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Engagement in Arts Based Activities:
A Qualitative Ethological Study of Individuals With Dementia in Long Term Care

by

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Art for Art's sake. Why not?

Art for Life's sake. Why not?

Art for Pleasure's sake. Why not?

What does it matter, as long as it is Art?

(Read, 1931, p. 152)

For Areej and Amal

ABSTRACT

The focus of this study was to explore and describe the interaction phenomenon of "meaningful engagement" in art-making activities by individuals with dementia living in long-term care. A video-based qualitative ethological approach was used to describe naturally occurring behaviors and interactions of four groups of three older individuals with dementia and the facilitator during art-making activities sessions. Art making activities provided multi-sensory stimulation, and included drawing, painting, collage, color sorting and singing.

The phases of interaction occurred at a group and individual level. The group phase of interaction and the individual phase of interaction were often desynchronized. The phases were: setting the scene, anchoring, co-creating and overcoming resistance. Challenges were evident during all phases of interaction. The interpersonal social environment was recognized as an important element of engagement in art-making activities in institutional dementia care for preservation of personhood, recognition of remaining abilities and a decreased focus on disabilities.

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Chapter 1

Introduction

The word "art" is usually associated with the use of skill and imagination in the creation of aesthetic objects, environments, or experiences that can be shared with others. The individual character of the art created depends on the artist's personality and will to create it. Without this 'will', there can be no significant art (Read, 1931). Leo Tolstoy described the creative will leading to art making process as:

> ... to evoke in oneself a feeling one has experienced, and having evoked it in oneself, then by means of movement, lines, colors, sounds, or forms expressed in words so to transmit that feeling that others experience the same feeling - this is the activity of art. (Read, 1931, p. 191)

Many health care facilities are currently incorporating a variety of arts in their programs and décor due to the role it can play in healing and recovery. Researchers in the area of arts for healing believe that encouraging the exploration, development, and practice of creativity is a means to promote wellness (Grasel, Wiltfang, & Kornhuber 2003). The arts in healthcare settings can improve the quality of life for individuals, family members, and caregivers by providing activities and environments that promote creative and positive responses to illness. For example, "Artists on the Wards" is a program, founded at the University of Alberta Hospital in 1999, where the artists share their creativity with patients and staff. Activities involving music, writing, dance, and visual arts are successfully employed to encourage creative expression in patients, allowing them to have choice and control over an aspect of their hospital stay, and

empowering them to be responsible for their own healing (Gorman, 2001). Research and development is being undertaken in terms of the use of the arts, combined with traditional medicine, as a coping tool for individuals whose life altering illness affects them physically, and/or emotionally. Individuals and family members who are dealing with chronic and life-limiting illnesses, palliative care, death, bereavement and other end-of-life issues, can be inspired by the creative arts, expressive therapies, literature, spiritual values, and cultural beliefs, for building the foundations of coping and for comfort (Bobar, McLellan, McBee & Westreich, 2002).

Background of the problem

Fisher and Specht (1999) suggest that a strong relationship exists between creativity and successful aging. As health declines in older individuals, physical activities may be limited, yet creativity may remain a viable outlet for self-expression. Dementia is one of the leading causes of declining health in the aging population. Therefore, it becomes significant, as in normal aging, to understand how the arts and creativity can play a role in generating a positive attitude for remaining active, as well as in coping with the challenges of illness in individuals with dementia.

The prevalence of dementia in North America and other developed countries has instigated research aimed at exploring and identifying best care practices for persons with dementia who reside at home and in long term care facilities. Dementia care entails dealing with disruptive or disturbing behaviors that accompany the gradual deterioration of memory, judgment, and language abilities (Rau, 1993). Some behaviors, for example sleeplessness and extreme restlessness, may be effectively managed through the judicious use of medication under the guidance of a knowledgeable physician. However, there is

no recognized effective treatment for the cognitive symptoms of dementia (Schneider, 1993).

To reverse, improve, or prevent further cognitive and intellectual deterioration is still an area of intense research. While researchers are progressing in their understanding of the causes of dementia, and developing more effective medical treatments, there is advancement in the knowledge and use of a variety of non-pharmacological interventions as well. Individualized intervention plans as well as group-oriented interventions are often used to control the disruptive behaviors, and to alleviate the emotional problems. Kuhn, Ortigara and Farran (1997) identify the social treatment of dementia, among other things, as structuring of a suitable social and physical environment and planning appropriate activities for patients. The goal of these treatments is to promote maximum independence, maintain physical functioning, and enhance self-esteem. To ascertain whether art making is one such activity that integrates all of these goals, behaviors need to be described as precisely as possible and then subsequent changes carefully monitored (Dyck, 1997).

Objectives of the study

The goal of the study was to explore and describe the interaction phenomenon of meaningful engagement in arts activities by individuals with dementia living in long-term care. The objectives of the study were:

1. To describe the verbal and non-verbal patterns of engagement behaviors, and interpersonal interactions between facilitator and residents during art making activities,

2. To identify the phases of individual and group engagement and work.

3. To identify the strategies used by the facilitator to engage the residents

4. To identify residents' responses to these strategies

5. Identify and describe forms of self expression by the residents

To achieve the above objectives, I used an inductive and qualitative ethological design informed by the Human Ecological perspective. Human Ecology focuses on humans as both biological organisms and social beings in interaction with their environment, and a key process is adaptation by humans of and to their environment (Bubloz & Sontag, 1993). The study was conducted in a long-term care facility in a major city in a Western Canadian Province. Four groups of three residents each were videotaped during twelve art making activity sessions. Arts activities such as painting, collage, drawing, and singing were employed to engage the residents in sessions of 40 to 50 minutes. Videotaping of the sessions allowed direct observation of actual interaction patterns. All but two of the families of the participants were met with and interviewed prior to starting the study. The interviews were about residents' personal history including sensitive subjects to be avoided during conversations, any medical conditions to be aware of during sessions, prior preference for particular activities, and interests that could provide a point of contact. During this time non-participant observation was conducted to describe the context and environment.

Significance

The body of knowledge on the impact of arts programming on older individuals with dementia, lacks in systematic descriptions of behaviors and interactions associated with the arts activities (Marshall & Hutchinson, 2001). Strategies used in interpersonal interactions during engagement in arts activities have not been studied. In general,

research on psychosocial environment in dementia care has remained a largely unexplored domain (Werezak & Morgan, 2003). Exploring the interaction of individuals with dementia, engaged in arts activities, using observational methods provided a starting point for attaining insights into the role of art making activities in enhancing their social-psychological environment.

While this study also generated artwork completed by the residents during the course of art making activity sessions, it was not the intention to assess the artworks for their therapeutic value in coping with symptoms, stresses and traumatic experiences of the illness. Activities were presented to the individuals to create immediate pleasure, provide meaningful tasks, and enable friendship amongst the participants, and reflected upon to understand the behavioral manifestation of the art making process.

This study will contribute to research in the field of Human Ecology, Gerontology and Arts Administration. It will help artists, administrators, and caregivers understand how individuals with dementia participate and engage in the art making activities. The visual data will reflect on the socializing behavior of individuals with dementia and their interaction with their fellow residents and with the facilitator during art making activities. The focus of the study on the domain of behavioral engagement will help caregivers understand how positive behavioral states are enhanced by involvement of residents in activities of a social and physical nature.

Chapter 2

Review of the literature

The literature review related to the arts for individuals with dementia in long term care provides a frame of reference for the reader in relation to dementia and the art making process as it manifests itself during art-making activities. The literature gathered for this study focuses on three inter-related areas: an introduction to the nature of dementia; arts activities for dementia; and empirical research findings and best practice guidelines used in art activities for individuals with dementia.

<u>Dementia and aging</u>

Population projections by Statistics Canada show that seniors comprise one of the fastest growing population groups. This rapid growth in size of the senior population is expected to continue into the future. Senior citizens will account for 21% of the population by 2026, and 25% by 2050 (Statistics Canada, 2001). This change in population profiles brings a greater proportion of people into the age group of 65 and over, placing greater importance on the diseases that are most common in old age. Among these diseases is dementia, and the most common form of dementia is Alzheimer's disease. As the likelihood of contracting this disease increases steeply with age, the current projected growth of older individuals in Canada puts an emphasis on the importance of dementia as a cause of disability, death, and as a reason for institutional care. Knowledge of the prevalence of dementia in Canada comes from the Canadian Study of Health and Aging Group (1994), one of the largest longitudinal studies of the epidemiology of the dementias, among community resident and institutional resident

Canadians. As of 1991, 252,600 (8%) individuals aged 65 and over suffered from Alzheimer's and other types of dementia (male/female ratio 2:1). Assuming the prevalence rate remains constant (8%), almost 600,000 persons above 65 years are likely to have the disease by 2021 and 778,000 by 2031.

Defining dementia

Molly and Lubinski (1995) define dementia as:

... a common clinical syndrome characterized by a decline in cognitive function and memory from previously attained intellectual levels, which is sustained over a period of months or years. The deterioration is of such severity that it impairs the affected individual's ability to work and to perform activities of daily living, including communication. (p. 3).

Memory loss in dementia sufferers is extraordinary and affects language, perception, attention, and motor skills. Losses caused by memory deficits include waning of attention and communication skills, inability to understand information, confusion, depression, agitation, wandering, delusions and suspiciousness (American Psychiatric Association, 1980).

According to Kitwood (1997), the dementing aspect of the disease progress is a consequence of both the neurological and the socio-psychological changes in individuals. Most of the reasons for dementia are attributed directly to the brain being less efficient, its function having declined, and usually, degeneration in its actual structure. These conditions lead to changes in the socio-psychological environment of the person with dementia in terms of patterns of relationships and interactions with family members and friends.

Dementia can be of the reversible or the irreversible type. Reversible dementia is amenable to treatment, and occurs in individuals who have compound symptoms that make the accurate identification of dementia difficult in the first place. The irreversible type of dementia is chronic, and characterized by progressive decline in cognitive functioning (Molloy & Lubinski, 1995). Dementia itself is an umbrella term that includes distinct subtypes. The three main subtypes of dementia are: Alzheimer type, vascular type, and 'mixed' type. Other dementias are caused by damage to brain structure. These include Pick's disease, Creutzfeld-Jacob disease, meningitis, neurosyphillis, AIDS-related dementia, alcohol related dementia, and poisoning related dementia. In addition, loss of neurons may occur as a result of gross brain damage, whether through a single major head injury or through repeated smaller injuries as in boxing (Kitwood 1997).

Caring for individuals with dementia

Many individuals with moderate to late stage dementia require intensive care. It is often difficult for even a loving family to provide the level of care that may be needed. Chenoweth and Spencer (1986) found that families moved their relatives to nursing homes or other institutions because of increasing incontinence or the assaultive behaviors of their loved one, and their inability to provide the intensive care these individuals required. Family members face the difficult choice of being overwhelmed if they try to provide all the care, or of feeling guilty because of placing them in a long-term care facility. Even when caregivers are unable to continue caring for a relative with dementia, they may require support and urging of a physician or family member before deciding to institutionalize their relative.

Although family members and caregivers of persons with dementia hope for a cure for the disease, currently there is no established proven pharmacotherapy available. In the absence of one, psychosocial management has become a necessary part of over-all treatment. Kindermann, et al. (2002) suggest that non-pharmacological therapy be used throughout the course of dementia for treatment of behavioral disturbances. Non-pharmacological therapies such as activities which engage individuals and facilitate memory, interventions for common behavior problems and specialized individual therapies for management of unique problems have been developed. These therapies, including arts activities, are time consuming and inexact; they require constant resourcefulness, inexhaustible patience, vigilance, and energy on the part of administrators and caregivers (Dowling, 1995).

Kitwood (1997) stresses the need to embrace a culture of care that is more fitting, appropriate and humanistic for the individuals with dementia. "Personhood" emerges as a very important concept in this regard, and indicates the status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust, and embodies all of those characteristics, values, experiences and nuances that make each person who they are. Kitwood (1997) further states that family members and caregivers often adopt a defensive tactic, and disregard personhood, particularly when the individuals cannot easily speak in support of their own interests. He identifies the need to move beyond the anxieties and defenses, so that life-giving relationships can grow between caregivers and individuals with dementia. Rader (1995) also notes that building relationships with the individuals suffering from dementia is crucial to understanding both their behaviors, and for developing a basis for identifying

underlying problems. When the environment of a care facility, including organizational, physical, and psychosocial aspects, is structured to meet the needs of a specific population, rather than asking the population to adapt to the environment, there is a dramatic improvement in the quality of life of residents and a decrease in the "problem behaviors" with which staff must cope (Mace, 1993).

The growing significance of dementia, followed by institutionalization of the elderly individuals has a bearing on the design of dementia care in institutionalized settings. Institutionalization may compel individuals to make significant adjustment, and entail loss of personal identity, and limited role-playing. Caregivers may see the suffering of these individuals as a mere biological problem, to be solved by some kind of technical intervention (Kitwood, 1997). Focus on cognitive functioning and patient management has contributed to the biomedicalization of dementia (Russell, 1996). However, increasing discontent with the nature of long-term care has led to a call for a paradigm shift away from a hospital-like model toward one that is resident-centered, individualized, and holistic in nature (Rader, 1995). The changing culture of care is evident in research surrounding social models of care, focusing on home-like environments, less institutional settings, and providing higher interaction between staff and clients (Morgan & Stewart, 1997; Chapman & Otfinowski, 2001).

Models of interventions for individuals with dementia

Interest in art-making activities centers on the possibilities that such activities have to offer for self-expression and socialization. Individuals with dementia who can exercise control over some of their physical and cognitive abilities may benefit from activities that support self-expression and socialization. Dementia almost inevitably robs

the individual of self-expression through the usual channels of communication such as speaking or writing. The possibility that arts may help re-open expressive channels or help slow the process of feeling isolated is very appealing (Allan & Killick, 2000). In creative collaboration between the individuals with dementia, and the facilitator of the arts activities, the artwork may also become an essential way to communicate and pass on the personal and cultural history of the individual (Perlstein, 1996).

With the continuing evolution of the social model of care, several interventions emerged as a means to working with the aging population with dementia. These interventions include psychological approaches such as Reality Orientation, Validation therapy, Resolution Therapy and Reminiscence Therapy (Kitwood, 1997). Within the context of a person centered approach, it is important to consider the psychological approaches that are based on the values and principles concerning the worth and dignity of individuals with dementia. However, there is variation in each individual's case of dementia, and therefore, different approaches may be used, individually, or in combination with each other to create beneficial effects. Holden and Woods (1995) agree that there is no return to complete normality from dementia, and therefore suggest that the term 'therapy' is inappropriate in view of its curative connotations. However, interventions can bring important and valuable achievements for individuals with dementia in the form of positive feelings and contacts with other human beings. "The expression of such states, however fleeting, is a worthy aim of dementia care" (Holden & Woods, 1995. p.78).

Reality Orientation

Reality Orientation is a therapy for confused or disoriented individuals that involves orienting them to time and place, reiterating their identity, and reinforcing regularity in their daily routine. Reality Orientation (RO) focuses on human relationships and general awareness of the confused elderly (Taulbee and Folson, 1966), although it originated as an attempt to rehabilitate severely disturbed war veterans, and not older adults with cognitive problems (Baines, Saxby & Ehlert, 1987).

Holden & Woods (1995) describe two ways of carrying out RO. These include: the 24 hour RO, carried out throughout the day whenever individuals seems confused, by way of telling them where they are and why; and RO classes that are held on a basic, standard and advanced level, geared to individual capabilities and progress, and for a limited amount of time during the day.

Reality Orientation attempts to provide individuals with a greater understanding of their environment, possibly resulting in an improved sense of control and self-esteem. Baldelli et al. (1993) applied RO in their study with institutionalized individuals having dementia and described the results as favorable in terms of improvement in cognitive status and orientation. However, as Baines et al. (1987) state, RO has been criticized in clinical practice for being applied in a mechanical fashion, being insensitive to the needs of the individual, and possibly contributing to mood and self-esteem problems. The existence of the dichotomy in results for RO however does not undermine its effectiveness and benefits. Holden and Woods (1995) suggest that findings on RO should be used as a springboard for developing more effective approaches for individuals with dementia.

<u>Validation Therapy</u>

Validation therapy (VT) focuses on feelings and emotions of individuals with dementia (Feil, 1993). It attempts to validate and respect the feelings of the individual in whatever time or place is real to them at the time, whether or not it corresponds to the present moment. VT is referred to as a humanistic approach developed by Naomi Feil in 1960s whereby elderly individuals are given an opportunity to resolve their life's unfinished conflicts through encouragement towards expressing their feelings. The main objective of VT is to give the confused individual a sense of identity, dignity and self worth by validating their feelings but without interpreting the individual's behaviors (Babins, 1988).

Feil (1993) recommends VT to be a more useful approach for individuals with late onset disorientation, in the age group of seventies and eighties. She categorizes the behaviors exhibited by the individuals into four stages of progressive deterioration in orientation, and describes techniques to be used for VT during these different stages. Feil (1993) states the techniques to be simple but requiring the validating caregiver to have the capacity to accept and empathize with the elderly disoriented individuals, and being able to put aside their own judgments and expectations of behaviors.

There has been a great interest in VT for its contribution to dementia care as an interactive technique for individual and group therapy (Bleathman & Morton, 1996). Claims have been made in support of VT for the humanistic and psychological care of individuals with dementia (Stokes & Goudie, 1990; Bleathman & Morton, 1996), however, there is a lack of theoretical and empirical evidence to support these claims. While acknowledging that VT is a potentially valuable humanistic framework for care of

individuals with dementia, Woodrow (1998) evaluates research on VT for challenges associated with it, and states it to be a time consuming therapy that may create more emotional pain in the absence of sufficiently designated time in the overall plan of care.

Resolution Therapy

The insights from reality orientation and validation therapy have been taken further in another approach known as Resolution Therapy (RT). RT was introduced by Goudie and Stokes (1989) as a supplementary therapy to Reality Orientation. Unlike Validation Therapy, RT focuses on present needs rather than past conflicts. RT emphasizes empathy, communication, and responding to current needs of individuals with dementia (Goudie & Stokes, 1989). The underlying premise is that observed behaviors of confused and disoriented individuals are likely to reflect concealed meanings in speech or actions, relating to current concerns.

Resolution Therapy is carried out using one-to-one counseling of individuals, through reflective listening, exploration, acceptance, and empathy. It is essential for caregivers carrying out RT to understand and acknowledge the feelings of the disoriented individuals, and not analyze why individuals are feeling the way they are (Stokes & Goudie, 1990). But, as Woodrow (1998) states, this one-to-one therapy during everyday social interaction seems to rely on caregivers with advanced interpersonal and counseling skills, and a positive working environment that may not always exist. Additionally, RT is vague in structure and may pose difficulties for the staff to carry it out as part of their care practice.

<u>Reminiscence Therapy</u>

"Reminiscence is a multi-faceted, multipurpose, naturally occurring mental phenomenon manifested across the life span in a variety of forms and contexts" (Webster & Haight, 1995). The development of reminiscence as a therapeutic intervention followed Butler's (1963) introduction of the life review concept, whereby the onset of a crises is understood to prompt the resurgence of memories. A reconsideration of these memories helps achieve the meaning and a greater understanding of one's life.

The effectiveness of reminiscence as a therapeutic intervention for individuals with dementia has not been fully established. Lai, Chi and Kayser-Jones (2004) discuss the issues of quantifying positive benefits in a randomized control trial study of using reminiscence with a life story approach with individuals with dementia. Yet, they noted some promising effects of using reminiscence to promote the well-being of nursing home residents with dementia, and recommend developing it as an effective psychosocial intervention.

Reminiscence Therapy involves providing encouragement for silent or vocal recall, sometimes using memory aids like music, photographs and personal items, of past and familiar people, places, and preferences to one person or a group of people. Reminiscence Therapy with individuals having dementia may be carried out by professionals and non-professionals, in a variety of settings, in various forms (Haight & Webster, 1995). Talking about the events in an individual's past often helps communication and interaction, and understanding the individual's past life and experiences can help make sense of their present conversation and behavior. In working with individuals having dementia, there is a need for research that shows how best

reminiscence can be carried out in different settings and for particular purposes (Holden & Woods, 1995).

Art as an intervention

If positive feelings, and humane contact are accepted as ends in themselves, then approaches other than those based on psychology merit attention in dementia care. Various ways of enriching the lives of individuals with dementia continued to be explored following the development of the psychological approaches, and include the use of music, dance, drama, and art (Kitwood, 1997). Art based activities share the humanistic values of psychological approaches and seek well-being of individuals with dementia as well as utilize their remaining abilities. They are aimed at engaging and developing interpersonal social environment, facilitating memory, and supporting existing skills (Grasel, Wiltfang &. Kornhuber, 2003). Additionally, arts may be used to improve physical environment. Innes (1999) described how design changes were made at one residential home for individuals with dementia in order to improve the environment. The staff gathered detailed life history material on residents, and used this to develop ideas for enhancing the physical environment at a simple and affordable level. They painted bathroom doorframes the same color all over the facility for easy recognition. Cupboard doors were painted the colors of walls to draw attention away from them. They made murals based on sea life theme familiar to residents and they brought in pets to provide stimulation to the individuals with dementia. The researcher reported that the life history work reinforced staff perceptions on the preferences of the residents, and contributed to improvement in the environment of care.

The overriding aim for engagement in arts is enhancing communication with individuals with dementia. This is often observed, during and after the activity, in their spontaneous creativity, enhanced communication, sustained concentration, and satisfying collaboration that serves to break down isolation (Killick, 2002). Collier (2001) describes the use of art making as a treatment medium for a group of older people experiencing mental health problems. She describes the spirit of fun and enjoyment that was experienced by the subjects in each other's company as they painted, printed or sculpted their pieces of artwork.

Individuals suffering from dementia appear to lose the reasoning part of the brain but may have the emotional, intuitive part intact. The arts, with their emphasis on feeling and the opportunities offered for non-verbal expression, may be a particularly appropriate means of communication for those with the condition (Killick, 2000). Art making activities may be an alternative form of expression and communication for individuals with dementia (Hellen, 2000). In addition, research shows that art-making activities can be important in encouraging the use of existing skills or of learning new ones (Seifert & Baker, 1998). Engaging individuals with dementia in art making activities provides opportunities for multi sensory stimulation which is an important element for increasing possibility of interactions (Zgola, 1987). Individuals usually derive pleasure from looking at pictures, and observing movement and color. Sensory stimuli like smell, taste, hearing and touch can enrich sensory experience. Finally, arts activities may be thought of as psychologically therapeutic (Allan & Killick, 2000). According to Allan and Killick (2000) engagement in art for the purpose of self-expression, communication, use and control of skills, aesthetic appeal, or psychological therapy are not likely to exist in

isolation from one another. Any one enterprise may be based on a combination of motives, whether implicitly or explicitly intended. Jarvis (1998) worked with an individual with dementia, in making a collage of visual reminders of significant times in that individual's life. Jarvis (1998) found that the finished artwork was a source of comfort to the individual who requested that the collage be hung in his room.

Although the research literature on art activities for institutionalized individuals who have dementia is relatively small, the implementation and effects of art making has been noted as positive. According to Miller et al. (1998), researchers have found that dementia may actually offer a window into creativity; they discovered a relatively rare form of dementia which brought out startling artistic talents in some people. FTD (Frontotemporal Dementia) is a degenerative condition of the anterior portion of the brain, marked by dramatic changes in personality and behavior. Miller et al. discovered that individuals with FTD, many of whom were going through a great deal of distress over losing communication skills, also experienced a sudden appearance of artistic and musical skills. Miller et al. (1998) hypothesized that the selective loss of function in the anterior temporal lobes of the brain may have a causal effect on the sudden appearance of artistic talent. They suspect that degeneration in one part of the brain can lead to enhanced function in another area, which in this instance would be the visual and musical areas of the brain.

Art as a vehicle for communication

Allan and Killick (2000) called attention to the significance of art activities for individuals with dementia:

Communication is a key concept in improving life for people with dementia, and many persons with the condition experience serious problems with language. By providing a number of alternative means of expression (mostly non-verbal) the arts may be offering the pathways they desperately need (p. 18).

As the cognitive capacity to utilize language meaningfully declines, it leaves the individual relying on non-verbal channels, including visual stimuli, tone of voice, body attitude and movement for both receptive and expressive communication (Johnson, Lahey & Shore, 1992). When the ability to communicate and understand ideas deteriorates, it becomes important to understand how individuals with dementia use non-verbal communication. Killick and Allan (2001) describe ways non-verbal communication can be used by individuals with dementia. These include communication through: the eyes, including eye contact, and direction of gaze; facial expression; touch and other physical contact; gestures; body posture and orientation; and non-verbal vocalizations. According to Kitwood (1997) non-verbal communication is significant as Dementia sufferers sometime seem to have a heightened awareness of body language and often their main meanings may be conveyed non-verbally. In the case of those who are very severely impaired it seems probable that the words and sentences are at times more of an accompaniment or adornment than the vehicle for carrying the significant message.

Since communication will be the fundamental process through which the art making activity will be introduced, it is important to consider the characteristics of communication pertinent to individuals with dementia that have implications during art making activities. Memory loss in dementia sufferers affects language, perception, and attention, making it difficult for them to communicate using conventional norms and

means. Kempler (1995) described some of the clinically diagnosed communicative weaknesses of individuals with moderate to advanced stage dementia. These are: difficulty with production and comprehension of language; having limited vocabulary and grammar; problems with word retrieval; speech that is difficult to follow; deficits in producing coherent writing and reading; incorrect word and sound substitution; lack of communication initiative; difficulty engaging in simple conversations; likely withdrawal from social situations.

Arts based activities in dementia care have close connections with issues of communication. In respect of the communication deficits, there is developing interest in the role of nonverbal communication and its implication for understanding the role of art making as a social experience. Neal and Ridley (1996) describe two projects in which individuals with dementia were engaged in the production of murals. In the first mural project, an artist directed the 10' x 5' production, working with individuals with dementia and their caregivers. The theme of the mural was the relationship between the persons with dementia and their caregivers. Some individuals painted onto the mural directly, while others painted on pieces of paper that were later attached to the mural as part of the overall design. The investigators reported that involvement in mural painting provided stimulation and pleasure to individuals with dementia and their caregivers. In addition, the finished mural inspired a greater understanding in the caregivers for the individuals with dementia who worked alongside them. A second mural project was initiated by an occupational therapist and a nursing assistant. The project was carried out at a day hospital, and allowed the attending individuals with mental health needs to contribute to the work as they constantly learned and shared skills from each other. The mural design

was developed and executed with input from the individuals, occupational therapist and the nursing assistant. The work stimulated old memories for the clients and provided opportunities for reminiscing.

Practice-based guidelines for art activities

Practice based guidelines bear significance in activity planning and presentation. Practice-based guidelines have developed out of the approaches used in congregate adult day care and residential programs for individuals with dementia. Zgola (1987) provides an understanding of the working of the mind of individuals with dementia, and of effective approaches when introducing activities to them. Zgola asserts the underlying principle for activities to be successful is that the activities must replace some tasks that have been lost to the individual, support positive roles, and make success possible for them. Dowling (1995) conveys the concepts underlying activities for individuals with dementia, describes the activities and how to implement them in detail. The practical and hands-on approaches described by Zgola (1987) and Dowling (1995) reflect on experiences of staff and clients from adult day programs or those of individual consultants. Depending on the characteristics of the individuals with dementia, activities should take maximum advantage of their abilities (Zgola, 1987) and include everything that an individual may do in a care environment, such as bathing, dressing up, grooming, and eating, as well as participating in arts or other recreational activities.

Meaningful engagement in art activities

Much is made in the literature of creating "meaningful" activities for individuals with dementia. Most of the authors, however, do not define what is meant by meaningful engagement. Accepting that there are diversities in the dementia experience and that the

meaning of these experiences are uniquely individual, the meaningfulness of an activity for each individual may be different, and, every activity in which the person feels emotionally involved could be his/her meaningful activity at that moment in time.

Gori, Pientini and Vespa (2001) describe some essential requirements of a meaningful activity as: simplicity; repetitivity; multi-sensoriality; safety; adaptability; and respect. Seifert and Baker (1998) consider increased positive affect and increased activity among persons with dementia indicative of meaningful engagement. In their study of procedural skills and art production, individuals with dementia utilized stickers for picture making. Seifert & Baker, documented "voluntary attendance" and a "high return rate" of 76.2%, as indicators of participants' satisfaction with the art class from week to week. According to Killick and Allan (2001), we need to recognize that the search for meaning within an experience does not stop when dementia develops. And, like other human beings, individuals with dementia need to make sense of their experiences, to find a satisfactory way of explaining things.

Gaps in literature

Although many studies have shown desirable effects across a range of arts activities, for most of the procedures, there is, as yet, no empirical evidence of effectiveness based on rigorous methodology. Arts based activities are growing in popularity in dementia care, but what has been described in the literature is insufficient detail to determine effectiveness and appropriateness. Given the scarcity of the publication of negative results, little is heard about the initiatives that were not considered to have had positive effects. Significantly, there is lack of interactional information, that is, the strategies through which the facilitators engage individuals with dementia.

Although guidelines are available for presenting activities to individuals having dementia, there is a lack of process and outcome evaluation of effectiveness and appropriateness of the current guidelines. There is also a lack of clarity over the meaning of meaningful engagement/activity, or how it is achieved.

The study will address some of the gaps in literature by providing a detailed description of the interactions and behaviors through verbal and non-verbal cues exhibited during art making activities. The indicators of effectiveness, as well as the challenges presented during the interactions will be identified. To assess that arts activities can be used to engage individuals with dementia meaningfully in the here and now, the study focuses on the process and not the end result of activities. In accordance with Killick and Allan (2001), it is assumed that what person with dementia say and do always has meaning, and secondly that meaning is essentially an interpersonal construct. But at the same time, individuals with dementia do not adhere to the normal patterns of meaning other individuals value. Therefore, the meaning imputed to the behaviors and interactions during art making will be considered as shared, and not necessarily reflective of the feelings of the individual with dementia.

Chapter 3

Methods

A qualitative ethological approach was used to carry out the study in the context of human ecological framework. The goal of the study was to explore and describe the interaction phenomenon of meaningful engagement in arts activities by individuals with dementia living in long-term care. It translates into the human ecological concept of human beings as social and physical beings that interact with each other and with their various environments. These comprise of physical, socio-cultural, and aesthetic environments, and include the material and human resources of these environments. The dominant value of human ecology is the well being of individuals and improvement of the conditions of their existence (Sontag & Bubloz, 1988).

<u>Research perspective</u>

Human Ecology focuses on humans as both biological organisms and social beings in interaction with their environment (Bubloz & Sontag, 1993), where a key process is adaptation by humans of and to their environment. Human Ecology has core concepts, competences, and values that are interrelated. The core concepts in human ecology fall into the four categories and these are congruent with the concepts and relationships identified in this study. Firstly, environmental concepts that relate to the setting for the study, its design, and socio-cultural patterns. Secondly, individual concepts that comprise of the participants' needs, values, personal history, life transitions, and decision-making. Thirdly, interaction concepts that take into account the relationship and interaction between the facilitator and the participants, between the participants and art

making activities, and between participants. Fourthly, outcome concepts include the goals to foster and enhance interpersonal social environment. The core values of Human Ecology are summarized in concern for "human betterment" (Sontag & Bubolz, 1988).

Method

A qualitative ethological approach was used to carry out the study. A qualitative inquiry explores naturally occurring phenomenon in its natural context and employs an inductive approach that allows ideas and categories to emerge from the data. Qualitative ethology was a suitable method for the study because it elicits information through observation of both verbal and non-verbal communication cues that assume significance in view of cognitive impairment accompanying dementia. This method uses techniques for eliciting complex behavioral patterns and clusters through systematic observation and inductive analysis. Ethological studies begin with an inductive descriptive phase during which important patterns of behavior are identified and described (Eibl-Eibesfledt, 1989; Bottorf & Varcoe, 1995). From the observation and description of behavior, conclusions are drawn about the organization of behavior and the significance of its function.

Ethological studies have systematically examined infants, children and deaf or mute individuals, with limited verbal expressiveness. For example, Solberg and Morse (1991) studied the comforting behaviors of caregivers toward distressed postoperative neonates using a qualitative ethological approach. Videotaped data comprising nurses' comforting behaviors towards postoperative neonates was analyzed using techniques of qualitative ethology. Observational techniques of video recording was used to investigate phenomenon that was unsuitable for self-reporting techniques like interviews and focus groups. Studies like Solberg and Morse (1991) demonstrate that a lack of verbal

communication or the inability to use the body language in a typical way does not imply a lack of communicative ability. Though words are normally the most efficient means of transmitting information and signals, expressive acts such as body language and gestures may actually be more reflective of internal feeling states and experiences than speaking for some individuals. Individuals with dementia often have clinically diagnosed communicative weaknesses (Lubinski, 1995) and exhibit behaviors that need to be considered in terms of both verbal and non-verbal cues. As Brooker (1995) states, the nature of dementia is such that traditional methods of gaining users' views (that is, interviews, questionnaires, or focus groups) are not suitable. And, because the characteristics of engagement in arts activities were not found in any scientific study, an inductive qualitative approach was used to identify the significant behaviors that should be observed in arts activities sessions and to facilitate the development of rich descriptions that could serve as a conceptual basis for further research.

The setting

The study was conducted in a dementia care unit of a continuing care facility in a major city in a Western Canadian province. This facility was chosen for the study following some other collaborative projects with the Department of Human Ecology that had been initiated at the request of the facility. These projects combined the need to create a hospitable, comfortable environment for persons with dementia and the desire to do it in a meaningful way.

The facility houses 225 residents on three floors. The Dementia care unit accommodates 75 residents with moderate to late stage dementia predominantly of the Alzheimer's type. The art activities groups were conducted in the residents' lounge on the

third floor. This location was chosen because it was already familiar and comfortable for the residents. Additionally, the lounge provided seating arrangements for residents and allowed convenient video recording of the session. The open side of the lounge was screened off while the activities session was in progress to allow for an uninterrupted proceeding and for video recording.

Inclusion criteria

Participant selection was based on convenience and purposive sampling. The criteria for resident participation were decided in order to bring out maximum participation and to reveal the greatest array of interactions during arts activities sessions. Inclusion criteria were: 1) at more moderate than late stage of dementia as assessed in their current clinical file record, 2) demonstrating the physical capability to engage in art making activities, assessed by the guardians and caregivers, 3) willingness to participate, and 4) less likely to wander away than some frequent wanderers, as assessed by their families and caregivers. Residents who were cognitively impaired or physically impaired to the extent of being unable to sit or communicate with the facilitator were excluded from the study.

The group facilitator

The facilitator for the arts activities was an artist and an educator. She had broad background and experience in art making and was able to conduct the sessions with insight and understanding. The group facilitator was also familiar with the cultural traditions and norms, and was able to use this knowledge in working with the participant groups. Additionally, the group facilitator having experienced her father develop

dementia, understood the disease and identified with the care giving experience in long term care settings.

Participants

Twelve residents participated in this study, including two males and ten females. They ranged in age from 66 to 92 years. At the beginning of the study, staff and families were consulted to do purposeful grouping of participants into small groups of three participants each. For example, two residents who were roommates were known to enjoy being together were placed in the same group. On the other hand, two residents who were likely to exhibit difficult behavior were put in separate groups.

Recruitment procedures

Recruiting the study participants began two months prior to the actual data collection phase. The Care Coordinator and the Resident Advocacy Council were met with, in order to explain the study and obtain feedback as to the feasibility and design. Following the Faculty of Agriculture, Forestry, and Home Economics Human Research Ethics Board (HREB) approval of the research proposal (Appendix A), and the letter of approval for the study from the facility, the study proposal was presented at one of the meetings of the Resident Advocacy Council, and at a morning staff meeting to explain the study.

Extreme caution was exercised in recruiting the participants due to the vulnerability of residents suffering from dementia. As recommended by the HREB, residents' consents for participation in the study were obtained through the legally authorized guardians or agents who, in most cases were a member of their family. Most of the family members had legal guardianship for their loved ones. Recruitment for the

participants was initiated through the care coordinator. The care coordinator identified residents who might be suitable and interested in participating, and then designated a volunteer to contact guardians or family members of these residents. Family members or guardians who agreed to discuss the resident's participation in the study were called, informed about the study, and appointments were made with them to meet with me at the facility. Participating residents were also present at this meeting. The families of two of the participants were unable to meet with me in person so their written consents were obtained through fax.

In order to talk about the study and their participation, meetings were held with individual participants and their families over a period of one month. This personal contact was important in terms of making introductions with the families and the participants, and for collecting information about the residents' personal histories (Appendix B). The personal history and exchange of information with the families formed contextual basis for interpreting the video taped data later. Information about residents' previous activity patterns and interests provided valuable clues in setting up activities for the sessions (Rader & Tornquist, 1995). Once the families indicated that they felt comfortable about their loved one participating in the study, the study was reviewed with them before asking the authorized guardian to sign the consent to allow the resident to participate (Appendix C). For the residents, verbal assents (Appendix D) were obtained in the presence of the family members. Family members explained the study to their loved one and confirmed their willingness to participate. Additional and separate consents for use of participants' videotaped face and body images and their artwork for educational and presentation purposes were obtained. Two more participants were added

to the study during data collection, to take the place of the residents who became too ill to participate.

Data saturation was achieved after twelve arts activity sessions, and the addition of two new participants, so no further recruitment was required. No new information about the dominant themes emerged, and the data was becoming redundant. However it must be pointed out that there were some areas that were chosen not to pursue because of the limitation of the study.

Reasons for declining to participate

It is important to identify reasons why families of potential participants declined their participation, or why participants were otherwise unable to participate. Declining to participate reduced variation of data at the later stage of dementia. Twenty residents' families were contacted according to the list provided by the care coordinator. Four families had verbally agreed to meet and talk about the study, but on contact they declined to allow participation for the resident they represented. The family members discussed with me that participation would place too much strain on the resident. One resident moved to another floor in the facility and two more residents moved to a different facility. Three residents, for whom written consent for participation were available from the families, were unable to participate because they became too unwell. These three residents were affected by an outbreak of flu going through the facility soon after consents were obtained, and before data collection could start. One of the three residents passed away during data collection. Loss of participants resulted in unanticipated and hasty recruitment of two more participants and a need for modifications in the planned groups.

Participant profiles

Two men and ten women participated. The ages of participants ranged from 66 to 92 years. Residents' characteristics varied with respect to cause of dementia, severity of illness, and complications. Nine of the participants had the more prevalent dementia of the Alzheimer's type; two had frontal lobe dementia and one had vascular type dementia. Mini Mental State Examination (MMSE) scores accompanied residents' diagnosis; this method is widely used for assessing cognitive mental status. Participants' Mini Mental State Examination Scores averaged: 13.4/30, ranging from 5/30 to19/30. These scores, however, may not have represented an accurate picture of the residents' mental status at the time of data collection. In some cases the available scores had been assessed 3 months before data collection, and, in some cases as far back as 19 months before data collection.

Participants interest in activities

Information about residents' personal history included their interest in activities before the onset of dementia. Knowing the residents' past and what has been meaningful to them helps in the planning of appropriate activity (Kasayka, 2001). The participants enjoyed a range of interests in their pasts including listening to and playing music, drawing/painting, dancing, playing games, gardening, reading, writing poetry, cooking, embroidery/craft making, and involvement in religious activities. Born in the first half of the twentieth century, many of the residents grew up on farms and were involved in farming activities. However, some of the residents, including females, pursued careers outside of their homes. Activities were then planned based on the information obtained about residents' past interests in activities. Topics for art making and conversations often included animals, growing flowers, farms, songs and traditional celebrations.

Characteristics of the participants' groups

There were four groups in all, and each group had three participants. Grouping was done purposefully, to maintain an environment of respect, good rapport and easy communication between the group members. Purposeful grouping was based on participant's capabilities, physical health, behavioral status and personal preference. In one group, at least one participant with a history of engaging in arts prior to onset of dementia was included. In any one group, no more than one participant with a care history of difficult behavior was included and no more than one participant with a known physical disability or hindered communication was included. In one group, two participants who were roommates and enjoyed being together were included. The groups each met three times over a period of one week for approximately forty minute sessions. Arts sessions were spaced close to each other, so the participants had a greater chance of retaining a memory or connection with the previous session thus increasing the scope of communication.

Characteristics of the arts activities

Participants in each group were engaged in activities including drawing, painting, sorting, collage, and singing that had shared as well as independent components. From initiating an activity to it completion, tasks were achieved either independently by the participant, or in sharing with other participants or the facilitator. For example, in making a collage, one of the participants selected and laid out the paper and fabric pieces independently, but glued it with the help of the facilitator. Goals of each activity were to: 1) Engage participants in art making activity, and 2) use activities as a vehicle to promote resident to resident and resident to facilitator interactions. Materials for drawing and

painting included white drawing paper, broad and fine tipped markers, flat and round paintbrushes and poster paints. Materials for collage included colorful and sometimes shiny pieces of fabric, glue, glitter glue, and shiny confetti in different colors and shapes (animals, flowers leaves, snowflakes, geometric shapes and figures, music notes). Color sorting was conducted using a variety of colored pieces of paper cut in squares. Multi modal stimulation was carried out using objects with distinct smells (cloves, perfume, cinnamon, vanilla, nail polish remover). Old songs that were familiar to the participants were selected for singing; these included Christmas songs. Visual and aural cues were used to stimulate, recall, and provoke conversation, as well as experience tactile and visual, and aural sensation. These included greeting cards, colored pictures, an artificial Christmas tree, Christmas bells, flowers, stuffed toys and a decorated hat. Some of the data collection was carried out around Christmas time and it provided opportunities for the facilitator to use cues related to this traditional celebration.

<u>Presentation of activities</u>

The activities sessions lasted for 30 minutes to an hour. As suggested by Rader and Tornquist (1995), and Zgola (1987), activities were presented at a level in accordance with participants' abilities, adapted to reduce participants' chances of failure, and making them feel useful and productive. There are limited activities available to the residents in long term care and any opportunity for meaningful engagement may constitute usefulness. When introducing the activity, the facilitator provided a tentative directive rather than offering an option, for example, "I thought maybe we could draw...". This was followed by visual cue, a picture or object, or a tactile cue. The facilitator provided one-step instructions for the activity and arranged steps in a logical sequence.

Participants' attention was drawn towards sensory experiences, such as smell or texture related to the activity. For example, when one participant touched the facilitator's sweater, the facilitator asked, "...feels fuzzy, doesn't it?" The facilitator demonstrated in simple steps how the activity could be carried out and encouraged further involvement by asking participants to help her with a particular activity. The facilitator did the steps or tasks that proved too difficult for participants. The facilitator took maximum advantage of participants' remaining abilities by providing assistance only as much as needed. The facilitator gave positive verbal and gestural reinforcement to participants regularly.

Activities were presented to the group in a manner conducive to social interaction. The facilitator of the activities provided opportunities for participants in a group to talk and engage with other participants. Long-term memory was tapped to initiate verbal interactions with participants. Activities were approached in a broad sense and did not concentrate exclusively on just the tasks or functions of art activity (Rader & Tornquist, 1995). Accompanying the activities were shared moments and personal encounters such as eye contact, exchange of greetings, shared laughter, and talking. These shared interactions were considered in conjunction with, and as part of, the activities.

Ethical concerns

This study was approved by the Agriculture, Forestry, and Home Economics (AFHE) Research Ethics Board, and the care facility's Research and Ethics Committee. Participants for this study were deemed unable to provide informed consent for participation due to their affliction with dementia. However, all participants were shown due respect and inclusiveness by including them in the initial screening and by seeking their tacit approval to become involved in the study. Legally authorized guardians/agents

were asked to give informed written consent for the individuals they represented. The Care coordinator at the continuing care facility was also asked to provide informed consent for including her observations as part of the data. The oral assent forms for participants, the informed consent forms for legally authorized guardians/agents, and the care coordinator can be found in Appendices 5, 4, and 7 respectively.

The legally authorized guardians/agents were assured of their right to withdraw their loved one from the study at any time. The legally authorized guardians/agents were also assured of the right of the participants to stop the videotaping at any time if it made them uncomfortable (no requests to stop videotaping were made). Data and the transcripts generated during arts activities sessions remained confidential at all times. Assurance was provided that transcribed data would be coded in order to maintain as much confidentiality as possible. Any identifying details would be removed from the transcripts. The data and transcripts were only to be shared with the supervisory committee, and the videotapes would not be released to anyone but the thesis committee for discussion purposes.

Videotaping can be intrusive. The legally authorized guardians/agents were informed that being videotaped would involve a loss of privacy and anonymity because the participants' images and voices would be recorded on videotape. It was not desirable to blank out participants' faces because facial expressions were an important dimension of the interaction. Therefore, permission for use of participants' images and faces in presenting the research results was specifically obtained on the consent form. All legally authorized guardians/agents agreed to the use of the tapes that showed their loved ones.

It was understood that the artwork completed by the participants during the arts activities sessions would be the property of the participants and their guardians. However, for presentation and dissemination purposes, consent was obtained for the artwork to be exhibited by the researcher and photographs of the artwork to be used in the thesis and subsequent presentations. To give credit to the participants, consent was obtained for the names of the participants to be displayed along with their artwork.

<u>Data collection</u>

The goal of this study was to describe naturally occurring behaviors and interaction of elderly people with dementia during arts-based activities. Twelve participants were videotaped in four groups as a facilitator engaged them in art making activities. Four groups of 2-3 people were videotaped three times each, during art activities sessions, producing a total of 8 hours of videotape. Secondary data sources comprised of observations and reflections of the group facilitator, the care coordinator of the care facility, and the researcher. Contextual data were collected using residents' medical files, and through interviews with the participants and their family members, about residents' personal history and socio-cultural background.

Data collection commenced following the Faculty of Agriculture, Forestry, and Home Economics Human Research Ethics Board's approval of the research proposal, the approval for the study from care facility, recruitment of participants and obtaining informed consent from guardians. Data collection occurred over a period of one and a half months from December 2003 to January 2004. Data collection was delayed from the initial schedule by two months due to an outbreak of flu at the care facility. Data collection began when the management gave clearance at the end of the flu episode in

December 2003. The repercussions of the flu are considered as a limitation of working with a vulnerable population. Three participants were severely affected by the flu and their condition deteriorated to the extent of not being able to participate in the study.

As is integral to qualitative observation research, multiple sources and kinds of data were collected (Morse & Richards, 2002). The primary data included videotaping of the arts activity sessions. Secondary data sources included field notes and memos from participant observations of the residents' sessions with the recreation therapist, contextual data from the family members of the participants, reflections and observations of the group facilitator and the researcher. The Care Coordinator wrote her observations in a letter (Appendix E). The Care-Coordinator was asked to provide an informed consent (Appendix F) and her letter was used as data. Multiple data sources of observation were used as a strategy to develop the most comprehensive picture of the behaviors and interactions engagement. The assumption was that the strength of one approach, such as videotaping, would compensate for the limitations of another approach, such as observation, and improve the quality of the collected data (Morse & Richards, 2002). The video data illuminated some aspects about the behavior and interaction of individuals with dementia in engagement with arts activities during the session (Bottorff, 1994) whereas observations helped address questions about the context of behavior and interaction in light of participants' daily routine and behavior in the facility. Aspects of behaviors and interactions that necessitated videotaping included their short duration, the need for a detailed description and the need for multiple viewing. Multiple videotaped sessions also helped record the changing participants' behavior from one day to another and enabled the distinction between idiosyncratic behavior and behavior in response to

the facilitator in the context of arts activities sessions. The change in behavior from one session to another led to exploration of multiple factors in residents' daily routine that had a bearing on their performance during art making sessions. The differences in residents' behaviors were estimated based on observations during the sessions and personal history and information provided by the caregivers.

Participant observation

Participant observations were a critical and legitimate compliment to this research, and provided a richer picture of the area of study (Mace, 1993). Observation was used overcome the absence of contextual data beyond what was videotape recorded (Bottorff, 1994). In qualitative inquiry, observational techniques differ in the visibility and involvement of the researcher in the setting (Morse & Richards, 2002). In the capacity of a non-participant observer, four visits were spent shadowing the recreation therapist on her routine group sessions with residents at care facility, in order to understand residents' normal level of activities, their responses, and recreation therapist's strategies for engaging them in craft making, story telling, reading and exercise. Field notes were written following these visits, as well as methodological and theoretical memos to guide the subsequent analysis. These observations and memos were used for comparison purposes, to interpret video data and to plan the group sessions. The group facilitator, as a participant observer, was involved in the setting and with the participants, and wrote her observations and reflections later when she was out of the setting.

As can be seen in Table 1 (following page), a total of 8 hours of video data were collected with 12 participants, and four groups, in 12 art-making activity sessions. Another 8 hours of video data were collected using the stationary video camera

Table 1

Summary of Group Participants and Duration of Taped Arts Activity Sessions

Groups	Participants	Session	Duration of Activity session in minutes	People Entering the Activity Area During Session
A	R9 R14 R19 R20	1	32	Staff
	R9 R14 R19	2	51	
	R9 R19	3	29	Staff, resident
B	R1 R12 R18	1	30	
	R1 R12 R18	2	43	Staff
	R1 R12 R18	3	40	
D	R4 R6 R11	1	44	
	R4 R6 R11	2	51	Staff
	R4 R6 R11	3	55	
E	R21 R22	1	30	
	R21	2	36	
	R21 R1	3	38	
Total Groups: 4	Total Participants: 12	Total Sessions: 12	Total Time: 7 hours, 59 minutes	

R= Resident

Together, the two cameras yielded a total of 16 hours of video data. Non-research participants, staff members, entered the videotaped session four times, sometimes to bring a participant in, or to take a participant to the washroom, or sometimes, to give medication to a participant. At these times, the group facilitator stopped and waited for staff to leave, and then resumed the activities. The hand held roving video camera, Cannon ZR 40, was focused away from the staff at these times. However, the stationary camera captured some clips with staff visible in them. Staff activities at these times were not used in the analysis, as they were of a short duration, and not pertinent to the study. Moreover, staff consents were not obtained in order to include them as participants in the study.

<u>Videotaping</u>

Two video cameras were used to videotape the sessions, to keep all participants in view, and provide supplementary footage of behaviors and interactions from different angles. On the morning of the session, the first stationary video camera was set up, which was mounted on a tripod for recording in the screened off lounge. The facilitator for arts activities set out the art materials. Staff members were given the names of the participants in advance so that they could prepare participants for the activity session. Usually, the staff members at the nursing station were approached to bring the participants in, but sometimes, participants were found sitting in the dining room, and approached directly. Participants were walked down to the lounge and sat around a curved table. Dowling (1995) suggested that the use of a round table facilitates the process of communication during art making.

The facilitator initiated the session and the roving video camera was taken up to start videotaping the proceedings. Occasionally, there was some delay in switching or moving the roving camera to obtain a required view and, therefore some data were lost. The loss in data were compensated for by the presence of the stationary camera, which was turned on to record a few minutes before the session and which recorded constantly until a few minutes after the session ended. It was suggested by Bottoroff (1994) that preparation of the locale, as in pre-placing the recording equipment is an essential component for capturing the whole event.

Participant reactivity

Paterson (1994) describes reactivity as the response of the researcher and the research participants to each other during the research process. Reactivity takes into consideration the effect of both the participant and the researcher on the construction and collection of data. In the present study, reactivity was viewed from multiple perspectives. At the onset of research, I was unfamiliar with the setting at care facility, and reticent about approaching the staff and residents. Reflecting upon my entry in the field, I attributed this reservation to strangeness with the setting and consciousness that my appearance and race was different from that of the residents'. This reactivity effect lessened, as I made more visits to the facility and became familiar with the setting after talking with some staff members, the care coordinator, and the recreation therapist, and writing my experiences and observations. Reactivity is an intrinsic feature of the researcher's perspective and needs to be acknowledged in order to achieve neutrality in conducting the study.

Participants' reaction towards the researcher and the group facilitator remained the same from the initial stage of entry until the end of data collection. These were characterized as open, sometimes curious, or confused. This unvarying reaction was attributed to participants' decline in cognitive abilities and therefore their inability to make a complete connection with people they came in contact with. They responded at times, with uncertainty and at other times with openness. Participants' uncertainty was resolved by making introductions, exchanging greetings, and reminding them of the purpose of the session.

The participants' reactions to videotape recording was negligible. Participants' behavior in the presence of video cameras was observed to be unaffected compared with their usual behavior. During the arts activity session the group facilitator drew participants' attention to the videotaping. For the purpose of participants' understanding, she explained that the camera was received by the researcher as a present and being tried out. Sometimes, at the group facilitator's request, participants were allowed to look through the lens to see how the camera operated. As the sessions progressed, most of the time, participants paid little attention to the videotaping. Occasionally the participants took notice of the researcher moving with the camera around the lounge. Participants looked only for a few seconds; they either smiled, or looked with no particular expression on their face. Their smiles were returned, and sometimes position changed to remove the distraction. Occasionally, a staff member entered the activity session to help a participant with a physical need, such as going to the washroom or to give medication. When this occurred usually the session was stopped until the staff member left.

Secondary data collection included writing post activity field notes. The researcher and the facilitator of the art making activities each wrote field notes following the sessions. These notes and memos were used to record observations and reactions to field contacts, participant contacts, reflections on the arts activities, participant affect, as well as observations about the context of videotaped interactions. The field notes written following the session were combined later with the data from the videotapes to ensure that important events associated with the session and camera-hidden activity were noted.

Field notes provide a way to distance the researcher from his/her preconceptions and look at the context and participant behaviors associated with the activity sessions in a more neutral manner. Although some discussion took place between the facilitator and researcher after the sessions, those discussions were focused on practical issues and preparations for the next activity session, and normally avoided discussions of individual observations and reflections that were more appropriately recorded in the field notes in order to maintain objectivity in writing reflections and analyzing the videotaped data.

<u>Data preparation: transcription for analysis</u>

For each of the twelve arts activity sessions, video data were transcribed using pencil and paper, and a detailed description of the observed behaviors and interactions were written (See Appendix G). Initially all videotaped data were logged in detail. All verbal and non-verbal behaviors and interactions were transcribed and described by time code. Following initial logging, transcription of verbatim conversation occurred as interactions were identified as relevant and interesting and were audible. Para-speech characteristics such as repetitions, incoherent or incomplete utterances were included. Body positions were described to indicate disengagement or disorientation of the

participants. Description included direct quotes from the facilitator and participants as well as pauses in the dialogue.

Analysis procedure

Once video data were described in detail, coding commenced. Following the comprehensive description of the behaviors (Eibl-Eibesfledt, 1989), coding was carried out to categorize behaviors and interaction patterns. The analysis of video data began in an unstructured fashion to identify specific recurring behavioral patterns as units from the flow of behaviors observed (Morse & Bottorff, 1990). Videotapes were observed to identify participants' response to facilitator's initiatives and strategies for engaging them in arts activities. Episodes of engagement and disengagement were identified, and within each episode, facilitator's contact with the participants for the purpose of engagement (i.e. to initiate contact, to overcome uncertainty and fear, to assist in activities or to provide encouragement) were analyzed and described. The types of activities used (i.e. drawing, painting, collage, sorting, and singing) were identified and observations regarding the pattern and purpose of interaction were noted. Each video recording was played repeatedly and watched, listened to, and asked questions of, the recorded events to identify patterns (Bottorf & Varcoe, 1995).

Both open coding, and some in vivo coding (a text selection in the transcripts was used to code it) was used. Initially, everything was coded, and through constant comparison and contrast the significance of each behavior emerged and contributed to the theoretical interpretation (Morse and Bottorff, 1990). Coding began with different types, including topical coding (for example, singing and reminiscing), descriptive coding (for example, humor), Open coding and in vivo coding (for example, "I don't know") to

identify and tentatively name the conceptual categories into which the observed behaviors and interactions were grouped. Codes were compared, contrasted and merged to create descriptive, multi-dimensional categories, which formed a preliminary framework for analysis. These categories were modified or replaced during subsequent stages of analysis. For example, some of the initial categories included attempting to engage participants, multi sensory stimulation, expressing appreciation, and non-verbal engagement. These were later modified to categories like setting the scene, anchoring, co-creating and overcoming resistance.

The next stage of analysis involved re-examination of the categories to determine how they were linked, evolving into theoretical coding, which is how the main themes and relationships developed. Once a comprehensive and explicit description and coding of distinct behaviors of individuals with dementia engaged in the art making activities was created, observations interpreting the behaviors of the participants and the facilitator were suggested. As coding analysis proceeded, it became clear that the nature of the interactions was best captured by the notion of phases of interaction; within each phase, specific interactional strategies were used to initiate and promote the phase and to move onto the next phase. As the data collection an analysis continued, and as the research question that guided the study was reflected on, it was modified. Initially, there was an interested, rather globally about how art activity could be used as a vehicle for promoting interaction. This became progressively defined as an exploration and description of the individual and groups phases of the art-making interaction and the interpersonal communication strategies the facilitator used to foster meaningful engagement, and lastly, the residents response to those attempts.

<u>Rigor</u>

Rigor, or the reliability and validity of the study is used to make evaluations of the worthiness, strengths and limitations of the study and help potential users determine if the findings are credible and useful (Morse, Barrett, Mayan, Olson & Spiers, 2002). The approach to ensuring rigor for this study was verification as described by all those people. Verification refers to inherent or built-in strategies in qualitative inquiry that cumulatively ensure reliability and validity by self-correcting problems or threats to rigor during the conduct of the inquiry (Mayan, 2001). Some of the strategies that ensured rigor through the conduct of the study are described as follows:

<u>Researcher's responsiveness</u>

Researcher's responsiveness refers to the researcher's creativity, sensitivity flexibility and skill during data collection and analysis. It is important and evident of adaptation of the methods being used to the type of data being generated, and vice versa. In regards to responsiveness, the initial sampling decisions were purposive; they were made on the basis of choosing the best instances of an event (Morse & Richards, 2002), that is, the ability of participants to reveal the greatest array of interactions through maximum participation in art making activities. Data collection and analysis took place concurrently (Mayan, 2001), resulting in the formulation of inferences and questions that forced further purposive sampling. To maintain the inductive process of inquiry during progressive stages of analysis, categories that evolved as a result of comparing, contrasting and merging the codes, were modified or sometimes replaced to support the data.

Methodological coherence

Methodological coherence requires the research question to match the method, which matches the data and the analysis procedures (Mayan, 2001). To achieve methodological coherence, the components of inquiry were structured around qualitative ethology. The process of data collection and data analysis was not linear, but cyclical; methods were modified to include other sources of data, and sampling was expanded to include more participants. Multiple sources of data were used to develop a comprehensive picture of the behaviors and interactions engagement, and to use the strength of one approach to compensate for the limitations of another approach, thus improving the quality of data.

Active analytical stance

To keep an active analytical stance, I continually reflected back over what I had already learned and engaged in dialogue with an experienced qualitative researcher, asking questions about the data, and subsequent analysis throughout the conduct of study. Data were collected and analyzed concurrently, which formed a mutual interaction between what was known and what needed to be known. From the review of the literature information was attained on the previously reported studies of art making with individuals with dementia, and that information was recognized and acknowledged whenever discovered in the study through the inductive process of inquiry. Post arts activity session field notes, reviews and reflections, and description and analysis were written. The group facilitator wrote her reflections separately. After some analysis, it was discussed with the qualitative researcher, thereby helping recognize assumptions I was making, as well as helping to improve the clarity and logic of my decisions. Subsequent

analysis was carried out and discussed with the qualitative researcher and the facilitator in a group meeting. Thinking theoretically required constantly checking and rechecking the data collection and analysis procedures, and building a solid methodological foundation. Together, all of these verification strategies incrementally and interactively contribute to and build reliability and validity, thus ensuring rigor (Morse, Barrett, Mayan, Olson & Spiers, 2002).

Chapter 4

Results

In this chapter, the results related to the arts activities, the phases of interaction, and behaviors of the facilitator and participants are presented in two sections. The first section describes the setting by providing some general insights about it, its physical layout, the daily schedule of residents, and routine staff-patient interactions. This section establishes the context for the analysis of behaviors, and phases of interaction during arts activities sessions by identifying the normal resident and staff routines at the study site. The second section describes the communicative contexts of arts activity sessions that create the potential for fostering the interpersonal social environment. How the group facilitator used arts activities to engage the participants and to create a social milieu in which they interact with each other will be described.

<u>The physical and the care environment of the facility</u>

The continuing care facility houses 225 residents. There are approximately 75 residents with moderate to late stage dementia predominantly of the Alzheimer's type on the dementia care unit. The team of staff members attending to the residents' needs include 8 Personal Care Attendants, 1 Licensed Practical Nurse, 1 Registered Nurse, 2 Recreation Therapists, 1 Unit Clerk, and the Care Coordinator. Support staff includes a Physical Therapist and an Occupational Therapist who are shared by all the floors. The Care Coordinator is a resident advocate, who supervises the day-to-day nursing needs of residents in addition to overseeing staffing requirements. The care coordinator liaises

with families and all departments in the facility as part of an interdisciplinary team in ensuring the needs of the residents are met.

The average age of the residents at the care facility is 88 years. There are more females than males and most have lived their lives in Canada. Most of the women come from a generation of homemakers and often engaged in typical household chores. There are also residents who, although their adult lives have been spent in Canada, originally belonged to a different culture and had mother language other than English. Perhaps as a result of dementia, these residents sometimes tend to revert to communicating dominantly in their mother language, for example Dutch, Vietnamese, or French.

Floor plan and space utilization

The main hub of activity on the third floor is a central area comprising the nursing station, dining area and the elevators (See Figure 1 on following page). Three long corridors branch out of the central area and end in locked fire exit doors. Located along three corridors are the residents' rooms, and towards the middle, each corridor has an open lounge area. Because there is no area purposefully designed for arts or creative activities, one of these lounges was used for holding the arts activity sessions for the study. The floors are linoleum and windows have curtains in soft colors with no patterns. The display of pictures on the walls is sporadic and inconsistent. Each of the three corridors is painted in a different color, pink, blue and yellow.

The dining room area is occupied by a good number of residents and staff at most times. Staff members provide care and assistance in feeding residents who are unable to sit up or feed themselves. Residents are assigned tables in the dining room with their names written to mark the spot on a table of four. Residents sit in their designated seats
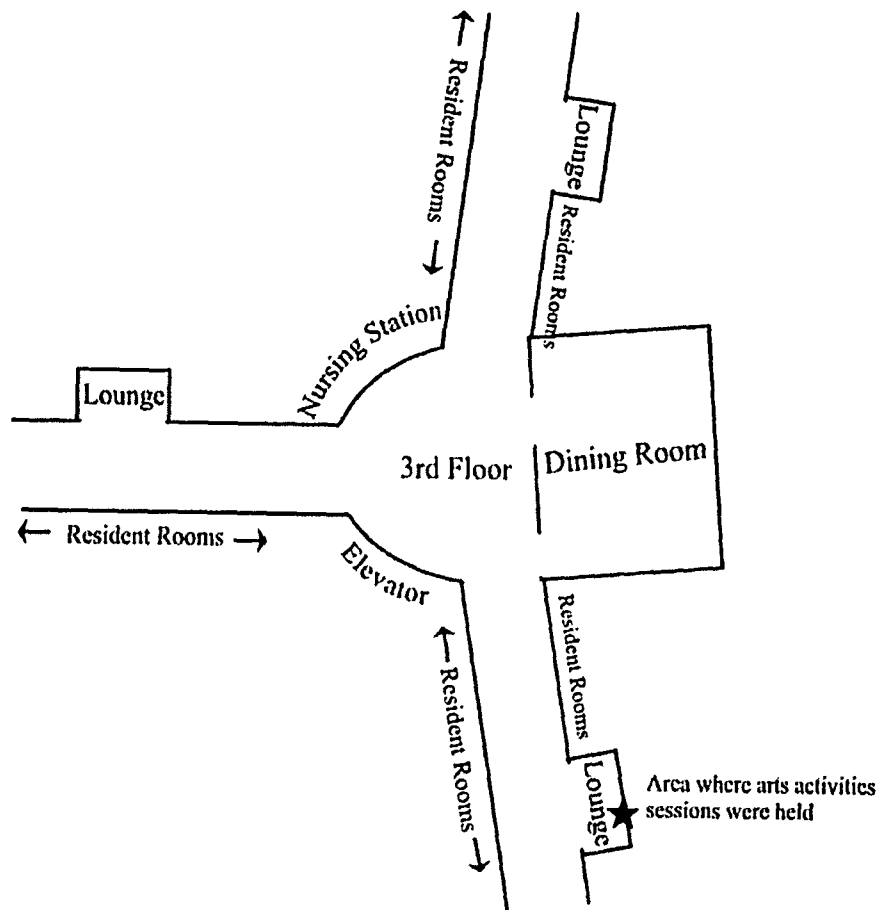
Figure 1. Floor plan of dementia care unit at the continuing care facility

for all the meal times, and at any other time they chose to sit in the dining room. Many residents sit in the dining room at other than the meal times. Some of these individuals are alert, and watch the activity in and around the nursing station, others sit dazed but awake and some are drowsy or sleeping. Interaction between the residents sitting in the dining room is almost non-existent. Most are dressed in street clothes while others are in pajamas. Some residents have visitors and some have none. Some stay in their rooms all day, and there are those who are in bed for the whole day. Some of the residents' rooms have personal memorabilia, while others are bare.

The floor's visiting area is located in one small quiet room. Residents' rooms, the dining room, or each of the three lounges are used for visiting with families and friends. The three lounge spaces are open, have no privacy, and serve more than one purpose. The lounges are used for holding recreation sessions, family meetings, for eating, watching television, listening to radio or music. One small room on the floor that could be used by families and friends for meeting their loved one is seldom utilized. This room is dark because it has a small window and does not receive much natural light, and, it cannot accommodate a group of people. Additionally, the majority of residents' rooms are double occupancy and do not offer much privacy. As reported by Chapman and Otfinowski (2001), family members of the residents communicated their desire for comfort and enhancement of the space to make it more homelike.

The ambience on the third floor correlates with its physical setting. Residents were seen wandering aimlessly in the corridors, and milling around the nursing station. They wandered, slowly and quietly or sometimes in an agitated manner, in wheel chairs or on foot, holding the rails on the walls or with the help of walkers. Wandering is often

characterized by gait problems including swaying, unsteady gait, short steps, shuffling, not swinging the arms, and difficulty making turns. There were a few residents who showed evidence of distress, and were isolated from the rest, and sat in the corridor. Some residents were too ill to sit up, and required close observation, so they were lying in beds alongside the nursing station.

<u>Daily routine of residents</u>

The care facility maintains a predictable daily routine for residents. Activities are scheduled between the three meal times. These include sessions with the recreation therapist to engage in craft making, exercising, group talking, reading, singing, and games. In addition to keeping activities short, simple and upbeat, the recreation therapist offers lots of choices. Two or three activities were offered simultaneously that residents could choose to engage in. Other activities include physical therapy with the physical therapist; personal grooming and hairstyling at the salon on the first floor; outings, and occasional performances by visiting musicians or singers. Residents enjoy participating in the music and singing, and sometimes sing along or dance a little during these performances. Residents did not always follow the schedule of activities or were unable to do so. Wandering is a common behavior adopted by some of the residents.

Residents can receive visitors at any time of the day. Family and friends of the residents stayed connected with their loved ones by visiting them and sending them cards and presents. Family and friends of the residents adopt different patterns of visiting. Some family members make daily visits. They read and talk, take residents out, sit with them through one or more of their routine daily tasks and help with personal grooming. Others visit weekly or monthly and a few visit only on special occasions. There are some

relatives who do not visit, because they are living in a different city, or their own health is compromised in some way. Some residents never married and have no close family to visit them. A small group of residents benefit from paid companions, which is staff from private healthcare firms who spend time socializing with the residents on a limited basis.

<u>Resident and staff interactions</u>

Most residents share rooms with other residents but little interaction takes place between them. This pattern continues as residents sit for meals, or wander in the corridors. Staff interactions with residents are mostly focused on accomplishing activities of daily living and other routine tasks, for example, bathing, dressing, toileting, feeding, giving medication, laundry and cleaning. According to the Care coordinator:

> Resources in Long Term care ensure that the basic personal physical needs are met. Staff have time to bathe, feed, and toilet our residents. Spiritual and recreational needs are met to the best of the ability of a small number of staff. One-to-one interaction is usually given only during the personal care. Social needs are delivered usually in large groups. The opportunity afforded by the project to engage persons in a very small intimate group is rare in our setting. While we rely on family and friends of the residents to nurture, we recognize many residents may not have visitors even on a weekly basis. Often times where the relationships exist, the quality of the interaction is lacking. Family or friends may not be prepared intellectually or emotionally to nurture in meaningful ways.

The second section of results describes the phases of interaction that constituted the main themes evident in the art making sessions. These phases were first in the hierarchy of behavioral patterns that constituted additional types and instances of

behavioral patterns. Recognition and description of these patterns is critical to understanding the interpersonal and social environment of the individuals with dementia.

Phases of Interaction

Before describing the interactional strategies used by the Facilitator to promote engagement, and the responses by the participants, the basic phases of the interactions will be described that occurred in the arts session and which formed the context for the facilitator's attempts to foster meaningful engagement with the residents. Four main phases of interaction were evident within each arts activity group. The first phase was setting the scene, second phase was anchoring, third phase was co- creating, and fourth phase was overcoming resistance. In addition to these phases, at times, contextual and environmental factors needed to be dealt with. These phases were distinct and to start with, happened in a sequence. Interaction phases were in action as a group, but also for each individual person. As a group, the facilitator tried to use these phases to make participants comfortable within the group, to introduce and engage them in the activity but on an individual level she went back to any one of these phases, to reorientate or reengage the individual person.

The facilitator started off by setting the scene. The goal of setting the scene was to make a connection with participants by engaging, and making them comfortable in the setting. The group facilitator did this by fostering ordinary rituals, and using strategies of normal social conversation, such as talking about the weather, special occasions, Christmas, reminiscences. The facilitator used conventional social habits that we have all learned throughout our life times, to tap into participants' long-term memory.

In the second phase the facilitator anchored the activity. When she was anchoring

the activity she was introducing the activity, but also trying to understand each participant's perceptual thinking, abstract thinking, abilities, and preferences. This information was then used to tailor the activity for the rest of the session and subsequent sessions.

Once participants were comfortable in the setting and the facilitator had initiated an activity, the third phase of co-creating started. Although the group facilitator and the participants were co-creating, there were some participants who resisted being engaged. Participants who would co-create for a while would get disengaged and the group facilitator returned to the stage of introducing the topic, anchoring, and engaging them. As a result of the participants entering a phase different than the facilitator, these phases followed a circular path more often than a linear one. The movement of participants and the facilitator in different phases produced two levels of analysis: the level of the group as a whole, and where in this process each respondent was located.

Phase one: setting the scene

The goal of setting the scene was to make a connection with the participants and make them comfortable in the setting. The interaction was focused on the facilitator building a rapport by *fostering ordinary rituals* of interactions, for example, greetings and introductions, and inviting participants to join the activity. This could happen either during or prior to the arts activity session. The group facilitator and the researcher greeted and introduced themselves to the participants and invited them to participate in the arts activity session. Participants were offered smiles, touched gently on the arm, and *attended to participants' physical needs* by offering help to either walk or wheel them to the lounge. The participants usually responded with a smile, a long look, and a hand

reaching out to accept help. The walk to the lounge provided opportunity for making *normal social conversation* with the participants, and start building a connection with them. In subsequent sessions with the same group, contact was initiated keeping a provision for a loss in participants' short-term memory. The facilitator repeated the introductions and started out setting the scene again.

The facilitator *established connections* with the participants using multiple strategies (see Table 2 on the following pages). To put the participants at ease in the setting and with each other, she started with introducing group members to one another and making normal social conversation. The facilitator talked with participants about their meals, hairdos, weather, clothes, and general well-being. For example, a typical exchange proceeded as follows:

F to R4: "Hi R4." (I am walking R4 in to the session, holding his arm)

R4 to F: "Hi." (He keeps walking and looks at F; his face has no particular expression).

F to R4: "How are you doing?"

R4 to F: "Good, really good."

I help R4 sit in his chair, and position it close to the table.

F gets up to fetch something and at the same time asks R4: "So, you're doing really good?"

R4 to F: "So far, yeah." (He keeps looking at F).

At another time, the facilitator showed the colors of the paint to one of the participants and made a comparison of the color with the color of his shirt:

Table 2

Phases of interaction observed during the art making sessions

Phases	Strategies	Micro Strategies	Challenges for the facilitator
Setting the scene	Fostering ordinary rituals Attending to participants' physical needs Normal social conversation Establish contact Establishing connections Picking up on cues provided by participants Humor and Playfulness Reminiscence	Greetings Eating Comforting touch Helping sitting down Talking Singing Visual, aural, tactile cues	Participants' inability for meaningful verbal communication Participant chooses not to connect Participant connects but passively Participant's response is non-committal Participant responds with negative comments Extraneous disturbances (e.g. fire alarms, television noises, loud conversations)
Anchoring the activity	Introducing the activity Engaging participants Keeping the activity going Positive reinforcement Using multi-sensory stimulation Demonstrating the use of tools Playfulness	Verbal cues Visual cues Helping with the activity Physical touch Playful talk	Participants' disinterest Excuses made by participants Tentative engagement Participants' lack of confidence Participant's inability for meaningful verbal communication Extraneous disturbances

Co-creating the activity	Facilitator asking participants for help Demonstrating the use of tools Initiating the activity and inviting participants to follow Doing the activity with participant Providing verbal and visual cues Giving positive feedback	Invitation to participate Telling a story	Facilitator unable to engage participants Participants engage passively Participants fall asleep
Overcoming resistance from the participants to get engaged	Making a connection Using verbal and visual cues Encouragement	Periodic prompting Getting participants' attention Making eye contact Assistance Reassuring touch	Apparent disinterest Participants' sleeping or going through periods of inattentiveness Participant making excuses
Overcoming contextual and environmental distractions	Refocusing participants' attention Stopping the activity momentarily Circumventing previous problems Attending to participants' physical needs	Getting participants' attention Making eye contact Making conversation Providing assistance	Staff intrusions Visitors and staff noises in the corridor Self engagement Physical needs of participants Participant walking away from the activity

F to R4: "Look, this makes orange; this makes green...and this makes yellow, just like your shirt." (F makes brush strokes in different colors on R4s sheet. R4 looks at the sheet of paper).

R4 to F: "Yeah, just like my shirt." (R4 briefly looks up at F and then down at the sheet).

In some sessions, a routine event of life became the focus of *social conversation* between the facilitator and the participant. In this example, the facilitator took the opportunity to talk about the participant's recent haircut. The participant in turn was pleased with the attention she received, which was evident in her smiling face. For example:

The Care Coordinator is walking R12 in to the session. As they enter, F turns around to look at them. F notices hair styling rollers in R12s hair:

F to R12 (looking at her hair and exclaiming): "Look at you!"

R12 to F: "Hello." (R12 stops walking, looks at F, and smiles).

F to R12: "I'm getting my haircut today too!" (F is standing and talking to R12).

R12 to F: "Well, I had mine cut already." (R12 is still looking F in the face and standing).

Weather was a common topic touched on by the facilitator in many encounters. In this example, one of the participants touched some artificial flowers inside a pot that was kept on the table in front of them. The facilitator *picked up on the cue* and talked to her about how she could not bring real flowers because of the freezing cold outside. One of the participants agreed. For example:

F has just walked R14 in to the session, and helped her sit in her chair. R14 looks

at the flowerpot kept on the table in front of her, and reaches out to touch it with her hand:

R14: "They're pretty eh?"

F to R14: "Aren't they pretty?" (F is now helping R9 sit in her chair).

R14 to F: "They're artificial but they're lovely."

R9: "Are they artificial?" (She looks and touches the flowers before she sits in the chair).

R9: "They sure are. I thought they were real." (R9 has sat down, and looks at the flowers).

F to R19 and R14: "I was going to bring some real ones, but it's too cold outside; flowers would get frozen you know." (F pushes R9s seat closer to the table).

R9: "Yeah, they would freeze." (She is still looking at the flowers).

The facilitator tried to *establish contact* using themes that participants could use for art making. Around Christmas time, she brought cookies baked in Christmas tree shapes to share with participants, and sang Christmas songs, with hand clapping to add rhythm to the song. Participants connected with most of the selected traditional songs using their long-term memory. The facilitator encouraged further participation with encouraging remarks such as:

F: "Hey, we could be a choir!"

Sometimes, participants connected well with the facilitator and responded by singing along or talking but tended to get disengaged after a while. And sometimes there were participants that had not made a connection with the facilitator at all. In such instances, the facilitator tried making a connection, and periodically attempted to engage

them employing a different strategy. She made conversation, used *humor*, *reminisced*, used *playful* gestures or provided visual or aural cues (See Plate 1).

Plate 1. Facilitator using humor to set the scene.

At times, participants spoke words that made no sense. The facilitator responded to them by acknowledging their communication, but did not draw attention to the participant's inability to make sense of their words. For example, in the following exchange the facilitator tried to make a connection with the participants by inviting them to sing Christmas songs when one of the participants made a comment that lacked meaning and context:

F is singing with the group. She sings different songs. R12 looks at F as F sings, and R1 looks in front of him, at nothing specific. R18 sings along with F.

F to group: "How about Noel, Noel, Noel, Noel, Born is the King..."

R12 to F: "That's an oldie too."(R12 looks at F, her hands folded on her chest).

F looks at R12: "That's right" and sings the song. R18 starts singing with F.

F to R18: "Hey, you're good!" (F smiles and R18 and R19 laugh joyfully).

R12: "You hear it, and you watch it and you do everything else and they still they want somebody else to do something." (R12 sits with hands folded on her chest, and looking at F).

The facilitator acknowledged the participant's comment and then refocused the group's attention to the initial topic of conversation:

F looks at R12: "yeah, that's true."

F turns to look at R18 and R1: "R1 knows a few words about the jingle bells too."

Sometimes the participants' attention drifted away from the interaction and their face assumed a blank expression. At other times the object of distraction brought out excitement or curiosity in the participant. The facilitator addressed the disturbance in the session by first acknowledging it and then leading the participant's attention back to the initial focus of interaction. For example, the facilitator started a *normal conversation* about the cookies she had baked in Christmas tree shapes and brought for the participants to eat. During this conversation one of the participants got distracted. For example:

F is sitting at the table with R18 and R1. F has just given them cookies. R1 is eating his cookie; F has shown R18 how to dunk her cookie to make it softer to eat. R18 is dunking her cookie in the milk:

F turns to look at R1: "What do you think? Pretty good?"

R1 looks at F as he eats: "hmm hmm."

F to R1 and R18: "I made them". (F looks at R1 and then at R18 as she says that).

R18 looks at F: "hmm hmm. You can make more of these."

F to R18: "hmm, okay". F and R18 look at each other and laugh.

The facilitator and R1 eat the cookie. R18 looks at me moving with the camera.

R18 points her finger and asks F: "Do you see someone on the side? That girl?" The facilitator reminded the participant about the researcher's presence, explained about the video camera and then refocused the conversation as follows:

F looking at R18: Would you like to dunk that (cookie) again?"

Although, in subsequent sessions with the same group, the facilitator kept a provision for a loss in participants' short-term memory by repeating introductions and setting the scene, the activity provided a bridge, and grounded the residents to some extent. In successive encounters, sometimes in the dining room or in corridors, the residents recognized the researchers, sometimes waved and sometimes exchanged greetings. Some were well oriented in their responses, for example, one of the participants asked the facilitator, "Where's your helper today?" But most of participants, inspite of recognizing us, were uncertain why they did. Their verbal responses were in line with this confusion, and disorientation, for example, "You live here, don't you?" or, "'You must give me a call sometime", or "I haven't seen you for a long time." The care coordinator observed the same outcome, and described it as follows:

Several residents would recognize the women at some level and respond to their presence happily. To me this demonstrated how when the intellectual memory is impaired, we still have a "knowing" on other levels of our being. I truly believe the project tapped into these levels for our residents. This brought a safe peace to

them. Engaging brought out fond memories and enhanced their sense of belonging, of being important, and listened to.

<u>Phase two: anchoring the activity</u>

The second phase of interaction started when the group facilitator moved onto anchoring the activity. In this phase, the facilitator *introduced the activity* and also tried to understand each participant's perceptual thinking, abstract thinking, abilities and preferences. This information was then used to tailor the activity for the rest of the session and subsequent sessions. The phase of anchoring the activity was established by the facilitator successfully using some strategies, and also challenged by certain factors (See Table 2). For instance, the facilitator *engaged* participants in singing and at the same time attempted to assess at what level the participants engaged and enjoyed it, and whether they could remember the words to the songs. Participants were helped with verbal and visual cues when needed to *keep the activity going* and making it achievable. On completion of a task, participants were given *positive reinforcement* with appreciating comments by the facilitator, for example,

> R18 is gone to the washroom. R1 is drawing quietly. R12 sits with her hands in her lap and head turned to look at F. F is putting an artificial Christmas tree on the table and talks to R1 and R12:
>
> F to group: "Do you remember that song we were singing last time?" (F finishes putting the Christmas tree on the table and walks back to her seat in front of R12).
>
> R12 keeps looking at F and sys nothing.
>
> F looks at R1: "you R1?"
>
> R1 to F: "No." (He keeps his eyes on the sheet and continues drawing).

F to R1: "I bet you do!"

F sings: "Jingle bells, Jingle bells..." (F leans close to R1s ear. R12 watches F).

R1: "Oh ya, Jingle bells, Jingle bells..." and sings with F, stopping his drawing momentarily.

F looks at R12, moving her hand in a rhythmic manner as she sings. R12 does not sing, and keeps sitting with her hands in her lap.

F turns to look at R1: "Oh. You're good!"

Not all participants made a connection with or had a preference for the activity. The facilitator respected participants' inability to participate or desire to remain passively engaged and shifted attention to another participant who might do so. In the process of anchoring, the facilitator sometimes used *playfulness* and physical touch to anchor the participants (See Plate 2).

Plate 2. Using touch to make a connection with the participant.

The facilitator also changed her approach to persuade the participants to engage by using *multi-sensory stimulation*, including visual, tactile or aural cues. For example,

F finished an activity of color sorting with the group. F is standing in front of the group, gathering the cards from the table, and initiates the next activity by showing them Christmas cards.

F to group: "The other thing that I brought back was I got some more Christmas cards in the mail from my friends. I was looking at these and just thinking about Christmas" (F sits down on the stool).

R1 sits, his head turned to look at F, his hands on the armchair. R12 sits looking down at the table, her hands folded on her chest. R18 looks at f, hands on the table. F hands out cards to each of the participants.

F shows one card to R1: "Do you know who this guy is?"

R1: "Yeah, Santa Claus!"

F smiles, turns to look at R18: "Santa Claus! And he has a sleigh and all these reindeer..."

R18 has her own card in her hand and is looking at it quietly.

Plate 3 is a drawing inspired by the Christmas theme. It was done by R1 using colored pens, and depicts a Christmas tree and some animal forms. R1 was extremely forthcoming when the facilitator offered him different colors of pens. His description of the drawing was lively and humorous. When the facilitator pointed to one of the objects in his drawing and asked, "What's this?" He responded with a hearty laughter, saying, "It's me".
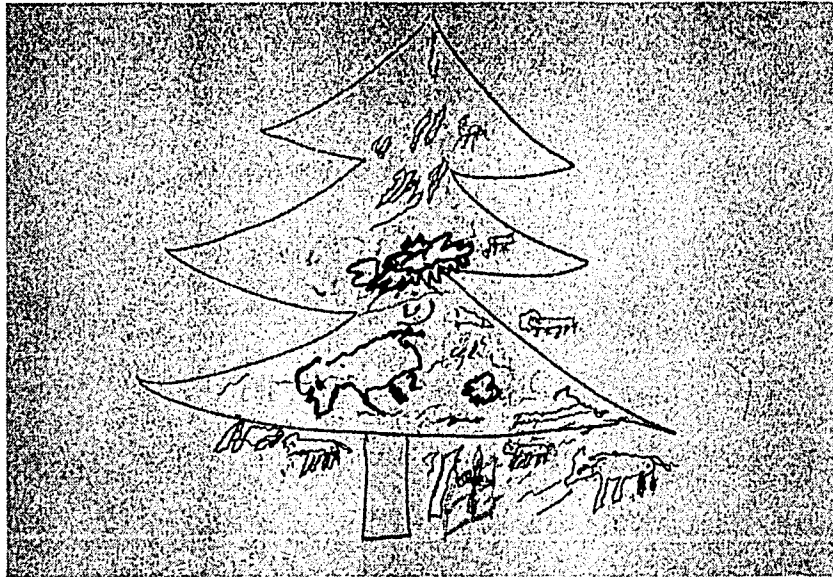
Plate 3. A drawing by R1, done in colored pens and inspired by the Christmas theme. It illustrates a Christmas tree and some animal forms.

The facilitator anchored the activity by describing and *demonstrating the use of art materials* and tools, drawing special attention to their attractive features like colors of drawing pens and paints and the possible ways these could be used for creative expression. For example,

> F is introducing the drawing activity. She puts a sheet of paper in front of each participant and takes out a bunch of pens from a bag. The group is sitting in chairs, around the table, listening and looking at F:
>
> F to group: I brought all these nice colors- blue and red and yellow, purple. You can use any one you want." (She puts the markers on the table and takes more out of the bag).
>
> Participants keep sitting and watching with no particular face expression. R1 sits

with hands on armchair. R12 has her hands folded on chest, and R18 has her hands on the table.

R18 to F: "You sure have a lot of them."

The facilitator demonstrated how the art tools are used in order to remind them. In one case, she made some pen marks on one participant's sheet and then continued to guide the participants through the drawing process as follows:

F to group: "And you can just draw with them." (F draws some lines on R1s paper).

Participants keep sitting and watching without reaching out or touching anything.

F to group: "Why don't we take the top off some of these (felt pens)? And then we can try some. What do you think?"

However, sometimes, the participants demonstrated a lack of understanding about the use of art materials. For example, when given some paint, R11 saw it as food and went to put it in her mouth. The facilitator quickly removed it from her hands, resulting in R11 being displeased leaving the session.

However, in another session, R11 was able to create with, and explore the potential of the felt pen. Plate 4 is a drawing by R11, a mix of shapes, lines and outlines. The facilitator continuously offered and encouraged R11 to work with colored pens, and when she finally picked up the pen, she was guided to make some marks and draw some shapes, lines and contours. The drawing developed into its final shape bit by bit, as the facilitator talked and drew with R11, and R11 followed her prompts and leads.
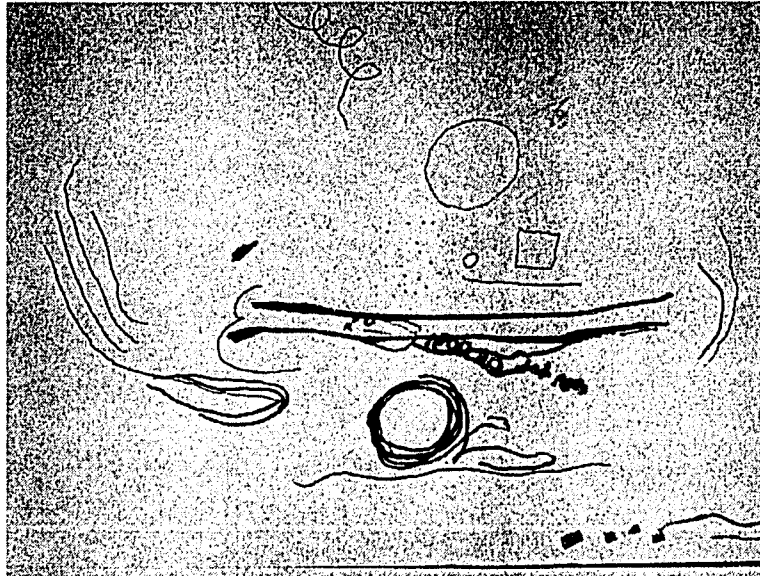
Plate 4. A drawing by R11, done in colored pens and illustrating a mix of shapes, lines and contours.

Sometimes, the facilitator was able to make a connection with a participant, but participant's interest in the activity was tentative.

F to group: "You can have any color you want. What do you figure?" (F puts a couple of pens on each participant's sheet).

R12 to F: "We've done that so often."

F to R12: "Have you? You can try again."

R18 moves forward in her chair to touch a pen. R12 picks a pen, draws a little and then leaves it, sitting back in her chair.

In the above example, the participant picks up the pen and draws on the sheet in front of her, then leaves it and sits back with hands folded on chest. The facilitator notices the participants disinterest and focuses on the other participants in the group, respecting her

choice for not deciding to draw at that time. Although participants were sometimes disinterested in the activity, interestingly they enjoyed certain moments of involvement that could be seen in their artwork. For example, in response to the facilitator's question, "Do you know what was always at the top of the tree?" R12 replied, 'A star". R12 drew, though not the star on top of the tree, but a star like object inside the tree (Plate 5).
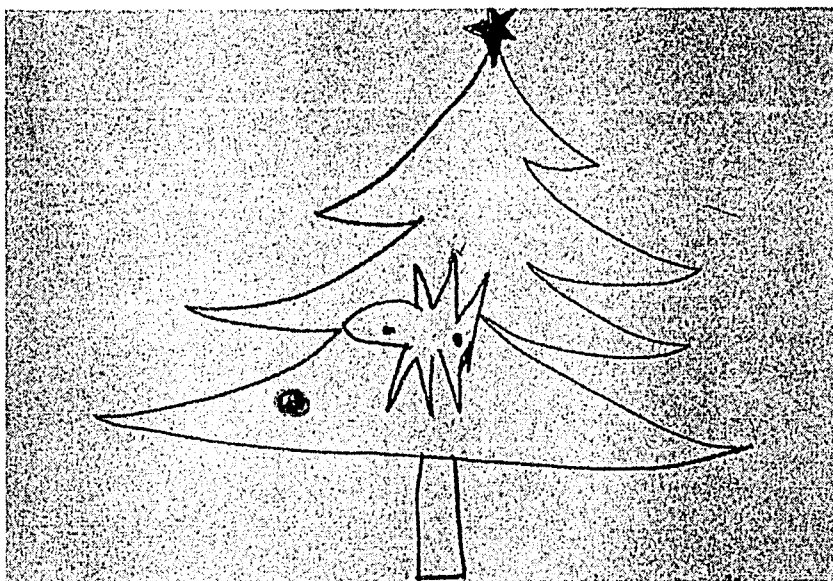
Plate 5. A drawing by R12, done in colored pens and inspired by the Christmas theme. It illustrates a star on top, and two more forms inside the Christmas tree.

In the following example, the facilitator attempted to *engage participants* to look at and imagine forms in an incomplete composition of lines and shapes drawn on paper:

F is introducing an activity of completing unfinished images. She has the papers with unfinished images in front of her. R9, R14 and R19 are sitting and looking at F.

F to group: "You know I was looking at some drawings this morning and I thought, "I can't figure out what these are." (F puts a paper with unfinished lines and forms in front of R19).

The participant did not wish to get involved in the activity and used her glasses as an excuse for not wanting to engage actively. This participant was observed using her glasses to look at flower pictures without difficulty and only used them as an excuse when the facilitator invited her to draw. For example,

R19 to F: "I can't see." (R19 touches her glasses, moving them up and down, shakes her head and licks her lips in a nervous manner).

F to R19: "Can't you? Can you put it up close?" (F leans closer to R19 and brings the paper close to R19s eyes).

R19 to F: "I've got the wrong glasses on." (She licks her lips again, and sits with her hands in her lap).

F to R19: "Where are your glasses? Are they in your room?" (F turns to talk to her).

R19 to F: "Yes, I don't want them though."

F to R19: "No? You don't wanna look?"

R19 to F: "No." (Shaking her head).

F to R19: "Okay." (Turning to look at and talk to R14 and R9).

The participant sat back in her chair and observed other participants interacting with the facilitator. She maintained her wish of not wanting to be involved by pushing away the papers that were moved her way by the facilitator and then sitting back in her chair to watch the others. However, this participant remained involved in the activity at a

passive level and without actively engaging in it. She watched other participants, and decided to comment about the activity or the group members from time to time.

The environmental distractions, which occurred randomly during all phases of anchoring an activity, and in every session, also posed challenges. They caused varying degrees of distraction to the participants, to the group facilitator, or in videotaping the session. Factors that contributed to the distractions included fire alarms ringing, announcements on the public address system, television noises, loud visitor and staff conversations in the corridor and vacuum cleaner noise. Other distractions included residents' crying, wandering residents' touching the screen, and staff entering the sessions to attend to residents' needs. If participants became distracted, the facilitator responded by diverting their attention and refocusing it back to the activity by talking to them. In times when staff entered the session to attend to a participant's need, the facilitator stopped the activity and waited for the staff to leave before resuming.

The interaction which developed between the facilitator, participants, and between participants was significant, and showed improvement. For example, residents who were sitting in the dining room disengaged, or alone in their rooms, watching television, sitting, or lying in the bed quietly, when given the opportunity to engage in arts activities, began talking, laughing, making choices, showing emotions, and being active. When given multi sensory stimulation, participants used their abilities to sing, identify smells, feel fabrics, toys, and other objects, to look at pictures, and get involved in conversations. The care coordinator's observations were akin to these:

It was an honor to facilitate the dementia research project as Care Coordinator of the dementia care unit. Throughout the project we were able to witness some

profound transformations of the residents. Residents who on a daily basis appeared "lost in their world" became animated, talking, drawing, smiling, and sharing themselves in many small yet meaningful ways.

Plate 6 shows one of the participants trying out a hat after she had looked at its decorations. She was pleased, and at the same time reminisced about wearing hats at special occasions in the past.

Plate 6. Using props for anchoring.

Phase three: co-creating the activity

Co-creating the art making activity refers to the collaborative and cooperative involvement of the facilitator with the participants with the aim of engaging in an activity. The facilitator employed strategies to engage participants in co-creating the activity, which created a bonding experience that facilitated further collaboration (See

Table 2). The facilitator often began by *asking participants for their help* in achieving a task. This approach gave participants an opportunity for active involvement in the activity and perhaps made the engagement more meaningful for them. For example, to get participants to do color sorting, they were told a story:

> The participants are sitting in their chairs, quietly looking at F and listening. R19 has her hand on her cheek, and is turning her head sideways to look at F:
>
> F to group: "You know, this morning, I was getting ready to come here and I dropped all these colors on the floor. I want them so they all belong to the same sort of group..."
>
> F holds the colored cards in her hand as she talks, and then spreads them out on the table.
>
> R14 to F: "Oh yeah." (Rubbing her chin with her hand and looking at the cards spread out on the table).
>
> F to group: " I thought maybe you could help me 'cause I can't figure out where these things go."

To maintain the phase of co-creation, the facilitator led participants to imitate her actions (See Plate 7). The facilitator *initiated the activity and invited participants to follow* her, and at the same time kept a check on participants' functional level and provided assistance and prompts accordingly.
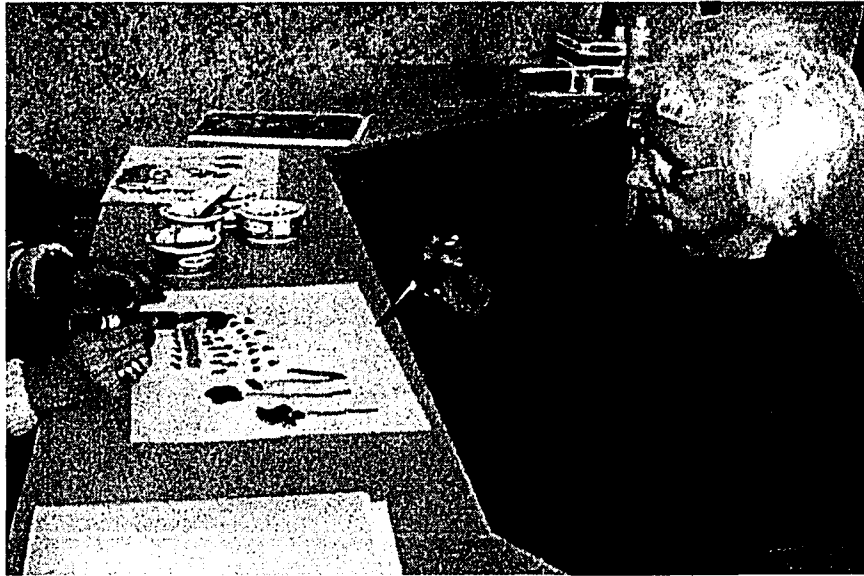
<u>Plate 7.</u> Co creating.

In the following example, the facilitator *got involved in the activity with the participant* and assisted her in sorting the colors. The participant demonstrated the capability for sorting colors, and only required help in execution. For example:

F to group: "What do you think?" (F looks at R19, who says nothing, and instead, R9 replies).

R9 to F: "Well, they'll all go with flowers." (R9 looks at the colored cards and then at F).

F to R9: "Well, that's the truth too." (F looks briefly at R9, and picks up a colored card).

F to group: "Is there any color here that sort of looks like this?"

R9 reaches out to separate a card from the pile on the table, and move it towards herself.

R9 to F: "No, but maybe this."

R14 is looking at the cards on the table with a blank expression. R19 moves forward in her chair to look at the cards and then briefly here and there.

R9 *co-created* the collage (Plate 8) with the facilitator. She enjoyed talking, and reminisced about her drawing experience in school during the conversation. R9s collage (Plate 8) is inspired by the garden and flower theme. R11 made witty remarks and stayed in high spirits through its making.

Plate 8. A collage by R9, made with colored pieces of fabric. It is inspired by the garden and flower theme.

The facilitator periodically came around to engage the participants who were not engaged in the activity. She addressed them by name, asked questions and prompted them gently in order to encourage participation. To encourage participation, *tasks were*

often simplified, accompanied by *visual and verbal cues* and closed-ended questions that could be answered with "yes" or "no". For example:
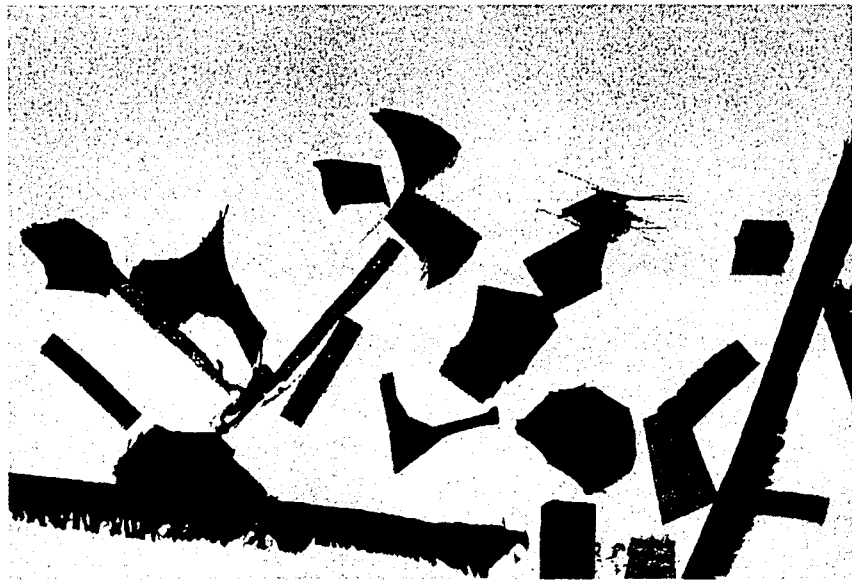
> F is still color sorting with the group.
>
> F to R19: "Is there other color that sort of looks like this one? I couldn't figure out. Can you R19?" (Facilitator looks at R19 and moves the colored paper closer to R19).
>
> R19 to F: "What's that?" (R19 moves forward in her chair, leans towards F taking a closer look at the card F is holding up in her hand).
>
> R19 to F: "Yes, that one here... just that, that blue one there." (Pointing with her arm stretched out and finger pointed in the direction of a colored paper).

The facilitator responded to successful co-creation with *positive reinforcement.* Positive reinforcement was given constantly throughout co-creating. It was an underlying strategy integral to every phase and occurred to motivate and keep participants engaged. For example:

> At the end of the sorting activity F talks to the group.
>
> F to group: "Well, thank you for helping me sort those things out. That was very nice." (Looking at R19, and then R9).
>
> R14 is falling off to sleep, leaning her head back on the chair. R19 looks down on the floor at something.
>
> R9 to F: "hmm." (Looking at F as F talks).

As the facilitator co-created with a participant, other participants in the group were sometimes disengaged. In the following example, the facilitator periodically attempted to engage a participant who was sleeping, and unable to engage (See Table 2) by using

verbal and visual cues, and *demonstrating the use of art materials*. For example,

F is sitting in front of R14, working on R4s collage that is on the table.

F to R14: "Look what I can make." (F looks at the collage and arranges some fabric shapes on it. R14, sits with her hand on her chin, and looks down at the collage).

F to R14: "Look at all my leaves and stuff."

R14 to F: "Yeah." (It is almost a whisper).

F to R14: "What do you think R14?" (F keeps her eyes at the collage).

R14 to F: "It's all right, I guess." (Looking up at F).

F to R14: "Can you make another flower there?" (F keeps looking down at the collage and working on it).

R14 says nothing but keeps looking at the sheet on which F is moving the fabric shapes around. R9 has her head bent and is busy working on her collage.

F to R14: "You can see I put this one like that. Can you make another one like this?

R14 looks at F and then the collage but says nothing.

F to R14: "What do you think?" (F looks at R14 briefly).

R14 to F: "Well, that looks nice."

In the above example, the facilitator permitted the participant to remain passively engaged (See Table 2) and shifted her focus on another participant in the group. When the participant was unable to get involved in the activity, the facilitator paused in her attempts to actively engage her and approached the same participant again later.

The facilitator also created artwork for participants who were unable to engage

physically. She brought up a topic for conversation with the participant, shared ideas on that topic, for example, flowers and butterflies, and *co-created* artwork inspired by the topic. The facilitator created the collage inspired by butterflies (Plate 9) with R6, and simultaneously, had a conversation about butterflies with her. After the collage was complete, the facilitator showed it to R6, who responded with radiant smiles that were the highlight of this interaction.
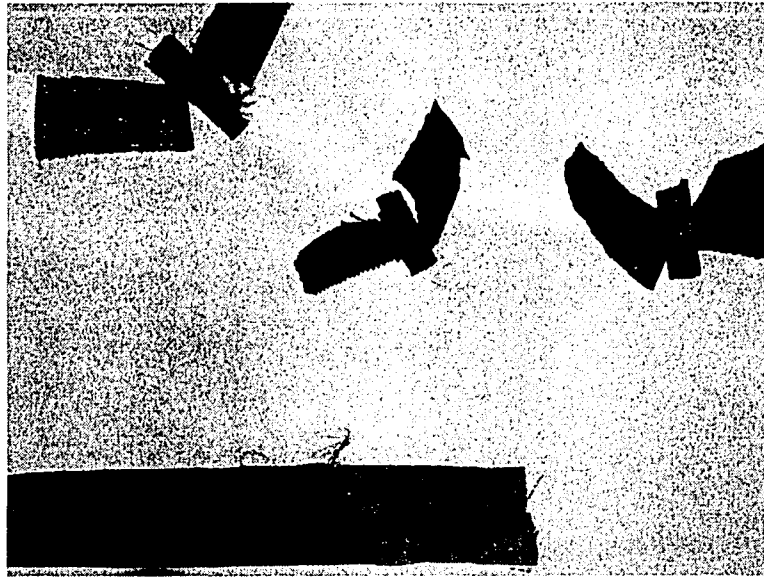
Plate 9. A collage by the facilitator, created for R6. It is inspired by butterflies and done in pieces of fabric and paper.

The interaction between the facilitator and the participants during co-creating was different from routine interactions. The facilitator and participants were involved in one-to-one interactions, which provided opportunities for a more personal understanding, connectedness, action, and empathy. Participants usually interacted with staff that were

focused on activities of daily living. General pressure of time and work created a routine whereby staff moved about the facility without seeking personal contact by the residents. Other interactions included the ones with the recreation therapists who involved the residents in games, conversation, exercise, storytelling and crafts. Recreation sessions, however, involved a bigger group of residents that did not allow for one-to-one interaction. Lack of initiative on the residents' part also restraind personal interaction during the recreation session time.

Participants' involvement in the arts activities varied with the degree of impairment, motivation and the type of activity chosen. All participants did not enjoy the same type of activity; some liked to sing, others liked to draw or paint; some simply liked to talk or watch (See Plate 10). Some were impaired to a level that did not allow them to be physically involved in the activity. Participants were not always consistent in their motivation from one session to the other; most of the time, it was their ill health on a particular day that caused a decline in their level of involvement in the activity. When the facilitator found someone not engaging, she tried either switching from one activity to another, or changing her focus from that participant to another participant. She periodically came back to try and engage the resisting participant - sometimes with little and sometimes with no success. The participants most of the time kept their positions of wanting or not wanting to engage throughout the session. The same participant sometimes behaved differently next time though. The care coordinator witnessed the engagement from her perspective as follows:

> What I witnessed with the research is the unique blend of intellect and compassion to connect and engage the residents in positive interactions. In our

efforts to witness we would be found to be eavesdropping or sneaking peeks behind the curtains. Invariably we found the resident engaged in what was taking place...sharing through stories, reminiscing, creating art all within a supportive, nonjudgmental atmosphere. The smiles, laughter, eye contact, and conversations from the residents are rare, and were true indicators of the "success" of the research. The paintings and art speak for themselves.

Plate 10. Participant watches her group members engaged in activity.

Phase four: overcoming resistance from the participants to get engaged

As the facilitator was *setting the scene*, *anchoring*, or *co-creating* with the group, one or more of the participants would show resistance to becoming engaged. Indicators of resistance and disengagement included looking else where, sleeping, sitting back in the chair with hands folded on the chest, making excuses, apparent disinterest and lack of

confidence (See Plate 11). Participants who co-created for a while got disengaged and group facilitator had to go back to the stage of *setting the scene, anchoring*, and trying to engage them actively (See Table 2).

Plate 11. Disengaged.

In the following example, the participant had brief periods of inattentiveness and stared into space. The facilitator addressed him by name and *encouraged* him and provided *verbal and visual cues*, to return to getting engaged in his collage making activity:

> F is standing at the table, working with two participants. R6 is in wheel chair; she is frail and talks very little. F finishes talking to R6 and turns to looks at R4. R4 is looking sideways with a lost-in-thought expression on the face.

> F to R4: "R4?" (Bringing her mouth close to his ear to get his attention).

R4 turns his head towards F, smiling. He eyes flutter as he looks at F.

F to R4: "You want me to make you a piece of paper for this?"

No response from R4.

F to R4: "You want me to cut a piece of paper for you?"

F picks a piece of bright green paper and starts tearing it in pieces. R4 looks at her.

R4 to F: "I suppose." (R4 says after a pause).

Although his concentration waned at times and he needed to be prompted back to attention, painting and collage engaged R4. Plate 12 is a painting done by R4, where he explored paints and the way colors mixed together when applied one on top of the other to create new ones. Interactions with R4 were characterized by his unique sense of humor, and laughter throughout the three sessions.

Plate 12. A painting by R4, where he explored paints and the way colors mixed together

and created new ones when applied one on top of the other.

However, the facilitator was not always successful in engaging participants. In the following example, the facilitator tried to *encourage* one participant to do color sorting but the participant used a defiant gesture and clearly refused to participate:

F is color sorting with the group. R18 has just left to go to the washroom. F encourages R12 to color sort with her. R12 is holding her hands together in her lap, and looking at F with a straight face.

F to R12: "Does this color belong to any pile?"

R12 to F: "Not that I know of." (R12 does not move; she is still holding her hands in her lap).

F to R12: "Does it look like this?" (F holds a blue card in front of R12 to see).

R12 to F: "I don't know." (R12s voice rises a little and indicates irritability).

F to R12: "This?"

R12 to F: "I don't know. No. I haven't seen it."

F to R12: "You don't see any of those colors?"

R12 to F: "No, I haven't been there." (Pushing the colored cards away with a quick, short sweep of her hand and then holding her hands in her lap again).

F ignored the exchange, turned her head and shifted focus on R1.

The facilitator tried to make a connection with resisting participants using words as well as physical *touch*. While singing in one of the sessions, the facilitator offered to hold hands with one of the resisting participants. The participant accepted the offer and got involved in the singing.

At other times, participants were visually focused on the activity in progress with

other group members, or actively listening to conversations of the facilitator and group members, but showed no interest in active participation. Although passive engagement was indicative of successful anchoring, perhaps the participant was choosing not to get engaged at a higher level, or it was all she was able to do that day. For example:

F to R22: "Now, would you like to make a colored flower?"

R22 to F: "No, you make it."

R22 is content to talk to the facilitator and share ideas as F paints some of the picture for her. R22s inclination to not paint could be attributed to her arthritis.

Plate 13 shows a painting done together by R22 and the facilitator inspired by the garden and flower theme, and illustrating some flowers and a railroad track. The facilitator asked R22 where the railroad track was going, she smiled, and answered with playfulness and imagination, "I don't know...Timbuktu".

Plate 13. A painting co-created by R22 and the facilitator. It is inspired by the garden

and flower theme, and illustrates some flowers and a railroad track.

Some participants responded negatively to the suggestion of attending the art making activity. With some participants, the resistance or disengagement became a pattern that carried through all the sessions. The facilitator was met with a recital of the reasons why they were unable to engage. If participants became unduly stressed at being engaged in the activity, their wishes were respected, and efforts for inclusion were abandoned. There was one participant who was used to sleeping late, and found it hard to wake up early and be active. It was deemed unfruitful to bring her to a session in the morning. Then there were participants who did not relate positively to any activity offered in the session. According to Zgola (1987), their attitudes could be attributed to their past socializing and activity patterns. For such participants, the three sessions were deemed insufficient for knowing whether or not they would become engaged in art making activity, if given more time and understanding of their situation. It was particularly rewarding to see participants who were effectively drawn out of their disengaged state, even if it was for a short period. The care coordinator describes the success of one such participant as follows:

> One lady in particular spent the majority of her waking hours wandering aimlessly throughout the corridors. She made no eye contact and did not respond to touch or voice to connect her. In the safe, quiet, uncluttered space of the project she was able to sit quietly for the entire interaction period. She was like a different person. It was beautiful to witness her peace for that time, such a priceless gift, at no cost. The need to express, to feel like you belong and are listened to and valued exists in all of us. The research project demonstrated to me that those needs are

heightened when we have lost our ability to remember as dementia folks have. If memory is core to who we are then the project gave back to these people some of themselves that was locked away.

<u>Overcoming Contextual/Environmental Distractions</u>

Environmental distractions were detrimental to the smooth proceeding of the arts activity sessions and occurred randomly throughout all the sessions. Contextual and environmental factors often contributed to loss of participants' concentration in the activity (See Table2). When participants became distracted or disengaged the facilitator used strategies to refocus their attention to the activity (See Table 2).

In one instance, while *co-creating* an artwork with the facilitator, a participant was distracted by a conversation taking place in the hallway. The participant commented:

R9: "They don't know why. I don't know either."

The facilitator successfully *refocusing participant's attention* to the task at hand which was to squeeze the glue out of a tube and paste a piece of fabric on the paper. For example:

F to R9: "Got to bring it down a bit. Got to squeeze it."

R9: "I'm squeezing it but it's not doing what I want it to do."

In another instance, a staff member entered the session to give medication to a participant. The facilitator *stopped the activity* and waited for staff member to complete the task before resuming and reminding the participants about the activity again:

R9, R14, and R19 are looking at the staff member as she finishes attending to R20, and leaves.

F to group: "Okey dokey!" (F gets their attention; they turn their eyes on her).

R19 moves in her chair periodically, looking here and there, seeming restless.

R9 to F: "What's okey dokey?"

F to R9: "It means 'okay'. That means we are ready to start talking about stuff.

We got sidetracked, didn't we?" (F laughs a little).

R12 to F: "Yes."

F to group: "We were smelling some nice smells."

While activity could engage a participant, it also required *circumventing any previous problems*, for example, if a participant had hearing problem, the facilitator talked closer to the ear to get their attention. *Attending to participants' physical needs* was also required to aid their concentration in the activity. Looking after the participants physical needs resulted in the facilitator taking the attention away from the activity for some time. In this example, I felt the participant was sitting too far from the table to engage successfully, so I came around to push his chair closer:

F to R4: "This is probably better."

R4 (looking at me): "It is better."

Environmental factors that contribute to disturbance should be minimized. Noises in the corridors and televisions with loud volumes can be controlled through careful staff debriefing. Staff entering the activity area to assist the residents and the noise of fire alarms were unavoidable. However, given more consideration to the needs of the residents, the physical environment can accommodate some of the required changes. The care coordinator also reinforced the need for an overall change:

The reaction of the residents in the research reinforced to me the need to find new and better ways to reach our residents' souls. We must continue to move towards

the 'social' model verses the 'medical' model in the way we care for our residents. It is my prayer that activities/interactions of this nature could exist in all of our long-term care facilities. Caring for another's body and not nurturing their soul no longer makes sense. To me the research taught it is so important to add "life" to our years and not the other way round.

Desynchronization of group and individual phases of interaction between the facilitator and the participants

The phases of interaction observed during the art making sessions were in action as a group, and also in action for an individual participant. Figure 2 shows how an individual participant moved in different phases of interaction. The movement happens clockwise and anti clockwise. The group phase and individual phase of interaction were not synchronized.
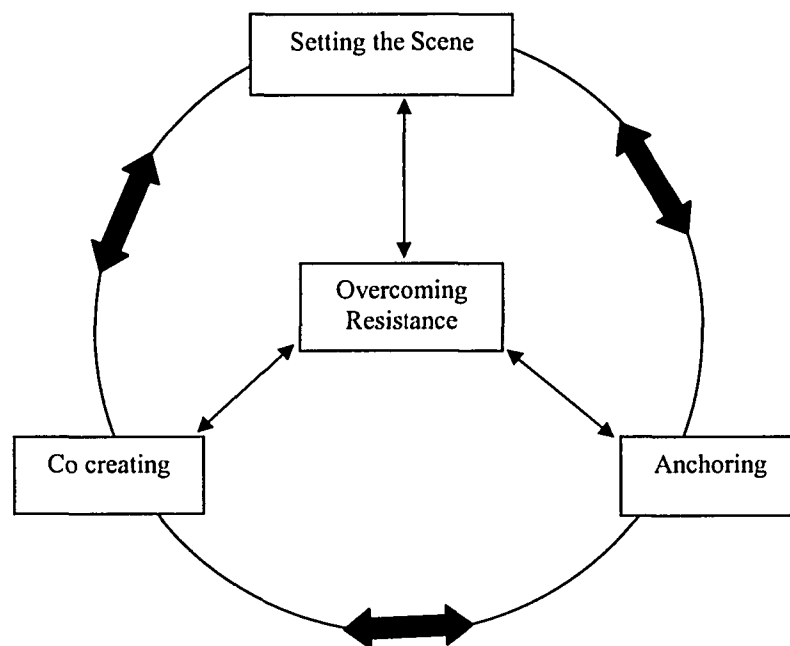
Figure 2. Individual phase of interaction.

Figure 3 shows the group phase of interaction, in which individual participants share and cross one another's phases for some time, but mostly stay disconnected. When all three participants are interacting together, the area is marked with the letter 'A' and happens only for a little while. The group facilitator tries to interact with all the participants and therefore encircles all the individual participants' phases of interaction. Although the facilitator tried to move the group as a whole through different phases, it was not successful due to the characteristics of the participants.
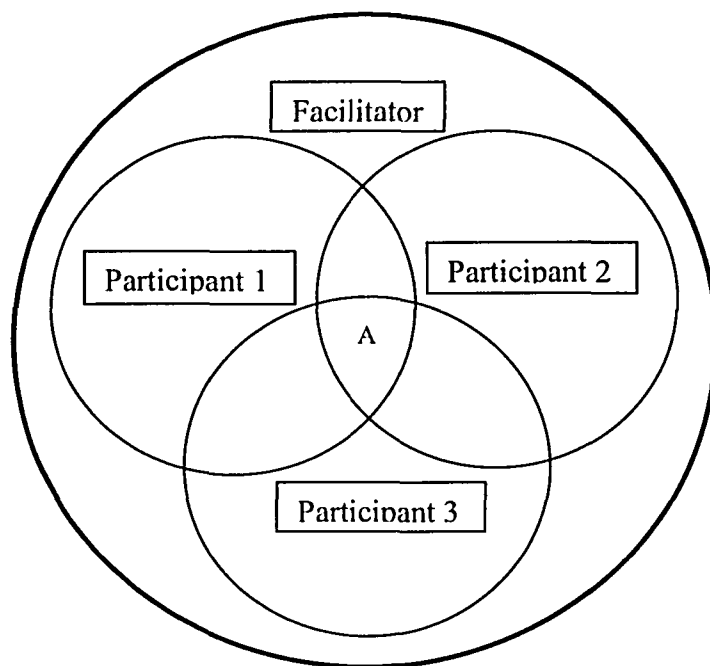
Figure 3. Group phase of interaction.

It was difficult for individuals with dementia to participate in group activities in a conventional manner, due to associated deficits in initiative, reasoning, judgment, language, and memory. As a result the group facilitator assisted participants in the

activity in whatever phase they were at. The group phase was planned based on temporal limitations. The sessions were one hour in duration. The facilitator started out by setting the scene, then anchoring, and co-creating. During any of these phases, individual participants could be present in any another phase. In these times the facilitator attended to them individually (See Plate 14).
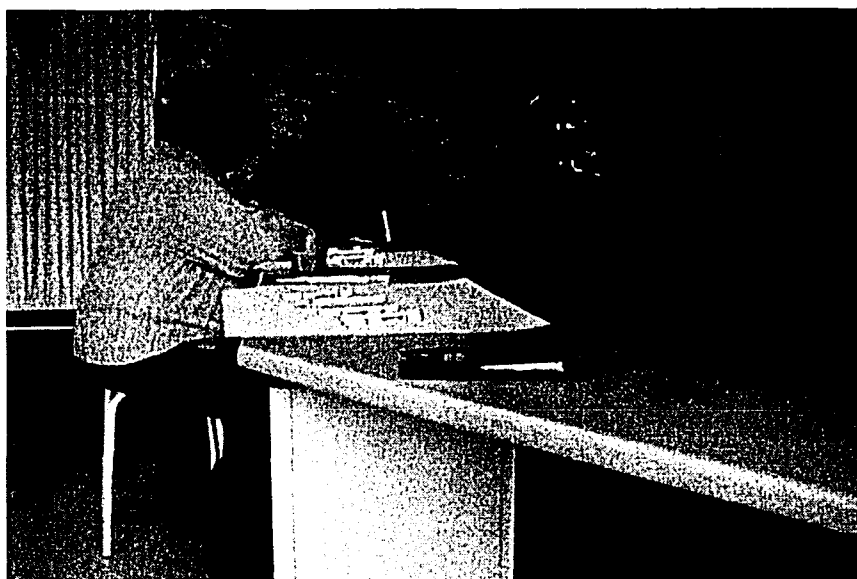
Plate 14. Co creating in group phase versus passive engagement in individual phase.

In the example below, the facilitator is leading the group through the co-creating phase, but being able to engage one of the participants only. The other two participants are going through their individual phases of interaction with the facilitator. One participant is in the anchoring phase, while the other one is disengaged:

> F (looking at R4 drawing) to R4: "That's a good way to do it. Just sort of go
>
> around like that right? Just like you're doing."
>
> F draws some spirals on R4s paper.

F to R4: "Are you making me a picture?"

R4 to F: "Looks like it."

F to R4: "Doesn't it?"

R4 to F: "Yeah."

From the above group phase, the facilitator moved to an individual phase. She turned to look at another participant and attempted to anchor her:

F (drawing a circle on R11s paper) to R11: "Look, I can make a circle too."

F (offering the pen) to R11: " Here R11, try it...try."

R11 reaches to take the pen but then pulls back without taking it.

F (drawing some lines on R11s paper) to R11: "Do you like red?"

No response from R11.

At this point, the facilitator leaves this participant and shifts her focus to the participant who was co-creating. The facilitator ignores the third participant, who is sleeping and thus disengaged.

Chapter 5

Discussion

The goal of this study was to explore and describe the interaction phenomenon of meaningful engagement in arts activities by individuals with dementia living in long-term care. In this chapter the findings of the study will be discussed from the Human Ecological perspective, and how these findings contribute to knowledge on the interaction phenomenon between the facilitator of the arts activities and the individuals with dementia during art making activities.

Each of the phases of interaction identified in this study represents a situation negotiated by the facilitator and the participants. The phases constituted both goals and conditions for interaction. The conditions for interaction correlate with the person centered approach and constitute preservation of worth and dignity of individuals with dementia. The goals for interaction were constituted within each phase. For example, setting the scene allowed the facilitator to foster a trusting and respectful relationship with the participants, which in turn formed the foundation for the art making activities. Anchoring the activity allowed the facilitator to assess participants' perceptual thinking, abstract thinking, abilities, and preferences, which in turn formed the basis for tailoring the activities to participants' level of performance. Co-creating the activity allowed facilitator to involve participants in a mutually collaborative achievement of activity through utilization of their remaining capabilities. There was a difference in the way each participant negotiated in a certain phase of interaction. Participants' disengagements or self-engagements led the facilitator to provide them with maximum opportunities for re-

engagement, re-anchoring, and co- creating, which in turn allowed participants to reconsider their position, and make their choices. The facilitator accommodated dissonance between the group phase and individual phase of interaction, which allowed all participants to function according to their distinct characteristics.

The phases of interaction observed in the study are congruent with the core concepts of human ecology. Human Ecology is concerned with interaction and interdependence of humans with their social environment, and as a result, with other individuals. As an applied discipline it seeks to identify the forces that enhance human development, actualize human potential, optimize human functioning, and improve the human condition (Westney, Brabble & Edwards, 1988). Parallel dynamics can be observed in the study, as the facilitator successfully used art activities as a vehicle to interact with the participants to enhance their interpersonal social environment.

The purpose of the following sections is to discuss the phases of interaction identified in the study and argue if these phases demonstrated successful use of arts activities to enhance the interpersonal social environment. The challenges presented during the phases, and the strategies employed to respond to them have also been discussed.

Setting the Scene

Setting the scene entailed making a connection with the participants, and making them comfortable in the setting. Strategies used for setting the scene in this phase were similar to some of those described by Killick (2001), and Hellen (2000), that is, greeting the participants, making introductions, and inviting them to the activity. The term 'setting the scene' has not been used in any of the studies, although Hellen (2000) uses "foster

connectedness" and "enabling of activity participation" that are comparable in meaning to the strategies used during interactions.

The indicators of positive interactions included participants' welcoming the contact, which was indicated by their smiles, eye contact, and keen responsiveness. Rentz (2002) identified similar indicators of engagement in her pilot project, evaluating an arts program for individuals with dementia. Expressions of pleasure like participants' smiles, easy conversation, have been identified as indicators of individual's sense of well-being. Socialization was reported to take place most commonly upon entering the art session, which is similarly experienced and described in this study. Development of interaction in the study using a careful touch for reassurance, and saying why we were there, "I thought we could talk and do some fun things together", and the positive aspects of the initial contact were discovered also by Killick and Allan (2001). It has been stated that these interactions helped the researchers connect with the residents as individuals, and realize their personhood.

Humor was another successful strategy both in setting the scene and during other phases of interaction. Participants were always ready to enjoy some shared experiences of a comical nature. Laughter, which was almost non-existent during normal routine outside of the group, was heard during the session. Humor provided opportunities for the participants to express themselves with openness, freedom, and enjoyment. It enhanced the interpersonal communication, and established the effectiveness of its use in working with individuals with dementia. Dowling (1995) also notes the effectiveness of using humor when working with individuals with dementia.

Additional strategies for setting the scene included normal social conversations about meals, hairdos, weather, clothes, and general well-being of the participants. Conversations were taken up and dropped through all the phases of activities, allowing participants to express their thoughts in their own preferred time. At times the participants' language was not entirely meaningful, but the facilitator responded with intuition, and did not make them conscious of their deficiency. Killick (2001) notes that normal conversations proved especially effective in gaining the attention and interest of the participants in such situations. However, there were participants who did not respond well to conversations, and for them, the facilitator fostered connectedness using a different strategy.

Reminiscing was used through more than one phase. Most of it revolved around personal memories of the participants' lives. The facilitator valued their personal experiences by listening to their memories, and sometimes sharing her own. Although the proof of the benefits of reminiscence as a therapy has not been made (Grasel, Wiltfang & Kornhuber, 2003), and since reminiscence has potential for shared pleasure or individual distress (Killick, 2001) the facilitator was careful to rouse memories in light of an individual's personal history, and cautions provided by the family. Reminiscing was enjoyed and carried no negative associations during these sessions.

Challenges presented during this phase included environmental disturbances, and the residents becoming distracted by various extraneous events. More often, environmental disturbances caused the residents to lose attention. Research on individuals with dementia shows consensus on the benefits of reducing environmental factors that affect the peacefulness and concentration, and well being of the individuals

with dementia (Hellen, 2000). Some of the sources that contributed to environmental disturbance during the study are similar to those described by many other studies, and include people's noises, alarms, intercoms, and television (Bonder & Wagner, 1994; Zgola, 1987).

<u>Anchoring</u>

Although the term 'anchoring' has not been used in any of the studies, the strategies and challenges constituting this phase of interaction have been stated (Hellen, 2000). In this phase the facilitator's aim was to introduce the activity to participants, and assess each participant's perceptual thinking, abstract thinking, abilities, and preferences, in order to tailor the activity for the rest of the session, and in subsequent sessions. Additionally, the facilitator tried to avoid reducing the functional capabilities of participants which can be caused by any one of, or combination of the four stressors identified by Bonder and Wagner (1994), namely fatigue, change, excessive demand and over stimulation.

Information on participants' life histories was perceived to be of vital importance in anchoring them. Knowledge of circumstances and events in participants' lives, past interests, occupations, and habits contributed to a greater understanding, and increased success in finding a point of contact and sustenance in communication. Jarvis (1998) and Hellen (2000) recognized the importance of gathering personal history information for accomplishing some level of shared activity with individuals having dementia.

The facilitator introduced the activity by asking participants to help her in completing it. This strategy supported participants' abilities to make choices, contribute to the activity, and to feel valued. Next, the facilitator encouraged the participants to get

engaged in the activity. Engagement focused on participants' abilities, and proved effective in upholding current strengths, in an atmosphere of fun and enjoyment. The need to involve individuals with dementia in an active way is supported by Collier (2001), and Allan & Killick (2000).

Multi sensory stimulation was used as a strategy to stimulate the senses, using familiar objects, textures, scents, and food. Although the role of sensory stimulation has not been the primary subject of any research study carried out with individuals having dementia, it has been suggested as an effective strategy for promoting communication, and for providing evocative triggers for memory (Killick, 2001; Hellen, 2000). Singing was appealing, and captured the interest of some participants. Signs of pleasure were observed as R21 sang along with most of the familiar songs of her times, and drummed with her fingers excitedly. R18 laughed out loud after finishing singing a Christmas song, and subsequently, began a conversation about Santa Claus. The study found that activities involving sensory stimulation promoted communication between participants and enhanced their sense of belonging to the group. The stimulation would also trigger memories and could result in associative conversation. However, whether the impact of arts activities is due to the specific effect of art making, as opposed to a more general effect of participation in a structured group activity cannot be conclusively determined.

Presenting the activity in a playful manner was accepted well by the participants. This strategy included 'pretend' games like activities of wearing a hat, telling stories to lead participants to do color sorting, creating stories about objects in the artwork, and using stuffed toys to 'pretend' they were pets. This playful mode triggered communication, brought out laughter, and created shared fun moments for the group. It

also allowed the facilitator to assess the preferences of individual participants.

To enable the participants to do the activities, the facilitator first demonstrated the use of art making tools and materials, and allowed participants to imitate her actions. Imitation of actions, in combination with verbal and visual cues, and positive feedback enabled the participants to carry out the action and gave them a shared feeling of participation. Helen (2000) and Bonder and Wagner (1994) recommend mimicking to be a useful strategy in achieving participation in activities.

Challenges encountered while anchoring included participants' indifferent attitude towards involvement in the activity, making up of excuses for not participating, tentative engagement, lack of confidence, inability to communicate meaningfully, and extraneous disturbances. However, these challenges were embraced in a positive spirit, to honor participants' choice and maintain their personhood in agreement with Kitwood (1997). At the same time, the facilitator offered all participants equal opportunities for participation by frequently coming back to them, and asking to see if they changed their position from before.

Co-creating the activity

The facilitator co-created the activity with the participants, using collaborative and cooperative strategies, and creating a bonding experience that facilitated action. Hellen (2000) uses the term "shared activity" that has a similar connotation. Some of the strategies employed in co-creating are similar to those used in other phases. These include the facilitator asking the participants to help in co-creating the artwork, which enabled them to make choices and to feel valued. Demonstrating the use of art materials, facilitated execution by allowing participants to imitate her actions and develop a feeling

of shared participation.

Since individuals with dementia are usually unable to initiate activity and maintain involvement, the facilitator got involved in the activity with the participants, and reinforced verbal and visual cues to focus and direct participants' attention in arts making. Successful interactions achieved through doing an activity "with" participants supports what has been experienced by researchers who worked with such individuals, on art projects (Killick, 2001; Collier, 2001; Allan & Killick, 2000; Jarvis, 1998; Neal, 1996; Weiss, Schafer & Berghorn, 1989).

Activities that involved the facilitator and participants in the process of co- creation, and became the vehicle for interactions, included sorting, singing, drawing, painting, and collage. The process of co-creation fostered connectedness, promoted active participation, and created a shared activity. Positive feedback from the facilitator provided reassurance, and helped participants continue creating. The suitability and success of using the above mentioned art activities has been related by Collier (2001), Killick (2000), Allan and Killick (2000), Killick and Allan 1999), Jarvis (1998), Neil (1996), Hellen (1992), and Weiss, Schafer and Berghorn (1989). Challenges presented during co-creating included participants' choice of not wanting to engage, participants' inability to carry out physical tasks, making excuses, going to sleep during the activity, and extraneous disturbances. In accordance with the principles of personhood, participants' choices were honored. The facilitator also acknowledged the inability of some participants to be physically involved in the activity, and resolved to engage such participants on a verbal level, while she carried out the physical tasks. Participants who went in and out of sleep were gently brought to attention by the facilitator, to give them

equal opportunity for engagement. Hellen (1992) describes similar limitations as characteristic of dementia and affecting the individuals suffering from it.

Overcoming resistance

Resistance and disengagement meant the participants phased out, looked elsewhere other than the activity, slept, sat back in the chair with hands folded on chest, made excuses, refused to get engaged, were disinterested, lacked confidence, became self engaged, and were passively engaged. The facilitator went back to the stage of reintroducing the topic, re-anchoring, and retrying to engage them.

To overcome resistance, the facilitator provided visual and verbal cues, which supported the participants in integrating information, which in turn increased awareness and enabled an appropriate response. The facilitator encouraged participants to interact by calling names, and referring to their co-creations, thus drawing the attention of group members to one another. It led to making conversation, and sometimes to engaging a resisting participant. Some of the activities, like sorting, were designed to involve the whole group, which nurtured a sense of community in participants, and enabled participation. Another strategy to overcome resistance involved the facilitator giving participants positive reinforcement for successfully completed activities. As stated by Zgola (1987), the efforts of the participants were praised and acknowledged realistically, sometimes with simple nods, reassuring glances, and at other times, with excited and joyful words. These strategies did not ensure that the facilitator overcame resistance all the time, but they have been successful to some extent, and therefore need to be considered carefully with reference to each participant's situation.

Participants refusing to engage, bringing up tangential topics for conversation,

getting self engaged, or only passively engaged, presented challenges for the facilitator during all phases of the sessions. The resistance or disengagement of participants may be attributed to any of the inherent characteristics of dementia, which are poor judgment, limited insight, conceptual difficulties, and visu-spacial and temporal difficulties. The facilitator acknowledged participants' fears, and assured them of her support in achieving success. But at no time did the facilitator pressure the participant into becoming engaged. The facilitator maintained a positive attitude, and dealt with participant's resistance in a casual manner, in order to avoid stress.

Overcoming contextual/environmental factors

Environmental factors caused disturbance in the activity proceedings, and were a source of stress for the participants. The facilitator's strategies to minimize the effect of these environmental factors included directing participants' attention away from the distraction, and refocusing it to the activity by talking to them, stopping the activity momentarily to wait for the disturbance to finish before resuming or circumventing previous problems and looking after participants' physical needs to aid concentration. The need to reduce disturbing environmental factors is emphasized by Bonder and Wagner (1994), and Zgola (1987).

Factors that challenged the peace and quiet of the environment included staff entering the activity area to attend to some of the participants' needs, talking noises in the corridor that overpowered the conversation happening in the session, participants' need to go to the washroom, and participants getting up and walking away to find out about the noises in the corridor.

<u>Conclusions</u>

Qualitative ethology was a suitable method for conducting the study. Videotaped data provides observations and information that cannot be obtained using conventional methods of data collection, i.e. interviews, focus groups, or surveys. The use of two cameras, one stationary and the other roving, proved effective in providing richer data and observations on behaviors and interactions between the facilitator and group participants.

Using arts as an intervention in dementia care is an emerging trend. Engaging individuals with dementia may create a sense of pleasure and well being momentarily, by fostering the interpersonal social environment. However, the therapeutic and long-term potential of arts is yet to be explored.

The facilitator was able to engage the residents in a range of arts activities and communicated with them during the arts activities sessions. The facilitator was also able to get the residents to interact with one another during the sessions, which did not happen very often in the residents' normal routine. However, residents do not always get actively engaged in the activity. Some residents chose to be passively involved: they only listen and watch.

A relationship was established with the residents for the duration of the data collection, whereby residents were able to recognize the researcher and the facilitator at some level. In some cases, residents took notice of the researcher and the facilitator six months after the completion of data collection.

Residents can respond to multi sensory stimulation and need initiatives from caregivers to engage them actively, so as not to spend time in passivity and isolation. The

facilitator was able to identify residents' inclinations toward a particular activity after introducing them to a whole range. The facilitator was able to make connections with residents during these activities, and was able to elicit positive responses such as conversations, jokes, laughter, reminiscing, and physical activity.

The group setting brought out a feeling of belonging and togetherness in the residents, provided a natural, normal adult setting for socialization and activities, encouraged social behaviors like greetings, questions about general well being, inspired participation, and provided support and encouragement for the participants. The group setting was useful for the facilitator because participants were sometimes reticent about active involvement and the facilitator allowed them to sit, listen, and watch other group members' activities and interactions.

Limitations of the study

Dementia and accompanying age related complications resulted in unpredictable changes in participants' physical wellness and behaviors from one session to the other, and a change in the chemistry of the group. Hearing, sight, ambulatory and cognitive impairments were a liability and needed continuous attention during the sessions. Participants' safety was also a primary concern that necessitated the use of safe and non-toxic art materials. Additionally, an unexpected event of the flu caused delay in data collection, and impacted the characteristics of the participants. Some of the participants worsened in their condition of dementia, and one participant passed away.

The study was conducted in an area that was not purpose-built for carrying out art making activities. It was not suitably equipped with sinks, water supply, round tables designed to accommodate wheelchairs and which could provide privacy and quiet for

residents to work in. The lounge used for conducting the activities had one open side, which was screened off during the art making sessions, but it did not serve to adequately maintain the required level of privacy and quiet.

Better training measures needed to be taken to orient the staff members and work in cooperation with them for conducting the arts activities. Steps could be taken to inform staff working on different shifts about preparing the residents for the session on time, and signs could be posted in the corridor to maintain a quieter atmosphere.

Recommendations

The fieldwork prior to data collection is important, and suggested to be carried out for becoming familiar with the staff, setting, routines, and norms of the facility. Collecting personal history on the residents is also vital for gaining personal information and understanding their vulnerable issues, points of interest, past preferences, patterns of behavior, and becoming familiar with the resident.

It is important to consider that some guardians and family members declined participation in the study, the reasons attributed to their loved one being vulnerable to strain of any kind. As well, some individuals became too ill to participate. Vulnerability poses difficulties in recruiting from this population, and raises questions about the recruitment procedures when working with moderate to late stage dementia. It is recommended that recruitment and data collection be done without much time lapse in between, to avoid the possibility of considerable decline in participants' health. In doing so, the recruitment and data collection may be done simultaneously. Only as many participants may be recruited at one time as needed for one group, followed by art making sessions and data collection, before the next group is recruited. It is also

suggested that study be conducted with individuals having dementia in early stage, which may reduce the challenges of recruitment and vulnerability.

The arts activities must be conducted in a purpose built area. The arts activities should be process oriented and not goal oriented. They are suggested to be multi sensory in nature. More than one activity should be planned that may be presented in turn, when one fails to engage the residents' interest. Moreover, inclusion in the group and the activity may be encouraged even when it only provide triggers for conversations.

The facilitator must be an artist, familiar with the residents, and be aware and able to cope with communication deficits of individuals with dementia. A trained artist is crucial to inspiring creative expression through use of colors, textures, and other multi sensory stimuli. A small group of two to three residents is good to work with. A small group allows the facilitator to attend to individuals, and engage them appropriately.

Keeping in view the nature of dementia, and variation in its presentation in every individual's case, it is recommended that facilitators for arts activities embrace the desynchrony in phases of interaction. It can allow residents to function according to their individual characteristics, and make the experience meaningful for them. However, choosing a maximum possible homogenous group of individuals may lessen the desynchronization to some extent.

The arts programming must be incorporated in long-term dementia care settings along with the other programs, because it may be suitable some of the residents, but not the others.

Suggestions for future research

There is a need for comparative research measuring pre and post performance in arts activities, to determine its long-term effects. Additional sessions with the same group may help understand patterns relating to resistance shown by individuals having prior interest in art making, and if that resistance can be overcome. Furthermore, research must be carried out with individuals at an earlier stage of dementia, to understand the impact and potential of art making activities with this population.

Summary

This research was in initiated through a request by the host facility that was interested in enhancing the environment of their dementia care unit for their residents in a meaningful way. To this end, small groups of residents at moderate to late stage of dementia were engaged in art making activities. For analysis purposes, qualitative ethology was used to describe the behaviors and interactions between the residents and the facilitator from the videotaped data. The phases of interaction that were evident within the art making activities sessions were described, and included setting the scene, anchoring, co-creating and overcoming resistance. The phases of interaction occurred at a group and individual level. The group phase of interaction and the individual phase of interaction were often desynchronized. The facilitator faced challenges during all phases of interaction. The interpersonal social environment was acknowledged to be an important element of engagement in art-making activities in institutional dementia care for preservation of personhood, recognition of remaining abilities and a decreased focus on disabilities.

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APPENDIX B

Personal History of the Participants

In an effort to enable the researchers to understand your loved one and to work with him or her most productively, please take a few minutes to tell us about them.

1. His/her name:

   _____

2. Your name:

   _____

3. Your relationship to the resident:

   _____

4. Your contact information: telephone or email (day/evening)

   _____

5. His/her age: _____ Date and place of birth:

   _____

6. Level of education:

   _____

7. Describe his/her early childhood:

   _____

   _____

   _____

8. What occupation(s) or career(s) did he/she follow?

   _____

   _____

9. Was/is your loved one married? _____ Is their spouse living/deceased?

   _____

10. Did he or she have any children? _____ How many?

    _____

11. What hobbies or interests did he/she pursue?

_____

_____

_____

_____

12. Describe any special accomplishments or talents? _____

_____

13. Indicate prior skills or interests in art, music, dance, writing, theatre, etc.

_____

_____

14. Type of dementia, if known:

_____

15. How long has your loved one had dementia?

_____

16. Does he/she take Aricept?_____ Other?

_____

17. Is there anything else about your loved one that might aid researchers in working with him/her?

_____

_____

_____

_____

Thanks for taking the time to provide this information,

Marlene Cox-Bishop and Uzma Chaudhry

University of Alberta

APPENDIX C

**INFORMED CONSENT FOR LEGALLY AUTHORIZED
GUARDIAN/AGENT OF THE PARTICIPANT IN ART ACTVITIES**

UNIVERSITY OF ALBERTA, EDMONTON
CONSENT TO PARTICIPATE IN A RESEARCH STUDY
An exploration of interaction between persons with dementia and selected art
activities.

A.   Purposes and Background
Uzma Chaudhry, Masters of Arts candidate in the Department of Human Ecology,
University of Alberta is carrying out a study examining how individuals with
dementia, of moderate stage, interact and communicate as they engage in art making
activities during a session of art-making activities. This information may be used to
help artists, caregivers and art administrators understand better the role of
communication in arts programming in dementia care. I,
_____, am the legally authorized guardian/agent of
_____. I hereby provide informed consent for his/her
participation in the study.

B.   Procedures
If I agree for the resident I represent to be in the study, the following will happen:
1. Uzma Chaudhry will assist art-making activities for about one hour in a
comfortable, lounge area on the ███████████████ Care
Centre. The resident I represent, and two other residents from the facility will use
painting and collage (A work created by affixing various materials -paper,
newspaper or cloth, to a picture surface) to create artwork in a group. The activity
session will be held at a time of the day suitable for the resident, as suggested by the
facility staff. The arts activity will be videotaped.
2. The resident I represent will be videotaped when the art activity session begins.
Uzma Chaudhry will conduct the videotaping. Professor Marlene Cox-Bishop will
introduce and assist the activity for the group. The videotaping will stop as soon as
the art activity session is over.
3. The researchers will contact the care giving staff at the facility in case of any need
posed by the resident I represent, during the art activity session.
4. This process will be repeated three times, in three sessions, approximately.

C.   Risks/Discomfort
1. Confidentiality: Participation in this research will involve a loss of privacy;
however   the records of the resident I represent will be
managed confidentially. The researcher will label his/her videotape with a code
number and not his/her name. The code list will be kept separate from the data in a
locked place. Only the researcher will have access to the codes and names. The
videotapes will be transcribed to written form, and these transcriptions will be stored
in a locked cabinet at all times. The transcriptions of the video will contain code

numbers and not the name of the resident. Any other identifying information will be removed from the transcripts. The researcher may use the services of a transcriber, who will view the video tape recordings, transcribe them to the written form, and give them to the researcher. The researcher and her committee will have access to the written transcripts and video information collected for this study.

Reports about the study that the researcher writes or presents will not identify the resident I represent. If the resident wants to see any of his/her videotaped material, I should contact either Uzma Chaudhry or her supervisor, Dr. Marlene Cox-Bishop at the addresses listed below.

The resident I represent may stop the videotaping at any time if it makes him/her uncomfortable, or withdraw from the study at any time. The videotapes will not be available for release to family members. The videotapes will be kept by the researcher for further analysis in another study if the researcher receives approval from the appropriate ethical review committee, and destroyed five years after the last study.

2. Privacy: The face of the resident I represent will be visible on the videotape but his/her name will not be exposed to anyone other than the persons present in the art activity session. His/her videotaped segments will not be used for presentations unless I give permission. If I expressly give permission on this consent form, the video image of the resident I represent maybe used for research presentations. If I give permission for his/her image to be used, his/her face will be visible to the audience. His/her name will not be used.

If I give permission in this consent form, the artwork that is completed by the resident I represent, during the arts activities sessions, may be used for exhibits by the researcher, and its photographed reproductions maybe used in the thesis and presentations.

If I give permission in this consent form, the artwork of the resident I represent will be displayed. I understand that I can decide if his/her name is displayed on the artwork in the exhibition.

D.   Benefits
The benefits for the resident I represent may be a sense of meaningful engagement and an opportunity of creative expression through the arts activities. The information gained in this study may help researchers better understand the impact of arts activities and programming on individuals with dementia. Caregivers, artists and art administrators may benefit from this because it will contribute to new information about implementation of arts activities and its affects on individuals with dementia residing in long term care facilities.

E.   Questions
I have talked with Uzma Chaudhry about the study and have had my questions answered. If I have any further questions about the study, I may contact either one of the researchers:

3.   I expressly give permission for the video image (face or body) of the resident I represent, to be used in research presentations. I understand that his/her face will not be blocked out and will be visible to the audience. His/her name will not be used.

_____	_____
Date	Signature of legally Authorized Guardian/Agent

_____
Signature of Researcher Obtaining Consent

4.   I expressly give permission for the artwork that is completed by the resident I represent during the arts activities sessions to be used for exhibits by the researcher, and its photographed reproductions to be used in the thesis and presentations.

_____	_____
Date	Signature of legally Authorized Guardian/Agent

_____
Signature of Researcher Obtaining Consent

5.   I give permission for the artwork that will be completed by the resident I represent to be displayed. I understand that I may decide if his/her name is included on the artwork in the exhibits.

_____	_____
Date	Signature of legally Authorized Guardian/Agent

_____
Signature of Researcher Obtaining Consent

6.   I give permission for the videotapes to be kept by the researchers for further analysis in another study provided approval from the appropriate ethical review committee is obtained. The videotapes will be destroyed five years after the last research study has been completed.

_____	_____
Date	Signature of legally Authorized Guardian/Agent

_____
Signature of Researcher Obtaining Consent

APPENDIX D

## ASSENT FOR RESIDENTS' PARTICIPATION IN ART ACTIVITIES

A.   Introduction

Hello, my name is Uzma. I am a student at the University of Alberta. I am here to tell you about a project I am working on. I am interested in Art, and how people make it.

B.   Questions

1.   I will be visiting here for the next couple of months. I am hoping some residents might want to create art or painting with me. Would you like to do something like that?
2.   A special part of the project is that I will be filming how people just as yourself, make Art. Does this sound like something you would like to do?
3.   The Art or painting that you make can be put in an exhibition for people to see. Would you like to put your art in an exhibition?

APPENDIX E

LETTER FROM THE CONTINUING CARE FACILITY CARE COORDINATOR
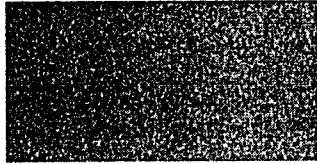
It was an honour to facilitate the Dementia research project as Care Coordinator of the Dementia unit. ████████████ Throughout the project we were able to witness some profound transformation of the residents. Residents who on a daily basis appeared "lost in their own world" became animated, talking, drawing smiling and sharing themselves in many small yet meaningful ways.

Resources in Long Term Care ensure that the basic personal physical needs are met. Staff has time to bathe, feed and toilet our residents. Spiritual and recreational needs are met to he best of the ability of a small number of staff. One-on-one interaction is usually given only during personal care. Social needs are delivered usually in large groups. The opportunity afforded by the project to engage persons in very small intimate groups is rare in our setting. When we rely on family and friends of the residents to nurture we recognize many residents may not have visitors even on a weekly basis. Oft times when the relationships exist the quality of the interaction is lacking. Family or friends may not be prepared intellectually or emotionally to nurture in meaningful ways.
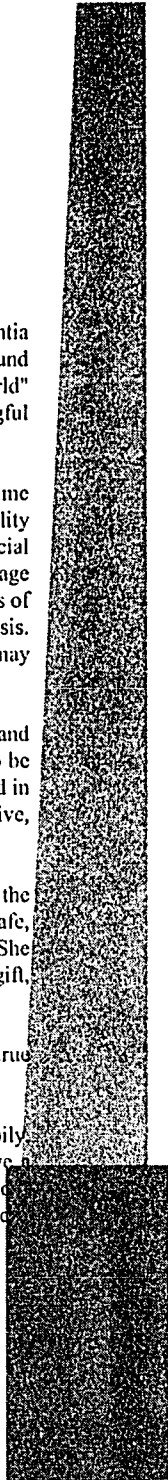
What I witnessed with the research is the unique blend of intellect and compassion to connect and engage the residents in positive interactions. In our efforts to witness we would be found to be eavesdropping or sneaking peeks behind the curtains. Invariably we found the resident engaged in what was taking place, sharing thru stories, reminiscing, creating art all within a supportive, nonjudgmental atmosphere.

One lady in particular spent the majority of her waking hours wandering aimlessly throughout the corridors She gave no eye contact and did not respond to touch or voice to connect her. In the safe, quiet, uncluttered space of the project she was able to sit quietly for the entire interaction period. She was like a different person. It was beautiful to witness her peace for that time, such a priceless gift, at no cost.

The smiles, laughter, eye contact and conversations from the residents in which this is rare were true indicators of the "success" of the research. The paintings and art speak for themselves.

Several residents would recognize the women at some level and respond to their presence happily. To me this demonstrated how the when the " intellectual" memory is impaired we still have "knowing" on other levels of our being. I truly believe the project tapped into these levels for residents. This brought a safe peace to them. Engaging brought out fond memories and enhanced their sense of belonging, of being important and listened to.

The reaction of the residents in the research reinforced to me the need to find new and better ways to reach our residents souls. We must continue to move towards the "social" model vs the "medical" model in the way we care for our residents. The need to express, to feel like you belong and are listened to and valued exists in all of us. The research project demonstrated to me that those needs are heightened when we have lost our ability to remember as Dementia folk have. If memory is core to who we are then the project gave back to these people some of themselves that was locked away.

I am grateful to have been able to facilitate the work on our unit. It is my prayer that activities/interactions of this nature could exist in all of our Long Term Care facilities. Caring for another's body and not nurturing their soul no longer makes sense. To me the research taught it is so important to add "life" to our years and not the other way around.
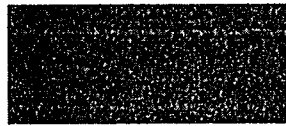
Care Coordinator

APPENDIX F

INFORMED CONSENT FOR CARE CO-ORDINATOR OF THE CONTINUING CARE FACILITY

UNIVERSITY OF ALBERTA, EDMONTON

CONSENT TO PARTICIPATE IN A RESEARCH STUDY
An exploration of interaction between persons with dementia and selected art activities.

A.   Purposes and Background

Uzma Chaudhry, Masters of Arts candidate in the Department of Human Ecology, University of Alberta is carrying out a study examining how individuals with dementia, of moderate stage, interact and communicate during art-making activities. This information may be used to better understand the role of communication in arts programming in dementia care.
      I, _____ , am the ████████████ Care Coordinator on the ██████████████████████████████████ I hereby provide informed consent for the researchers to use my comments and observations made during the course of data collection for the sudy, and given to them by me. I consent to the use of this information as part of the research data for their study examining the how individuals with moderate dementia interact and communicate during art making activities.

B.   Risks/Discomfort

1. Privacy and Confidentiality: Participation in this research will involve a loss of privacy since the researchers will use my name, position and acknowledge my contribution towards data collection in writing of the thesis.

Reports about the study that the researcher writes or presents may acknowledge my name, position and contribution in the study. If I have any concerns, I may contact either Uzma Chaudhry or her supervisor, Dr. Marlene Cox-Bishop at the addresses listed below.

C.   Benefits

The researchers will acknowledge my contribution in data collection, however, there will be no direct benefit for my participation in the study. The information gained in this study may help researchers better understand the impact of arts activities and programming on individuals with dementia. Caregivers, artists and art administrators may benefit from this because it will contribute to new information about implementation of arts activities and how these affect individuals with dementia residing in long term care facilities.

APPENDIX G

SAMPLE OF HANDWRITTEN TRANSCRIPT

Data Analysis - Shooting Sheet

Group ▓▓▓▓ Session 3 Date ▓▓▓▓▓▓

Participants   R21 , R1

Time Code	Description
0:00:20:00	M sitting across from R21, adjacent to R1. M talks to R21 "You did some artwork yesterday; we were making some painting". RR1:"yes" M turns to R1, continues "you're my star pupils" "that's what I think".
0:00:28	R21:" the best thing is to relax & see what you can do". M replies " That's true, that's right".
0:00:34	M:' R1 made me a beautiful Christmas tree at Christmas time" R21:' oh isn't that nice" M:' it was very nice; and he had Rudolph the red-nosed reindeer in it' R21 make a comment and M & R21 laugh. M continues' and he had his face up in the tree; it was really very nice". M continues:' but that was a long time ago". R1:' hmm, it was last year".