

ABSTRACT

OPENING MINDS THROUGH ART (OMA): AN ART PROGRAM FOR PEOPLE WITH DEMENTIA

by Elizabeth Lokon

Art programming for people with dementia in long-term care facilities tends to fall short when it comes to providing opportunities for creative self-expression. The Opening Minds through Art (OMA) program is designed to fill this unmet need. It is a program led by artist facilitators with the assistance of staff/volunteers. The program has four major goals: (1) to promote the social engagement, autonomy, and dignity of people with dementia by providing creative self-expression opportunities; (2) to show the public the creative self-expression capacities of people with dementia through exhibitions of their artwork; (3) to provide staff and volunteers with opportunities to build intimate relationships with people who have dementia; and (4) to provide volunteers with community service opportunities. This report presents the conceptual foundation and methodology of the OMA program. It includes an overview of person-centered care philosophy, the rationale for doing the OMA program, and research evidence on the use of the arts in dementia care.

OPENING MINDS THROUGH ART (OMA):
AN ART PROGRAM FOR PEOPLE WITH DEMENTIA

A Thesis

Submitted to the
Faculty of Miami University
in partial fulfillment of
the requirements for the degree of
Master of Gerontological Studies
Department of Sociology and Gerontology
by
Elizabeth Lokon
Miami University
Oxford, Ohio
2008

Advisor _____
Dr. Suzanne Kunkel

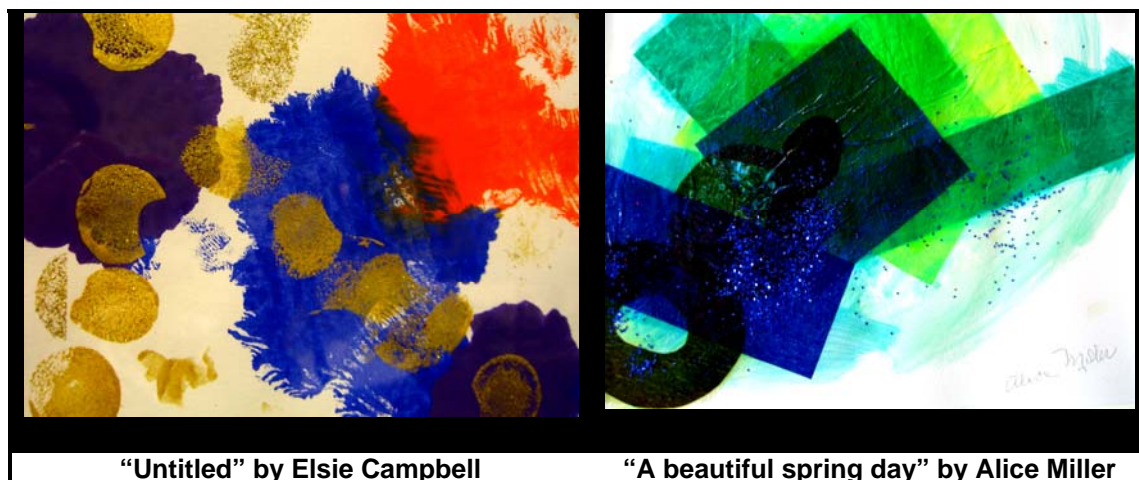
Reader: _____
Mr. William Ciferri

Reader: _____
Dr. Jennifer Kinney

Reader: _____
Dr. Jane Straker

Table of Contents

Acknowledgments	iv
Background	2
Introduction to the Opening Minds through Art (OMA) program	4
Types of art activities for people with dementia.....	6
Formal/medical art activities	6
Informal/social art activities.....	7
Craft activities	7
Person-Centered Care (PCC)	9
What is a person?	9
What is person-centered care?	11
The dialectic nature of personhood maintenance	14
Research evidence on person-centered care	16
Rationale	17
Why have people with dementia engage in the arts?	17
Why have artists/volunteers/staff engage in making art with people who have dementia?	19
Research evidence on the arts in dementia care.....	20
Opening Minds through Art Methodology	25
Training for staff and volunteers	25
Training for artist facilitators.....	26
The OMA process.....	27
Commentary on OMA program design	37
Conclusion	39
References.....	40
Appendix 1: Volunteer Training Evaluation	46
Appendix 2: Volunteer Training Evaluation Summary	47
Appendix 3: Session evaluation for participating staff/volunteers.....	51
Appendix 4: Artist Facilitator's Reflections	52
Appendix 5: Overall Program Evaluation.....	53
Appendix 6: Overall Program Evaluation Summary	54
Appendix 7: Evaluation of the Art Exhibition.....	58
Appendix 8: Evaluation of the Art Exhibition Summary	59



"Untitled" by Elsie Campbell

"A beautiful spring day" by Alice Miller

This work is dedicated to
 Elsie Campbell, Marjorie Fast, Charles Magolda, and Alice Miller,
 OMA artists who can no longer paint with us.



"What is it?" by Charles Magolda



"Untitled" by Marjorie Fast

Acknowledgments

Over the last three years I have been given so much and learned so much from so many people. I am deeply grateful for the mentoring, assistance, and support that I have received in my effort to learn about dementia and the arts. First and foremost, I would like to thank everyone at the Scripps Gerontology Center at Miami University for giving me a graduate assistantship for 2.5 years, the Intergero scholarship to study in the Netherlands, and for instances of help and support too numerous to list here.

My advisors at Miami University have been very supportive throughout the project: Jennifer Kinney inspired me to do this project and provided research support; Bill Ciferri helped me formulate the organization of the project; Jane Straker provided her insights into ways to evaluate the program; and I am especially grateful to Suzanne Kunkel for her continuous guidance in all aspects of this project, both academic and practical. Despite her busy schedule, she patiently listened to me as I tried to sort things out and helped me stay on course. I would also like to thank Kelina Basnyat for faithfully videotaping the sessions.

The Knolls of Oxford has been very open and generous toward the development of this project. I would like to thank the artists at the Memory Support Unit at the Knolls of Oxford for their creativity and willingness to experiment with a variety of art projects. The assistance and support of Suzanne House, Tim McGowan, and all the staff there has been critical. I would like to thank my collaborators, Irene Friedman and Brad Simcock, for being there every week and for all the fun times we have had “playing” with the art materials, designing the activities and debriefing afterwards. All the Miami students and Oxford community volunteers have been essential to this project.

OMA would not have been possible without the variety of internship experiences that I had in Milwaukee, Cincinnati, Gainesville, and Amsterdam. I would like to thank the individuals listed below for opening doors and letting me enter into their organizations, and for guiding and teaching me during these internships. Every single person on the list below has allowed me to shadow them in their work and/or made time to answer my questions on multiple occasions:

- Anne Basting (Center on Age and Community, University of Wisconsin, Milwaukee, Wisconsin) for inspiring and guiding me in the Summer of 2007 and beyond.
- Beth Meyer Arnold and her staff (Luther Manor Adult Day Center, Milwaukee, Wisconsin) for showing me the practice of person-centered care toward clients and staff and letting me stay at Luther Manor CCRC while I was in Milwaukee.
- Jill Sonke-Henderson and Rusti Brandman (Center for the Arts in Healthcare Research & Education, University of Florida) for introducing me to the use of the arts as an integral part of the healing process in

- hospital settings and for the scholarship to attend the 2007 summer intensive course at the University of Florida on this topic.
- Susan Gilster and her staff (Alois Alzheimer's Center, Cincinnati, Ohio) for letting me explore and learn all about people with dementia during my internship there in the Fall of 2007.
 - Michael A. Keys and Gail Rudolph (Lindner Center of Hope, Cincinnati, Ohio) for letting me come along on their psychiatric rounds at Alois Alzheimer's Center and patiently teaching me the geropsychiatric perspective on dementia care.
 - Joan Hock and Sharon Sellet (The Greater Cincinnati Chapter of the Alzheimer's Association) for letting me observe multiple sessions of Memories in the Making and for making the time to process my reflections on these observations.
 - Marja Aartsen, Vrije Universiteit (Amsterdam, the Netherlands) for connecting me to others in Amsterdam and for allowing me to participate in the EuMag summer intensive course in Berlin.
 - Julia van Weert (Universiteit van Amsterdam, the Netherlands) for teaching me about Snoezelen and for connecting me to others in Amsterdam.
 - Annette Stellard, Jessica Harberts, Wilma Groot, Noemi Lieveld, and Jan Peter (Bernardus Zorgcentrum, Amsterdam, the Netherlands) for hosting and guiding me in my summer 2008 internship and teaching me about the practice and challenges of doing person-centered care and Snoezelen in the dementia wings there.
 - Joke Bos and Diana Kuipers (Amsterdamse Ontmoetingscentrum, Amsterdam, the Netherlands) for including me in the work team to serve people with dementia at the adult day center and for making the professional DVD on OMA.
 - Marieke Westra (Theater Veder, Amsterdam, the Netherlands) for allowing me to shadow her throughout the summer while she was coaching long-term care staff on how to implement her innovative theater program for people with dementia.
 - Aukje Post (Zorgkwadrant Fryslân Oost, Burgum, the Netherlands) for teaching me about issues associated with institutionalizing Dementia Care Mapping in long-term care facilities.
 - Astrid Van Dillen, Rika Posthuma, and Hans deQuartel (Beweging 3.0, Amersfoort, the Netherlands) for showing me what is possible in dementia care programming at the end-of-life stage of the disease.
 - Alan Chapman and his staff (Dementia Services Development Centre, University of Stirling, UK) for teaching me how to teach others about person-centered practices in dementia care.
 - Peter Magolda (Miami University) for his photography work throughout the year.

I also would like to express my gratitude to the following people and organizations that have been sponsoring OMA activities in various ways:

- Summerfair Cincinnati (Cincinnati, Ohio) for giving OMA a grant that helped launch the expansion of the program.
- Cedar Village Continuing Care Retirement Community (Cincinnati, Ohio) for adopting OMA and supporting its development in 2009-2010.
- The Partnership Office at Miami University (Oxford, Ohio) for its continuous support in the Miami-Knolls collaboration that has been critical in the pilot stage of OMA development.
- The Office of Community Engagement and Service at Miami University (Oxford Ohio) for getting Miami students to volunteer with OMA.
- Oxford Community Art Center (Oxford, Ohio) for hosting OMA exhibitions and for providing studio space for OMA staff and volunteers to gather and experiment with the various projects.
- Scripps Gerontology Center at Miami University, Oxford, Ohio: I would like to thank Mike Payne and Buffy Hanna for publicity support; Cheryl Johnson and Arlene Nichol for showing me the ropes; and Bob Applebaum and Suzanne Kunkel for providing the rope.

Finally, I am deeply indebted to Karen Eberly, Steve Flocks, and Dennis May for giving me shelter while I was on some of these internships and for being excellent company in the evenings.

Opening Minds through Art (OMA)

An art program for people with dementia

Conceptual Foundations and Methodology



**Artists (clockwise from top left):
Phyllis Blocher, Cora Goins, Bill Schaner, Marjorie Fast ("Allistical Easter")**

Art programming for people with dementia (PWD) in long-term care facilities that do not have art therapists on their staff tends to fall short when it comes to providing residents with opportunities for creative self-expression. People with moderate to advanced dementia may lack the ability to communicate through logical, verbal channels, yet their need to communicate and express themselves remains. Art as a means for people with dementia to connect to the world is the main focus of this manual.

The Opening Minds through Art (OMA) program is designed collaboratively by artists and gerontologists to fulfill the need of people with dementia to express themselves creatively. It is a program led by artist facilitators with the assistance of staff/volunteers. The program has four major goals: (1) to promote the social engagement, autonomy, and dignity of PWD by providing creative self-expression opportunities; (2) to show the public the creative self-expression capacities of PWD through exhibitions of their artwork; (3) to provide staff and volunteers with opportunities to build intimate relationships with PWD; and (4) to provide volunteers with community service opportunities that tap their talents.

This report presents the conceptual foundation and methodology of the OMA program. It includes an overview of person-centered care philosophy, the rationale for doing the OMA program, and research evidence of the use of the arts in dementia care. This report is a part of a triptych. The other two parts not included here are a training manual and DVD to teach staff and volunteers effective communication with people who have dementia and a manual of visual arts activities that contains actual examples of tried and evaluated activities for people with early to moderate dementia.

Background

The Opening Minds through Art (OMA) program is an attempt to expand and deepen the possibilities for creative self-expression for both women and men with dementia. Since women live longer than men (National Center for Health Statistics, 2007) and dementia prevalence increases with age (Plassman, et al.,

2007), there are more women than men with dementia in long-term care (LTC) facilities. Furthermore, long-term care facilities are staffed mostly by women. These facts result in the tendency for activity staff to design creative activities that appeal more to women than to men. While women's needs for creative self-expression are not necessarily met by routine craft activities such as cutting construction paper patterns of hearts in February, stars in July, pumpkins in October, and turkeys in November, these activities are of even less interest and relevance to men in these facilities.



**Examples of the more typical arts & crafts programming
in long-term care facilities**

Moving away from gender-typed craft activities, OMA provides men and women with dementia the opportunity to engage in more open-ended, authentic art activities. Art here is defined as “any medium used for creative expression” (Basting, 2006, p. 16). Although this definition includes music, theater, dance, poetry, and so on, in this first phase of OMA development, the focus is on the visual arts (e.g. painting, drawing, print-making, collage).

Types of dementia

Butler (2008) estimates that Alzheimer's accounts for about 55-65 percent of cases of irreversible dementias and that misdiagnosis is between 10 and 20% (p. 125). The remaining 35-45% of dementia cases are associated with the

following conditions: 20% vascular dementia (or multi-infarct dementia characterized by repeated mini strokes in the brain) and 10% a combination of Alzheimer's and vascular dementia. The remaining five or so percent are caused by various other diseases such as Pick's disease, Parkinson's Disease, Lewy Body Disease, Creutzfeldt-Jakob disease (CJD), Huntington's Disease, HIV/AIDS, head trauma, Wernicke-Korsakoff Syndrome, and Normal Pressure Hydrocephalus.

Although there are a variety of diseases that cause older adults to have dementia and the behavioral manifestation of these diseases varies greatly across individuals, they share the same general psychological needs that should be met in order to help people live with dementia. The OMA program is aimed at meeting the creative expression needs of people with dementia at whatever stage (except the advanced stage), regardless of the type of dementia they have.

Introduction to the Opening Minds through Art (OMA) program

Facilitating a group art session with people who have dementia is like directing a play with improvisational actors who are good but unpredictable. The director is not in control, but the play must unfold in a meaningful way for the actors. There is a screenplay prepared with all the appropriate props ready to go, but where the actors will take the play and how they will use the props are never clear at the outset. As the director or facilitator of this organic improvisational play, we need to be open and attentive to the moods, talents, and desires of the actors, and we need to be willing to let them take the play in any direction they choose. This is because the most important goal in programming for people with dementia (PWD) is to provide opportunities for creative self-expression and positive engagement with the world around them: the creative task, the materials, and the other people in the room.

Positive engagement here is defined as a process where people with dementia are voluntarily expressing themselves. They may be making design or color choices, stating preferences, communicating with others, or even refusing

to do the activity. Whatever the person with dementia decides to do during the session, so long as she is making that decision on her own, showing a sense of agency and autonomy, she is positively engaged.

As Kitwood (1998) writes, having dementia makes one physically and psychologically dependent on others:

A person who has dementia is, *ipso facto*, relatively powerless, and may have to endure many kinds of mental anguish: confusion, frustration, grief, fear, anger, and despair. Moreover, the ability to understand what is happening, both within the psyche and in the outside world, may be impaired, and with that the capacity to enter fully and realistically into decisions affecting the course of life. Dementia, then, makes a person exceptionally dependent on others: not only in the physical sense, but in a psychological sense as well. (p. 23)

This psychological dependency is all too often intensified by the medicalization of the relationship between the institutional or family caregivers and the people with dementia. Over time, the confidence and capacity for self-expression of the people with dementia can be undermined not only by the dementing illness, but also by the way they are re-defined as mentally and physically incompetent by the very people caring for them.

One of the primary goals of the Opening Minds through Art (OMA) program is to reverse this sense of dependency and lack of control, even if just for a fleeting moment, by providing participants with a new role as an artist who can create something original that they can be proud of and others can genuinely appreciate; and a situation where their opinions are solicited and aesthetic choices are encouraged. People with dementia will still need assistance in various areas, but empowering interactions can help to transform the patient-caregiver relationship from a dependent to an interdependent one.

The other goal of OMA is to educate the general public about dementia. The program is called “Opening Minds through Art” not only because it attempts to open the minds of people with dementia through the art-making process, but also to open the minds of the rest of us about people with dementia. OMA gives

artists, staff, and volunteers opportunities to interact closely with people who have dementia. The typical one-to-one or one-to-two ratio during the creative process allows staff/volunteers to build close relationships with people who have dementia and reflect upon their own beliefs about it.

Furthermore, through art exhibitions, family members and the general public can witness the creative capacities of people with dementia. The result is a shifting away from focusing on what people with dementia *can no longer do* because of their cognitive challenges to what they *still can do* despite the diseases that affect their brains. Such a shift in worldview about dementia will positively affect the relationship between cognitively intact people and people with dementia.

Ultimately, the goal of OMA is to give people with dementia opportunities for creative self-expression and in the process to give staff and volunteers opportunities to recognize the humanity of the person with dementia and grow as a result of this recognition. Dementia changes *the way* people think, feel, and interact, but it does not change the fact that they still have the fundamental needs, rights, and abilities (however unconventional) to think, feel and interact with others around them. OMA is simply a vehicle to enable people with dementia to express these needs, rights, and abilities to the maximum extent possible.

Types of art activities for people with dementia

There are three types of art activities for people with dementia. The first two types are categorized by Allan and Killick (2000) as formal and informal; whereas Basting (2006) categorizes them as medical and social. The third type is crafts.

Formal/medical art activities

In the formal or medical version, trained and certified therapists facilitate the art activities. These activities tend to have specific therapeutic goals (diagnostic and evaluative assessments to document individual improvements),

as well as other “immeasurable but positive impacts on quality of life” (Basting, 2006, p. 17). Harlan (1993), an art therapist, states the following goals for art therapy with PWD: “(1) to help preserve a sense of identity, (2) to facilitate the venting of emotions accompanying the disease process, so that remaining cognitive skills can be fully available, and (3) to counteract social isolation through sharing common concerns with peers” (p. 100). Kasayka (2001) lists the following goals for art therapy: “Increasing orientation and activation, facilitating reminiscence and remembering, increasing self-understanding and acceptance, developing meaningful interpersonal relationships, and building communal spirit” (p. 10-11). If attained, these goals are expected to have a positive impact on a PWD’s quality of life.

Informal/social art activities

The informal or social version of art programming for PWD, on the other hand, is facilitated by family members, activity staff, artists, volunteers, or direct-care workers with passion and skills in the arts and dementia. Although the activity may seem to be therapeutic to the person with dementia, informal arts programming does not explicitly have therapeutic goals. The goals of informal programming tend to focus more on increasing opportunities for self-expression, communication, and relationship building, which are also the goals of art therapists. Thus, the two versions overlap, but they differ in the training background of the facilitator and the explicit statement of (diagnostic and evaluative) therapeutic goals.

Craft activities

The third type is art activities that are aimed at keeping people with dementia busy; maintaining their remaining skills such as cutting, gluing, and coloring; and creating decorations that can be displayed. Abraham (2005) considers this type of art activity as occupational therapy and contrasts it with the more creative processes with opportunities for emotional expression done in art therapy sessions. Because of the lack of opportunity for creative individuality

and emotional expression, this third type of activity is best described as craft rather than art activity. In my experience, this third type is the most commonly practiced version in LTC settings. There are plenty of “idea books” for such activities, utilizing inexpensive and readily available materials, with very little preparation and artistic skill needed on the part of the facilitators. Unfortunately, these activities tend to be perceived as both “childish” (Kovach & Henschel, 1996; Signore, 2007) and at the same time, paradoxically too challenging because they require cognitive and fine-motor skills that may be impaired by the dementing illness.



The lack of variation between the finished products is an indicator that this craft activity lacks opportunities for creative self-expression.



Coloring does not provide opportunities for creative self-expression and may be too challenging for the person on the right.

The OMA program is of the informal/social type, led by practicing artists and assisted by staff and volunteers. It was developed in response to the dominant presence of these craft type activities and the lack of art therapists in many long-term care settings. This informal/social version can be done without the presence of an art therapist, and yet it can transcend the limitations of the typical craft sessions. But the OMA program has been developed in response to more than just observation of current weaknesses in activities for PWD's. It also draws from foundational concepts in Person-Centered Care (PCC).

Person-Centered Care (PCC)

What is a person?

Before going into the more applied concept of person-centered care, it is important to first explore the foundational definitions of a person and how dementia affects these definitions. Reviewing the debate in bioethics, Fleischer (1999) explains two fundamentally different concepts of what it means to be a person: the personalist and the physicalist positions. "Personalism argues that a human being achieves a claim to life and medical resources if he possesses certain capacities, primarily cognitive abilities and self-consciousness" (p. 309). The physicalist, also called the vitalist position, on the other hand, "contends that every human being, even one who lack capacities, is entitled to have a life" (p. 309). Central to this debate is the distinction between being human and being a person. Baldwin and Capstick (2007) put it this way:

For those in the personalist camp there is a distinction to be made between the human being (a descriptive term signifying belonging to a particular species) and personhood (an evaluative term signifying and granting membership to a moral community). In these terms, it is possible to be human but not granted moral status. ... For those in the physicalist or vitalist camp, a focus on capacities requisite for being granted the status of personhood is too narrow in that it, by definition, excludes those who cannot 'measure up' and also takes too narrow a view of what it means to be human. (p. 176)

From the personalist perspective, people with dementia fail to ‘measure up’ to all criteria for membership to a moral community: consciousness of self; rationality (capacity for abstract reasoning); agency (being able to form intentions, to consider alternatives, and to direct action accordingly); morality (living according to principle, and being accountable for one’s actions); and capacity to form and hold relationships (the ability to understand and identify with the interests, desires and needs of others) (Quiton, 1973 cited in Kitwood, 1997, p. 9). Because people with advanced dementia cannot fully meet all of the above criteria for personhood, Dan Brock (1993), a prominent bioethicist¹, makes the following statement:

I believe that the severely demented, while of course remaining members of the human species, approach more closely the condition of animals than normal humans in their psychological capacities. In some respects the severely demented are even worse off than animals such as dogs and horses, who have a capacity for integrated and goal-directed behaviour that the severely demented substantially lack. The dementia that destroys memory in the severely demented destroys their psychological capacities to forge links across time that establish a sense of personal identity across time. Hence, their lack of personhood. (Brock, 1993 cited in Baldwin & Capstick, 2007, p. 176)

Kitwood (1997) and Post (1995) critiqued the above perspective, stating the importance of recognizing the personhood of all human beings regardless of mental capacities. They also assert that overemphasizing the importance of cognition in Western society, which Post refers to as a “hypercognitive world” undermines the importance of the affective aspects of being human. Agreeing with Post, Kitwood writes, “Personhood, ... , should be linked far more strongly to feeling, emotion, and the ability to live in relationships, and here people with dementia are often highly competent – sometimes more so than their

¹ In 1993 Dan Brock was “Professor of Philosophy and Biomedical ethics and Director of the Center for Biomedical Ethics at Brown University, a member of the Ethics Working Group at the White House Task Force on National Health Care Reform, a member of the Rhode Island Hospital and Miriam Hospital Ethics Committees and a member of the Executive Board of the American Association of Bioethics” (Baldwin & Capstick, 2007, p. 187).

carers” (p. 10). To Kitwood, the essence for granting PWD full membership in the moral community lies in these principles: “the equality/equal worth of all human beings, ... the uniqueness of individuals, ... the necessity of relationships, ... the subjectivity and suffering of individuals, ... the link between personhood and caring, ..., [and] the importance of love” (Baldwin & Capstick, 2007 reviewing Kitwood’s life work, p. 179-180). Thus, Kitwood concludes, “we are all, so to speak, in the same boat; and there can be no empirically determined point at which it is justifiable to throw some people into sea” (p. 10).

Although the rhetoric in dementia care reflects Kitwood’s more inclusive physicalist perspective, the personalist view still greatly influences daily interactions in long-term care facilities. Likewise, in bioethics the personalist perspective still dominates the debate today (Fleischer, 1999; Kittay, 2005). The OMA program is one attempt to counter this personalist perspective on dementia.

What is person-centered care?

Person-centered care is founded on the physicalist notion of what it means to be human. Tom Kitwood is recognized as the founder of this movement in dementia care (Brooker, 2007, p. 14). Person-centered care is the central theme in the culture-change trend inside long-term care (LTC) facilities. Rooted in the basic principles of Rogerian psychotherapy, person-centered care philosophy is founded on the belief in the inherent tendency and capacity of human beings to continue to grow and develop throughout life (Kitwood, 1997). In LTC settings, this process of continued growth requires unconditional positive regard and the empathetic understanding of each and every resident. This implies a complete acceptance of the personhood of all people, regardless of health condition and disabilities.

Kitwood (1997) defines personhood as “A standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect, and trust” (p. 8). And that “the primary task of dementia care ... is to maintain personhood in the face of failing of mental powers” (p. 84).

Dawn Brooker (2007) reviewed the literature on PCC and concluded that despite the diversity of the definitions of PCC, all authors share the following four elements:

1. Valuing people with dementia and those who care for them; promoting their citizenship rights and entitlements regardless of age or cognitive impairment.
2. Treating people as individuals; appreciating that all people with dementia have a unique history and personality, physical and mental health, and social and economic resources, and that these will affect their response to neurological impairment.
3. Looking at the world from the perspective of the person with dementia; recognising that each person's experience has its own psychological validity, that people with dementia act from this perspective, and that empathy with this perspective has its own therapeutic potential.
4. Recognizing that all human life, including that of people with dementia, is grounded in relationships, and that people with dementia need an enriched social environment which both compensates for their impairment and fosters opportunities for personal growth. (p. 12-13)

Brooker (2007) then simplified the above elements into the now commonly known "VIPS" of PCC:

V = Value base that asserts the absolute **value** of all human lives regardless of age or cognitive ability.

I = An **individualised** approach, recognizing uniqueness.

P = Understanding the world from the **perspective** of the service user.

S = Providing social environment that **supports** psychological needs. (p. 13)

Edwardson, Winbald, and Sandman (2008) reviewed Kitwood's work and came up with the following components of PCC:

The acknowledgement that the individual is a person that can experience life and relationships, despite the progressive disease; offering and respecting choices; the inclusion of the person's past life and history in

their care; and the focus on what the person can do, rather than the abilities that have been lost owing to the disease. Person-centered care has been defined as supporting the rights, values, and beliefs of the individual; involving them and providing unconditional positive regard; entering their world and assuming that there is meaning in all behaviour, even if it is difficult to interpret; maximising each person's potential; and sharing decision making. (p. 363)

The two lists of components of PCC above clearly overlap. Implicit in both lists is the notion in PCC that the personhood of people with dementia is “increasingly concealed rather than lost” (Edwardson, et al., p. 363).

Person-centered vs. Institution-centered care

Person-centered care can be contrasted with institution-centered care. The institution-centered model of care focuses on the convenience and efficiency of care delivery from the staff's point of view. Residents must comply with practices that support the convenience and efficiency of the staff. The person-centered care model, on the other hand, focuses on the residents' autonomy, vitality, and desires. Care delivery is individualized to fit with each residents needs, desires, and preferences. Residents are actively involved in decisions about their daily life. As in their pre-institutional setting, residents in a person-centered care environment have more choices in daily operations, such as food variety, meal times, bath times, and activities. In contrast to an institutional-centered care facility, the staff in person-centered care is not rotated to care for different residents on a routine basis. Maintaining staff consistency is important in fostering the development of caring relationships between the residents and their immediate caregivers (Misiorski, 2005).

Person-centered vs. Illness-centered care

Person-centered care, which is based on the biopsychosocial model of dementia care, is also contrasted with illness-centered care, which is based on the biomedical model (Ronch, 2003). The biopsychosocial model recognizes

that each person has a particular autobiography, talents, and quirks. The disease is just one factor in the total constellation of that person. The biomedical model, on the other hand, focuses on the illness and ignores other aspects of the person who is afflicted with the disease. Ronch explains that in person-centered care “the patient, not the dementia, is cared for in an atmosphere rooted in collaborative, interpersonal relationships because illness is “a social state of affairs” ... that involves people, social institutions, cultural practices, and shared meanings” (p. 325).

Although the OMA program is not strictly speaking a “care” practice, it is designed based on the biopsychosocial model. During the creative process, collaborative interpersonal relationships between the person with dementia and the assisting staff/volunteers are developed in ways that maintain the personhood of both.

The dialectic nature of personhood maintenance

Although the elements of PCC as outlined above focus on the person with dementia, it is important to note here the dialectic or bi-directional nature of personhood maintenance. Indeed, in a LTC setting that embraces PCC, people with dementia are regarded with recognition, respect, and trust. But the personhood of the cognitively intact staff/volunteers is also enhanced by their relationships with people with dementia. Maloy and Hadjistavropoulos (2004) write:

Both the patient and the caregiver have the opportunity to grow authentically through the caring process. In cases of extreme dementia, it may only be the caregiver who is capable to grow – to take this opportunity away from the caregiver by putting emphasis upon institutionalization and frozen roles and procedures is to lessen the authentic possibilities of the health care profession. Moreover, the caregiver finds meaning in his or her authentic relationship with the patient and this ‘role’ (e.g. nurse, physician) also becomes a means through

which the caregiver's own personhood is developed and authenticated. (p. 153-154)

Baldwin and Capstick (2007) agree with Maloy and Hadjistavropoulos' observation above. They propose that we view dementia "as a combination of tragedy and opportunity for growth" (p. 19). The growth here refers to spiritual growth as new meanings and new levels of relationships are made possible by dementia. They propose that we explore the contribution made by people living with dementia to the lives of others. Here they cited a daughter caring for her mother with dementia:

She is part of the home, she's part of the family and she enriches us in ways that are phenomenal sometimes, this is the lady who has never been particularly fond of babies but she met her two nephews, one is 1 and one 4 ... and she was enthralled with the baby. She's never loved babies in her life but at this moment in time babies are what fits, she likes babies and you can't, to have that amount of pleasure given to you, it makes everything worthwhile. (p. 19)

Ronch (2003) sees this dialectic nature of personhood maintenance as "the essential process of mutual personal change in the care giving relationship that defines the process of becoming (continual evolution of the self)" (p. 328). Citing Morris (2000), Ronch writes,

Telling stories of their illness ... constitutes a moral action by which the ill negotiate the reshaping of their own lives. Listening to such stories and responding to them with empathy constitutes for the listener an equally important moral act that also contains a possibility of significant life changes. (p. 328)

It is clear from the above that relationships with people with dementia have the potential to provide the cognitively intact partner with opportunities for authentic growth. In other words, PCC is concerned not only with the personhood of the people with dementia, but also that of the staff/volunteers/caregivers. Together, the one cared-for and the one-caring (Noddings, 1984) are at the center of the caring relationship (Misiorski, 2005).

The ultimate goal of person-centered care is to establish relationships between people with dementia and their caregivers that nurture the mind, body, and spirit of both parties. The nearly one-to-one ratio between staff/volunteer and person with dementia in the OMA program is designed to maximize the potential development of such relationships.

Research evidence on person-centered care

Unfortunately, research on the effect of PCC on the life of people with dementia in LTC settings tends to lack theoretical and empirical rigor. Edwardson, et al. (2008) cite the following reasons: “small sample size, a lack of control groups, the inclusion of confounders, interventions with many components, and great variation in the types and stages of dementia in the participants” (p. 365). Ronch’s (2003) review of person-centered innovations comes to a similar conclusion, “The effectiveness of these improvised innovations was difficult to study under strict controlled conditions because controlled studies are confounded by definitional, ethical, and measurement problems. ... Uniformity was lacking in treatment approaches, making direct comparisons elusive” (p. 316).

There are, however, a few studies that meet the rigor criteria and support PCC. For example, a randomized control trial study by Hoeffler, Talerico, and Rasin (2006) shows that implementing PCC reduces PWD’s discomfort, agitation, and aggression, without compromising hygiene during bathing experiences. At the same time, the staff performing the bathing tasks were more gentle, verbally supportive, and felt more at ease.

Another study that meets the rigor criteria according to Edwardson et al. is a cluster-randomized trial design by Fossey et al. (2006). They randomized 12 nursing homes in the UK with at least 25% of residents with dementia taking neuroleptics. The experimental homes received 10 month person-centered care training and support for staff that focused on alternatives to drugs for the management of agitated and disruptive behavior. At 12 months, they found that the proportions of residents taking neuroleptics in the intervention homes was

significantly lower in the control homes without significant difference in the levels of agitated or disruptive behavior between the two groups of homes. The average reduction in neuroleptic use was 19.1%.

Although more studies of this type need to be done, I agree with Edwardson et al.'s (2008) conclusion that PCC in dementia care “should be adopted because it shows respectful, humanitarian, and ethical values in practice and entails few potential risks” (p. 365).

Rationale

Why have people with dementia engage in the arts?

There are various reasons for engaging PWD in the arts, both psychosocial and physiological.

Psychosocial reasons

Anne Basting and John Killick (2003) give the following reason for engaging PWD in the arts: “Creative expression is important for everyone, but it is even more important for those with dementia for whom other avenues of self-expression can be severely limited” (p. 8). Basting (2004) further states that “Because there are no right or wrong answers in the creative process, creative activities allow people with dementia to enter from where they are – with memory gaps, word fragments etc. – without judgment” (p. 7). As access to rational language is limited by the disease, people with dementia need to rely more on their emotions to connect with the world, and art is one way to do that.

Basting and Killick (2003) also write when PWD no longer perceive themselves as productive workers, or active community members, or contributing family members, often times they are left only with the role of a “sick person.” The arts can potentially provide PWD with a new social role--“an artist”-- as the other social roles are eroded by the disease. The arts enable PWD to express themselves and create something new, which can give them a sense of having something to contribute to society. The ability to create something original that is aesthetically satisfying gives them a sense of control and mastery of their own

life. And the ability to contribute to society enhances their sense of confidence and self-esteem.

Expression through art can also foster a closer relationship between the caregiver and the PWD because the intimacy during the creative process can reveal to the staff the self that remains within the person with dementia that may normally be concealed in their daily interactions. Also, the arts have the potential to increase communication and socialization among PWD as they share the art-making process and products (Allan & Killick, 2000; Basting, 2006; Basting & Killick, 2003).

Physiological reasons

Cohen (2006) explains that engaging in the arts in social settings is good for our health. This is because of the connections between behavior and health and between mind and body, or psychoneuroimmunology. Weekly participation in creative activities provides for social engagement that has been linked to improved cardiovascular, endocrinological, and immunological systems. The arts provide repeated opportunities for elders to create something new, resulting in a greater sense of control, mastery, and empowerment. This sense of control is experienced as a positive emotion, which triggers the brain to send a signal to the immune system to produce more immune system cells, such as T cells—small, white blood cells and NK cells or “natural killer” cells that attack tumor cells and infected body cells. Creative expression activities also create sustained challenges and new experiences that stimulate the development of new dendrites in the brain, improving the communication among brain cells (Cohen, 2006).

Lane (2005) writes that creative work alerts parasympathetic arousal, stimulates the hypothalamus, and causes the brain to release endorphins and other neurotransmitters. These translate into slower heartbeat, lower blood pressure, slower breathing, balanced blood flow and hormone level, and improved functioning of the immune system, in addition to relieving pain and causing the body to go into deep relaxation. Citing findings in neurophysiology

research, Lane reports, “art, meditation, and healing ... are all associated with similar brainwave patterns and mind-body changes” (p. 123).

Miller (2008), a neurologist, studies brain scans of people with degenerative brain diseases, including various kinds of dementias. He finds that in some cases, dementia actually enhances rather than detracts from his patients’ artistic abilities. He concludes that art, for people with dementia, is a way to recognize their strengths, rather than their weaknesses.

In conclusion, engaging PWD in creative arts experiences is worthwhile because it has positive effects on their social, psychological, and physical well-being.

Why have artists/volunteers/staff engage in making art with people who have dementia?

As discussed above, the dialectic nature of personhood maintenance benefits artists, volunteers, and LTC staff as well as the people with dementia. For the staff, this weekly art program gives them a chance to sit down with their clients and assist or collaborate in making something beautiful for its own sake. The emphasis on the interaction, the joy of the moment, and the art-making process rather than the finished product, should provide them with a refreshing alternative to their busy, task-oriented workday. Though initially this opportunity may be perceived as “a nice break,” in the long run, with adequate training, monitoring, and structured reflections, the staff’s recognition of the humanity of their demented clients should result in their increased readiness to embrace a more person-centered care perspective in their work. Basting (2006) reports that staff engagement in creative story-telling activity (TimeSlips) with their clients who have dementia actually increased their job satisfaction, and increased the number of client-resident interactions.

Intimate contact with people who have dementia would enable artists and volunteers to confront their own understanding, values, and beliefs about dementia. The experience should help them build a sense of caring for elders who have been marginalized by society because of their disease. With adequate

training, monitoring, and structured reflections, this experience should eventually result in the demystification of the disease.

Furthermore, engaging practicing artists and art students in the design of creative activities should improve the quality of programming for PWD. Although coloring photocopied pages from a coloring book with children's crayons does keep people with dementia busy, it does not provide them with the creative expression opportunities that they need.

Research evidence on the arts in dementia care

Similar to the research evidence supporting person-centered care, empirical evidence for the arts in dementia care is still limited. Basting (2006) cites small sample size and the lack of control groups as limitations. Brooker (2007) adds the following reasons:

Given the heterogeneity of this [dementia] population, the varied skill level of staff, the enormous variety of settings where activities take place alongside the problems of finding suitable outcome measures, it is not surprising that the research evidence for most of these activities appears weak. (p. 25)

Marshall and Hutchinson (2001) systematically reviewed the literature on activities for people with Alzheimer's published between 1991 and 2001, noted the same limitations, and added to the list the lack of theoretical frameworks used to guide the studies; and a lack of emphasis on gender, ethnic, racial, or cultural differences. Other systematic reviews of psychosocial, non-pharmacological interventions for people with dementia also include similar critiques (Ayalon, Gum, Feliciano, Arean, 2006; Bartels, Haley, Dums, 2002; Finema, Drees, Ribbe, van Tilburg, 2000; Livingston, Johnston, Katona, Paton, Lyketsos, 2005; Verkaik, van Weert, Francke, 2005). These systematic reviews of studies conclude that for the most part, study findings for these interventions are contradictory and inconclusive.

Research on formal/medical art activities in dementia care

Given these caveats, there are a few studies that evaluate the impact of art therapy on the well-being of people with dementia. Of the various forms of art, the benefits of music therapy are the most well-documented (Livingston et al., 2005). A review of abstracts in the PsychInfo database yielded over forty studies on music therapy and only a handful of the other art therapy modalities (visual arts, drama, dance/movement, pottery/sculpture). Studies on music therapy will not be reviewed here because the focus of the OMA program in its current phase is the visual arts.

Research evidence on the visual arts in dementia care tends to evaluate the formal/medical version of art activities, i.e. those that are facilitated by trained and certified art therapists. Nearly all of these are qualitative case studies reporting the observed benefits of art therapy for people with dementia (see for example, Jensen, 1997; Kahn-Denis, 1997; Kamar, 1997; Kovach & Henschel, 1996; Stewart, 2004; Wald, 1993; Wood, 2002). The benefits observed across these case studies include: emotional outlet, calming effects, improved communication and social interactions, facilitating reminiscence, assisting with diagnosis and evaluation of cognitive status, enhanced self-esteem and autonomy, increased concentration, and reduced depression. Descriptive observations, occasionally with illustrative photographs of completed artwork, are provided as evidence. Rusted, Sheppard, and Waller (2006) summarize the state of research in art therapy as follows: "In general there is little adequately controlled, systematic, evidenced based research conducted on the use of the art, drama, or music therapy with this particular [dementia] client group" (p. 518).

To fill this gap, Rusted, Sheppard, and Waller (2006) conducted a longitudinal study utilizing a randomized control group design that compared the effects of art therapy with occupational therapy activities on people with dementia. Forty-five people with mild to severe dementia, ranging in age from 67 to 92, were randomly assigned to participate in weekly art activities or other non-creative, non-specific recreational activities for forty weeks. The specifics about these activities were not elaborated other than the fact that the group sessions

were led by an art therapist and an occupational therapist with up to six PWD in each group session. Standardized measurements of depression, behavior and mood, cognitive status, short-term memory, sustained auditory and visual attention, verbal fluency, and mood changes within session were taken at baseline, after 10, 20, and 40 weeks of intervention with one and three months follow-up. Twenty-one participants completed the entire study period. Their data show, ... that over 40 weeks of therapy, art therapy participants showed session-to-session cumulative changes in measures of responsiveness. Mental acuity, sociability, calmness and physical engagement within art therapy sessions increase on a slow, upward, linear trajectory. ... For the recreational activity group, we see a short-term improvement in responsiveness demonstrated by a steep positive change over the first 10-20 weeks of the programme. However, this is not maintained, and is followed by a similarly steep decline in engagement with a flattened response in the second half of the programme (at a level lower than baseline measures). Thus, the comparable test of change between baseline and 40 weeks for the recreational activity participants produces a significant negative change over time. (p. 529-530)

The study findings clearly support the use of art therapy to improve the well-being of people with dementia. This is a significant conclusion because to my knowledge, the author's assertion in 2006 still holds true in 2008: "To date there are no reported longitudinal, control group studies on the value of group participation in art therapy for people with dementia" (p. 518).

Research on informal/social art activities in dementia care

Research on informal/social art activities in dementia care is even more limited than research in formal/medical art therapy. The fact that art therapy is an established field of study with graduate degrees, professional associations, and journals, is undoubtedly a factor. I found only four studies that evaluate art activities led by artists who are not art therapists in dementia care settings.

Additionally, there is one important study of artist-led programming, even though the population studied are healthy elders without a formal diagnosis of dementia.

A longitudinal, quasi-experimental study comparing 150 cognitively intact elders participating in weekly creative arts activities with 150 equivalent elders who did not participate in such activities found that creative arts expression is good for the elders' physical health and sense of wellbeing (Cohen, 1998; Cohen, 2006; Cohen, Perlstein, Chapline, Kelly, Firth, 2006). The average age of the study participants was 80. Using five questionnaires, data in three domains were collected: (1) physical health: medication and health utilization data; (2) mental health: depression, loneliness, and morale; and (3) nature, frequency, and duration of social activities in which the study participants engaged. The findings of this study revealed that the group that engaged in creative arts weekly experienced less physical decline and improved health compared to their own baseline, had fewer visits to the doctor, used less medication, and scored better than their own baseline on the depression, loneliness, and morale scales when compared to the control group (Cohen, 2006).

Similar endorsements for the arts were also confirmed for people with dementia. Basting (2003) found that regular engagement in creative storytelling activity (TimeSlips) increased "communication and socialization among people with dementia, improved job satisfaction among staff, and positively affected the perceptions of staff, families, and student volunteers about the potential of people with dementia" (p. 9).

Kinney and Rentz (2005) measured improvements in quality of life as a result of participating in "Memories in the Making©," an art program for people with dementia. Using the Greater Cincinnati Chapter Well-Being Observation Tool, they observed twelve people with dementia at two adult day centers. The participants ranged in age between 65 and 85 and they engaged in weekly Memories in the Making© art activity followed by another structured activity such as current events, word games, and crafts. Each activity lasted about 40 minutes and observations were made every ten minutes. They found that "participants

demonstrated significantly higher levels of interest, sustained attention, pleasure, self-esteem, and normalcy during Memories in the Making than during the other activity” (p. 225).

Rowe, Fowell, and Montgomery (2006) observed 32 individuals engaged in creative (e.g. sculpture, flower arranging, pencil art, jewelry making, sewing) and non-creative activities (e.g. baking, crosswords, ring toss, bingo). The average age of the participants was 81.8 years and their average Mini Mental State Exam Score was 19 (the MMSE range is 0-30). Twenty-nine percent of the study population scored the full 30 points on the MMSE. Using the Observed Emotion Rating Scale they observed the participants for a total of 34 hours across six weeks. Observations were recorded every ten minutes. They concluded that creative activities are more enjoyable and more engaging than non-creative activities for both the participants and the staff.

Pepin, Holley, Moore, and Kosloski (2006) observed 10 participants engaged in daily communal activities led by staff members (e.g. singing, movement, social interaction) and art activities led by visiting artists (music, collage, dance, painting, and sculpture). Both communal and art activities were observed daily for two weeks, with each activity lasting approximately one hour. Participants were observed by two observers in five-second intervals every 50 seconds for the following behavioral outcomes: engagement, interest, and pleasure. These behaviors were defined using the Apparent Affect Rating Scale (Lawton, Haitsma, Perkinson, 2000). The observers recorded whether the behavior outcome was present (yes or no), or they selected “no determination could be made” or “subject could not be seen.” The interobserver reliability across all outcomes is 0.78. They concluded, “all of the arts activities elicited engagement, interest, and pleasure at levels comparable to or higher than the communal activity” (p. 35), with music and dance taking the lead in all three behavioral outcome measures among the arts activities.

In conclusion, I agree with Livingston et al. (2005) who identified 1,632 evidence-based studies of psychological interventions in dementia care, and reviewed 162 of them that meet inclusion criteria; they conclude that, although

the study findings are contradictory and inconclusive, some therapies may provide people with dementia and/or their caregivers with momentary pleasure and thus be worth doing even if the interventions do not alter the person's conditions. More rigorous studies need to be done, but given the positive findings above, both formal and informal art programming are definitely worth doing in dementia care settings. Next I will turn to ways that OMA attempts to ensure that its art activities will indeed be beneficial to participants with dementia.

Opening Minds through Art Methodology

"Just because I can't remember things, it doesn't mean that I am stupid!"

--a person with dementia

Basting (2006) lists the following criteria for successful creative arts programs for people with dementia: "The arts are used to build skill (mastery), yield products in which the artists and their community can take pride, build a sense of self, build social networks, and present no risk of failure" (p. 17). These criteria are applicable whether the arts program is formal/medical or informal/social. In this section, I will elaborate on how the OMA program attempts to meet these criteria for successful arts programming for PWD.

Training for staff and volunteers

As mentioned earlier, the OMA program requires the involvement of staff members and volunteers in order to maintain the maximum one-to-two ratio of assistant to participants. This requires at least a two-hour training, but ideally a day-long session for staff and volunteers to learn how to assist in the OMA program. In the day-long version, the content of the OMA training session includes: an overview of dementia, person-centered care philosophy, effective communication with PWD, and an observation and reflection on a real life art session with a group of people with dementia. For this reason, the training session needs to take place at the site where the PWD reside. Using the DVD

created for this training, trainees have the opportunity to analyze real interactions between PWD and assisting staff/volunteers and to develop the necessary knowledge, attitudes, and skills to support the personhood of people with dementia. In the shorter, two-hour version, the training is focused on effective communication and assistance skills with a more abbreviated overview of dementia and without the opportunity to apply and reflect upon lessons learned from working with an actual group of people with dementia. (See Appendix 1: “Volunteer training evaluation” for the blank evaluation form of the training program and Appendix 2 for the summarized evaluation of OMA volunteer training pilot programs).

Training for artist facilitators

Practicing artists and gerontologists interested in becoming OMA artist facilitators need to start out as volunteers and go through the training session for volunteers described above. After a period of volunteering they can begin designing and facilitating the art sessions under the guidance of OMA artist facilitators. Through journaling, discussions, and feedback, they will develop their capacity for reflection-in-action (Schon, 1987). Donald Schon defines this reflection-in-action as:

... the capacity to respond to surprise through improvisation on the spot.
... [It] is tacit and spontaneous and often delivered without taking thought, and is not a particularly intellectual activity. And yet it involves making new sense of surprises, turning thought back on itself to think in new ways about phenomena and about how we think about those phenomena. (p. 4-5)

Schon gives jazz musicians as an example of people that are good at reflection-in-action as they improvise and respond to one another during a jamming session. We engage in reflection-in-action when we have an ordinary conversation or when riding a bicycle. We “know-in-action” what we need to do at each given moment even if we cannot articulate what it is that we know. This “knowledge-in-action” is possible because of our capacity to “reflect-in-action.”

He contrasts this knowledge with “school knowledge” that is molecular, formal, and categorical. School knowledge is:

... explicitly formulable in propositions that assign properties to objects or express in verbal or symbolic terms the relations of objects and properties to one another. ... [I]t is built up of pieces which are basic units of information or basic units of skills which can be assembled together in complexes of more advanced and complicated information. (p. 3-4).

To be effective artist facilitators of people with dementia, both artists and gerontologists certainly need to have some “school knowledge” about the diseases that cause dementia and about art materials and their properties. But more importantly, they need the art and talent to reflect-in-action, and I believe that this is best developed through a period of apprenticeship with an experienced OMA team of artists and gerontologists.

The OMA process

The OMA process involves nine carefully staged steps aimed at maximizing the possibility of “flow” (Csikszentmihalyi, 1990) among PWD as they engage in the creative process. Flow is experienced during optimal experiences as “joy, creativity, the process of total involvement with life” (p. xi). After decades of research, Csikszentmihalyi identified the eight major components of flow shared by artists, dancers, athletes, game players and others:

First, the experience usually occurs when we confront tasks we have a chance of completing. Second, we must be able to concentrate on what we are doing. Third and fourth, the concentration is usually possible because the task undertaken has clear goals and provides immediate feedback. Fifth, one acts with deep but effortless involvement that removes from awareness the worries and frustrations of everyday life. Sixth, enjoyable experiences allow people a sense of control over their actions. Seventh, concern for the self disappears, yet paradoxically the sense of self emerges stronger after the flow experience is over. Finally, the sense of the duration of time is altered; hours pass by in minutes, and

minutes can stretch out to seem like hours. The combination of all these elements causes a sense of deep enjoyment that is so rewarding people feel that expending a great deal of energy is worthwhile simply to be able to feel it. (p. 49)

The same components need to be present for people with dementia to experience flow. Incidentally, Csikszentmihalyi notes that all flow experiences share the above components, but not all eight components need to be present for flow to occur. The nine steps in OMA methodology are designed to create structures that enable the above components to occur so that the possibility of flow among participants with dementia is maximized. These nine steps are : (1) planning time, (2) “the huddle”, (3) inspiration, (4) demonstration, (5) material distribution, (6) the creative process, (7) closure, (8) debriefing, and (9) art exhibition. In addition to the capacity for reflection-in-action described above, artist facilitators also need to be familiar with how dementia affects people’s biopsychosocial conditions; they need to be familiar with the particulars of the PWD they work with (histories, preferences, and personalities); they need to be familiar with the art materials and processes; and they need to believe in the moral necessity of person-centered care philosophy in dementia care. Once these elements are in place, then they are ready to implement OMA using the nine steps below.

1. Planning time

This is a weekly meeting between the artist and the gerontologist to plan the week’s activity. (The team of activity designers is called the “artist facilitators” or simply “facilitators”.) This meeting is also dubbed “play time” because at this time the artist facilitators play with ideas and materials for the week’s activity. The session generally lasts 2-3 hours and takes place at an art studio where supplies are readily available. Particular attention is paid to ensuring that the activity is age- and stage-appropriate, i.e. not “childish”, interesting and appropriately challenging, keeping in mind the particular cognitive and fine-motor limitations of each participant. Variations and

alternatives are designed to accommodate the various stages of dementia of the participants. This is why it is critical for the artist-gerontologist team to know as much as possible about each participant (e.g. social history, habits, current interests and capabilities). Collaboration with staff members should facilitate the artist facilitators' learning process in this regard (see "The Huddle" below on how this is done).

To maintain the personhood of the participants, the activities need to be failure-free (Basting, 2006). This means that the activity cannot require cognitive and fine-motor abilities that are impaired in the person with dementia. One practical guideline used in designing OMA activities is to compare the artwork made by the person with dementia with the one made by the artist facilitators (or others) without dementia. If the piece made by the person without dementia is clearly aesthetically superior to the one made by the person with dementia, then the activity privileges intact cognitive and fine-motor capabilities and is considered inappropriate for people with dementia. I believe that this very practical comparison test is one of the most important factors behind OMA's strength as a program for people with dementia. For illustration purposes, try to identify from the paintings below, the one piece made by a person *without* dementia².

² The answer is the one on the bottom left. Artists (clockwise from top left): Evelyn Shaver, Maxine Peters, Dorothy Dahoda, and Brad Simcock.



The activities that pass this comparison test are written about in a separate activities manual, not included here. Currently, the activities manual contains eighteen activities that have been tested and evaluated during a two-semester pilot study in a long-term care facility that serves people with a moderate level of dementia. Only activities that have been well received by the participants are included in the manual. Well-received activities are those that promote engagement, enjoyment, and social interaction in most of the participants with dementia, and resulted in artwork that they are proud of. This information is obtained from observations by the volunteers/staff members who

worked closely with each participant and reported at the end of each session on an evaluation form (see Appendix 3: “Session evaluation for participating staff/volunteers”). In addition to reporting their observations of how the people with dementia responded to the activity, the assisting volunteers and staff members also gave their personal evaluation of the activities. Their overall rating of the activities on a 5-point scale is included at the beginning of each activity in the activity manual. Only activities rated above 4.0 in this five-point scale are included in the activities manual.

Two out of the twenty activities piloted are excluded from the manual because they do not meet this minimum requirement. A clay activity was given a 4.0 rating by the staff and volunteers and a “Color Surprise” activity was rated 3.8 out of five points, the lowest rated activity of the year. The clay activity was led by a visiting artist who was not familiar with dementia programming and assisted by OMA artist facilitators who were not familiar with clay. A store-bought kit was used in the “Color Surprise” activity without doing the usual “play time” before the session. From these two experiences, it is evident that planning time and close collaboration between artists and gerontologists are critical in activity design.

Another critical element in activity design is the importance of genuine creative expression opportunities for PWD. Because no two people are alike, no two artworks should look alike. If the finished pieces of artwork do look alike, then the artists were not given adequate opportunity for creative self-expression. For this reason, each activity in the manual includes two photographs of the finished product done by people with dementia. These photographs are included to illustrate the aesthetic qualities and the diversity of outcomes possible as a result of individual creative expressions.

2. “The Huddle”: Coaching staff and volunteers

Each session begins with a 15-20 minute “huddle” with all assisting staff members and volunteers. During this huddle, the staff informs the rest of the group of the particular needs and concerns regarding particular residents on that day. The artist facilitator will in turn inform the rest of the group of the day’s plans

and work assignments. Emphasis is made regarding the built-in choices offered to participants in this particular activity, as well as suggestions for communication topics related to the art-making process. For example, when making masks, it is suggested that the staff/volunteer inquires about the kind of mask the participant would like to make, the colors s/he wants to use, and the name to be given to the character depicted on the mask. After the huddle is completed, all staff/volunteers take their places in between the participants, greet them, assist with putting on art aprons if necessary, and direct the participants' attention to the next step of the process.

The art aprons function not only as clothing protector, but also as a symbol that they are about to engage in a creative process. Aprons are worn by chefs, artists, bakers, and others who make things with their hands. This symbol of the apron is not lost on people with dementia. The apron also marks the boundary of creativity time as they put on and take off the apron.

3. Inspiration: Experiencing authentic art

To inspire participants in the day's art activity, they are exposed to authentic art at the beginning of the session. These art pieces should somehow relate to the project at hand. For example, before starting a Japanese calligraphy activity, they are shown authentic Japanese scrolls. Inspiration pieces could also be some examples that came out of the facilitators' planning session. These pieces are shown individually to all participants. (In a group of a dozen participants, two facilitators should walk around with these inspiration pieces in order to speed up the process.) Each participant is then asked which of the two pieces they prefer. Adequate wait time is given for each participant to make this decision.

There are several reasons to take the time to do this inspiration step in the process. First of all, it helps orient the participants to the art activity. Second, it stimulates the orbito-frontal cortex of the brain, the part of the brain that is activated when the eyes look at something beautiful (Crompton, 2007). Third, to elicit their aesthetic preference is to engage them in an evaluative process, which

is complex, yet requires only a pointing gesture, a jutting out of the chin in one direction, or a simple utterance, “This one.” Asking them this question also signals to them that their opinion matters and it gives them the opportunity to communicate what they think is beautiful. All of the above contribute to the maintenance of the participants’ personhood. This is an important and unique element of OMA’s program design.

4. Demonstration

Demonstration is a brief part of the session where the activity process and materials are shown and explained. The purpose of this demonstration is to teach the staff/volunteers about the day’s processes, not necessarily the participants. For the participants, the demonstration serves as another orienting and inspiring element in the process. Another purpose of the demonstration is to show how easy the process is in order to build the participants’ confidence in the failure-free nature of the activity. While time should be slowed down to the pace of the person with dementia in the inspiration part of the process, the demonstration should be targeted at the cognitively intact staff/volunteers. Demonstrations are necessarily brief because one of the symptoms of dementia is shortened attention span (National Institute of Health, 2006). It is perfectly fine at this point in the process if the participants do not quite understand the specific art-making process. They will individually learn from the assisting staff/volunteers.

5. Material distribution: “Gifts” – Offering manageable choices

It is critical that materials are well organized and prepared in advanced in order to minimize the confusion that can easily arise at this stage of the process. It is also important to present materials in an attractive manner so that they appear as “gifts” and if applicable a number of manageable choices are offered. For example, when making a collage, an attractive variety of shapes, sizes, and colors of the collage pieces are assembled in transparent zip-lock bags. Each participant then chooses between two or three of such bags. Besides minimizing

confusion, this is another opportunity for the participants to state their aesthetic preferences. Aesthetically pleasing presentation of materials also helps address another common dementia symptom: the loss of spontaneity and initiative (National Institute of Health, 2006). Presentation of materials as “gifts” is more likely to invite participants to engage in the activity than simply and unceremoniously placing them on the table.

6. The creative process: Making something new of value

This part takes the bulk of the activity time, approximately 40-50 minutes. Each staff/volunteer works with one or two participants. The staff/volunteers need to be able to communicate with the participants, encourage their participation, assist as needed, and maximize the participants’ autonomy. The art-making process is the primary focus here. The artwork created, though also important because each one is an expression of the person’s individuality, is of less concern. It is critical that staff/volunteers do not get over-invested in producing a beautiful piece of art and end up controlling the creative process by making aesthetic decisions for the participants they are assisting. They have to clearly understand the boundaries of their role as an assistant in the creative process. This point is clearly addressed in the staff/volunteer training session.

The art project itself is failure-free, flexible, and open-ended in order to enable “flow” to occur during this creative process. In the end, every piece has to be unique. And because each piece is a stamp of the artist’s self, s/he has created something new of value, which is a definition of art.

7. Closure: Sharing and taking pride

In this very last step in the art-making process, participants are asked to sign and title their finished work if they are able. If assistance is required, the staff/volunteer writes on the back of the artwork. Dating the artwork is also advisable. Participants are encouraged to show each other their finished work. The artist facilitators could also walk around the room with a few examples of finished work. Alternatively, the finished pieces are displayed on a counter or

wall and participants are invited to view the group's work. With people in the early stages of dementia, I found that they enjoy having the group divided into two: half the group sit by their own finished work while the other half come over to admire the work and ask questions. They then switch roles.

Finally, the artist facilitators officially close the session with a short remark, complimenting everyone for their work and thanking them for their participation. All assisting staff members and volunteers clap to signal the official ending of the session. This closure ritual is important for several reasons: it builds the participants' sense of pride in their accomplishments; it builds a sense of community among the participants through art sharing; and it clearly marks the completion of the session. Clear starting and ending rituals create distinct time boundaries, thus potentially help to reduce confusion and anxiety about what is supposed to be happening.

8. Debriefing: Soliciting staff/volunteers' input

If time is available, the day's session ends with a 15-20 minute debriefing session with all assisting staff members, volunteers, and artist facilitators. At this time, everyone's input is solicited about the day's activity and how each participant responded to the activity. If time does not permit oral debriefing of the session, it can be done in writing (see Appendix 3: "Session evaluation for participating staff/volunteers). The artist facilitators' reflections are also recorded at the end of each session (see Appendix 4: "Artist facilitators' reflections"). This information is used to improve the program by further customizing the activities to meet the needs of each participant. At this point it is also beneficial to reflect and discuss with all assisting staff and volunteers their contribution to and performance in the program. Practices that undermine the personhood of people with dementia are discussed in concrete terms using examples from the weekly art sessions. A report summarizing everyone's input is prepared at the end of each module³ and submitted along with the overall program evaluation to the

³ A module can vary in length depending on the need of the facilities. The current OMA program follows the university schedule and each module lasts 12-14 weeks.

facility's managers/administrators. (See Appendix 5: "Overall program evaluation" for the blank evaluation form and Appendix 6 for a summarized evaluation of OMA pilot program)

9. Art exhibition

At the end of the module a formal gallery exhibition is arranged with a festive opening, hosted by program participants. Publicity and arrangements are made to invite the artists' families, all staff members in the long-term care facility, all volunteers, and the general public. Besides celebrating the artists and their creations, the exhibition also educates the general public on the creative capacities of people with dementia. Gallery visitors are given an opportunity to assess the impact of the art exhibition on their own impressions about people with dementia by completing a brief evaluation form. (See Appendix 7: "Evaluation of the art exhibition" for the blank evaluation form and Appendix 8 for a summarized evaluation of OMA pilot program).



Artist facilitator, artist, and artist's relative at an OMA art exhibition (2008)

Commentary on OMA program design

Based on the above description of the OMA process, it should be apparent that the following elements are key to the program design: the participants' opportunity for self-expression and for relationship building.

To give OMA participants opportunities for creative self-expression, they are provided with failure-free activities, manageable choices, and expected to be an active agent in their own creative process. These in turn promote their autonomy and build their self-confidence.

Research evidence confirms that PWD are able to state basic preferences (Feinberg & Whitlatch, 2002; Whitlatch, Feinberg, Tucke, 2005). They studied 51 and 111 people with dementia respectively and concluded that people with mild to moderate dementia (Mini Mental State Exam ranging between 13 and 26) are "reliable and accurate in their ability to respond to questions about demographics and basic preferences⁴" (Whitlatch et al., p. 171).

Citing a study by Rogers et al., Ronch (2003) writes that there is evidence that PWD become more autonomous if they are expected to be active participants in the care process. In this study when PWD were expected to be passive, bathing them required more work for the staff than when independence was encouraged. Staff's expectations and encouragement for the PWD to be independent may actually reverse their "excess disability (reduced optimal level of function created by care practices or medical intervention with the patients)" (p. 328). In short, PWD are able to make choices and expecting them to do so promotes their autonomy. I find this to be true in my observation of OMA participants.

The low participant-to-assistant ratio in OMA program is designed for several reasons: (1) to encourage and assist/support participants so that they can feel in control of the art-making process and (2) to give participants ample

⁴ The questions used to measure PWD's ability to state basic preferences in Whitlatch et al.'s (2005) study are: "(a) Do you like to watch television? (b) Do you prefer winter or summer? (c) Which of these [three] colors do you like the best?; and (d) Which of these three ways do you prefer to have your eggs cooked? (scrambled, fried, boiled, or don't eat eggs)" (p. 175).

opportunities for relationship building with the assisting staff and volunteers. Reviewing the literature, Cohen (2006) reports,

Studies on aging show that when older people experience a sense of control—that is a sense of mastery in what they are doing—positive health outcomes are observed. Similarly, when older individuals are in situations with meaningful social engagement with others, positive health outcomes are also observed. (p. 11).

Other studies have also shown that PWD show positive affect and behaviors when engaged in intergenerational programming (Jarrot & Bruno, 2003; Ward, Kamp, Newman, 1996). In the OMA program, all assisting staff/volunteers go through a training session where Kitwood's (1998) "positive person work", or "The ten kinds of interaction"⁵ that are clearly conducive to the maintenance of personhood and well-being" (p. 27) are inductively introduced using Part II of this manual. With adequate understanding of the program's person-centered care philosophy and effective communication skills, these trained staff/volunteers provide OMA participants with meaningful, intergenerational social engagement opportunities that enhance their health and affect. And because of the dialectic nature of personhood maintenance, the health and affect of the assisting staff/volunteers are enhanced as well.

Let us now revisit the criteria for successful art programming for PWD stated at the beginning of this section: "The arts are used to build skill (mastery), yield products in which the artists and their community can take pride, build a sense of self, build social networks, and present no risk of failure" (Basting, 2006, p. 17). I believe that the OMA processes as described do meet all of the above criteria. The impressive annual art exhibition by OMA artists is an indicator of this success (see Appendix 8 for detailed evaluation and comments of the art exhibition).

⁵ The ten kinds of interactions that maintain PWD's personhood are: recognition, negotiation, collaboration, play, stimulation, celebration, relaxation, validation, holding, and facilitation.

Conclusion

In this report, I have outlined the why and how of effective creative arts program design for people with dementia. The Opening Minds through Art program was developed to meet the creative self-expression needs of people with dementia and is based on person-centered care philosophy. Tapping into pedagogically sound principles, artists and gerontologists collaborate in the design, delivery, and on-going evaluation of the program. Key design elements that define the Opening Minds through Art program include:

- (a) The nearly one-to-one ratio between staff/volunteer and person with dementia;
- (b) The training program required of all assisting staff/volunteers;
- (c) The carefully designed failure-free art activities that do not privilege intact cognition and intact fine-motor skills;
- (d) The use of authentic art to orient and inspire participants;
- (e) The built-in elicitation of aesthetic preferences in a manner that does not overwhelm the participants;
- (f) The presentation of materials as “gifts”; and
- (g) The built-in communication channels among all assisting staff/volunteers to continuously review the creative process and the participants’ responses.

The design and delivery of the art activities presented in this report is carefully guided by the conviction that people with dementia have the human right to the experience of “flow” in their daily life. For our purposes, flow is the sustained experience of un-self-conscious immersion in, and enjoyment of, acts of creative expression that improve the quality of life for PWD in LTC facilities.

References

- Abraham, R. (2005). *When words have lost their meaning: Alzheimer's patients communicate through art*. Westport, CT: Praeger.
- Allan, K., Killick, J. (2000). Undiminished possibility: The arts in dementia care. *Journal of Dementia Care*, 8(3), 16-18.
- Alzheimer's Disease Education and Referral Center (n.d.). Alzheimer's Disease: Unraveling the mystery. Retrieved on September 13, 2008 from <http://www.nia.nih.gov/Alzheimers/Publications/UnravelingTheMystery/Introduction.htm>
- Ayalon, L., Gum, A. M., Feliciano, L., Arean, P. (2006). Effectiveness of nonpharmacological interventions for the management of neuropsychiatric symptoms in patients with dementia: A systematic review. *Archives of Internal Medicine*, 166(20), 2182-2188.
- Baldwin, C., Capstick, A. (2007). *Tom Kitwood on dementia: A reader and critical commentary*. Berkshire: Open University Press.
- Bartels, S. J., Haley, W. E., Dums, A. R. (2002). Implementing evidence-based practices in geriatric mental health. *Generations*, 26(1), 90-98.
- Basting, A. D. (2006). Arts in dementia care: 'This is not the end ... it's the end of this chapter'. *Generations*, 30(1), 16-20.
- Basting, A.D. (2004). *TimeSlips: Creative storytelling with people with dementia*. Milwaukee: University of Wisconsin Milwaukee, Center on Aging and Community.
- Basting, A. D. & Killick, J. (2003). *The arts and dementia care: A resource guide*. Brooklyn: The National Center for Creative Aging.
- Brooker, D. (2007). *Person-centered dementia care: Making services better*. London: Jessica Kingsley Publishers.
- Butler, R. N. (2008). *The longevity revolution*. New York: Public Affairs.
- Cohen, D. G. (1998). Creativity and aging: Ramifications for research, practice, and policy. *Geriatrics*, 53(Supplement 1), S4-S8.
- Cohen, D. G. (2006). Research on creativity and aging: The positive impact of the arts on health and illness. *Generations*, 30(1), 7-15.

- Cohen, G. D., Perlstein, S., Chapline, J., Kelly, J., Firth, K. M. (2006). Impact of professionally conducted cultural programs on the physical health, mental health, and social functioning of older adults. *Gerontologist*, 46(6), 726-734.
- Crompton, S. (2007, November 10). Arts and Minds: Scientists are discovering how love, art and beauty affect our brains, reports Simon Crompton. Retrieved on October 29, 2008 from http://women.timesonline.co.uk/tol/life_and_style/women/body_and_soul/article2840207.ece
- Csikszentmihalyi, M. (1990). *Flow: The psychology of optimal experience*. New York: Harper Perennial.
- Edwardson, D., Winbald, B., Sandman, P. O. (2008). Person-centered care of people with severe Alzheimer's disease: Current status and ways forward. *The Lancet Neurology*, 7, 362-367.
- Feinberg, L. F., Whitlatch, C. J. (2002). Decision-making for persons with cognitive impairment and their family caregivers. *American Journal of Alzheimer's Disease and Other Dementias*, 17(4), 237-244.
- Fleischer, T. E. (1999). The personhood wars. *Theoretical Medicine and Bioethics*, 20, 309-318.
- Finema, E., Dries, R., Ribbe, M., van Tilburg, W. (2000). The effects of emotion-oriented approaches in care for persons suffering from dementia: A review of the literature. *International Journal of Geriatric Psychiatry*, 15, 141-161.
- Fossey, J., Ballard, C., Juszcak, E., James, I., Alder, N., Jacoby, R., Howard, R. (2006). Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: Cluster randomized trial. *British Medical Journal*, 332(7544), 756-761.
- Harlan, J. E. (1993). The therapeutic value of art for persons with Alzheimer's and related disorders. In M. P. Lahey, R. Kunstler, Grossman, A. H., Daly, F., Waldman, S., Schwartz, F. (Eds.), *Recreation, leisure and chronic illness: Therapeutic rehabilitation as intervention in health care* (pp. 99-106). New York: Haworth Press.

- Hoeffler, B., Talerico, K. A., Rasin, J. (2006). Assisting cognitively impaired nursing home residents with bathing: Effects of two bathing interventions on caregiving. *The Gerontologist*, 46, 524-532.
- Jarrot, S. E., Bruno, K. (2003). Intergenerational activities involving persons with dementia: An observational assessment. *American Journal of Alzheimer's Disease and Other Dementias*, 18(1), 31-37.
- Jensen, S. M. (1997). Multiple pathways to self: A multisensory art experience. *Art Therapy: Journal of the American Art Therapy Association*, 4(3), 178-186.
- Kahn-Denis, K. B. (1997). Art therapy with geriatric dementia clients. *Art Therapy: Journal of the American Art Therapy Association*, 14(3), 194-199.
- Kamar, O. (1997). Light and death: Art therapy with a patient with Alzheimer's disease. *American Journal of Art Therapy*, 35(4), 118-124.
- Kasayka, R. E. (2001). Introduction. In A. Innes & K. Hatfield (Eds.). *Healing arts therapies and person-centered care* (pp. 9-17). London: Jessica Kingsley Publishers.
- Kinney, J. M. & Rentz, C. A. (2005). Observed well-being among individuals with dementia: Memories in the Making, an art program, versus other structured activity. *American Journal of Alzheimer's Disease and other Dementias*, 20(4), 220-227.
- Kittay, E.F. (2005). At the margins of moral personhood. *Ethics*, 116(1), 100-131.
- Kitwood, T. (1998). Professional and moral development for care work: Some observations on the process. *Journal of Moral Education*, 27(3), 401-411.
- Kitwood, T. (1998). Toward a theory of dementia care: Ethics and interaction. *The Journal of Clinical Ethics*, 9, 23-34.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham, U.K.: Open University Press.
- Kitwood, T. (1993). Toward a theory of dementia care: The interpersonal process. *Ageing and Society*, 13, 51-67.

- Kitwood, T. & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. *Ageing and Society*, 12, 269-287.
- Kovach, C. R., Henschel, H. (1996). Behavior and participation during therapeutic activities on special care units. *Activities, Adaptation & Aging*, 20(4), 35-45.
- Lahey, M. P., Kuntsler, R., Grossman, A. H., Daly, F., Waldman, S., Schwartz, F. (Eds.). (1993). *Recreation, leisure, and chronic illness: Therapeutic rehabilitation as intervention in health care*. New York: Haworth Press, Inc.
- Lawton, M. P., Haitsma, K. V., Perkinson, M. (2000). Emotion in people with dementia: A way of comprehending their preferences and aversions. In Lawton, M. P. & Rubinstein, R. L. (Eds.) *Interventions in dementia care: Toward improving quality of life*. New York: Springer Publishing Co., 95-119.
- Livingston, G., Johnston, K., Katona, C., Paton, J., Lyketsos, C. G. (2005). Systematic review of psychological approaches to the management of neuropsychiatric symptoms of dementia. *American Journal of Psychiatry*, 162(11), 1996-2021.
- Malloy, D. C., Hadjistavropoulos, T. (2004). The problem of pain management among persons with dementia, personhood and the ontology of relationships. *Nursing Philosophy*, 5(2), 147-159.
- Marshall, M. J., Hutchinson, S. A. (2001). A critique of research on the use of activities with persons with Alzheimer's disease: A systematic literature review. *Journal of Advanced Nursing*, 35(4), 488-496.
- Miller, B. (2008). *Art and dementia*. San Francisco: American Society on Aging.
- Misiorski, S. (2005). What is culture change? Retrieved on February 25, 2007 from http://www.almosthomedoc.org/changing/culture_change_essay.cfm
- National Center for Health Statistics. (2007). Life expectancy. Retrieved on October 22, 2008 from <http://www.cdc.gov/nchs/data/hus/hus07.pdf#027>.
- National Institute of Health. (2006). The changing brain in Alzheimer's disease. Retrieved on November 2, 2008 from

- <http://www.nia.nih.gov/Alzheimers/Publications/UnravelingTheMystery/Part1/ChangingBrainInAlzheimer.htm>
- Noddings, N. (1984). *Caring: A feminist approach to ethics & moral education*. Berkeley: University of California Press.
- Plassman, B. L., Langa, K. M., Fischer, G. G., Heeringa, S. G., Weir, D. R., Ofstedal, M. B., Burke, J. R., Hurd, M. D., Potter, G. G., Rodgers, W. L., Steffens, D. C., Willis, R. J., Wallace, R. B. (2007). Prevalence of dementia in the United States: The aging, demographics, and memory study. *Neuroepidemiology*, 29, 125-132.
- Ronch, J. L. (2003). Caring for people with Alzheimer's disease and related dementias: Strengths-based approaches. In J. Ronch & J. Goldstein (Eds.) *Mental Wellness in Aging* (pp. 315-341). Baltimore: Health Professions Press.
- Rowe, J. M., Fowell, H. L., Montgomery, R. J. V. (2006, November). *Impact of creative activities at an adult day center*. Paper presented at the annual conference of the Gerontological Society of America, Dallas, TX.
- Rusted, J., Sheppard, L., Waller, D. (2006). A multi-centre randomized control group trial on the use of art therapy for older people with dementia. *Group Analysis*, 39(4), pp. 517-536.
- Schon, D. (1987, April). *Educating the reflective practitioner*. Paper presented at the meeting of the American Educational Research Association, Washington, DC.
- Signore, D. D. (2007). Review of Kaleidoscope...Color and form illuminate darkness: An exploration of art therapy and exercised for patients with dementia. *Art Therapy: Journal of the American Art Therapy Association*, 24(4), 195-196.
- Verkaik, R., van Weert, J., Francke, A. L. (2005). The effects of psychosocial methods on depressed, aggressive and apathetic behaviors of people with dementia: A systematic review. *International Journal of Geriatric Psychiatry*, 20, 301-314.

- Wald, J. (1993). Art therapy and brain dysfunction in a patient with a dementing illness. *Art Therapy: Journal of the American Art Therapy Association*, 10(2), 88-95.
- Ward, C. R., Kamp, L. L., Newman, S. (1996). The effects of participation in an intergenerational program on the behavior of residents with dementia. *Activities, Adaptation & Aging*, 20(4), 61-76.
- Whitlatch, C. J., Feinberg, L. F., Tucke, S. (2005). Accuracy and consistency of responses from persons with cognitive impairment. *Dementia*, 4(2), 171-183.
- Wood, M. J. M. (2002). Researching art therapy with people suffering from AIDS related dementia. *The Arts in Psychotherapy*, 29, 207-219.

Appendix 1: Volunteer Training Evaluation

Today's date: _____

1. I have a better understanding about people with dementia (PWD).	Strongly disagree 1 2 3 4 Strongly agree 5
2. I learned <u>how to better interact</u> with PWD.	Strongly disagree 1 2 3 4 Strongly agree 5
3. I feel <u>more confident</u> in my ability to facilitate the creative process of PWD	Strongly disagree 1 2 3 4 Strongly agree 5
4. The trainer explained things clearly.	Strongly disagree 1 2 3 4 Strongly agree 5
5. The video clips and discussions were helpful in my learning process.	Strongly disagree 1 2 3 4 Strongly agree 5
6. Please comment on the length and pacing of the training session.	Length: Pacing:
7. I am interested in participating in more OMA training and discussions If yes, please check the topics of interest →	<div style="display: flex; justify-content: space-around;"> No Yes </div> <div style="margin-top: 5px;"> <input type="checkbox"/> Dementia in general <input type="checkbox"/> Communication skills with PWD <input type="checkbox"/> Customizing art activities for PWD Other: </div>

The strengths of this training session:

Suggestions for improvements:

Appendix 2: Volunteer Training Evaluation Summary

September 25, 2008

Training date: Thursday, September 25, 2008, 7-9 PM

Number of people attending: 17

Number of training evaluations completed: 13

Number of people signing up to become volunteers: 11

On a 5 point scale (1 = strongly disagree and 5 = strongly agree), below are the averages for each question.

1. I have a better understanding about people with dementia (PWD).	4.0
2. I learned <u>how to better interact</u> with PWD.	4.3
3. I feel <u>more confident</u> in my ability to facilitate the creative process of PWD	4.4
4. The trainer explained things clearly.	4.8
5. The video clips and discussions were helpful in my learning process.	5.0
6. Please comment on the length and pacing of the training session.	Length: Positive comments on both Pacing:
7. I am interested in participating in more OMA training and discussions If yes, please check the topics of interest →	<p style="text-align: center;">No = 0 Yes = 13</p> <p>Dementia in general ----- 3</p> <p>Communication skills with PWD ----- 7</p> <p>Customizing art activities for PWD -- 12</p> <p>Other:</p> <p style="text-align: center;">None mentioned “other”</p>

The strengths of this training session:

- Eleven people mentioned that they liked it in general and liked the video clips & discussion in particular.
- Three people liked the mix of art and gerontology students.
- One person liked the real artwork we brought in as examples.

Suggestions for improvements:

- One person recommended to get to the video clips sooner, shorten the beginning part.
- One person suggested another time, 7 PM is too late.
- One person suggested talking more about uncomfortable situations.
- One person suggested more video clips.
- One person suggested showing several clips together for comparison.
- One person mentioned the lay out of the classroom does not facilitate discussion.
- One person mentioned the need for a short break (when polled in class, they wanted to continue without a break).
- Seven people left this section blank

Volunteer Training Evaluation Summary

October 5, 2008

Training date: Sunday, October 5, 2008, 2-4 PM

Number of people attending: 8

Number of training evaluations completed: 6

Number of people signing up to become volunteers: 5

On a 5 point scale (1 = strongly disagree and 5 = strongly agree), below are the averages for each question.

1. I have a better understanding about people with dementia (PWD).	4.8
2. I learned <u>how to better interact</u> with PWD.	5.0
3. I feel <u>more confident</u> in my ability to facilitate the creative process of PWD	4.2
4. The trainer explained things clearly.	4.8
5. The video clips and discussions were helpful in my learning process.	4.8
6. Please comment on the length and pacing of the training session.	Length: Positive comments on both, except one suggestion below Pacing:
7. I am interested in participating in more OMA training and discussions If yes, please check the topics of interest →	<p style="text-align: center;">No = 0 Yes = 5</p> <p>Dementia in general ----- 0</p> <p>Communication skills with PWD -----3</p> <p>Customizing art activities for PWD-----4</p> <p>Other:</p> <p style="text-align: center;">None mentioned “other”</p>

The strengths of this training session: (verbatim copy)

- Showing the physicalities of brain deterioration with dementia.
- Knowing/learning what is the real outcome of OMA = active involvement of artists.
- Relaxed learning environment.
- Purpose of training obvious and appropriate.
- Great comparison between clips; really gets the point across.
- Great.
- This session took real situations which made understanding how to handle different situations a lot easier.
- Real situations, videos very helpful, yet sometimes emotionally challenging.

Suggestions for improvements: (verbatim copy)

- Try to involve all attendees in discussion.
- More discussion may come from clips with people that we do not know .
- Better to be divided into two sessions.
- Four people left this section blank.

Appendix 3: Session evaluation for participating staff/volunteers⁶

Today's date: _____ Site: _____

Your position (circle one): Activity/Nursing/Volunteer/Other: _____

1.	Did you personally enjoy today's activity?	very much 5 4 3	not at all 2 1
2.	How well did you work with the participants in this activity?	very well 5 4 3	very poor 2 1
3.	How appropriate was the activity for the participants?	very appropriate 5 4 3	not at all 2 1
4.	Overall, how would you rate this activity?	very good 5 4 3	very bad 2 1

Please complete the section below for the two participants that you observed most closely today.

		Participant's name: _____	Participant's name: _____
5.	Did s/he participate in the activity?	all the time 5 4 3 2 1	all the time 5 4 3 2 1
6.	How much enjoyment do you think s/he gets from this activity?	very much 5 4 3 2 1	very much 5 4 3 2 1
7.	Did s/he appear happy or content during the activity?	all the time 5 4 3 2 1	all the time 5 4 3 2 1
8.	Did s/he interact socially with others (including staff) during the activity?	all the time 5 4 3 2 1	all the time 5 4 3 2 1
9.	Did the s/he appear to be proud of his/her finished work?	very much 5 4 3 2 1	very much 5 4 3 2 1
10.	Did you notice any special reactions (positive or negative) to the activity expressed by the participants? If so, please specify and include quotes as exactly as you can:		

⁶ Adapted from Basting, A. D. & Killick, J. (2003). *The arts and dementia care: A resource guide*. Brooklyn, NY: The National Center for Creative Aging, pp. 27-8 and from Legacy Health System Family Support Services (1995). *I can Create! Arts programming for people with Alzheimer's disease and related disorders*. Portland, OR: author.

Appendix 4: Artist Facilitator's Reflections

Today's date: _____ Site: _____

You may choose to use this form each week, or please write a more free-form journal entry that addresses the points below.

1.	Did you personally enjoy today's activity?	<div style="display: flex; justify-content: space-between;"> very much not at all </div> <div style="display: flex; justify-content: space-between;"> 5 4 3 2 1 </div>
2.	How much enjoyment do you think the participants get from this activity?	<div style="display: flex; justify-content: space-between;"> very much not at all </div> <div style="display: flex; justify-content: space-between;"> 5 4 3 2 1 </div>
3.	Did you notice any special reactions (positive or negative) to the activity expressed by the participants? If so, please specify:	
4.	Did any of the participants comment to you directly (positively or negatively) on the activity? If so, please quote as exactly as you can:	
5.	Did anything happen today that you found difficult/uncomfortable? If so, please specify:	
6.	What other information or support do you wish you had today?	

Please use the other side for additional comments

Appendix 5: Overall Program Evaluation

Today's date: _____ **Site:** _____

Your position (circle one): Activity / Nursing / Other: _____

Number of OMA sessions attended: _____

1.	Overall, how would you rate the OMA program?	very good 5 4 3	very poor 2 1
2.	Overall, how much did you enjoy the OMA activities?	very much 5 4 3	not at all 2 1
3.	Overall, how well did <u>the artist facilitators</u> work with the participants throughout the program?	very well 5 4 3	very poorly 2 1
4.	Overall, how well did <u>the volunteers</u> work with the participants throughout the program?	very well 5 4 3	very poorly 2 1
5.	Overall, how well did <u>the residents</u> respond to OMA's art activities?	very well 5 4 3	very poorly 2 1
6.	Overall, how appropriate were the activities in the program for the participants?	very appropriate 5 4 3	not at all 2 1

Overall, to what extent did the OMA program:

7.	encourage residents' creative self-expression?	Very much 5 4	so-so 3	not at all 2 1
8.	encourage residents' social interaction?	Very much 5 4	so-so 3	not at all 2 1
9.	improve residents' mood and/or behavior?	Very much 5 4	so-so 3	not at all 2 1
10.	<u>Before</u> participating in the OMA program, I thought it was possible for people with dementia to express themselves creatively	Did think so 5 4	Did not think so 3 2 1	
11.	<u>After</u> participating in the OMA program, I think it is possible for people with dementia to express themselves creatively	Do think so 5 4	Do not think so 3 2 1	

What have you personally learned from participating in the OMA program?

(Please feel free to make other comments/suggestions too). Thank you.

Appendix 6: Overall Program Evaluation Summary

Spring 2008

Number of people completed the evaluation: 11 people

Average number of sessions attended by these 11 people: 6.4 sessions (range: 1-11 sessions)

		Group Average (5=high; 1=low)
1.	Overall, how would you rate the OMA program?	4.8
2.	Overall, how much did you enjoy the OMA activities?	4.8
3.	Overall, how well did <u>the artist facilitators</u> work with the participants throughout the program?	4.8
4.	Overall, how well did <u>the volunteers</u> work with the participants throughout the program?	4.7
5.	Overall, how well did <u>the residents</u> respond to OMA's art activities?	4.2
6.	Overall, how appropriate were the activities in the program for the participants?	4.5

	Overall, to what extent did the OMA program:	Group average
7.	encourage residents' creative self-expression?	4.9
8.	encourage residents' social interaction?	4.5
9.	improve residents' mood and/or behavior?	4.3
10.	<u>Before</u> participating in the OMA program, I thought it was possible for people with dementia to express themselves creatively	4.4
11.	<u>After</u> participating in the OMA program, I think it is possible for people with dementia to express themselves creatively	5.0

What have you personally learned from participating in the OMA program?
(Please feel free to make other comments/suggestions too). Thank you.

Verbatim quotes:

I have really enjoyed this. Thanks for including me. (OMA artist facilitator, attended 11 sessions).

That building a roster of excellent programs will take time and practice. (OMA artist facilitator, attended 11 sessions).

We basically have the right ideas, approaches, and philosophy. We just need to tweak the details to improve the program, and experiment/try out other activities. (OMA artist facilitator, attended 11 sessions).

I knew from readings and past experience that people with dementia could express themselves creatively. Seeing the art exhibit uptown compounded my feelings for art in this setting. Art is, to me, very important and to have this program take place will hopefully open our society's eyes to what these people can do; and that they are still a viable part of the community. Thanks to Like and Irene for their time spent on this project and will be looking forward to new things to come in the fall. (Knolls activity staff, attended 9 sessions).

I worked 3 times so far with a resident. Non-verbal was used. VERY SUCCESSFUL with him. He does better with less communication, openly demonstrate. Bill Schaner. Love him! (Knolls activity staff, attended 5 sessions).

This was a wonderful program for our residents. For the most part when OMA people were there, the residents were attentive and quiet. The ones that I thought were passed the stage of being really creative surprised me when they get one on one and examples and a structured activity they did really amazing!! Thank you! (Knolls activity staff, attended 5 sessions).

This program is wonderful as an engaging, expressive activity for the residents. As a family member, it's great to watch the residents explore their creativity. I'm so pleased that it will continue! (Family, attended 7 sessions).

That it is important that the artist enjoy themselves and feel good about themselves, no matter how temporarily. My hat is off and my heart is out to all involved. (Volunteer, attended 1 session).

Overall Program Evaluation Summary

Fall 2008

Number of people completed the evaluation: 9 people

Average number of sessions attended by these 6 people: 5.25 sessions (range: 2-9 sessions)

		Group Average (5=high; 1=low)
1.	Overall, how would you rate the OMA program?	4.8
2	Overall, how much did you enjoy the OMA activities?	4.8
3.	Overall, how well did <u>the artist facilitators</u> work with the participants throughout the program?	4.7
4.	Overall, how well did <u>the volunteers</u> work with the participants throughout the program?	4.3
5.	Overall, how well did <u>the residents</u> respond to OMA's art activities?	4.7
6.	Overall, how appropriate were the activities in the program for the participants?	4.3

	Overall, to what extent did the OMA program:	Group average
7.	encourage residents' creative self-expression?	4.7
8.	encourage residents' social interaction?	4.5
9.	improve residents' mood and/or behavior?	4.4
10.	Before participating in the OMA program, I thought it was possible for people with dementia to express themselves creatively	3.6
11.	After participating in the OMA program, I think it is possible for people with dementia to express themselves creatively	5.0

What have you personally learned from participating in the OMA program?
(Please feel free to make other comments/suggestions too). Thank you.

Verbatim quotes:

Control issue: How important it is to give artist control of their work; Mutual benefit: Artist & volunteer. (MU Volunteer, attended 5 OMA sessions).

I've learned that I can get through to dementia patients and help them. It's made me appreciate creativity and the importance of choice more. (MU Volunteer, attended 4 OMA sessions).

They can make choices about art and can express themselves. It is an area they have choices rather than having everything controlled. (MU Volunteer, attended 5 OMA sessions).

I have learned that someone remembering my name is less important than the satisfaction they get from making decisions and enjoying themselves. (MU Volunteer, attended 5 OMA sessions).

How to be at ease and work with all kinds/levels of dementias. (MU Volunteer, attended 9 OMA sessions).

The importance of staging each activity process very carefully to avoid confusion among volunteers and artists; I learned that OMA benefits the students/volunteers that come regularly in a very meaningful way and their face-to-face encounters with people with dementia gave them a greater understanding of the depth and possibility of creative expression and human connections possible despite the disease. (I drew this conclusion after the end-of-semester debriefing session and reading their evaluations.) (Artist facilitator, attended 9 OMA sessions).

Great program – have to continue (activity staff, number of OMA sessions attended: left blank).

Staff helping the residents with art is much more likely to take over and produce art for them (Volunteer, attended 3 sessions).

I really feel like I have learned how to work with people with dementia which will make me a better art teacher. I hope to participate next semester! Great job! (Volunteer, attended 2 OMA sessions).

Appendix 7: Evaluation of the Art Exhibition

Opening Minds through Art (OMA) Art Exhibition

Please share your thoughts about OMA's art show⁷.

I found the exhibit to be (circle as many as you like)

Depressing
Humorous
Confusing
Helpful
Other _____

Hopeful
Frightening
Magical
Informative

Thought provoking
Charming
Nothing special
Uninformative

Before viewing this exhibit, I thought it was possible for people with dementia to express themselves creatively:

1	2	3	4	5
Did not think so				Did think so

After viewing this exhibit, I think it is possible for people with dementia to express themselves creatively:

1	2	3	4	5
Do not think so				Do think so

Other thoughts about the exhibit:

I have had personal or professional experience with people who have dementia:

Yes No

⁷ Adapted from: Basting, A. D. & Killick, J. (2003). *The arts and dementia care: A resource guide*. Brooklyn: The National Center for Creative Aging, p. 32.

Appendix 8: Evaluation of the Art Exhibition Summary **Spring 2008 Exhibition Feedback**

NOTE: (1) Although it is estimated that about 90 people saw the exhibit (about 60 at the opening and 30 afterwards), only 36 completed the evaluation forms, and four people sent emails afterwards. The summary below is based on these 36 completed evaluation forms and the four emails. (2) Sixteen artists participated in the exhibit.

Adjectives about the art show	Number of times mentioned
1. Magical	23
2. Charming	23
3. Thought provoking	22
4. Hopeful	21
5. Informative	11
6. Wonderful	11
7. Helpful	6
8. Beautiful	6
9. Want more exhibits like this	6
10. Inspirational/inspiring	4
11. Enjoyable/fun	4
12. Very nice	3
13. Uplifting/upbeat	3
14. Respectful	2
15. Celebratory/celebrative	2
16. Heart-warming	2
17. Humorous	2
18. Life affirming/affirming talents of artists	2
19. Thrilling	2
20. Therapeutic	2
21. Exciting	2
22. Made me feel good	2

Other phrases used once:

Impressive, amazing, special, professional, fabulous, remarkable, warm energetic feeling, made an extraordinary impact on all involved, a revelation, moving, artistic, classy, consciousness raising, touching, brilliant, inspiring, reassuring, purposeful, interesting, surprising, unbelievable, revealing, challenging.

Neutral or negative adjectives available on the evaluation form but NEVER selected:

1. Depressing
2. Confusing
3. Frightening
4. Nothing special
5. Uninformative

Self-reported change as a result of the show
Question:

Before viewing this exhibit, I thought it was possible for people with dementia to express themselves creatively:

1	2	3	4	5
Did not think so				Did think so

After viewing this exhibit, I think it is possible for people with dementia to express themselves creatively:

1	2	3	4	5
Do not think so				Do think so

Responses:

Art Show 2008

Before	After	Change
5	5	0
4	5	1
5	5	0
5	5	0
5	5	0
4	5	1
4	5	1
3	4	1
5	5	0
2	5	3
3	5	2
5	5	0
5	5	0
5	5	0
4	5	1
5	5	0
3	5	2
2	5	3
2	5	3
5	5	0
5	5	0
4	5	1
2	5	3
3	5	2
4	4	0
1	5	4
5	5	0
1	5	4
4	5	1
3	5	2
5	5	0
5	5	0

Summary of self-reported change:

- Number of respondents for self-reported change: 32 people.
- After the exhibit, everyone thought that it is possible for people with dementia to express themselves creatively. Thirty people rated 5 out of 5 and two people rated 4 out of 5.
- The number of people who were not changed by the exhibit (0 change): 15 people. All of these people were already fully aware before the show that people with dementia are capable of expressing themselves creatively.

- The number of people whose rating about the possibility of people with dementia to express themselves creatively increased as a result of the exhibit:
 - increase of 1 point: 7 people
 - increase of 2 points: 4 people
 - increase of 3 points: 4 people
 - increase of 4 points: 2 people (These two people signed their names on the evaluation forms. They are the daughter and the wife of one of the artists who initially refused to give consent for their relative to participate in the OMA program “because he won’t understand”. As a result of the exhibit, they shifted their position from thinking that people with dementia cannot express themselves creatively (rating of 1) to thinking that they can (rating of 5).
- Eleven out of the 32 respondents (34%) have not had any personal or professional experience with people who have dementia.

Artists’ evaluations of the reception:

Seven artists and three staff members from the Knolls attended the opening. At the end of the two hour reception, the artists were asked “How much did you enjoy tonight’s party?” and given the choice between “very much” (3 points), “some” (2 points), and “not at all” (1 point). The average rating by the artists was **2.6 points**. Their rating would probably have been higher if the assessment was done earlier in the evening. The artists were also making comments such as, “I did that, didn’t I?”; “I didn’t know that I am an artists”; “This is such an honor.” Families of five artists attended the opening reception and several more went to see the exhibit after the opening.

Narrative Comments by Gallery Visitors

From Emails

I just want to tell you how thrilled I was with the exhibit and celebration this evening. It was remarkable in every possible way, and you have made an extraordinary impact on all involved: artists, families, and community. The art is beautiful and so is the project. Thank you so much.

You did a fabulous job on that event! I completed my evaluation accordingly. I can't tell you how impressed I was with the concept of the OMA, the beauty of the artwork, and the nature of the opening reception. The display was beautiful, the tone of the event was upbeat and celebratory, and it was one of the most enjoyable evenings I've spent in quite some time. You and the staff at the Knolls really showed your respect for the artists. [My dad] was thrilled with the whole

thing. And so were we! Thanks for brightening his life by allowing him to participate in your art classes. Thanks,

Your art show was wonderful. It had such a warm energetic feeling. I believe those feelings came through in the art as well. We both enjoyed it. Also, the invitations are just beautiful. Thanks again.

Hello! I stopped by the OMA exhibit today and absolutely LOVED IT!! Great job! So amazing! I was wondering if any of the art work is going to be for sale? Let me know!

From evaluation forms

- What a wonderful project – to be able to reach deep into these confused minds to find beauty and organizational skills. I wish my mother could have participated in something like this!
- The artwork was displayed very effectively; nice arrangement of food/beverages; nice touch to have photos of artists. The whole event was very professional and affirmed the talent of the artists. Great job!
- It was a fabulous evening. I loved the exhibit and having the artists present was an outstanding idea. I recognize and sincerely appreciate the creativity and energy the organizers invested in this project.
- Infinity is the limit! Keep us this great work — spread the word – give framed pieces to families.
- This is wonderful. I think art is an expression of a person's soul. It doesn't matter the limitations of one's cognition.
- More activities like this should be done to keep all people active and creative no matter what the mind set.
- Left me aching for more of this—the perspective and the process. Thank you so much.
- Wonderful exhibit! Would love more exhibits like this!
- I found it to be touching and heartwarming. I was touched deeply by how happy the program participants (artists) seemed. Also, and just as important, I was taken by how happy and heart-warmed the participants' family members and friends were, and how rare it must be for them to see their loved ones succeed at something late in life. Wonderful, brilliant, way to go!

- I truly believe that the artists were extremely pleased and proud of their work. It was wonderful to see their beautiful creations that have helped them express that creative side of them.
- I thought that the exhibit was very nicely done. The room was well laid out. The brochures were informational and purposeful. A really interesting project and exhibit!
- I'm so surprised they are so nice. It is unbelievable what they can really do. I'm enjoying this. My husband is at the Knolls with dementia (EP).
- My dad (JP) is one of the exhibitors. I enjoyed every minute. This is wonderful for the families of parents with dementia. It is so informative. And gives us a good feeling (CP).
- Many of these pieces are quite wonderful. A very uplifting show.
- Congratulations for a wonderful job!
- Just a beautiful exhibit.
- I had no idea what to expect and I'm so glad I stopped by! Good luck to all involved.
- Impressed by the art! The fact that it has therapeutic benefit is icing on the cake.
- Truly amazing. More wonderful than any of the above words [referring to the selection of adjectives on the evaluation form.]
- This art/education program is so life-affirming! **Thank you!**
- Very nice to see. My grandpa has dementia and this exhibit made me feel good to be here and make others feel special.
- Very nice! Special for the artists!
- All art is therapeutic. It's heart-warming to see it used by these folks!!
- Thank you for helping these people.
- Like "Art Brut" in Lausanne, Switzerland.
- Great set up! I would have loved to be there for the opening ceremony.

- Keep up the good work.
- This is such an exciting opportunity for the patients and my grandmother loves this chance.