the Australian economy more than $6 billion per annum (Alzheimer's Australia: 2003). Dementia affects every culture and community and, in the absence of authorative assertions to the contrary, one must rely on unambiguous statements made by leading scientific authorities in the field. Dr Ronald Petersen, Director of

Alzheimer's Research at the Mayo Clinic in Rochester, Minnesota, and Dr Richard Hodes, Director of the National Institute on Aging, USA, are of the opinion that whilst there is much hope in scientific circles for a cure for Alzheimer's disease sometime in the indefinite future, neither expert is prepared to forecast that any definitive medical breakthrough is on the horizon (Peterson & Hodes: 2013). The scientific reasons why no breakthrough is expected soon are clearly delineated by Jerome Groopman, Recanati Professor at Harvard Medical School, in the recent 24 June 2013, edition of *The New Yorker* (Groopman: 2013).

By 2016, dementia is set to be the biggest disability burden in Australia's history (Alzheimer's Australia: 2003, 2005, 2006). To meet this challenge, many practitioners in the creative arts field are working on developing psychosocial interventions to meet the ever increasing wellbeing needs of those living with dementia's many and varied forms. As a result, there is a steadily growing body of knowledge that links the development of healthcare projects with the dementia related healthcare needs of communities worldwide. The reasons why much of the current psychosocial research related to this rapidly developing healthcare crisis are not always properly considered are complex and are discussed in this paper.

## THE BACKGROUND AND MOTIVATIONAL FACTORS THAT DROVE THIS ART-BASED COMMUNITY RESEARCH PROJECT

For more than a decade my professional work facilitating the MAC.ART program, combined with my academic doctoral research, has been almost exclusively focused on the fascinating world of gerontology and dementia. As mentioned in the glossary of terms the MAC.ART program was written to meet the requirements of Australian aged care legislation. In particular, it was designed to address the minimum 'lifestyle' regulations of aged care facility accreditation. There is no expectation under Australian aged care legislation that recreation activities have an ongoing or long-term therapeutic outcome. Put simply, the MAC.ART process uses art in purposeful recreation, and it is a best described as a 'here and now' activity.

One of the prime motivations of my work has been to produce a body of evidence that challenges the stereotypical myth that, because those living with dementia can no longer remember things, they are no longer creative or capable of fully engaging in life-affirming and purposeful activities.

The communal artworks created by the MAC.ART program are what the art therapist Edith Kramer (2007) might describe as examples of 'modern folk art'. The works pictorially capture moments in the life and times of the artists who create them. As such, they can be shown to be uniquely sensitive to the varying and different social contexts in which they evolve. In more than thirty individual projects, the images have embraced the feelings, aspirations and cultural diversity of more than three thousand individual participants who have taken part in the program in Australia and North America.

I have been very fortunate. I have spent my entire adult career working in the creative arts. Always seeking a challenge, in 2001, I embarked on what was to become a decade-long academic course of dementia study that culminated in the completion of a doctoral research degree in early 2012. My involvement in the creative arts has been both intellectually sustaining and emotionally fulfilling.

During my career as an art facilitator in aged care I have often seen individuals with very advanced dementia pick up and use a paintbrush with consummate ease, even though the destructive progression of dementia can be devastating. Even with diminished language skills, and quite obvious neurological damage to other core functions, contrary to common perception I have observed thousands of individuals living with dementia become totally absorbed in the creative process. This positive reaction to painting often appears to mirror my own sense of pleasure and satisfaction in creativity, making me wonder how absorption in the 'flow' of painting contributes to a general feeling of wellbeing (Csikszentmihalyi: 1996). As my academic knowledge and interest in dementia grew, the desire to learn more about how art relates to wellbeing became the primary motivation for my research project. My interest was driven by sustained curiosity and a keen desire to document what I had so often observed during the lived experience of many artists over the years.

A comprehensive literature review conducted by Gottlieb-Tanaka and Graf (2011) revealed that only a few dementia-specific art related studies exist that meet biomedical performance criteria. And, within those few, researchers rarely detail the physical processes involved in the implementation of their art activities. And, because most artists are usually so taken up by an instinctive response to the experience they rarely document what is actually felt during the process. Finlay (2002: 132), writing in her book *Color: A Natural History of the Palette*, observes, 'when we see a finished painting we tend to access it for such things as composition, emotion, colour and perspective', but she has difficulty pinpointing what an artist thinks about from moment to moment. She poses several questions and wonders whether the 'laying down of paint happens without any mental images at all'. Finlay makes the suggestion that whether an artist thinks of 'butter or tiramisu or diesel', or nothing at all, the tactile act of stirring and splattering and smearing paint is sometimes an act 'where time is forgotten'. She believes artists look at paint and measure its ability to drip, and then they carefully assess each colour to see what it goes with when deciding 'whether it is welcome on the palette'.

Art related wellbeing may be experienced under many different circumstances and conditions. I was thus keen to see if I could identify whether it is the phenomenon of forgetting time, as Finlay suggests, or whether other parts of the engagement with art contribute most to what usually culminates in a palpable sense of accomplishment. In my own personal experience, finding both the time and the opportunity to finally finish a painting is what ultimately leads to a real sense of completion, but creative fulfilment is different and for me it comes from producing art that is layered in colour. If it can be isolated, it is a combination of the physical sensation of automatically moving the brush across a smooth surface, and the layering of the colours, to the point when it feels and looks like nothing more needs to be added. To me becoming absorbed in layering colours is what contributes most to that creative element. This ignites a feeling of accomplishment and creative fulfilment that culminates in an overall sense of wellbeing that art supremely, if not necessarily uniquely, seems to inspire.

I set myself the task of documenting some observations that would contribute to an even smaller body of literature on the relationship between art and dementia-specific wellbeing and began by researching what other investigators had discovered. After an exhaustive search, I was disappointed to find that few, if any, publications to date, with the exception of Dalia Zaidel's, *The Neuropsychology of Art: Neurological, Cognitive and Evolutionary Perspectives* (2005), have explored the neuropsychological stages of an art activity beyond a few basic steps. Because the creative process appears to be little understood even as experienced by able-bodied participants, the correlation between a dementia-specific art activity and wellbeing is even less well known or comprehended. There are many theories on the role art has played in human development (Dissanayake: 1988, 1995, 2000). Some theories are more hotly contested than others, but that does not mean that Dissanayake's contribution is not significant. I became fascinated with the prospect of exploring what inherent skills humans retain as dementia progresses.

## SETTING THE RESEARCH PARAMETERS

It was never my intention at any time to scientifically validate the MAC.ART process using biomedical criteria during the research project; because, firstly, the program is not a medical intervention and secondly, it has already undergone rigorous assessment on five separate occasions by the Australian Aged Care Standards and Accreditation Agency. On each occasion independent assessors have determined that the program fulfils the requirements of Australian aged care legislation and the 'here and now' purpose for which the art as recreation therapy program was initially designed. However, the art activity component of the MAC.ART program, which I have facilitated more than three thousand times, provided the study with both a formal structure and an empirical base on which to scientifically conduct the art activity. But even so, to research the process, I had to identify a way to fully document each component.

As mentioned, most psychosocial interventions in aged care are 'here and now' activities that are not designed to be either medical or curative. That said, unfortunately, in the assessment of their efficacy they are almost always expected to deliver 'evidence-based' biomedical research outcomes measured by randomised controlled trials (RCT). The Cochrane Collaboration, the peak body that oversees and determines the classification of medical research, has for nearly two decades recognised that dementia-specific psychosocial interventions are sufficiently different from medical and drug interventions to warrant the design of specific assessment tools of their own.

In 2010, the Cochrane Collaboration published an updated Consolidated Standards of Reporting Trials (CONSORT) guideline document, and terminology flowchart extension. This document is specifically designed to assist researchers to conduct and report medical research trials into 'non-pharmacologic treatments', even though most researchers studying psychosocial interventions rarely seek to prove a medical outcome.

On further investigation I found that the CONSORT document was not suitable for use in this particular research project. Primarily, this is because it is not always possible to produce valid data from a RCT when one is trying to access individuals who, collectively, live with as many as eighty different types of dementia or combinations of more than one type of dementia. In addition, participation is often compounded by other disabilities and/or the influence of medication. Cognitive impairment levels vary widely and no two people are the same. It is also rare to find individuals who share exactly the same background and life experiences. Those living with dementia in care can often be as different as apples and oranges, or potatoes and bananas; a fact rarely mentioned or even addressed in medical research journals. One wonders if researchers ever seriously consider such diversity, when they conduct what they confidently describe as 'evidence-based' biomedical dementia-specific research projects. Often, the only common denominator among those living with dementia is that they are a group of disabled elderly people who happen to live together in an aged care facility.

My task was to find and develop a set of assessment tools sensitive enough to explore what I believe to be a strong, tangible and affirming link between art and wellbeing within each individual. By mapping out a plan, and by basing the project within a solid theoretical base, I was able to select what I believe was the best methodology to suit the individual, the subject matter and the aged care sector. I then considered how I would gather the data and report the outcomes most effectively, to avoid some of the more common pitfalls and criticisms associated with dementia-specific psychosocial assessments that are clearly noted in journal articles and across most systematic literature reviews (Ayalon et al. 2006; Basu & Brinson: 2010; Bird et al. 2002; Finema et al. 2000; Livingston et al. 2005; Opie, Rosewarne & O'Connor: 1999; Robinson et al. 2006; Verkaik et al. 2005).

Given that the RCT is at the top of the medical research methodology pecking order, systematic literature reviewers are generally guided by this standard in their labours to try to match up and categorise each project against the Cochrane Collaboration 'gold standard' or a similar medical assessment tool. A prime example of this is encapsulated in the Livingston et al. (2005) review. The authors claim to have identified in excess of sixteen hundred studies of psychosocial interventions, but, using the Oxford Centre for Evidence Based Medicine criteria, they claim, except for one hundred and sixty three studies, neither the methodology nor the data analysis was 'rigorous enough' to satisfy 'evidenced-based' medical scrutiny.

Most researchers recognise, when embarking on an art-based project or any scientific research for that matter, 'gold standard' or otherwise, that every attempt must be made to fully explain and accurately measure all of the components of the project to avoid the kind of out-of-hand rejection as outlined above. Researchers are faced with a maze of research methodologies and assessment tools to choose from. My first aim was to explore the essence of an individual art activity experience for individuals living with dementia by recording and comparing both quantitative and qualitative research data using appropriate dementia-specific tools. And, secondly, my aim was to produce useful outcomes to be used in the development of psychosocial interventions for wider application across the healthcare sector.

## THE RESEARCH METHODOLOGY COMPONENTS COME TOGETHER

After exploring many possible methods, including action research, a phenomenological approach was finally chosen because of its simplicity and its particular suitability for use in aged care. Writing about the nature of phenomenological research studies, Creswell (2007) notes that:

> *A phenomenological study describes the meaning for several individuals of their lived experience of a concept or phenomenon. Phenomenologists focus on describing what all participants have in common as they experience a phenomenon... The basic purpose of phenomenology is to reduce individual experiences with a phenomenon to a description of the universal essence... To this end, qualitative researchers identify a phenomenon... The enquirer then collects data from persons who have experienced the phenomenon, and develops a composite description of the essence of the experience for all of the individuals. This description consists of 'what' they experienced and 'how' they experienced it... (Creswell 2007: 57-58).*

To determine 'what' and 'how' individuals experience a common phenomenon, and then distil and accurately describe the 'universal essence' of that experience, the primary aim of any empirical investigation must be to develop a process that is delivered uniformly to every participant and is able to be replicated under the same conditions. This process logically began by identifying the steps that I work through, as an able bodied person, in my own creative process. Starting with a blank sheet of paper, I was surprised to find that commencing an artwork takes me about twenty steps. I then separated, into steps and stages, the art activity process that I normally work through with individuals living with dementia and I documented each component. Working with those living with dementia is complex, but I never expected that this exercise would result in the identification of as many as thirty-nine distinct steps. This finding reinforced my assessment that I was correct in identifying the art activity as the appropriate 'phenomenon' under investigation.

To complete a purposeful phenomenological research structure, the next task was to create assessment tools that would produce not only valid data but also outcomes that could be easily replicated. The identification of the thirty-nine steps led to the development of an art activity matrix. This solved the problem of how the art activity could be presented uniformly to each person. The remaining question was to discover what tools to use to accurately assess 'what' and 'how' each participant experienced the phenomenon.

The second matrix, the Creative Expressive Abilities Assessment (CEAA) tool, is copyright and cannot be reproduced in this paper, but it was specifically designed and tested by researchers in Canada and Australia to determine 'what' individuals living with dementia experience during creative expressive activities. Finally, to document 'how' each participant lived the experience, a third matrix, based on Kitwood's 'positive person work tenets' was created. Now known as the 'MAC.ART wellbeing assessment tool' (discussed below), this matrix was used to determine and document the emotional responses of each participant to the art activity. I hoped that the product of all three matrices would produce both a replicatible method, and a means to enable the distillation of a 'universal essence' from all of the individual experiences in the overall phenomenon.

## THE RESEARCH PROJECT BEGINS

With three assessment tools in hand I was confident that the research objectives, to document the relationship between art and dementia and wellbeing, could be achieved. The Ethics Committee of Victoria University had approved the research methodology and assessment tools, some months earlier. I knew that the study would be small because only thirty-five individuals, living with some form of non-specific dementia, were permanent residents at the participating aged care hostel in Melbourne, Australia. All the residents were invited to participate in the art activity, but only twelve people - seven females and five males – agreed to join the research study.

The data collection began in August 2010 and ended five weeks later in September 2010. The information was gathered during the production of what is now known as the *"Getting to Know You"* artwork - a large-scale collaborative, permanent mural on canvas measuring approximately 2.5 metres by 1.5 metres. The images were pre-drawn in outline on the canvas by me in my research role as the facilitator. They consist of the illustrative interpretations of the diverse thoughts and ideas contributed by each participant in personal life-story interviews conducted with me before the art activity. Using a variety of paint materials, aids, props and brushes, I worked one-on-one through the set thirty-nine steps of the art activity with each individual as they painted their section of the work. I worked one-on-one because no individual is the same, they all experience different levels of disability and cognitive impairment and each requires a varying degree of assistance. One-on-one also ensured that the actions and/or painting style of other artists did not influence the activity and that no one else's painting style or colour preference could be copied. This ensured an independent appreciation of each research participant's skills and responses.

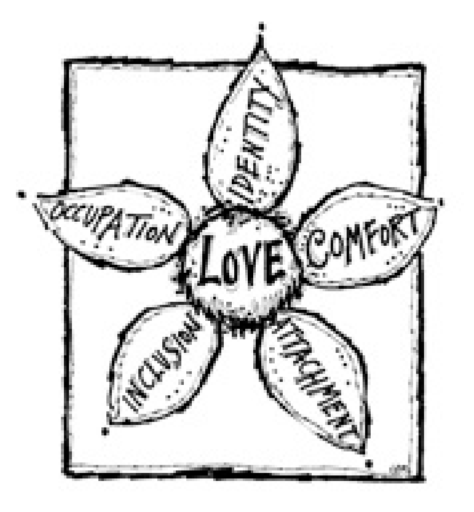
During the art activity, a researcher, independent of the facilitator, tick- scored the CEAA tool, which is divided into boxes that relate to a set of predetermined wellbeing domains. The researcher tick scored the domains relating to memory, attention, language, psychosocial, reasoning, problem solving, and emotion by recording the number of times a clearly defined behaviour or action occurred during the activity. I had permission to photograph and videotape all of the research participants as they painted; so some weeks later, the video footage was viewed and tick-scored against the CEAA tool again, first, by a staff member, and then by myself. This resulted in three independently obtained sets of data of the phenomenon for analysis, comparison and evaluation.

## KITWOOD'S INFLUENCE AND LEGACY

To further determine the parameters of dementia-specific wellbeing I decided to explore Kitwood's wellbeing and 'illbeing' theory (Kitwood 1997). This meant sifting through his writings on the impact of social culture on wellbeing and the careful consideration of his many observations, recommendations and practical workplace interventions. Basically, Kitwood's theory hinges on the creation of a workable dementia-specific 'culture of care'. This incorporates two themes – meeting the individual needs of the person and through the introduction of person-centred care practices. To function effectively both strands must work in parallel and in finely balanced harmony. Kitwood was convinced that in order to practice an optimum level of dementia care, using a person-centred approach, care partners must begin by understanding that five primary psychological 'needs' of those in their care must be met.

The five primary psychological needs Kitwood identified are comfort, attachment, inclusion, occupation and identity. To make these needs understandable he simply, but graphically, illustrated them using a visual image of a flower.

*Kitwood's primary psychological 'needs'.*



The five overlapping 'needs' form the petals that are attached to the flower's central core. This core is symbolic of unconditional love. Love, no matter how elusive it might seem at times, is the essential emotion at the core of every individual. Kitwood maintained that unconditional love enables someone living with dementia to 'remain in one piece' when uncertain emotional circumstances are present and when individuals find themselves 'in danger of falling apart'.

In addition, Kitwood further described twelve 'positive person work' tenets that would make his wellbeing concept easy to understand and implement in the workplace. Kitwood believed that if the most basic of psychological needs go unmet, most humans living with dementia are unable to sustain wellbeing. And, if ignored and left unsupported, the so-called 'behavioural and psychological symptoms of dementia' may rise to the surface. It follows that work practices, sensitive to these needs are necessary to maintain wellbeing in those living with dementia, and when such actions are in place those living with dementia are more likely to feel emotionally secure and their wellbeing will flourish. Kitwood likened all of these actions to 'beads on a string', each fits together and 'provides a higher level of detail'. In turn, such detail leads to a greater understanding of the person with dementia and his or her wellbeing needs, particularly those living in care. These humane and considered concepts established the foundations of what is regarded as the world's first workable dementia-specific, person-centred care model.

After a detailed process of elimination I settled on eight of Kitwood's tenets and incorporated them into the MAC.ART wellbeing assessment tool.

*The MAC.ART wellbeing assessment tool*

| Participant's name | Response to questions |
|---|---|
| Holding | |
| Attachment | |
| Timalation | |
| Relaxation | |
| Celebration | |
| Play | |
| Creation | |
| Giving | |
| Wellbeing outcomes | |

Directly after the art activity, I wrote up my immediate impressions of the activity. Using the 'MAC.ART wellbeing assessment tool', as outlined above, I documented 'how' I thought each individual experienced the art activity by asking myself the following questions:

1. Was a 'holding container' in a 'safe psychological space' established at the start of the activity? (Holding)

2. Was a rapport established between the participant and the facilitator? (Attachment)

3. How closely did the facilitator sit to the participant and could that individual tolerate touching the art materials? (Timalation)

4. Were there signs of relaxation and comfort for the participant in the facilitator's presence during the activity? (Relaxation).

5. Did the participant become involved in the activity and then work independently? (Play).

6. What sort of skills and ability did the participant display during the activity? (Creation).

7. Did the participant express happiness or joy and/or appear to be free of fear and responsibility? (Celebration).

8. Did the participant express gratitude or any spontaneous comments about the activity and/or his or her participation? (Giving).

After documenting responses to the above questions in the adjacent box I was in a good position to determine the overall picture of 'how' the participant experienced the activity.

The trio of matrices worked well by complementing each other in different ways. Together they provided a reliable methodological structure to gather a wealth of quantitative and qualitative research data to document the phenomenon. After detailed analysis I was able to make an informed assessment of the art activity enabling me to formulate numerous recommendations; if taken up, these recommendations have the potential to significantly improve dementia care services.

## SOME RESEARCH OUTCOMES

In Canada, Graf and Gottlieb-Tanaka (2011) discovered that individuals living with dementia are too often denied access to creative arts therapies for a variety of reasons that represent what Malone and Camp (2007) have identified as a disturbingly pessimistic and even nihilistic therapeutic trend in aged care. There is a common misconception that participants with dementia cannot concentrate on art activities beyond a few moments. Then, often, art is seen as a messy aesthetic experience where participants have the propensity to get dirty and 'eat the paint' (Wald 1983). These two reasons are closely followed by a third reason which is commonly driven by the sense that a failure to remember the engagement means that the activity is not worth doing and is therefore a waste of resources. Happily, none of these misconceptions are borne out in the evidence gathered from most art-based research projects.

In my own research project, the assessment tools proved they were sensitive enough to capture creative engagement and animated enjoyment in every participant. In fact, some participants engaged up to and beyond an hour, rather shaking the myth surrounding the ability of individuals to concentrate beyond a few minutes when absorbed in an interesting activity. And, because every participant was encouraged with gentle conversation to engage in the creation of an artwork, it was not surprising that no one was tempted to smear the paint or eat the art materials.

To combat boredom and social isolation, Australian aged care legislation mandates that aged care facilities provide purposeful activities that acknowledge and promote lifestyle choices for residents (Commonwealth of Australia: 1997, 1997a, 1998, 1999). At a minium legislators acknowledge that engagement in activities designed to enhance the quality of life of those in care are not a waste of time or resources. And, individuals living with dementia taking part in this project have shown that they are inherently creative and that the ability to pick up a paintbrush and begin to paint appears to be as natural as breathing. And, even if art was only a 'here and now' activity, not necessarily remembered later, it does not alter the fact that individuals living with dementia need regular human contact and enjoy much the same physical and mental stimulation involved in fulfilling activities as anyone else. The only difference is they need a little more help than most to achieve their goals.

## CREATING A 'HOLDING CONTAINER' IN A 'SAFE PSYCHOLOGICAL SPACE'

This research project identified and documented the skills and abilities encompassed in the role of the facilitator. It also attempted to isolate the components critical to the successful outcome of all dementia-specific art activities. And, if one skill in particular emerged that represents the key element in that critical facilitation role, it has to be the importance, before the activity commences, of carefully establishing a 'holding container' in a 'safe psychological space' for every individual living with dementia.

The concept of a 'holding container' is not new. Kitwood (1997: 91), for example, throughout his work, draws on a substantial body of work developed by the psychoanalyst D.W. Winnicott. Winnicott (1971) was so convinced of the significance of a 'safe' emotional environment that he coined the term 'safe container' to describe its importance. In terms of the key role any therapist or facilitator must play in creating such an environment, Knill, Levine and Levine (2005: 50) stress it is essential the participant be made to feel safe. He or she should be open and 'free to be [themselves] without constraints'. Such freedom ultimately presents everyone involved in the activity with an opportunity to fully engage in the creative process.

The research project also documented new insights about the preservation of skills, specifically how those living with Alzheimer's disease visually process and perceive line images whilst retaining the ability to process colour until very late in the disease progression. (The full five hundred page report, can be accessed at the following website: www.vuir.vu.edu.au/view/people/McAdam=3AJulieGross=3A=3A.html)

## CONCLUSION

This paper began with a glossary of terms and a description of dementia as it relates to art-based research. It sets out the author's motivational impetus and why the investigation took a phenomenological approach when examining the lived experience of a group of residents with dementia living in aged care in Australia. Three dementia-specific assessment tools were explained which led to a discussion of how the writings of Thomas Kitwood provided the theoretical terms of reference on which the research project was based. A select list of research outcomes was highlighted to address the effectiveness of the research methodology.

Art is one of the few human activities that naturally prompt the expression of a wide range of emotions. And, it's where the psychosocial wellbeing of an individual living with dementia can be naturally and readily observed and measured. Luis Fornazzri (2011), a leading neurologist studying dementia in Toronto, addressing delegates at an international conference on health, aging and the creative arts, commented on the importance of the 'artist's studio space' in residential care. He made the observation that 'regardless of its location, [the studio space] is a natural laboratory for the investigation of neuroscience and neurology and creativity'. Allen (2006) believes that those who create the studio space have the potential to contribute much to social action and social justice and the lived experience of those for whom they advocate. Allen outlines the responsible role that an art facilitator plays in community arts projects and writes and the importance of their commitment to those who come to the studio. She believes that often those who come to the studio 'need to be held and seen, to be affirmed and welcomed by the studio and the art-making process' and that the facilitator's primary role is to activate 'new pathways'. This, she suggests, can be achieved through listening to the 'silence between sentences' and by taking into account the needs of the participants. She sees the role of the facilitator as offering 'art as a respite, a momentary pause in an awful reality' (Allen 2006: 81).

Few would disagree with the notion that the progressive loss of one's memory represents a loss of personhood for those who experience it, and that the stigma that surrounds dementia is one of life's awful realities. Nonetheless, Allen entreats us to 'chart the grief-filled places' while affirming that it's not good enough to stand back and 'refrain from working in the world because it is too big for us to finish' (Allen 2006: 86-87).

There is no doubt that the problems surrounding the positive promotion of art-based research in dementia-specific healthcare settings are considerable, but not so daunting that they cannot be overcome using creative imagination and perseverance. Speaking at a symposium on the advancement of the understanding of dementia in July 2011, the Baroness Greenfield, Professor of Pharmacology at Oxford and one of the world's leading scientific experts in Alzheimer's disease research, made two simple but seminal recommendations; Firstly, 'we must abandon the traditional dogma that there is only one approach [to dementia research]'; and, secondly, as she counselled delegates, 'when at a crossroad, and you can take many paths, take them all' (Greenfield 2011).

The path leading to the wider acceptance of research into psychosocial interventions, such as the creative arts therapies, in aged care was never going to be easy, particularly when clinicians and reviewers continue to regularly dismiss qualitative research, and continue to push for the assessment of art programs against a biomedical performance criteria. Such attempts at the 'clinification' of art in healthcare negatively influences organizational management perceptions of art activities, and shrouds psychosocial interventions in unnecessary mystery. These circumstances will do nothing to progress the quality and humane disposition of the aged care sector, nor will they serve the best interests of the most needy recipients of care in our society. With the baby boomer generation about to exponentially increase the number of individuals living with dementia, and with so few adequate measures yet in place to meet future demand, the strain on both the Australian and the world economy will be great. Without fear of overstatement, these matters are of grave international concern. Australia, with its wealth of talent, is ideally positioned to lead the world in the research, design and development of person-centred psychosocial interventions and programs for the aged care sector.

## RECOMMENDATIONS

In February 2012, an opportunity to address the serious issues surrounding dementia research came when the Australian House of Representatives Committees, House Standing Committee on Health and Ageing, called for submissions to assist them in an inquiry into the early diagnosis of dementia and the development of possible interventions. I made eleven recommendations that sprang directly from the findings of my four-year research project. They are as follows:

**Recommendation One:**

A stock resource of psychosocial interventions for those living with dementia and their care partners be developed for immediate and future use.

**Recommendation Two:**

The Australian Government should embrace dementia-specific psychosocial interventions and build partnerships to promote the nationwide use of the creative expressive arts across aged care.

**Recommendation Three:**

A Kitwoodian person-centred care model be adopted across Australian aged care facilities and healthcare.

**Recommendation Four:**

Dementia be reinstated as a National Health priority.

**Recommendation Five:**

Individuals living with dementia be fully informed of their care options, and be fully consulted and encouraged to exercise choice and self-determination during the formulation of an advanced care plan.

**Recommendation Six:**

Culturally appropriate assessment tools be developed to better assess dementia, and the wellbeing and quality of life needs of those newly diagnosed with dementia.

**Recommendation Seven:**

The Australian Government should adopt elements of the British National Dementia Strategy and its recommendations.

**Recommendation Eight:**

The Australian Government recommend the adoption of terminology such as "living with dementia" in recognition that those with dementia can continue to lead fulfilling lives after diagnosis.

**Recommendation Nine:**

The Australian Government acknowledge the expertise and contribution that dementia-specific healthcare professionals, other than biomedical research scientists, make to the quality of life of those living with dementia. Recommendation Ten:

The Australian Government study and make available information on outstanding dementia-specific programs in North America, such as Artists for Alzheimer's (Zeisel 2009), Creative Discovery Corp (Cohen 2000), StoryCorp (Isay 2007), Timeslips (Basting 2009), Opening Minds through Art (OMA) (Lokon 2007), Therapeutic Thematic Arts Programming (TTAP) (Levine-Madori 2007), Memories in the Making (Kinney and Rentz 2005; Rentz 2005) and the Eden Alternative (Thomas 1994, 1996).

**Recommendation Eleven:**

A palliative approach to dementia care, that includes a variety of psychosocial interventions, be implemented at the time of diagnosis.

So far, the Australian government has only taken up recommendation number four. They have very wisely reinstated dementia to the level of a national health priority but, unfortunately, there is still no funding or budget allocation for research into any kind of psychosocial intervention.

Like cancer, dementia randomly picks and chooses its host and does not discriminate. The general public remains seemingly ignorant of the fact that whilst the cause of Alzheimer's disease, for example remains unknown, no genuine research into an effective cure for that form of dementia can commence. The drug treatments currently available to treat Alzheimer's disease cannot stop the progress of dementia, and almost invariably tend only to be effective for a very limited period of time. While they can perform a memory enhancing function, it is well documented they also can have serious side effects in some individuals (Shenk: 2003).

The continuing use of psychotropic medication to chemically restrain individuals who exhibit so-called 'behavioural and psychological symptoms of dementia' is quite unacceptable, particularly at a time when art-based activities and research are regarded as of marginal relevance in the rush to find a cure for dementia. It would seem that the pharmaceutical juggernaut has its own priorities.

In the meantime, the pressing needs of those living with dementia and their care partners continue to remain unmet. Whilst we wait for that 'silver bullet' cure for dementia assuming it ever appears, who among us can seriously justify ignoring the growing body of community-based research into psychosocial interventions that offers safe solutions to the real needs of real people who genuinely need our help.

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