“Grace Filled Moments”

CREATIVE ARTS AND PASTORAL CARE WITH PATIENTS LIVING WITH DEMENTIA IN THE HOSPITALIZED SETTING

By

DEBORAH THERIAULT

A Thesis Submitted to
Atlantic School of Theology, Halifax, Nova Scotia
in Partial Fulfillment of the Requirements for
the Degree of the Masters of Arts in Theology

April 3, 2017, Halifax, Nova Scotia

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Abstract

Grace Filled Moments: creative arts and pastoral care with patients living with dementia in the hospital setting

By Deborah Theriault

Abstract**:** This thesis describes the creative arts therapies being implemented throughout Canada and in two major areas in the United States. Creative art therapies include art, music, poetry, dance and movement therapy, improvisation and life review. I conducted phenomenological research on spiritual/pastoral care providers that worked in acute care hospitals in long-term facilities to ascertain their experience in using creative art therapies. The information gathered will hopefully assist clinical pastoral education (CPE) students, parish nurses, spiritual/pastoral care providers, chaplains, theology students, recreation therapists, social science students and other populations that wish to implement creative arts therapies. The research revealed unique insights into the inner experience of the spiritual/pastoral care providers and indirectly into the hospitalized clients living with Alzheimer's. The research provided an opportunity for spiritual/pastoral care providers to express themselves and an opportunity to share their creative art therapies with many cultures thus supporting community and healing. The question of this thesis is how do spiritual/pastoral care providers assist this population and what creative art therapies are being implemented.

April 3, 2017

Signature Page

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Certificate of Ethical Acceptability for Research Involving Humans

This is to certify that the Research Ethics Board has examined the research proposal:

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Faculty Supervisor:	Dr. Susan Willhauck
Student Investigator	Deborah J. Theriault

and concludes that in all respects the proposed project meets appropriate standards of ethical acceptability and is in accordance with the Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans (TCPS 2) and Atlantic School of Theology's relevant policies.

Approval Period: 27 June 2016 to 27 June 2017

Dated this 27th day of June, 2016 at Halifax, Nova Scotia.

____

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With love, I thank my husband Francois for his support and patience.

GRACE FILLED MOMENTS

CREATIVE ARTS AND PASTORAL CARE WITH PATIENTS LIVING WITH DEMENTIA IN THE HOSPITAL SETTING

DEBORAH THERIAULT

Introduction: Personal Lenten Reflection March 12/2016.

All week I have been searching for missing pieces in order to be able to write this thesis. Imagine reading the daily Bible readings and having tree symbolism in passages such as Ezekiel 47: 1-12, and Miller-McLemore's (2012) reference to trees in her book jump off the page.[1] My religious revelation while reading was profound because I wondered if I was right in following this path in pastoral theology. When I was completing my undergraduate degree, I felt God call me to create the "Tree of Life" and I presented my proposal to the university library that wanted student art. I molded this tree out of clay onto a board to be used as a doorway. From that experience I was on my academic religious journey and I continued training to be an art therapist. For the past ten years I have provided "art as therapy" to many populations including seniors.

Art therapy education involved learning about symbols and one of the greatest symbols is the tree (represents the self and many other things). What else could be important about a tree? In religious passages Jesus was crucified on a tree (cross); the Tree of Life; olive trees; the burning bush; the fig tree; amongst other biblical passages. My work with seniors involved many art

[1] Miller-McLemore (2012). She worshiped in a sanctuary almost identical to her home church. Instead of the tree of life there was a cross. As she sat there she was reminded that as an early believer she gazed on God "embedded in a fruitful tree of life, a tree that grows right out of the baptistery where Christian's begin their life in Christ, sinks it roots deeply… in the early Church, and sprouts an abundance of symbols of worship…" (20). Until that moment she had not realized the impact of symbols and "acts of regular worship on our religious thoughts and feelings" (20).

designs with trees which include holidays, landscapes and more. Memorable sessions include one with a senior resident during a Christmas themed collage. I asked if she was going to put a star on top of the tree and she shook her head “no” and put a bird on top of the tree. She was so pleased because I praised her for “showing me” what was real and helping me “see” her perspective. Tree designs done by dementia clients can reveal so much, for example, the client that added cactuses in her designs and could not explain at that time why. She had lived in Aruba, but I had not known this until the next session when the aid shared this with me. The designs done by another resident showed trees on one side having two unhealthy trees with holder type bases ready to tip over. Upon discussing this privately with the personal care worker, it was revealed that there were two palliative residents in the home (this woman was mourning that the residents were dying). All that is painted, put into collages has meaning revealing the daily aspects of the seniors’ lives. My experience is one example of how the arts can be a conduit for spiritual care.

God revealed to me when reading about tree metaphors and biblical metaphors that he is working through me to assist people living with dementia. What could be more rewarding than having this revelation during lent. Working with a senior who says, “I don’t remember how to draw a tree,” can give them a session of rediscovery, joy and accomplishment. Many residents, when the art work is completed, hold up the finished art piece, attach the art work on the wall and discuss it with each other.

My purpose for writing this thesis is to discover how chaplains or others are providing pastoral care that connects with people with dementia by using creative arts. I know by working as a nurse and an art therapist that there are time constraints and although allied health care

professionals have the goal of providing holistic care they may not be able to do so. I ascertained a need to qualitatively explore current experiences of caregivers using creative arts with dementia patients and to identify and review theoretical rationales for doing so.

Some Christian scriptures and tradition apply to working with seniors that live with Alzheimer's. I was moved by Paul Tillich's words, "Neither power alive or reason alone created the works of art and poetry. The Spirit creates them individually and universally, powerful and full of reason at the time" (5). I was moved by his words because when this population creates, it is like standing on holy ground. Sitting closely and looking into their eyes is looking into the face of God. Tillich wrote about "dreaming innocence," his term for essential human nature uncorrupted [2]. The innocence, the trusting, the powerful connection and the resulting art piece is greater than anything that I have ever seen done with another person.

Also, Saint Francis of Assisi wrote, "He who works with his hands is a labourer. He who works with his hand his head is a craftsman. He who works with his hands, his head and his heart is an artist" (1). This is so important because with this population many of them never had the chance to create. Many of them had started to work at a young age and never knew that they had any artistic abilities. Again the innocence of these people is reflected when they create. The wonder, the joy and the heart felt expression is a gift to behold.

I am a Licensed Practical Nurse and an Art Therapist who works with the Alzheimer's population. I have noticed that when pastoral workers at my employment, deliver the sacrament, they say a prayer to this population while they sit in groups, but do not converse with them. The need for pastoral care in various ways is increasing which is evident in the numbers of persons

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[2] James, C. Livingston and Francis Schussler Fiorenza, (2006). *Modern Christian Thought.* Vo2, 2. Fortress Press, MN: 144-145. I saw this evidenced in the people with whom I worked.

with reduced communication capacities. What is being done in pastoral care to assist this population? My research question is: How do pastoral care providers assist people with dementia and what creative arts therapies are being implemented? In chapter 1, I will provide background on Alzheimer's Disease, symbols, creative therapies and spiritual or pastoral care. In chapter 2, I will include various theories used within the pastoral care context and describe the research methodologies. Chapter 3 will include the demographics and presentation of the findings. Chapter 4 will discuss the research data with implications and conclusion.

I have noticed there is a problem in some hospitals when there are many wards of seniors awaiting placement that are discharged and considered off-service without the services of Occupational Therapists or Recreational Therapy. They have the services of people that are hired to entertain them on special occasions. This situation raises the important question of how do we meet the deeper pastoral care needs of persons whose ability to communicate is diminished. CBC news reported on June 23/2015 that Lloyd Brown, the executive director of the Alzheimer's Society of Nova Scotia said that about 17,000 Nova Scotian's have dementia and that number is expected to double with the next 10-20 years. Brown said that "we've got to get ready for it" (1).

This problem is interesting because when I was taking an introductory clinical pastoral education (CPE) course I was allowed to practice art therapy on the off-service ward. I practiced this as well poetry therapy and assisted a patient to journal her life review. Art therapy as stated by Edwards (2004) and Malchiodi (2014) is the use of visual arts in intervention, counselling, rehabilitation and psychotherapy. According to Malchiodi, "it is used with individuals of all ages, families and groups" (122). Music therapy as defined by Wheeler (2014) and Malchiodi is

the use of music used for psychological, physical, cognitive problems or with individuals with health or educational problems. Poetry therapy as defined by Malchiodi is the use of poetry for healing and personal growth. I was talking with a replacement Chaplain who voiced his unease with visiting patients that were non-verbal. He was at a loss of how to communicate with them but had used music previously with special needs children to engage them. This was interesting to me because I wondered if spiritual/pastoral care workers in other hospitals engage with the patients using any of those methods.

Another factor in this question for me was that years ago a fellow art therapy student quoted Hildegard of Bingen and recently my professors also mentioned her. Kienzle, Stoudt and Ferzoco (2014) revealed that Hildegard through her visions was able to create and illuminate manuscripts, write music, poems and created a special language which she shared with her monastic sisters. It was used as an antiphon in musical compositions. Kienzle et.al. stated that she used the symbolism from the book of Ezekiel and used prayer and rocks to heal. This interested me because two chaplains when I was training used symbolic rocks as well. One used rocks with hand written messages as hope, love, peace and faith and the other used them to engage a non-verbal psychiatric patient and gave them as gifts. Hildegard also created mandalas and circular shaped art forms and this lead me to research Jungian symbolism and archetypes.

I wondered why the book by Bauer (2013), on art ministries had many artists referenced but had no reference to art therapy. I then found references which documented that psychotherapy and pastoral care had historical differences described by Miller-McLemore (1993), O'Connor (2014), Woldemichael et.al.(2013) and Graham (2006). I was confused about this and my professors directed me to check the stance of the Roman Catholic Church on art

therapy in pastoral care. I googled and found the Jean Paul II School and the Center for Special Learning in PA, USA that teaches adults and children art therapy and music therapy, pet therapy and creative drama; and the Catholic Church of Montreal has a mental health program that incorporates art therapy.

I was also led to an article by Kae-Je (2015) where she describes her use of art therapy in her ministry. She is a RN, Psychologist, Pastoral Counsellor and an Art Therapist. This was also evident in the study by O'Connor et.al. regarding non chaplains that were interviewed who use music, poetry, stories and sacred texts when caring for the patients. This was especially poignant when I read about Halpern (2000) attending Clown Chaplaincy School. On one occasion dressed as a clown, she could not interact with a crying boy who was severely burned and went to him and provided pastoral care by creating images on paper. He stopped crying and she drew for an hour keeping him company thus creating a sacred space (1).

There is a gap in the existing research on what clinical spiritual care providers are doing in Canada utilizing art and music therapy and this inspired me to pursue my research.

CHAPTER ONE: BACKGROUND AND LITERATURE

1.1 DEMENTIA

(a) Cause and effect

According to Kestel (2009) dementia is the medical term for a group of symptoms. The decline in areas of intellectual ability interfere with the daily function and results in a loss of mental processes such as vocabulary, speaking, mathematical ability, abstract thinking, judgement and physical coordination and cannot be reversed. It may also include a change in personality. Alzheimer's disease is the most common cause of dementia and affects individuals aged sixty-five or older. The cause may be genetic and environmental factors may increase the likelihood and as the disease progresses neurons in the brains structure are destroyed resulting in the loss of memory, intellectual abilities and physical abilities (18). This thesis will focus on the last two states with the latter characterized by the inability to think and reason. The dementia symptoms may be caused by the continuation of repeated strokes destroying small areas of the brain.

According to Lenshyn (2016) up to 70 percent of the dysfunction of the brain related to Alzheimer's disease is located in the left hemisphere of the brain which controls thinking, memory and language capabilities. Lenshyn states, the right hemisphere responds to "emotion, art, metaphor, picture, stories, touch and music" (2). He also stated that persons living with dementia are freed, as the left hemisphere diminishes, to "experience more of the divine in a truly experiential way rather than a way dominated by the intellect" (2).

Kestel (2009), states that those providing pastoral care need to have knowledge of dementia, to be able to effectively care for them. People with mild dementia are still able to go to

church and most people are not diagnosed until they reach the moderate stage. Caring for the person in the severe stage requires experience and both silent and vocalized prayers for and with the individual are needed (52).

(b) Isolation

Kestel (2009) learned that isolation is a key issue for those living with dementia both living at home and in care centers especially when the person no longer recognizes the visitor. She believes in many areas of need and one comes from “the isolation from self that one experiences gradually through the stages of dementia” (53). Kestel states parish pastoral care can assist the person to retain their self-identity to assist them to not forget who they are.

Brackey in Kestel (2009) describes many ideas for dementia caregivers that can be adapted for parish pastoral caregivers for those that are still able to speak. The person living with dementia only knows the present moment and once a favorite topic or story is discovered the caretaker can use this to trigger the joyful moment. Reminiscence packets with familiar religious articles (a Bible, rosary, booklet of prayers, prayer cards, and small statues) may also be included. Kestel’s suggestion during the severe stage of dementia was to continue to visit the patient and, their care-taker whom could listen and affirm the “dignity of the person struggling to communicate” (54).

(c) Pastoral visits

Kestel (2009) states that people living with dementia deserve pastoral visits even when they are unable to respond or are unaware by providing music, singing traditional religious hymns or listening to someone pray. She had family that did not receive pastoral care and now she provides care to women in the Alzheimer’s unit. Kestel states that she believes they deserve

to "have the parish community listen and respond to their needs… and although they become forgetful they do not deserve to be forgotten by the parish community" (55).

Kevern (2009) stated that care for those with dementia has been rethought as a result of Tom Kitwood's work arguing that it is not only a neurological condition but affects a network of social relationships. He also referred to the work of Stephen Sapp who stated that memory is not only the responsibility of the individual but there is also the community who can remember on "behalf of the individual and in the name of God…do this in remembrance of me." (4) Kevern quoted John Swinton, "it can be seen that human beings are created from and in loving relationships, for loving relationships." (5) Kevern stated that the God found in dementia is the God that is human and divine and not to settle on "social trinity" but to "think together God's vulnerability and God's power" (7).

(d) Spiritual implications

Lenshyn (2016) stated that Alzheimer's disease affects everything about the person with profound spiritual implications and he felt that some could be positive. He said that spiritual change could be affected when sermons, book studies and counselling fail to bring comfort and must be replaced by "other vehicles of grace as the disease progresses" (1). Lenshyn stated that as memory is lost, so also is the conscious, emotional, historical memory of God's acts in the world. Time is "now" and the experience puts them into an encounter with God "I am" (2).

Many references as well as Lenshyn (2016) condemned the philosophy of Rene Descartes in his statement, "I think therefore I am" (2). According to Lenshyn, church people question whether people living with Alzheimer's have a soul. Lenshyn stated they have a soul and should be regarded as being one, because soul and spirituality include more than thinking and include

emotions, body, relationship, hopes and dreams (2). He found in his ministry that people enter an intense, deep, immediate experience of God and quotes John 1:5, "The Light shines in the darkness, and darkness did not overcome it" (2). An example of this happened while I was working as a LPN after a Christmas party. The daily audio playing of the rosary was not played because the machine was put in another room. I sat with a resident and she recited the end of the Hail Mary and said that "they think I didn't notice but they skipped the rosary tonight" and she nodded her head, and then her thought process was gone.

Lenshyn (2016) stated that persons living with Alzheimer's disease live emotional lives and live through the senses (touch, smell, taste and hearing), rather than through the intellect. Spiritual reality can be brought to them by "symbols" such as wearing a large cross, pictures of church or other items from the person's tradition. Lenshyn stated that music and praying are emotional events and emotional memories remain longer than other kinds of memory so "sing and pray" (3). Creating (flowers, little animals, leaves) also have an impact on the soul and puts them in contact with the Creator. Lenshyn said that many people living with Alzheimer's insist on holding onto someone's hand because "touch is a primary need" (4). Silence according to Lenshyn brings peace and divine comfort and to listen affirms the person by sharing of themselves in the "simple" ordinary things of life (4).

(e) Workshops

Sapp (2015) was drawn to Alzheimer's and care of patients, 20 years ago. He held regular workshops and invited religious leaders to attend so they could educate the communities in their area. He noted the workshops were hardly attended and reported the trend has not changed today. He stated the reason is that people are scared of Alzheimer's, avoid it and only

seek information and support when someone close to them is affected. Sapp stated that even people willing to care for them such as (parish nurses, pastors, nursing home chaplains) often do not visit cognitively impaired people because they do not know what to do. He said that it was imperative to educate pastors, congregations and care teams and not only those living with dementia but their families.

Lenshyn (2016) asks and responds to the question of what to do in caring for persons with dementia. As a minister he has brought pictures of Jesus, churches, icons, a large rock and wore a clown nose which allowed for laughter and celebration. He has prayed familiar prayers, Psalms and sang hymns. He has been spontaneous, flexible and led by the residents into their journey and experiences of the Divine. Lenshyn said the people living with Alzheimer's minister to him and helped him to learn about himself, "relationships, time and space, creation, and God" (1).

1.2 LANGUAGES OF FAITH

Having provided a brief overview of the Alzheimer's condition, I will now look at some of the languages of faith that the literature and practice suggests are key in pastoral care with this group.

(a) Symbols

Tillich (1957) stated every writer that used the term symbol, must explain his understanding of it. He identified six characteristics of symbols: 1) Symbols have one characteristic in common with signs, "they point beyond themselves to something else" (41). Symbols participate in reality and unlike signs cannot be replaced. 2) An attack on a symbol is considered blasphemy. 3) It opens up levels of reality and an example is how art creates symbols. Tillich stated that "a picture and a poem reveal elements of reality which cannot be

approached scientifically" (42). 4) Symbols unlock elements and dimensions of our soul which correspond to reality. Symbols open up hidden depths of our being. 5) Symbols cannot be produced intentionally. He stated that symbols which have a social function such as religious symbols are created and accepted "by the collective unconscious of the group in which they appear" (43). 6) Symbols die because they can no longer produce a response in the expression of the original group. Symbols are created in several spheres of man's cultural creativity. Tillich stated that symbols of faith are "manifestations of the divine in things and events in persons and communities in words and documents. Holy things are not holy in themselves but they point beyond themselves to the source of all holiness that which is of ultimate concern" (48).

According to Carl Jung (1964), we use "symbolic terms to represent concepts that we cannot define or fully comprehend" (65). The number and quality of man's senses limit the perception of the world and Jung stated that at some point he reaches "the edge of certainty beyond which conscious knowledge cannot pass" (65). Jung called archaic remnants "archetypes" and defined them as conscious representations (67). Archetypal forms manifest themselves in spontaneous impulses in dreams, visions and can appear in thoughts and have their own energy (78-79). He claimed that we shall find archetypes and "symbolic fantasies, thoughts and actions" in every field of human activity (304).

I refer to symbols and archetypes because through the years of working with late stage dementia clients, I noted that many of them paint circular shapes. I often wondered if the circular shapes were the person trying to paint a head but as I kept watching it stayed as a circular or oval shape. Over and over, the clients applied paint within this shape. It reminded me of a mandala shape (sacred circle) with the client in a meditative state continuing to go around the circle. It

also reminded me that God was present and the person was enveloping themselves and God within this space. Symbols, according to the books in pastoral care, may speak to person with dementia in non-verbal ways. The completed artwork looked embryonic, protected within, cherished by God and finally revealed some form of communication with us. The clients painted in a state of wonder and all had completed painting worthy of displaying on any wall. I helped by loading their brushes and encouraging them to use many different colors of paint. They kept applying the paint until they were finished. Most completed designs by this population stayed within this circular oval design. This need to create does not end because they have dementia but for some begins because they do not hold back and are less inhibited. I have had clients paint within days of their passing away. I believe these paintings are gifts from God and I have had some families take them and share them with their loved ones.

I displayed some of these paintings in the entrance of the local hospital and a woman that had just finished her chemotherapy treatment at the clinic stopped and asked to purchase them. This artwork touched the Alzheimer's resident while producing it, touched the family, touched me and touched the people looking at it. Most of the artwork displayed that day was done by a female client living with Alzheimer's that needed one on one assistance. Without aid the paint brush by her was mistaken for a utensil and although the paint was non-toxic she needed someone to point the brush downward and assist with refilling the brush with paint. This resident could not speak and could only verbalize "yes." This resident had quilted in her life-time and she was still able to create instead, by painting. I am inspired to share this story in her memory.

(b) Hildegard and music

Frieson (1995) wrote about Hildegard's creativity and the healing color green which she called "viriditas" which means life-giving energy, of which she found evidence in biblical writings (18). Hildegard became famous in theology, music, medicine, philosophy, poetry, visual arts and more. Hildegard had a visionary experience when she was in mid-life and found her inner call to record her experiences. She developed the viriditas concept as "life giving creative energy in which human beings participate in order to adorn and complete God's creation" (18).

According to Frieson (1995) Hildegard was convinced that everything in the world (flames, plants, rocks) is kindled by viriditas and becomes alive with energy which results in wholesome life (23). Frieson stated that "God assists eagerly in human creativity and wants people to share in divine creativity" (23). Hildegard stated that creativity depended on good works and virtues and the soul had three powers, "comprehension, intelligentia and motio" (25). The later was the energy of the action of creativity.

Frieson stated that in Hildegard's songs she praised the greening life energy and portrayed them as a circular mandala "rooted in the sun…and embraced by the mysteries of God" (26). Although she was supervised and examined by the patriarchal church Frieson stated she believed in traditional models with regard to male dominance but still portrayed female imagery such as "the womb of God and the cosmic egg cooked by life experience" (26). Frieson stated, that in her fourth illumination of her book Schivas she described the cosmos as an egg "with manifold layers of fires, waters, winds and cosmic forces" balanced inside being both beneficial and harmful (24-25). In her ninth image of Schivas, Frieson said she Hildegarde portrayed nine choirs of the angelic hosts in circles (mandala) and she stated that "angels marvel

at the works of humans and fill the heavens with the praise of human creativity" (25). Hildegard's art relates to this thesis by her doing her artwork in circular forms as was seen in the art work of many residents that I provided art therapy to. While I facilitated art therapy with the residents we also listened to music which assisted some of the residents to remain awake and also sing with the music. Frieson's description of the cosmic egg's manifold layers could also refer to the residents layered artwork except the completed art work is not harmful.

According to Malchiodi (2007) mandalas are circular forms in art. She said that in Sanskrit, mandala means "sacred circle" and is also known by Tibetan Buddhists as the Wheel of Time symbolically illustrating the structure of the universe (122). She stated mandalas and circular forms have been used in healing ceremonies such as the sand mandalas used by the Navajo people in the Southwest. Carl Jung believed the mandala image was encoded with humans and represented a potential for change, transformation and self- actualization (123). With the information by Jung, Hildegarde and myself regarding mandalas and circular art, I wonder if other spiritual/pastoral care providers utilize mandalas in their creative arts practice.

(c) Icons and relevance today

Tobin stated that art therapy could be used and icons could be created and were defined as "pictorial images that nonverbally represent the clients' transcendental conceptions" (8). Tobin (1988) stated that clients in therapy talk about physical survival; psychological such as (belief, behaviours, emotions, and experiences); esthetic (what pleases the sense, feels good); ethical such as (rights or fairness and issues such as guilt or forgiveness); and transcendental includes (religious, metaphysical, spiritual). Transcendental knowledge as described by Tobin goes beyond the limits of sensory experience and is intuitive and mystical and involves talk

about “God.” (3) Theorists such as James, Maslow, Jung and Grof view transcendental concerns as an essential valid aspect of the human psyche which includes God, angels and heaven. Tobin stated that therapists should not ignore transcendental discourse but tap into it, evaluate it, encourage sharing and enter into the client’s experience in a non-judgemental way.

In pictorial representation the verbal layer is stripped away leaving the client to focus on the nonverbal the one’s personal transcendental world connects to the person on the emotional level making a difference to their well-being. Tobin stated that after a client finishes a depiction he encourages them to spend quiet time with it and discuss their feelings. Tobin also looks at the paintings color, structure, form, size and shape and asks the client to tell him about the painting. According to Tobin the question the therapist asks is, “what does the icon tell me about how the client experiences self?”(13).

Tobin’s six generic insights of transcendental perspective include: 1) Religion involves a set of communally shared beliefs and practices and may be the conventionalized response to spiritual experience. Spirituality involves an experience of the unity of self and the world in God and one may have spiritual awareness without being religious. 2) Spirituality is not preoccupied with the supernatural or the magical. 3) God is inside the person and is not just inner experience. 4) Satisfaction is being aware of God’s presence. 5) The icons are projections of self as a representation of God and this insight may lead to the realization of God as a resource within self. 6) Spiritual experience is likely to be found as one becomes less rigid about it. The presence of God may involve inner receptive conceptual quietness (14). Tobin stated that clinicians can only assist clients to the point in life where they themselves have reached and cannot “assist anyone farther down a path that we ourselves have walked” (14). Although his work was not

with dementia patients, his descriptions of how icons work help illuminate what could happen at the level of the sub-conscious in persons unable to communicate verbally.

(d) Aphasia

Aphasia is the loss of language or voice, can ironically be a language of faith because the person relies on God and his intervention to assist with activities of daily living. Caretakers need to watch the person's body language in order to comprehend what the person is communicating. Richard Heatley, a chaplain found that in order to provide pastoral care to a hospitalized female, he could not rely on his interpretation of her continual repeating of "Swanee River" meant (the only words she could verbalize). After listening to her saying it in many contexts, Heatley realized that she used it to communicate and that if he conversed with her and she used "Swanee River" that he would continue to converse with her by following the emotional inflections that she used behind the word and watching her body language (10). Heatley says that even to those that cannot say anything, times of joy and grief are apparent and the important thing to remember is their cognitive abilities are not affected and that God wants us to use our voice to communicate "to them" and not "at them" (10). According to A. Ask (2016) of the American Speech Language Hearing Association a person with aphasia often has intact non- linguistic cognitive skills.

Aphasia as defined by Johnston (1999) is a name given for "interference with the comprehension and use of language, or loss of voice" (27). With aphasic people there also can be changes in behavior especially when the person becomes frustrated that they cannot communicate. The disturbance occurs in the left hemisphere of the brain and may also affect memory (28). An example as described by Johnston was an art therapist that worked with

aphasic patients by using drawing and symbols. Sometimes aphasia is accompanied with Parkinson symptom's (shaking) or problems with visual acuity. It is important for the art therapist to find activities that the patient is interested in and physically able to do. Johnston stressed the importance of all nonverbal skills and the interaction of the art process which also included the patient's integrity and pride in the art pieces (38).

(e) Creativity language and neurological considerations

Zaidel (2014) studied the biological roots of creativity and examined the consequences of brain damage as they apply to the visual art productions of people living with dementia, Parkinson's and autism. Zaidel found the roots of creativity were not limited to social or communicative considerations, but noted the motivation to communicate through art, when language fails. Gonen-Yaacovi et.al. (2013) in Zaidel found neuroimaging evidence in healthy volunteers. When they were being creative they showed left hemisphere activity and both cerebral hemispheres were functional in exceptional creativity. According to Renzi (1982) in Zaidel, when the right parietal lobe had been damaged the left half of the canvas was left incomplete by the person. He wrote of patients that started to practice visual arts after brain damage occurred with the explanation that art is a communicative system and conveys emotions, ideas and concepts. As dementia progresses there is a degeneration of neural pathways and the person that never did art may now be less inhibited and becomes creative (7).

According to Zaidel (2014) and other scientists the interplay of frontotemporal lobes and dopamine may also cause a loss of inhibition (8). Zaidel found a patient began to write poetry within the first month of taking medication. He concluded that healthy neural connectivity and normal levels of the dopamine neurotransmitter are likely essential for creativity. Zaidel stated

that dormant creativity, esthetics and art are exhibited by people that had never expressed it before and the answer partially may "lie in our biological past" (8).

(f) Art therapy

I include art therapy as a language of faith because I believe that it is a way that God communicates to the person living with dementia. I believe that people engaged in creating allows them to find joy when in some instances even in loss. Art therapy has its roots in philosophy, psychotherapy and science. Functional magnetic resonance imaging (fMRI) studies as described by Aziz-Zadeh, Liew and Dandekar (2013) measured neural activity in right handed architect students with normal vision. The students according to Konopka (2014) were given a visual creative task and a control task with the result supporting the "notion that higher motor planning may be a component of creative improvisation (visual, verbal or auditory)" (8). Konopka stated that art therapy modifies the brain's physiology which leads to a more flexible, adaptable individual (1). Konopka stated that using art is a novel way to engage the brain's way of processing information, incorporating internal and external data and developing new brain connections (2).

Bagan (2016) stated that making art or even viewing art causes the brain to reshape, adapt and restructure "thus expanding the potential to increase brain activity" (1). According to Carr (2014), Edith Kraimer's (2000) third hand technique intervention (becoming the patients hand during the visit and doing the art as per the patient's directive) helps the patient co-design and view artistic images (55). Carr stated that third hand interventions were effective because the "imagined phenomena are not just a fragment of our imagination they are part of our embodied experience" (63). Many patients have photographs of their loved ones in their rooms. She

explains there is a link between love and aesthetics in the brain and looking at an image of a loved one activates the production of dopamine (feel-good chemicals) in the brain. Holland & Kensinger (2010) in Carr state that studies have demonstrated that emotional events are remembered more than neutral events.

Susan Dodge-Peters Daiss (2016) in 2002 created and implemented “Art at the Bedside” (56). Dodge-Peters Daiss was an art historian who ventured into this from taking a CPE course and seeing a need for being able to use the tool to facilitate communication within an acute hospital setting. She intertwined her dual training of art museum curator and hospital chaplaincy and evolved the practice into training chaplains, medical and nursing students, to introduce them to understand observation and apply it to their professional practice. The question left with Dodge-Peters Daiss was “how might the art and observation practice be applied to training practitioners for “Art at the Bedside?” (57). Dodge-Peters Dais, during her CPE training, observed there was a need to utilize her God given talent to facilitate a communication technique to minister as well as to teaching this holistic care to others within the community (58).

(g) Music therapy

What are the benefits of music therapy in Alzheimer’s and dementia care? Kirkland (2015) described a small study by Morberg et.al. (1986) measured heart rate, breathing, eye blinking and mouth movement responses. Music accessed the right hemisphere and limbic systems and Sacks stated that “we listen to music with our muscles and is process at the brain stem level and activate the limbic system” (1). Music Therapy as stated by Kirkland is a catalyst for reminiscence and some patients that rarely speak or can put sentences together may remember all of the words and still be humming it after it finishes (1).

Kirkland stated that the autonomic nervous system is sensitive to pitch which causes tension and low pitch is more relaxing (2). Music played during meal-time assisted the clients into sitting longer and eating better (3). Many patients pace and their bodies become exhausted, but they cannot stop. Kirkland stated that he remembered a client that was put in a restraining chair after his session with a large bell tree that he would lay on its side and give her a wooden mallet to play for sometimes 2 hours at a time. This gave her body needed rest (some restraining chairs cannot be used at some institutions). Kirkland stated that physical restraints for clients were not needed during the music therapy (2).

(h) Narrative therapy

My aim is to seek spiritual/pastoral care providers that provide art, narrative, poem or music therapy to seniors that have Alzheimer's disease or aphasia. Long (2013) stated that narrative therapy was developed by Michael White (d. 2008) who was an Australian social worker who ran the Dulwich Centre for therapy. Narrative therapy is understood by listening as people relate their experiences through stories about their lives. White felt that Narrative therapy viewed client/patients as part of a community and that if the client has a problem they are capable of changing their narrative which is not "fixed" (2). Long stated that spiritual care providers who utilize narrative therapy, are to help their clients uncover their strengths and alternative stories (2).

(i) Singing for the Brain

According to Osman et.al. (2014) singing for the brain (SftB) was established by the Alzheimer's Society in 2003. SftB is a service provided by the Alzheimer's Society which uses singing and other activities to bring together people with dementia or memory loss. Twenty

paired participants were interviewed in the UK. A thematic analysis revealed the themes of social inclusion, shared experience, positive impact on relationships and memory, spirits lifted and acceptance of the diagnosis (5). SftB provided a shared enjoyable positive experience for the people with dementia and their caregivers. SftB stimulated memories and provided topics on which to reminisce. The memories evoked were specific, recalled faster and had emotional substance. According to Johannessen & Berntsen (2010) in Osman the music acts as a cue to stimulate involuntary autobiographical memories (8). SftB's aim was to improve quality of life, communication and social engagement and followed themes such as the "the weather or places" (3). According to Osman et.al., "for the person with dementia the realization that their ability to remember, helps to give them a feeling of hope and positivity" (7). The findings support the claim that people with dementia should be included in research that focuses on meaning and demonstrated the value of music for people with dementia.

1.3 POST MODERN PASTORAL CARE IN THE HOSPITAL

(a) Pastoral care in the postmodern age

Post modernity has signaled some relevant changes in pastoral care. Thorstenson (2012) was explicit in his description of re-defining pastoral care for the postmodern age. Symbols, language and concepts in 20th century religious thought were being replaced with new discoveries in neuroscience, scientific theories, and process thought. Thorstenson stated that the shift does not mean the demise of religion, but in health care settings it is combining needs and requests of patients; meeting the expectations of colleagues in other medical disciplines; the administrators focus on patient satisfaction scores and the “efficient use of every dollar” (5). Thorstenson states that chaplains and pastoral caregivers in contemporary times involves, healing the mind and the spirit as to assist people to face “existential struggles of the human condition with “resourcefulness and courage” (5).

(b) Canadian eras of Pastoral care

The Canadian eras of pastoral care (or spiritual care as some chaplains refer to it) are relevant to this paper because the thesis entails research in Canada and the United States, where pastoral care has evolved impacting the need for creative arts.

O’Connor (2014) stated there have been three eras of pastoral care and the model of clinical pastoral education became increasingly influential. In 1964 the development of the pastoral counselling program occurred and medicine and social sciences united “theology, therapy and health” (6). At that time the theology of Paul Tillich was crucial to the pastoral counselling program and courses on his theology were offered to students in pastoral care and counselling (6). From 1977-2003 the Association of Theological Schools (ATS) was founded

and Clinical Pastoral Education (CPE) units were required as part of the Master's degree for many schools. Many sites were used which included hospitals with classes that consisted of social work, theology, counselling and marriage and family students (7). In 1982, ATS moved into a multi-faith dimension (9). From 2003-present the name was changed from pastoral care and counselling to spiritual care and psychotherapy (9). Another change was to replace the name of the Master's from Pastoral Counselling to a MA in spiritual care and psychotherapy (9). The third change was the connection to other professional associations. The fourth change was the greater emphasis on research and publication (10). Through the three eras the pastoral counseling model was extended to the practice of non-Christians and as stated by O'Connor, "there is an emphasis on inclusiveness and diversity"(11).This is important to discuss as most of the research participants had CPE units and some had done extensive training for accreditation within their provinces to enable them to continue working in the field.

(c) Pastoral identity within postmodern and multicultural contexts

Park's (2012) conducted 20 interviews with chaplains and pastoral counselors from varied religions with the research question "of how pastoral caregivers establish pastoral identity in their care-giving practices within postmodern and multicultural contexts?" (3). He noted that care seekers share their stories while caregivers are present with them and respond to their stories and needs (9). Park concluded that his findings found the social construction perspective occurred during the pastoral visit through care-giving interactions and as the relationship proceeds the helpers provide pastoral presence and support (9). By being present with, listening to, learning from and accompanying the care-giver relationships with the care-seeker was deepened and God's presence and power was realized. Park stated that future studies were needed to "examine the influence of institutions on pastoral identity" (9). Although Park's

research does not mention the population that care was provided to, one can assume that it also accompanied patients living with dementia and their care-givers. Pastoral identity in post-modern times is impacted by increased dementia by the types of technology utilized by spiritual/pastoral care providers such as hand held devices (i-pads, phones) and many other programs utilized by recreational therapists. Spiritual/pastoral care providers have to consult with other health care professional as to what they can do to assist the patients after making their own assessments.

(d) Aesthetic solidarity

Aesthetic Solidarity as defined by O'Connell (2011) is the determination to become fully human by risking "the vulnerability that comes with creative self-expression so that we might tactilely experience together in our bodies and hears what it feels like when we are all really responsible for all"(14). Higbee in O'Connell says it is the freeing vulnerable experience with the feeling of joy and energy taking control. An example in O'Connell were the Juntos dancers that performed to all age groups in Guatemala in civic spaces, schools, the retirement community, dance workshops and at a juvenile detention center (84).

According to O'Connell some characteristics of aesthetic solidarity include that it breaks people out of narrow, hierarchical ways of understanding themselves so that different insights might take hold. It turns to the arts to create space for people to share, "to read and be read by others to engage difference" (85). Aesthetic solidarity motivated (creative acts) where people create something new and fosters an embodied experience of living in right relationships. O'Connell stated that one dancer said, "I saw dance's power to transport an individual back to a certain time and place and to act as a window into one's memory" (85). Aesthetic solidarity fits in with post-modern pastoral care because whatever used to work in the past concerning patients

living with dementia may not work today. Spiritual/pastoral care providers that think that they can go in and say a prayer and leave, is not spending time to know and communicate with the patient. Postmodernism may also include when care is provided in group settings and time must be spent to identify what the patients like and respond to. Aesthetic solidarity is a need that has been identified which is particular to post-modernism because as long as people can still spend time with the patient and not just push a button on a CD player or turn on a television then go, then spiritual care assessments can be done and care provided in appropriate ways.

According to Pope Jean Paul II (*Solicitudo Rei Socialis*) in O'Connell (2014), suggests that solidarity is the pre-condition for the common good and shared vision where all members of society be empowered to contribute their gifts. A rejuvenated imagination creates the possibility for creative encounters among persons that unleash the creative power of justice (85). When oriented toward justice the common good is a way of envisioning the spirit of creativity within people and created ties among them. O'Connell stated that "aesthetic solidarity ensures that all persons involved in creative acts of justice experience a kind of transformation that comes with tactilely knowing what it means to become more and more human" (85).

(e) Aesthetic agency, marginalization, imperialism

Edwards (2013) refers to aesthetic agency as the "conditions, capacities and states that inform creative and artistic forms of acting and exerting power on social structures" (13). Aesthetic agency is exercised through creative art making, culture and through critique in order to challenge domination practices. Edwards articulated a process for aesthetic agency in Christian communities and states that the ethical problem of cultural marginalization is a theological one (13). Although Edwards writes about the marginalization of black women, her

research could also inform the situation of seniors living with dementia. I feel that many people living with dementia are living in the time of their lives when they have no fear of trying something new. I think that our culture must make space for the aged, as they should be our valued elders and have contributed to not only our past but our futures as a human race. Aesthetic agency that opposes marginalization depends on challenging power structures by presenting visions of the marginalized and expressed collective voices. Edwards states, “a shift from self-centered subjectivity to collective subjectivity is required because marginalization is not most potent at the individual level, but at the social or community level” (11). Marginalization, oppression, realism and sexism caused division and efforts to counter them established community and humanity. Wholeness and salvation are found and provided through the community by God. Edwards stated that song composers, creators of litanies communicate not only to each other but reach out to the spirit that “transcends them all” (10). Aesthetic agency applies to seniors living with dementia because they should not just be hidden away in homes but have outings that take them out to art galleries, concerts, church and church picnics, and anywhere where there are children, family pets and families. We as a society are seen as not valuing what is not productive and that must change because the aged are not to be forgotten or seen as just people that sit in chairs and sleep.

1.4 DEMENTIA AND PASTORAL CARE

(a) Studies of spiritual care in dementia

A phenomenological study was conducted at an urban tertiary care center in Atlantic Canada in 2011 by nursing researchers asking the question of what it is like to receive or provide spiritual care in dementia. The study was conducted on the geriatric care unit by Carr, Hicks-Moore and Montgomery (2011) and had 29 participants which included patients, families, R.N’s

LPN's and five hospital chaplains. Interviews were conducted, recorded and a thematic analysis provided common themes and meaningful findings such as "the little things" (405). According to Carr et.al. the "little things" were described as the inclusion of needs they "might not have been able to verbally articulate" and religious acts such as "singing hymns, saying prayers and reading scripture" (405-406). The implications showed that health professions need to incorporate a broader understanding of what constitutes spiritual care in dementia. Caring for patients in dementia include the "little things" like talking to them and building a relationship. Unfortunately, spending time with vulnerable persons is still sometimes criticized as not really working by some in both practice and supervisory positions (411). The authors not only included chaplains in their study but suggest that administrative support, social workers, recreational therapists, physicians and others needed to be included in also providing this level of spiritual care needed by the dementia population. It is important that any person that comes in contact with a patient living with dementia must provide care by respecting the fact that although some of them cannot communicate, the patient may still understand what they have said verbally, audibly and emotionally.

An ethnographic study in Waterloo, Ontario was conducted by O'Connor, Chow, Payne, Young, Rivera et.al. (2010) from a sample of 20 health care professions. The health professionals included music therapists, psychologists, occupational therapists and recreational therapists who utilized music, poetry, stories and sacred texts such as Christian scriptures. Many barriers to spiritual reflection were noted among nurses, social workers and occupational therapists and included a lack of time. Interviewees used music, art, poetry, literature, stories and sacred texts, personal experiences and family friends and colleagues as their sources for spiritual reflection. Eleven out of 20 people interviewed used music, art, poetry and literature as their

spiritual source for reflection. A comparison group with chaplains, pastoral counselors and theological students was studied and they mainly used Christian scripture. Some of the similarities between this study and the comparison group that were meaning making and reflection were essential for spiritual care whether done by a medical professional or a chaplain. The question for this study was whether health care professionals and chaplains could collaborate and share resources and the findings invite such a collaboration. This study revealed that many health care professionals want to provide spiritual/pastoral care but do not have the time or resources to do so. This study as well hopes for continued collaboration between health care professionals, chaplains and spiritual/pastoral care providers.

(b) Namaste care for dementia patients in the hospital setting

Namaste care is a Hindu term meaning to honor the spirit within. Namaste care was developed by Joyce Simard who is a social worker and dementia care specialist who has been working in long term care for over 38 years. She developed a program for people with memory loss to enable them to "honor the spirit within" because they can no longer tell us who they are or were, or care for themselves unassisted. Through this program Simard helps people live and not just exist. She stated that just helping people to be clean, fed and groomed merely exists. She stated, "people need to be engaged in meaningful activities, they need to feel wanted, loved and need to feel as if they can contribute" (1). She hears stories of residents talking when they had stopped having conversations with family members.

St. John & Koffman (2015) wanted to see if Namaste could be implemented in the hospital setting. Eight interviews were conducted with healthcare staff and two themes emerged. One was the difficulty in establishing relationships because of lack of time and resources and

another was the benefit of reduced agitated behaviour and improved communication (valuing and care). St. John & Koffman, referenced a study of Bell and Troxel (2001) which described the spiritual needs of people with dementia that includes the need to: connect with others; to be respected and valued; to be loved and serve others; to feel recognized, known and understood; to be helpful; productive; involved in the community where they live; to be in the flow of life; to find meaning, hope and purpose; to engage in religious activities/behaviours; and others. In order to achieve this they advocate for Namaste care.

Namaste care as devised by Simard in St. John & Koffmann is a programme for people who are socially withdrawn, have severe cognitive impairment and limited verbal abilities and require total care. The program uses touch, music, colour, reminiscence, massage and aromatherapy. A caregiver would provide this care for example by combing their hair, giving a shave to a gentleman, painting the nails of a woman, applying lotion to their extremities, providing aromatherapy by putting a vase of lilacs on the table in the spring or burning a cinnamon candle in the fall and having multi-colored fall leaves for them to touch. The findings showed that many patients required one to one care and the staff could not manage this while working on the ward. Fullarton & Volicer (2013) in St. John & Koffman found that people with advanced dementia spend long hours left alone in communal rooms with minimal interaction with caregivers or are alone in their rooms (9). Namaste care in the hospital setting helped bridge this gap and provided a means of improved communication, in the participant's sense of connection with patients and provided pleasure to staff delivering the care as well as the patients receiving it (9).

(c) Communication strategies among people with dementia

The Communication Enhancement Model is based on the individual cues and caregivers that modify their behaviour in order to meet the needs of the older adult. This may include becoming aware of the environment (such as removing noisy triggers such as turning off the television) and facilitating an adult's conversation and participation (such as singing old hymns). Communication stated by Ryan et.al. (2005) and Martin et.al. (2010) also means attending to nonverbal cues such as "tone of voice, eye contact, timing, facial expressions, gesture, body posture and touch (49). Reminiscence and connecting through life stories is beneficial with persons with dementia and recording life stories for a family legacy is important as the teller loses verbal connections. Everett (1996) in Ryan et.al. suggested that even the most "severely affected individual can experience God's presence through sensory experiences of life that are richly symbolic" (54). Sitting quietly in an outside courtyard can assist the person living with dementia to stimulate the senses and honor "the relationship with God and the universe" (54). Simple interactions as swaying to the beat of music, savoring a meal and engaging in activities that have symbolic meaning, making them feel valued while refreshing their spirit. Julian Hughes in Martin et.al. sought to identify the dilemmas posed by the absence of verbal communication when trying to understand the wishes of a person with dementia. Hughes said that our knowledge of their narrative history; psychosocial; spiritual and cultural background assists us by "being with someone rather than doing" and through this the meaning is felt (286).

(d) Relational spirituality and social constructionist perspective

The philosopher Ochs (1997) in Favor (2004) has her "relational spirituality" model featured by "the insight of interconnectedness" (242). Och's definition of spirituality is defined as "the process of coming into relationship with reality" (242). This definition is consistent with

Berger & Luckmann (1966) in Favor's social constructionist perspective which "holds that humans created reality by assigning meaning to symbols, events and interactions" (242). According to Favor, in addition to Och's definition of spirituality, relatedness involves connection with a sacred other, with people and with meaning beyond oneself which sustains the capacity for caring and produces joy and vitality (242-243). The constructionist perspective relates to pastoral care with dementia by working with caregivers and families to understand what the patient may want such as reciting favorite prayers, going to the chapel to be with others during the service or connect with nature by having cards featuring nature scenes. The most important feature is relating to others and be present to be able to recognize the patient's needs.

1.5 SUMMARY OF CHAPTER ONE

Dementia is a medical term for a group of irreversible symptoms that include a loss of mental processes which includes loss of vocabulary, speaking and affects the person's activities of daily living. Having the loss of many abilities results in the person being alienated from society and withdrawing into themselves, forgetting their loved one's names and their lives except for the present. Studies are being done in some acute hospitals in which allied health care specialists do spiritual assessments and provide holistic care is a beginning in the understanding of the needs of the dementia patients. Researchers have tried to involve people in taking workshops to provide care to persons living with the dementia. The result showed they will attend workshops if a family member is afflicted but it is fear that prevents them from participating sooner.

Hospital chaplain's roles include pastoral care visits to all populations within the hospital settings. Studies have shown that creative arts assist people living with dementia to connect with

their loved ones, to socialize and decrease episodes of agitation. Moreover, studies have shown that spiritual connection through religious objects, pictures, art, music and prayer assists the patients and their caretakers. I included cases of people living with dementia to portray symbolism, relationships and personhood involved in the caregiver/patient relationship.

The next chapter will describe the demographics, the methodology of the research and the description of the gathering of participants for the interviews conducted at various major hospital settings, related to spiritual/pastoral care visits and people living with dementia.

CHAPTER TWO: METHODOLOGY

2.1 METHODOLOGY

My research question is how do spiritual/pastoral care providers assist people living with dementia and what creative art therapies are being implemented. I used a phenomenological approach to my qualitative research. Phenomenology as defined by Merriam (2009) is both a twentieth century school of philosophy associated with Husserl and a type of qualitative research with its own focus and methodological strategies (24). Van Manen in Merriam stated that phenomenologists are interested "in our lived experience" (24). It is a study of people's experience of their "everyday life and social action" (24).

Allen (2005) states that philosophical phenomenology and its relevance for the phenomenology for religion has 5 characteristics (189,197). 1) Descriptive nature. Phenomenology is a rigorous descriptive science approach that is directed toward intuition and description of phenomena as they appear. It attempts to describe the nature of the phenomena, the way it manifests and the human experience. It attempts to avoid reductionism and describes the diversity, complexity of the experience. 2) Antireductionism. It is concerned with freeing people from preconceptions and thus allows them to broaden the experience with more accurate descriptions. In opposing oversimplification phenomenologist aim to deal with what phenomena reveal, "in their full intentionality" (189). 3) Intentionality. Phenomenology analyzes acts of consciousness on an object given in the intentionality of the structure. Scholars must be attentive to the object in order to be able to identify, describe and interpret the meaning. 4) Bracketing (epoche). Is defined as a suspension of preconception, judgment and assumptions and enables the phenomenologist to become more aware of the phenomena of the experience so they can

gain insight. Bracketing entails the suspension of value judgements and is an experience of ultimate reality (199). [3] The essence (eidetic vision). Essences express the "whatness," the necessary feature of phenomena that allow us to recognize "phenomena of a certain kind" (190). Phenomenologists aim at "intuiting, interpreting, and describing the essence of religious phenomena "and essence refers to unapparent experience and must be uncovered and interpreted" (199).

Merriam states essence of a phenomenon can be for example the essence of loneliness, being a mother, or being a participant in a particular program (25). The task of the phenomenologist is to depict the essence (basic structure of experience) and the phenomenological interview is the primary method of data collection (25).

After phenomenological reduction occurs the essence is revisited and the phenomenon is isolated in order to comprehend its essence (Merriam 26). Horizontalization as defined by Merriam is the process of examination the data, treating it equally with "all pieces of data having equal value at the initial data analysis stage" (26). Imagination variation views the data from various perspectives and the data is then organized into clusters or themes (26).

The phenomenological approach as defined by Merriam is suited to studying affective, emotional, human experiences, imagination and creativity and the reader comes away with the feeling that they understand what it was like for the person. This phenomenological research can reveal ways in which spiritual/pastoral care provider's value and interpret the imaginative experience of their patients and suggest challenges that others need to address if imaginative experience is to be legitimated and sustained as worthwhile pastoral care practice.

[3] Bracketing (epoche) is of utmost importance. Although I have worked with this population nothing ceases to surprise me. There can be no preconceived assumptions.

(a) Phenomenology of perception

In 1964, Merleau-Ponty examined how art (specifically painting) “displays the act of viewing the world with openness and immersion that is more truly representative of the continuum of existence” (1). According to Wilson (2003) Merleau-Ponty stated that it is through the body that perception becomes the means through which consciousness establishes itself. By painting, the mind rejects the conception “that space is an entity separate from, outside of, and indeterminable by perception” (2). Merleau-Ponty insists that the body is the center of perception and in order for consciousness to exist it must be embodied.

Kontos (2014), questions whether the ability to paint as Alzheimer’s disease progresses in a person, resides deeper than cognition? She states that Merleau-Ponty’s definition of perception offered an alternative to the distinction between conscious will and unconscious intuition. (3) Merleau-Ponty, stated the body itself has a “primordial capacity for movement and gesture and locating aging is in the body (an embodied know- how process) and not just the mind” (4).

Kontos referred to the abstract expressionist Willem de Kooning who lived with Alzheimer’s and from deep within himself continued to paint. His creative actions painting according to Fraser were informed by humanity and feeling. [4] Kontos argues that the persistence of creativity despite advanced Alzheimer’s disease “exemplifies the existential expressiveness of the body that is a fundamental source of selfhood” (4). This is an example of how rethinking selfhood is the recognition of the human dimension of how individuals living with Alzheimer’s disease can improve their quality of life and quality of care (8).

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[4] See example of his art work @https://wwwtownsendcenter.berkeley.edu/…/painting-memory-aging-willem-de-under view pdf

Kontos research focuses on selfhood theories of embodiment and the use of art- based methodologies which also includes using drama to improve person- centered dementia care. Kontos (2011) developed a 12 week training program for health care professionals working with people with dementia. Her findings suggested that drama was an educational tool and practice outcomes included the awareness that resident's body movements and dispositions convey meaning and supports resident's independence. Kontos worked with a playwright to create vignettes to teach practitioner to see the true person and reveal the importance of non-verbal self- expression for person centred care (2).

Bourque's (2014) review of Angelica's (2014) book stated that when she cared for her Mother living with Alzheimer's she used improvisational theater. Rather than correct her Mother's statements she would follow the thread of the conversation "to make the scene partner look good" (1). She said that by improvisation and insight it was fundamental to "Healing Moments" of which she founded an organization after. Bourque stated that Angelica explained how the "improv way of being in the world can open doors to spirituality," based on mindfulness and being in the moment (1).

2.2 RESEARCH PROTOCOL

(a) Methodology

1) For my study e-mails were sent out to major hospitals in Canada and the United States to invite spiritual/pastoral care providers who work with the Alzheimer's population using creative arts to participate in research. 2) Those who volunteered to participate signed a consent form, stating they understood that the interview was on a voluntary basis and their identity protected. 3) The time was scheduled for the interviews accordingly. 4) I interviewed the

participants about their work. 5) The interview transcripts were listened to and transcribed. 6) The Spiritual/pastoral care provider was sent a copy of the verbatim. 7) A thematic analysis resulted from the interviews. 8) All revealing information such as names and places were changed for confidentiality.

(b) Research questions

The questions asked to each spiritual/pastoral care provider were:

1) What is your position at this hospital?

2) How long have you provided pastoral care to the Alzheimer's population?

3) How do you introduce the therapy?

4) What kinds of creative arts therapies do you use with this population?

5) How do you perceive the benefits and impact of these types of therapies in contrast to other modes of provided care?

6) How are the creative arts methods perceived by the staff and family members? Do you include family members?

7) Do you have time constraints? Do you use creative art therapies only in groups?

8) How did you receive your training to enable you to provide care?

9) Can you share any stories after using therapy? How do you know when pastoral care using creative arts is effective?

10) What area of the hospital do you conduct creative arts?

11) Do you provide creative arts sessions on request or for rituals or special holidays?

12) Do you display the creative art work? Does the hospital provide materials?

13) What else can you tell me that I haven't asked you?

(c) Demographics

Thirty-one emails were sent to the U.S. and 42 e-mails sent within Canada. I sent a letter to the Canadian Association for Spiritual Care (CASC) and the webmaster sent out a mass invitation letter across Canada. Within a short time 59 e-mail respondents sent me notes either to participate or sent in best wishes. Some respondents also sent me referrals for who they knew used creative arts. Some respondents were from parish nursing, corrections, pediatrics, mental health, oncology and those providing creative arts for grief support.

The end result was 13 females and 9 male participants. One male and one female were from major areas within the U.S. and 1 male referred to his rural U.S. experience. I named the 22 participants as Brendon, Bruce, Lila, Pierre, Fiona, Anne Marie, Laura, Roger, Alice, Betty, Anne Marie, Gwen, Sally, Brian, Samuel, Josephine, Marilyn, Joshua, Judith, Barry, Robert and Bonnie.

2.3 THEORY

This section examines some specific theoretical concepts that undergird creative arts in pastoral care with dementia patients.

(a) Concept of hope

Browning in Hiltner (1975) described William Beardslee's work on the meaning of "hope." Beardslee stated that healings are signs of the coming of the Kingdom and active hope is the response of the early Christian to the "not yet fully realized Kingdom of God" (161).

Beardsley described creativeness as a cultural process providing a motion toward complexity and intensity which can "come to consciousness as hope" (44). He believes that hope can appear if men believe that creative possibilities have not been exhausted. Beardslee's three aspects of the meaning of hope include: 1) Eternal life as contribution to the culture. 2) As everlasting valuation and remembering by God. 3) As the actual renewal of the self after death (138).

Mackinlay & Trevitt (2012), states that hope is personal and communal. An elderly person who has belief in their own abilities has hope even though there might not be physical evidence to support the hope (153). They also state that for most there is belief in the after-life which gives a sense of hope of "things to come, not only focusing on the things of this life" (153). In Mackinlay & Trevitt, Frankl (1984) a psychiatrist and holocaust survivor saw among those that survived the concentration camps of World War II people who hoped in their hearts to be reunited with loved ones after the war. Frankl also witnessed those that lived in the same circumstances had no sense of hope and died.

Wolverson et.al. (2010) in Mackinlay & Trevitt studied hope among people with early dementia and found 8 themes by studying the transcripts and interviews (157). They are: 1) Prayer. Participants included those of Anglo-Celtic background with dementia in residential care. One of the residents prayed every evening and saw hope as part of her every day journey. 2) Sense of acceptance of life and all that it brings. It was evident in some of the comments that the participants had such as being ready to die and being ready to face the final part of life. 3) Hope and faith. Some of the participants spoke of the support that their faith brought them. 4) Still wanting to engage with life. Some participants hoped for good health and wanted to travel. 5) Family. Some participants had concerns for children and grandchildren. 6) No sense of hope,

resignation. A participant saw no hope in life but seemed to continue to live without "any perceived source of hope" (164). Another participant associated "hope with activity" and that because she could not play bridge with her friends, life was over (165). 7) Struggle. It depended on the participants to where in the experience of struggle the person was. "Struggle is a part of life and is not regarded as being negative. It is often through struggle that transcendence and subsequent spiritual growth occurs" (166). 8) Expectation of eternal life. Some participants spoke of life after death. Wolverson et.al. concluded that participant's sense of hope and identity came through memories of families proving the importance of the need for connectedness and relationship.[5] I think that by Mackinlay and Trevitt stating that fear is also common among older people is important because "fear may be a strong emotion that blocks hope" (169). I did not agree with the statement that fear was mostly with independent older people. When I give medication to some of the persons living with dementia in the special care home, they ask me if they need to pay for it, or when I bring them to their rooms they ask who is paying for it. I have also seen this at meal times when they panic that they do not have the funds to pay. I have witnessed fear at night and have been asked to leave the lights on or the fear they will have their belongings taken from them.

The concept of hope is important because I believe that without hope a person gives up and dies. I noted that the spiritual/pastoral care providers that provided music as therapy had patients that became engaged while they were playing and exhibited "hope with activity." After participating with music Alice noted that the client talked about life after death and his expectation of eternal life. In Pierre's case he had a client that had no sense of hope and

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[5] I have noted that some seniors are resigned and state they have no hope. That is a symptom of dementia. The mood and affect change many times during the day and hope increases with interaction and activity. The struggle may also occur with the increase of paranoia, delusions, sundown effect, pain, etc.

resignation, but when he played crib with him he showed that he still wanted to engage with life. It was also Samuel that by having weekly visits with his client to pray and create poetry with the psalms that although palliative lived another five years.

(b) Concept of redemptive remaking

Edward Farley in Edwards (2013) used the concept of redemptive remaking to describe an aesthetic and ethical process that reveals beauty in the Christian faith by restoring the divine image. The concept of redemptive remaking depends on: 1) The divine image. 2) The corruption of the divine image by sin. 3) Redemptive transformation in evaluation, that we are able to be remade because of the embedded divine image within. (6) Redemptive re-making needs to include diversity in communities suggesting works are situated in a variety of public contexts. Jensen (2004) in Edwards stated that artistic forms are beyond liturgy and worship and are employed to meet needs in specific locations such as classrooms, music for devotional purposes and photographs used to accompany a sermon about poverty.

I included this theory because of the example of Lila's client that layered torn sheets of tissue paper and said "Jesus, Jesus, this is my Jesus." The lady was known for wandering and Lila brought her into her office to give her something to do while she charted. She was alarmed because she had done the art exercise four times that day with the Alzheimer's clients using tissue paper and mode- podge onto a paper surface and none of her other clients had this reaction. Redemptive re-making was also apparent when Roger was also asked to play music from Newfoundland. When the client said that people from Newfoundland prayed, she was asking him to include music from her home because she missed it and after this he started to

incorporate folk music and personal favorites into his visits because this enabled them to associate songs with the love of home thus reaching beyond liturgy.

(c) Nouwen's notion of wounded healer

Nouwen's (2010) notion of the wounded healer is that caregivers must not only look after their own wounds but must be prepared to heal the wounds of others, at the same time and are wounded and healing ministers (88). Words used to name the wounded condition are alienation, separation, isolation and loneliness and the latter enables us to understand our brokenness. Ministers according to Nouwen experience loneliness, false hope and expectation may prevent them from offering any "real service to the many who do not understand their own suffering" (91). He states that ministers understanding their own pain make it possible to convert weakness into strength and offer their experiences as a source of healing to those lost in their misunderstood suffering (93). Nouwen adds the word hospitality to other words used for the Christian minister to provide healing. He states that hospitality is the virtue that helps break through fear and makes disciples into witnesses with new ideas and insights. Nouwen states that concentration is necessary, which then leads to meditation and contemplation (97). Ministers that come to terms with their own loneliness can then be hospitable. He defines healing ministry as "healing because it does not take away the loneliness and the pain of others, but invites them to recognize their loneliness on a level where it can be shared" and therefore they can accept it as an expression of the human condition (99). Nouwen (2010) concludes that hospitality becomes community when it "creates a unity based on the shared confession of our basic brokenness and upon a shared hope" (100).

My participants confirm this notion because of the nature of the work. Many while being interviewed spoke about the grief of their clients and how they supported them. During two interviews the participants spoke of providing counselling to other staff members within their work settings. Participants spoke of their own health issues; being widowed; losing their jobs without warning; living with grief from a young age onward; having to work at many jobs to survive; and working in the evenings to provide care to those that have not had any visitors all day. The notion of the wounded healer is important for persons using creative arts with dementia patients because many of them have lived with loneliness and loss. Some of them are living with spiritual distress and not just physical distress. Providing creative arts invites them to either share their emotions in a group or on a one to one basis. Robert expressed that when he sang and played guitar in front of a woman slouched sideways in her chair. He moved closer to her and emulated her posture. Within moments she started to sit upright and he noted that she was keeping beat with her little finger.

(d) Karl Barth's elements of encounter

Demmons (2008) states that traditional forms of care are challenging for persons with disabilities and include cognitive aspects involving speech. Demmons utilized Karl Barth's form of care which focuses on care as friendship to enable her to provide pastoral care. Karl Barth was a Swiss theologian who maintained that a true being is a "being in encounter" (366). Barth in Church Dogmatics (1936-1962), said the "being in encounter" is an encounter with God, others, self and time which constitutes a true form of being" (367). Barth states there are four elements of encounter which include: 1) Looking the other in the eye. 2) Mutual speech and hearing. 3) Rendering mutual assistance and 4) Responding in gladness. (369) Demmons hopes that a form

of care was not just based on human ability but on the "power of the spirit present in relationship" (369).

1. According to Barth, looking the other in the eye, is the way in which we see other persons and communicates that the other is seen and must be accompanied by openness to the other (369). Barth warns that if people are not looked in the eye their humanity is not seen (mutual seeing). Demmons suggested that if people were in wheel chairs for the pastoral care worker to be at eye level and an "intermediary space should be established" (370). Demmons also stated that eye contact should not be forced but reciprocal as the care receiver permits. 2) Mutual speech and hearing. Barth stated that words and speech are not genuine self- expression when they are a guise or false in any way (371). He stated that hearing is not just hearing words but hearing the others humanity and self-expression. The "essence of being in the image of God" is also the basis of speech and hearing, "that cares for the other" (371). Demmons stated that it is important to assess the person's senses if they can hear, see or speak. Demmons writes that communication includes motions, gestures and expressions and mirroring of the other person's movements. [6] Demmons reports that some clients "spoke" through music, song, dance art and creating (372). 3) Rendering mutual assistance. Barth stated that mutual assistance must be mutual and that fellowship exists when the assistance is offered and received. Barth establishes that to be human is to need and call out for help and that the reason for assistance is "an emulation of the acts and nature of Christ" (373). 4) Responding in gladness. Barth argues that a human may be seen, heard and assisted but if it is done without "gladness" then it is unhuman (374). "Humanity lives and moves and has its being in this freedom to be oneself with the other, and oneself to be with

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[6] Mirroring is important during an art therapy session. Clients panic and state, "they do not know what to do." Having a caretaker or facilitator do an art-piece at the same time allow them to "look off it." When they start to paint the painting transforms to include their own ideas.

the other" (Barth 375). Demmons stated that "gladness" is best communicated in spending time with a person in a "shared form of being" which may include painting, listening to music, and more (375). Through "embodied encounter" facilitated by the arts and imagination, alienation and loneliness "might be loosed" and people can be freed (Demmons 375).

All of the participants shared stories of elements of encounter. Lila mentioned that after creating art her clients were so excited and wanted to do an art show. The clients felt so accomplished and during an art show the senior living with dementia asked her daughter what she thought of her painted sail boat and she responded that "it was a piece of junk." Persons living with dementia are full of hidden talent and all people need embodied encounters. The person living with dementia that has never spoken during the music therapy and all of a sudden breaks out in song is another example of embodied encounter. Just as the persons living with dementia that remember their created songs after being away from them until the following week during Samuel's sessions.

(e) D.W. Winnicott's formulation of potential space

According to Dalley (1996), Winnicott describes "potential space" as a space in which inner reality and external space" as a space in which inner reality and external life both exist, an area between "therapist and patient where fantasy and reality meet" (87). Winnicott (1981) adds that potential space branches out into personal relationship between individuals where communication takes place (65). The overlap of potential spaces forms the common ground in interpersonal relationships resulting in "health." He claimed that his clinical work became linked with the idea of communication in the potential space and that psychotherapy was done in the overlap of the patient and of the therapist (65). Society has much to be gained by the potential

space in terms of individuals contributing creativity and enriching culture and also by giving of the self (66).

According to Winnicott the realization of contributing to culture and continuity in the human race depends upon the holding environment (66). One's potential cannot be realized if life is impinged, "its place is taken by antisocial acting out" which is the search for a boundary or framework (66). Trust is the environmental factor that results in the individual emerging on the journey towards independence, "at the place where continuity is giving place to contiguity, the separating out is softened" (Winnicott 66).

Winnicott believed that freedom to grow, create, and contribute needs society's support (158). Winnicott says that the potential space is where play and cultural experience depends "for its existence on living experiences, not on inherited tendencies" (160).[7]

Regarding potential space Winnicott asks the question of what are we doing when we listen to a Beethoven symphony, or visiting a gallery or reading but enjoying ourselves (160)? Winnicott answers by saying that we are neither in the dream or fantasy world but in "paradoxical third place: that partakes of both these places at once" (160). Winnicott states the potential space is concerned with symbols and the environment that becomes part of the inner psychic reality, resulting in meaning and freedom of ideas and functioning. In the potential space, playing arises out of the relaxed state and there develops "a use of symbols that stand at one and the same time for external world phenomena and for phenomena of the individual person who is being looked at" (Winnicott 161). He stated that the potential space has the

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[7] In art therapy potential space is the session. The holding environment is the canvas, paper, medium used (i.e.-clay). It is where creativity flows and a container for emotions. If the client is angry, it is better for them to express themselves on paper. It is important to know the medium for example paint increases emotions.

capacity to expand, the place where experience builds upon itself and allows man a certain degree of control over his destiny (166-168). Winnicott concludes that self- discovery occurs in the potential space and is the same thing as realized individual potential (169).

Josephine provided art as therapy to clients that were hospitalized and had just been sent to the hospital because their loved ones could no longer provide care at home. They were being assessed for what level of care that was needed and they were angered to be away from their caretakers. She was sent to their rooms to do art work. This potential space allowed them to create and remove themselves from their problems. Although she was told by them that her services were not needed the following week she was asked by the nurse upon arriving to revisit them. For some the potential space as in Bruce's collaborative art piece was in amongst hundreds of symbols and messages of hope. Bruce never thought that this piece would literally take years to complete. Many of the participants have died but the art piece just keeps being added to. In Sally's visit with her client she provided pictures of the Alberta landscape. The potential space was when the client viewed some of them and when seeing one with an opening in the sky cried out that she couldn't take the pain. The opening was her symbol of dying and going towards the light. This woman had not spoken and the picture enabled Sally and the staff to know of her spiritual and physical health.

(f) Abraham Maslow: Hierarchy of needs

Abraham Maslow a psychologist created a pyramidal hierarchy of needs in order of physiological, safety, social, esteem and finally self-actualization. Maslow as stated in Reitan (2013) contends that self-actualizing individuals are highly creative independent of their "mental health or lack of it" (1). 1) According to Reitan, physiological needs are hunger, thirst, air and

sleep. [8] 2) Safety needs are needs for security and protection and become prominent in social or political instability. 3) Social needs include belongingness and love. 4) Self-esteem includes the need for self-respect and positive feelings. 5) Self-actualization is indicated by the need for creative self-development in terms of working toward a goal and having meaning in life.

Maslow in Reitan contends that the basic survival needs must be met before the highest level of needs. The self-actualizing person may find meaning in "confrontation in death and the dialectical contrast between life and death…"when safety or physiological needs are threatened. (Reitan 2) She states that she believes that spiritual needs may be fulfilled in any circumstance of life and that self-actualization people may occur at any level and not follow Maslow's pyramidal steps.

Reitan (2012) states Maslow's focus was on cognitively and psychologically healthy individuals.[9] Maslow stated in Reitan that creativity is a prominent quality in self-actualizers and people might love "reading or writing poetry and enjoying art" (3). She stated Maslow's understanding of self-actualization occurs in the mental realm of the self and it is defined by creativity. Reitan stated that self-actualization occurred at every level when people create and conscious and unconscious awareness became unified through artistic expression and reception resulting in transcendence. She stated that poetic expression and other forms of art enhanced the psychological health of the individual culminating in self-realization by means of personal illuminations.

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[8] Physiological needs must be met before any other needs.
[9] Although Maslow's focus was on psychologically healthy individuals it is used for people living with Alzheimer's. It is only recently that spiritual needs are referenced.

Samuel believed that self-actualization could occur at any age and with persons living with dementia. He and a songwriter started working with people with dementia to write songs. He noted that he could not tell from the finished product that the songs were written by people with dementia. The end result was they honored this population by playing the music on holy days in the synagogue and also had the songs published. Not only did he do this with poetry but as well with the client's art work that was sent to an exhibition in the main synagogue that promoted art work from every age group. The synagogue's store also featured cards that the clients made and were sold at special holidays. This was also featured in the veteran's hospital gift store when the hand- made artistic cards were printed and sold to enable the staff to continue to buy art supplies with the earnings for the veterans.

(g) Erikson's stages

Pruyser (1995) emphasized the importance of Erikson's later stage (identity formation) (113). Pruyser stated that the latter half of life was not just a decline but a period of new personality integration. Erikson said that "mature man needs to be needed and maturity guided by the nature of that which must be cared for and (generativity and care) is an essential quality for psycho-social evolution" (58). According to Erikson the late stage of aging can be a time of integrity which is an acceptance of one's life with no regrets (159). Integrity involves a "detached yet active concern with life" despite declining health and approaching death (Hiltner 159). According to Butler and Lewis (1975) humans need to leave something of themselves behind when they die (Hiltner 160). Examples of this may be their children, work, art, possessions and memories giving the person continuity after their death.

Erikson as described by Little (2002), interpreted the strength of integrity versus despair, as that of wisdom. Little stated that dementia is a “reversal of the stages of Erikson’s life cycle” (41). Little supports this view because of the support of caregivers who witness that patient’s need assistance with care, decision-making and may exhibit behavioural problems. Little responded that to find meaning at the end of one’s life is to utilize spirituality which does not “refer to any specific religious tradition” (42). Little stated that cognitively, spirituality is a search for meaning and emotionally involves, “hope, love, connection, peace, comfort and support” (43). By working with this population I am uncertain as to whether there is a “reversal of stages” because although the patient requires assistance with care they are not children and have already learned at one time how to care for themselves. Some days the person living with dementia may assist you in their care and other days they may not. I believe that a person living with dementia may go back and forth in the stages of Erikson’s life cycle.

Erikson’s theory of integrity versus despair was evident when Anne Marie worked with a music therapist to produce a CD, with a client’s favorite songs and hymns. This CD also featured the community of patients that were at the hymn sing. The Mother wanted her children to have this for a keepsake after she passed away. They were amazed and touched to hear her voice talking about why she chose certain songs throughout the CD and heard her sing. Anne Marie played the CD for them when the client was in palliative care.

(h) Life review theory

According to Haber (2006) Erikson viewed life review as vital to stage 8 (ego integrity versus despair). He stated that life review helped individuals accept their life with few or no regrets (157). Melia (1999) as mentioned in Haber (2006) studied the lives of 39 older “Catholic

religious" and found that ego integrity needed to be "grabbed" with each new loss, death of significant other and health problems and was encountered throughout the life span (158). [10] Erickson's ninth stage of "The Life Cycle Completed: Extended Version" was released after his death by his wife and has not been subjected to many investigations (158).

Life stories according to Haber (2006) et.al. are constructed and reconstructed through the telling of stories in order to maintain positive identity. The Life review process according to Wilson et.al. (2002) in Haber can be interpreted as part of activity theory "(an active mental activity) that might sharpen mental acuity and postpone dementia" (161). Puentes (2004) in Haber suggested that life review can strengthen cognition reviewing life's themes. Chandler & Ray (2002) in Haber states that most memories were told through "dynamic reminiscence" with feelings and meanings still evolving (161). Beechman & colleagues (1998) in Haber speculate that life reviews allow institutionalized residents an opportunity to gain a sense of control over their life story in contrast to "a lack of control over independence, medical decisions and their institutional environment" (162). [11]

At Betty and Laura's facility life review was done in a special way. It involved putting a large paper sheet on the backside of the closet door to inquire the likes and dislikes of clients and included their favorite foods, pets, photographs of family, music, sports, hymns, what they did for a living, hobbies and more. The family was encouraged to fill in the topic areas left blank by the client. When it was filled then it was laminated and resembled a collage of the person's life. Roger at his facility had hundreds of laminated pictures. When showing them to his clients this

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[10] If the senior repeats their life story in a monotone voice (like an exact word for word recording) there is a reason. Talk to them and find out if aspects of the past may be affecting their life in the present.

[11] The assistance provided in journaling with a senior helps them move beyond their vocabulary (word for word recording) to remember details long forgotten. The journal left at the bedside gives the family a lasting memory of their loved one.

also facilitated life review and he said that he did this when he felt it was appropriate. He said that when he showed Psalm 23 and it featured a stream the client remembered the stream that he lived beside in his youth.

(i) Catholic social teaching

The praxis of Catholic social teaching was discussed in O'Connell's (2014) article and she mentioned engagement with the arts as renewing and focusing this central moral capacity. Before arts in solidarity can be accomplished and embodied each stage of the Catholic social teaching should be explained before it is implemented. Catholic social teaching as stated by the United States Conference of Catholic Bishops (USCCB) (1998) is based on and inseparable from human life and human dignity. 2) Catholic social teaching themes are: a) Life and dignity of the human person. b) Call to family, community and participation. 3) Rights and responsibilities. 4) Option for the poor and vulnerable. 5) The dignity of work and rights of workers. 6) Solidarity. 7) Care for God's creation. Catholic social teaching comes into play when looking at spiritual care of person with dementia because many of the patients are non-verbal; have care takers that may be experiencing burn out; are alienated from their religious communities because of failing health; and may be experiencing spiritual distress because of feeling displaced, lonely and at loss of where their loved ones are.

1) Life and dignity of the human person. The Catholic Church proclaims life is sacred and dignity is the foundation of moral vision for society and all principles of our social teaching. Every institution is measured for whether it threatens or enhances the life and dignity of people. Barry provided care for people living with dementia on an on call basis and in the evenings. He assists them by reading to them and stated that it is what they want to listen to. He stated that

many of the books are contemporary. He said that many of these people would have no personal interaction because the family lived too far away. He is asked by the chaplain to visit them. 2) Call to family and participation. The Catholic proclaims that the sacred person is social: supports the capacity for individuals to grow; the support of family; for people to have the right to participate in society; for the well-being of all including the poor and vulnerable; and for the Church, government and other institutions to protect life. Many of the spiritual/pastoral care providers had family that lived with dementia. Marilyn related that she sang to her mother while talking with her on the phone and her mother remembered her and said "they were good together." She involves staff and family members to connect with people living with dementia through music and worship services that include reflection and tactile things such as leaves, rocks and sand. 3) Rights and responsibilities. The Catholic tradition teaches that human dignity can be protected if human rights are protected with every person having the right of life and a right to things required for human decency. Both personal and social responsibilities are necessary to one another, our families and to society. Laura related that she noted that a client was not moaning and asked a staff member what was different that day. She was told that the client has had her "spa" day which included aromatherapy, lotions being applied, and the visual of watching shapes projected onto the ceiling. Roger mentioned this as the "snoozilin" room and in other centers this would be called Namaste care. 4) Option for the poor and vulnerable. Bonnie has the most seniors/ capita in Canada and many of them are place in alternate levels of care and are waiting for placement. Her hospital has undergone cutbacks and there is only an OT and the nursing staff that assists with spiritual care. The chapel is not large enough to have group activities. Spiritual care is provided by her as well as nurses, laymen from 2 churches and volunteers. Catholic teaching proclaims that a moral test is how vulnerable members are faring

and our tradition recalls the story of the Last Judgment and instructs us to put the needs of the poor and vulnerable first. At the hospital that Bonnie works at there is a recreational therapist on the psychiatric floor but no services are in place for the geriatric floor except of the use of CD players. Many patients cannot afford to pay for the T.V. service. And she hopes that the T.V's could be used to create a spiritual care music station. Bonnie stated that just sitting with the women and discussing the flowers in a magazine brings them joy and contentment. 5) The dignity of work and the rights of workers. Work is a way to make a living and the rights of workers must be respected with decent wages, unions, etc. promoting an economy that protects and defends human rights and advances well- being. Bonnie said that she attends a debriefing once/month for herself and her colleagues. She said that this is important and wants to provide herself with self-care and feel less isolated. She provides spiritual care to the nurses that she feels are overloaded and to the families of the patients. 6) Solidarity. Catholic social teaching proclaims that we are one family whatever the differences and to love our neighbor by committing oneself to the common good and be responsible for all. Alice said that in the hospital that she was working at the population was 50% Italian speaking. In order to provide spiritual care she learned some simple Italian folk songs and although not Catholic listened to the mass in Italian in order to provide care and interact with them. She also provided spiritual care to an Asian speaking man by playing her flute by using a Pentatonic scale which resembled his cultural music. 7) Care for God's creation. The Catholic tradition insists that caring for the earth and protection of human life especially for the poor and vulnerable. The teaching offers ethical criteria for action, moral guidance for the future and is a central part of our identity. These Social teaching are not just for Catholics to know but other faiths may apply these principles in family, economic and community life. Lila uses what- ever natural materials that she can, such as rocks.

She has the client put their thumb print onto a rock and then has them look at it and determine if they can see an animal. She says this causes them to become vibrant and they see dogs and sheep and she writes a little passage to go with it. These examples demonstrate that Catholic social teachings apply to persons with dementia and their caregivers and it is important that they not be segregated from mainstream society but be included. In Bonnie's hospital some community members are starting to donate CD's and magazines to the hospital to provide music and discussion materials for the staff to utilize.

(j) Sabat's social model of the self

Steven Sabat is an American psychologist who has offered alternative ways of describing and defining dementia (71). Sabat according to Swinton (2012) advocates that dementia does not destroy a person's sense of self and he shows that in the later stages of the disease, the self remains intact if carers recognize its presence and effectively stay with it (94).

Sabat in Swinton and Temple-Jones (2012) states the concept of self has three aspects called Self- 1, Self- 2 and Self- 3. Self- 1 uses the first person in the present moment and uses personal pronouns such as "me, myself, my mine and our" (94). They take responsibility for their actions, feelings and experiences as being their own and tell their autobiographical stories. A person in self- 1 can forget who they are, those around them but still have a sense of "self in the present" (95). According to Sabat, Self -1 remains throughout the experience of dementia. Self- 2 is one's physical and mental attributes such as height, weight, eye color, sense of humor religious and political convictions, education and vocation. Self-2 sees the name "dementia" as a negative identity and counters assumptions with more positive stories about their experience. Dementia has a negative stigma and the person may withdraw, be depressed, angry, and

uncooperative and may be frustrated trying to maintain a positive Self- 2 when those around them see only the worst (96). Sabat states that Self -1 and Self- 2 are under the individual's control, but Self- 3 is different and is dependent on the "cooperation of others" (96). Self- 3 is dependent on some form of relationship and community and requires the assistance of others. Self-3 requires people to respond positively so that they can maintain a positive construct (admiration) (99).[12] "If we prevent or curtail the person's ability to tell her own story well or prevent it from being told effectively on her behalf, then attaining and maintaining Self 3 will be impossible" (98). Sabat states that, "any dissolution of the self, reflects a dissolution of community" (98). These Self's were apparent with the example of Josephine while completing her art therapy session. The client told her that her services were no longer needed. They wanted her to know that they were still in charge. Even though they had expressed bouts of anger with their loved ones they wanted to be seen as being able to handle their losses by themselves.

(k) Paternalism and autonomy

Paternalism according to Sjostrand, Eriksson, Juth, Helgesson (2013), refers to courses of action (including decision) that are done in the assumed interest of a person, but without or against that person's informed consent. Autonomy as stated by Sjostrand et.al. is the right for patients to have a say about their care. [13]Lindley's empirical assumption on anti-paternalistic societal policies according to Sjostrand et.al. include: 1) Autonomy develops in those who are allowed to practice their own decisions even when those decisions are unwise. 2) People know their own interests. 3) People need a private sphere to develop their individuality. 4) People do not want restrictions on their freedom by public institutions. 5) People may abuse their power to

[12] Relationship and community also occurs at meal-times. Socialization is important and time given for them to sit and have warm beverages. If rushed the person living with Alzheimer's will not eat. Cooperation with others includes family, staff and especially other residents.

[13] Historically from Kant's Moral Theology. John Christman (2015), "Autonomy in Moral and Political Philosophy.

promote their own interests without recognizing that people do not want them (721).[14] This is related to where Bonnie works and there are many clients awaiting placement and have to wait until a space becomes available.

There could be reason in specific situations in favor of paternalistic approaches for the sake of autonomy. Patients that are not competent experience overruled decisions “in order to protect or promote their own autonomy” (Sjostrand et.al. 72O). Here is an example of a pastoral visit when I was taking a CPE course in a neighboring city. The patient required a place to live, could still mobilize and with family present could have remained autonomous.

When I did my CPE training I was put on a geriatric unit for dementia patients that were awaiting placement. We were to call them “clients” because they were medically discharged. While there every time I went onto the unit I asked the nurses who needed a pastoral visit. I was referred to a client who I will call Molly. She sat daily in the ward, alone near the window with her hands folded as if waiting for someone or something to happen. When talking to her I noted that her religious faith was apparent when she took her Bible out and said that if she did not pray that she would not be alive today and that her faith got her through many difficult times. When I asked her if she would like me to read her favorite passage she declined and said that she did not need to read it because the words were ingrained onto her heart and soul. Religious faith was evident in all the nurses that cared for Molly ensuring that family brought her supplies and ensuring that her spiritual needs were met. The nurse manager worried that she had not prepared her for discharge. I reassured her that all Molly could talk about was going to the town where she had spent time as a youth and near to where her parents homestead. Molly’s faith in God

[14] Dementia patients are admitted with diagnoses of loss of autonomy, loss (will to thrive) and not able to do activities of daily living (ADL’s).

assisted her at this time because people that were touched by her presence began to leave her "things." An artist was on the ward and when Molly described her home he painted for her and left her two small paintings at her bedside. Nurses left magazines of the shore-line and birds of her childhood island. I found an article of the anniversary of the hospital she worked at and went through pictures of the building and the staff that she worked with. Molly was alone many hours of the day but God was in her heart and many of the staff could not walk by without talking to her. The last day that I visited her I asked if I could write down her favorite story. An hour later I left it on her night stand. The next shift when I returned she had been transferred to the nursing home and I was happy for her but stood at her door lost in thought. By caring for Molly God helped me in caring for future patients and using whatever means to connect with them either by listening to their stories, painting, journaling, singing and praying.

Religion and faith in God led me into the practice of providing care to this population because as a nurse I could not take time away from my duties to care for people in spiritual distress. The only time I could care for them was when I provided art therapy and I required the CPE training to provide me with the knowledge of "being with" and not "doing for."

Molly had been hospitalized for many weeks previous to my visits as a CPE student. Molly had been assessed as having lack of autonomy. This happens to people living with dementia and has several designations. I do not know Molly's full history but the nurse in charge was upset when she described how Molly asked her daughter permission to live with her. Her daughter refused and Molly had to leave her apartment and be placed in the hospital to await placement in a home. As per the nurse's verbal report Molly took her daughter to court and lost the case incurring a financial loss from the proceedings. The nurse was angry and

negative towards the family member. Molly talked about a step-son and having had a daughter. She never spoke of her in a negative light but said that "she was going home." Molly had left home at a young age and there was the possibility there were no living relatives left in the town where she was going to live. Home was a place in her heart, where she wanted to feel useful, writes letters, do housework, have fellowship and more. Molly never left her room to socialize, sing at the monthly concerts, attend chapel or walk in the hall.

(l) Feminism- capabilities perspective

O'Connell (2014) quoted American political feminist Martha Nussbaum, that an ethics that wants to serve responsible and creative persons will give attention to emotions, affectivity and sensitive values that lie in man's being and are "expressive of the human longing for inner wholeness, integrity, and integration" (82).

Nussbaum in Eberl, Kinney & Williams (2011) terms correlative concepts of rights and duties as the capabilities approach (550). The central human capabilities according to Nussbaum (2001) in the World Health Organization (WHO) are: 1) Life- being able to live a normal length of life, not dying prematurely or before life is reduced as to "be not worth living" (64). 2) Bodily Health- to have good health, be adequately nourished and to have adequate shelter. 3) Bodily Integrity-being able to move freely place to place is secure against assault (sexual and domestic violence). 4) Sense, Imagination and Thought- being able to imagine, think and reason in a "truly human way," a way informed by education. Being able to use imagination and thought by producing works of one's choice such as musical, literary, religious, etc. Being able to express oneself (political, religious and artistic), and being able to have pleasurable experiences (64). 5) Emotions- having attachments to things and people; to love, to grieve, to

experience justified anger. [15]"Not having one's emotional development blighted by fear and anxiety" (64). 6) Practical Reason-being able to engage in planning one's life (conscience and religious observance). 7) Affiliation: a) Able to live with others, engage in forms of social interaction and to be able to imagine the situation of another. (Protecting this capacity means protecting institutions that nourish such form of affiliation. b) Having self-respect and being treated as a dignified worthy being with non- discrimination on the basis of race, sex, ethnicity, religion, etc. 8) Being able to have concern for animals, plants and nature. 9) Play- being able to laugh, play and enjoy recreational activities. 10) Control over one's environment: a) Political- being able to participate in political choices that govern one's life such as political participation and free speech. b) Material- being able to hold property (land and movable goods) on an equal basis with others, work, and entering into meaningful relationships with other workers (64-65).

According to Nussbaum in O'Connell, "narrative imagination" is essential for judgements associated with empathy or compassion since it involves the ability to think what it is like in someone else's shoes and to understand someone else's wishes and emotions. This according to Nussbaum helps to see through the eyes of others how they see and are seen by the dominant culture in terms of race, and gender (82).

Feminist philosophers as stated by Nussbaum in WHO are challenged to produce a new form of liberalism more attentive to need and its institutional conditions. Nussbaum also stated they should also further develop theories that make it possible for all citizens "to have the support they need for the full development of their human capabilities" (62). The capabilities approach would show respect for the elderly and disabled as equal citizens (63).

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[15] Justified anger may occur when "reality treatment" has been given. Client should not be constantly brought back to reality. Sudden movements and increased sensory noise may cause anger.

The Feminism-Capabilities Perspective was evident in many of the participants that were interviewed. Joshua did not believe in using coloring books to provide creative art with people living with dementia because he felt that it was "just using someone else's viewpoint." He said that the male clients were more hands on (painting and clay) and the women liked to draw. Barry when walking in the room filled with seniors sitting asleep in their chairs did not know what their capabilities were until he started to play music when he was a CPE student. The clients became animated and started to clap to the music and dance with the nurses. Samuel even after working with the Alzheimer's population for sixteen years still feels that he has just scratched the service and wants to continue to provide creative arts. It was noted that many family members do not know of their family member's capabilities and Marilyn wants more family to observe them singing and worshiping in the chapel. Sally when training as a CPE student wanted to move hospital politics out of the way and have a space for the seniors to have the hymn sing and the following creative art session. She felt that so much had been gained and to not let the population fall back into sitting in their chairs and not having engagement with each other and using their imaginations.

Feminist theory provides ethics for treatment of persons marginalized by dementia but so is additional education needed. All participants wanted more education in order to provide additional creative arts. All wanted a chance to have time to write about their experiences. Many knew of the capabilities of their clients and some mentioned their CPE training as "trusting the process" and that experience and wisdom would follow. In some instances there was no control over one's environment and even though there is collaboration between the staff, there is still scrambling around to get people to the creative arts sessions and never enough hands or time to give the persons with dementia weekly sessions. With cut backs many hospitals have scaled

back their services and marginalization has occurred thus widening the gap of equal services offered to seniors. Some volunteers were noted to be as old as 99 years old and it was those stories that also showed the Feminist-Capabilities Perspective because they were still able to engage with others and were still valued and needed.

2.4 SUMMARY OF CHAPTER TWO

All the theories described in this chapter are valid and needed when providing care for this population. It is important to understand that the person living with dementia be seen in a positive light as being still able to interact with others in their environment regardless of their stage of dementia. The information allows spiritual/pastoral care providers to know that clients living with dementia offer a life time of knowledge and life experience and are still capable of doing many things with provided guidance. Gathered information will be of upmost importance as this population grows in numbers.

Many e-mails were sent across Canada and the United states and a nation- wide e-mail was sent across Canada by the Canadian Association of Spiritual Care (CASC). This gave a varied demographic of participants that included chaplains, spiritual/pastoral care providers, students just completing clinical pastoral education (CPE), a nun and a rabbi. Many stated they did not have much experience with the studied population. The interview process resulted in interviews that had of duration of 25 minutes to over an hour. The open-ended questions enabled the participants a chance to move between their experiences with the population, volunteer, palliative care or grief support within their staff and care-takers. They were all requested to speak from their hearts.

The next chapter will describe presentation of the findings, themes, challenges and a summary.

CHAPTER THREE: RESULTS

3.1 PRESENTATION OF THE FINDINGS

Thematic analysis revealed the themes of: breaking down barriers; multiculturalism and connection; resourcefulness and different programs created; holding environment; prayers, symbols and spirituality; and education training and needs. I will discuss each of them in the order presented using fictitious names. The patient is referred to as “client” because in clinical spiritual care training (CPE) it is taught that it is empowering because using the term patient suggests the person is sick. Spiritual/pastoral care providers visit clients while nurses visit patients.

(a) Breaking down barriers

At the veteran’s hospital, Brendon a spiritual/pastoral care provider stated the hospital population was divided into 2 main units of 55-65 patients/unit. He stated that each unit had a full time chaplain and that he was present in the evenings to provide one on one support for the clients and the families. While providing care he noted that some of the clients were from the Korean War and some had dementia. He stated that between 35-55 % attend the creative arts program and are brought to participate by many volunteers. He then makes assessments and coordinates care with the music and art therapists. He educated himself on what had to be done to enable him to provide care. Many of the veterans sculpt and many of their art works are hung on the hospital walls with artist’s statements that feature titles and explanations of what is presented. Brendon stated that no matter what stage of dementia the client was in, it was the time the clients spent together as a community that had the greatest importance.

Bruce, a chaplain, provides creative arts mostly to the dialysis population with a 3 by 4 foot collaborative painting of a landscape. A woman living with dementia motioned for him to bring the painting closer to her bedside for her to participate. The physician stated that he could not believe that she wanted to participate (health, dementia and multicultural). Bruce stated that once the clients see the painting that many ask to paint onto the design. One was a sight impaired patient. He stated that it "opens up conversation and breaks down barriers." He felt that art helped the clients be able to tell their stories. Bruce also stated that when he ministered to other people living with dementia he uses a scriptural verse and draws small personal designs such as a "sparrow" and how God cares for all including the greatest to the least.

Josephine an art therapist and spiritual/pastoral care provider facilitates by using art at the bedside (with pencils, pencil crayons, markers or palettes of water color if the patient had done previous art work.). Josephine works with clients that have dementia that prevents them from doing activities of daily living (ADL's). When this occurs many are hospitalized and because their loved ones no longer can care for them, the family notifies Josephine to provide creative arts. Many cannot cope with their loved one's anger and their daily requests to "go home." They express themselves and she keeps the art-work in safe keeping for the family as a memento if they request it upon their death. Josephine says the art "is not about having a pretty picture," but is their way of expressing themselves. When the client becomes advanced in their stage of dementia and becomes palliative, she plays music at the bedside. Josephine will be thanked at the end of the session but sometimes dismissed by the client as "you don't have to come next week." She recounted that many times upon arriving at the nursing station, the nurses ask her to re-visit the client weekly because of their increased agitation.

Lila, a chaplain, uses music as a creative arts method and related a lady with advanced dementia as droning in a sad monotonous voice. Her volunteer an aged woman nearing 100 years was playing hymns page by page and when Lila tried to skip a hymn the volunteer flipped back to the old hymn. The sad droning patient started to sing and sang the whole song and exclaimed, "I remembered." Her joy was infectious and Lila felt that it was miraculous how the emotional attachment to the song revealed a side to this woman that she had not previously seen.

Laura, Roger, Alice and Betty mentioned sensory stimulation offered to clients that live with advanced dementia. In Alice and Betty's work-place the sensory stimulation is offered in a group setting in the common area and in the other settings it is offered on a one on one basis. Laura called the sensory stimulation the clients "spa day." Her client was known to audibly moan throughout the day. She asked the nurses why she was not moaning one day and they told her that she had her "spa day" and that the effect could last sometimes for days. The "spa day" consisted of staff that put on music, rub lotion onto the limbs and have a monitor project colors and shapes onto the ceiling (day or night-time). This enables the person's senses to be aroused such as sight, smell, hearing and touch. Marilyn stated that sensory stimulation was also given by spiritual /pastoral care providers during the chapel services and included tactile things such as fall leaves, rocks, shells and sand that are put in the center of the room. The clients touch the items then respond to them. The items allow them to reflect and share with each other. Marilyn a chaplain stated they also use psalms, prayers and music to encourage spiritual connections. When Joshua has his one on one spiritual/pastoral care visits he used rubber shapes for the client to touch and express themselves with. He also used the "Full Circle" spiritual program for the elderly that uses many themes in the sensory cues. The cues included what they feel in their body

such as their pain of discomfort in their hands, feet and reveals certain aspects they are struggling with at the time. He also had discussions on their emotional feelings as well.

Laura, a spiritual/pastoral care provider, said that she would use what she could to enable the people with advanced dementia a chance for communication and response. She asked me if dog therapy was a “creative art.” I responded, “yes” because I provide many animal pictures for collages and the response is widespread. She brings her collie dog on her spiritual/pastoral care rounds with her. A woman that was sitting in her wheel-chair had limited range of motion and had been verbally unresponsive in her chair for weeks. She moved a finger to beckon and the dog went to her and put its nose under her hand. She then lifted her head and smiled. Stuffed animals and dolls are given to people living with advanced dementia. It has been my experience that improvisation (a creative art) is used on many occasions when taking to the client to include in the conversation what- ever the person is holding onto. This provides the client a chance to interact and communicate in positive ways.

(b) Multiculturalism and connection

Alice a spiritual/pastoral care provider in her using her “recorder” flute stated she used this in playing music to her multicultural population. She overcame language barriers by being able to learn songs and hymns from various cultures. She found ways for her clients to teach her and in return was able to “soothe the soul.” She found those with language limitations and loss of memory that the music filtered through, weaved amongst the barriers and created a spiritual encounter.” She especially remembered an Asian man living with dementia that could speak some English. She said she was able to reach him by playing a “pentatonic scale” which sounded somewhat Celtic at times. She stated that was profound and it was like standing on “sacred

mysterious ground." He engaged with the music and was intensely emotional. He then talked in his limited English of spiritual themes and where he would go when he died. He expressed calming and gratitude and she felt that he had a limited understanding of who she was but the connection and his motions (conducting the music) was "unified and profound."

Fiona an art therapist and a nun had a male Danish client. He always drew many of the same kinds of pictures every week that included a house, a road and cars. He grew up in Denmark and he told the group stories of what it was like when he was young. Another example is Pierre, who talked about his work in rural Oklahoma with an African American client. He sang spiritual songs with him such as "Swing Low, Sweet Chariot" and "I'm the Captain of My Ship." Pierre said that after his visit the nurse had said that he reconciled with his estranged daughter and that this heart had opened up. Pierre stated that he was a "total believer of what the client can teach us, of things felt but not spoken of our own humanity and imperfections."

Roger, a chaplain, talked about connection and stated a client originating from Newfoundland wanted folk music played from her province. He laughed when he remembered how she greeted him as "I'm not doing too baldly" because he is a man with a fringe of hair. Before leaving the day room she told him that "she went to church in Newfoundland" and asked him to play folk songs. From then on, he incorporated folk music and Maritime music amongst the hymns that he played. He made a connection with this client and since has incorporated songs from other cultures and different eras as well. He had a Scottish lady with dementia and when she was palliative he sang her favorite song, "Where you Go Lassie Go." He also utilized for her photos, posters and candles, "creating a gentle ambience."

Roger doesn't want to be known as "just the guitar guy," and he does creative arts as well with "hundreds of laminated photographs" to give to clients when it is appropriate. He connected spiritually with one male client when he read Psalm 23 and the "calm water" in the psalm helped him remember a favorite fishing story. He mentioned for me to use the term "spiritual care" so that I could maintain connection with a broader population. He explained to me that many people that have not been to church for many years perhaps because of health reasons need to know that you are part of the health team that includes "mind, body and spirit."

Brian, a spiritual/pastoral care provider just started to utilize music in his creative arts approach. To maintain connection he utilized his i-pad and phone to google music whenever he assessed it to be appropriate. Connecting with this population also means connecting with the nurses who sometimes go into the room to see where the music is coming from. Brian stated that he connected with people that had "no visitors" because he does on-call visits and evening work. He said that frequently he is asked to "read" whatever novel the client asks him to. He stated this assisted them to be less anxious and open the lines of communication

Samuel, a Rabbi, worked with a client that had advanced dementia who was familiar with 3 languages but was unable to speak. To be able to provide spiritual care with music he looked for hints and signs that she was participating. He saw her little finger keeping beat with the music. He stated that people exhibit different ways of being involved with the music.

(c) Resourcefulness and different programs created

Samuel created a program 10 years ago that involved the study of the Psalms and Story that evolved into working alongside a musician, groups of clients and himself. He discovered early in working with clients that lived with dementia that others had "given up on them." With

patience, he discovered not only that they could write songs but were able to remember their songs and start the next session with adding to the song. Samuel discovered how to work with art, poetry and music and feels that in his 16 years of practice that "he's just scratched the surface of what people living with dementia are capable of."

It was with surprise when I noted that Sally who had just completed her CPE unit created a program for people living with dementia to look at a variety of paintings from Canadian artists to facilitate conversation. She chose clouds, a ship on the ocean, trees, animals and more. She was not aware of the project "art at the bedside" that was implemented in 2001 and featured the same month as when she had submitted her own project. Although Sally was an artist (BFA) she stated that she did not want to interfere with anyone else's work. Roger stated that in his hospital there is more than enough work for everyone and Brandon stated at his hospital that all health care professionals and the spiritual care department work together as a team.

Gwen, a chaplain and artist developed a "Guided Journal" for all populations at her hospital. She also provides a booklet on her reflections and booklets for those that grieve, including one for the staff. She utilizes singing and poetry therapy and inspires teams of volunteers. Gwen stated that she has written all of her life and the hospital prints the booklets for her. Her hospital does not provide recreational therapy so anything that she provides is readily accepted.

Judith, a minister and spiritual/pastoral care provider devised a improvisation program and workshops for all healthcare professionals, including physicians and chaplains. She has been doing this for 9 years and devised a "modality of learning that incorporates body, mind, heart and spirit." She felt that it is different from all other therapies because it incorporates "THOU" which

is God and opens the mind to joyful connections. She believes it should be taught to all families and professionals. She cared for her mother living with dementia. She learned that saying "yes" to her was accepting and affirming. When she said "no" and tried to bring her mother back to reality that annoyed her. She has produced a CD and is currently producing a play for DVD regarding the Alzheimer's population.

Laura, a chaplain, utilizes body mapping for her staff to debrief once/month. Body mapping was devised 50 years ago by an occupational therapist. Laura has the staff debrief by drawing onto the paper their body and its physical responses. She started with 14 staff members and had 7 still participating at the end of 12 weeks. They do art, talk about creativity and monitor the physiological response after a session resulting in all having reported they had a restful sleep.

Laura believes that intelligence is carried in our bodies as well as peace and mindfulness. Laura has taught at conferences and promotes her Aboriginal culture. She states that energy healing has been utilized at her hospital for the past 35 years. She stated that the therapies have different goals and that "art as therapy" for persons with dementia is not psychotherapy. She believed the benefits for creative arts included, "pleasure, color, textual agency and those are the gifts that we can give."

Lila, a chaplain developed a program in 2002 called, "Legacy within the Elder's," and it was featured in the hospital paper "news rag" where she has worked for 13 years. It featured quoted, cartoons, friendship and good advice even with travelling tips to Mexico and beyond. People started looking forward to see what would be written in the next version. The newspaper articles boosted the client's egos and when they saw that a person they knew wrote an article then they also wanted to participate.

Lila felt that art done with the Alzheimer's population linked them back to child-hood and helped bring back "wholeness and memory." When the clients created in a group they smiled, shared stories and created within themselves with no-one passing judgement." Her boss at the hospital wants her to start to publish her ideas that music and art "speaks."

Lila as well assisted clients in the T.V. lounge that were traumatized by watching CNN. A woman living with dementia experienced fear and started to cry. She shared with Lila that anti-Semitism was growing and Lila noted that she thought the sights and sounds of what she was watching "were not real." With news of airplane crashes and more, the minds of this population cannot filter the negativity out and they sit numb and not talking to each other. Lila offered to put on a movie and a lady asked her if "they had time for a movie?" Although Lila stated there are not enough people to be present she felt saddened by the T.V. being on channel CNN. She felt that time was what the client had, when in their minds they have none.

Josephine gave support for people considered "on the other side of the war" during Remembrance Day. She stated there are those that were forced into the military in Germany and if they did not fight then their families would be harmed. She provided care to the German aging population that still have post- traumatic stress from the events of the past and process it by doing art. She said that Remembrance Day is not just for the military.

In Betty and Janice's long term care facility their main area of interest is with using music and the "Java Music club" was implemented. It provides the people living with dementia a place to share stories, form friendships, give advice and support each other. It is implemented in a group of between 8-12 clients with the use of music, photographs, discussion topics and the use of quotations. It was designed in B.C. at first for clients with cognitive impairment. Betty and

Janice were also excited to relate their new mediation program was offered 2 times/week and said it had calming effects.

Robert a spiritual/pastoral care provider implements "somatic bio-energetic analysis when he plays music for clients living with dementia. During a Christmas gathering he stated that he saw a woman sitting slumped in her wheelchair sleeping. As he sang to the group playing his guitar he said he approached her and played near her. He mimicked her expression and she started to sit straighter and responded to his body movements with the end result of her smiling. He stated that once he sees for example clenched jaws, he invites them to make sounds to ease their jaw. Robert said that he moves back and forth when he plays and sings and his clients become engaged and mimic his body movements. He believes the music also provided the clients body with an emotional connection.

Bonnie works as a chaplain in a 260 bed hospital which she stated has the highest concentration of people living with dementia in Canada. She stated that since there is no recreational therapist available she provides CD players for nurses to use for clients that are agitated. She said that although the players are hard to keep track of, she knows they are being used. With the donation of several hundred CD's she said that many of the clients also needed stimulation. She felt that since there was already T.V.s in each room, that a music station should be available so they could play or listen to music. She reported the biggest problem she experienced is "boredom." Because of many cut-backs the hospital has experienced, creative arts services are provided for the mental health unit only. She relies on the assistance of lay persons that visit the people with Alzheimer's to provide them with sing and talk to them.

(d) Holding environment

Shawn McNiff in Rubin (2001) stated the holding environment is the creative space used to support the person in finding understanding (322). The environment may be a studio, or the specific techniques for integrating the arts which includes painting. He also stated that "different arts inform and enhance one another, and how even the most focused practice in a particular medium is advanced through an understanding of how all of the faculties work together within the process of creative expression (323). I also consider the holding environment as being the canvas, paper, and any medium used to create. It is where creativity flows and is a container for emotions.

Brendon participated in a unique flag ceremony given when the clients become palliative and die. This ceremony provided support to the family by providing a space for the family to share memories and stories of their loved ones. Of the rituals provided this is what the families frequently thank the spiritual/pastoral care team for. Brendon stated that if the veteran wanted to dress in uniform on Remembrance Day it was honored. If they did not want to dress for the ceremony it was also honored. He said that they had "ownership because it was their moment." He stated that participants with early dementia played instruments at the Remembrance Day ceremony. Brendon stated that no matter what stage the client was in, it was the community time spent together that was of the greatest importance.

A client of Samuel had failing health and had an "end of life meeting" when the medical staff determined that she would have 1 year or less to live. The client asked Samuel to "teach" her. Samuel providing a holding environment every Friday at 4 p.m. where she went to his office for a one on one visit that utilized reading the Psalms and writing poetry. This client lived for

another five years and Samuel says he misses her and every Friday afternoon he looks at the clock. He understood her and he stated that “her life buoyed” and he learned from her. He knew there was no scientific explanation but a spiritual one as to why she lived longer.

Lila would have groups of people at the weekly gatherings to sing while she played music and used art, prayer and expression. A man attended but mostly sat and slept in the corner without participating or saying anything. The holding environment changed him. After one song he spoke, “that was good.” She had never heard his voice before and he sat upright, awake and was smiling.

Lila also talked about doing an art project where she used music, tissue paper and mode-podge. She had done the project with the seniors four times that day and on the way to her office noted a woman wandering. She knew this woman did not participate often and said that she could speak but it took time for her to formulate her thoughts (sometimes many minutes would pass before she could finish a sentence). She invited the woman to her office and gave her tissue paper. She was doing her paper-work and the woman stacked the paper and started to exclaim Jesus, Jesus…. Lila said she looked up and was concerned because no one else had this reaction to the art exercise. This woman sitting with the stacked paper said, “this is my Jesus.” This is an example of the holding environment where this woman created layer by layer her version of Jesus.

Anne Marie while a CPE student along with another CPE student who played the guitar established a holding environment when they re-established the hymn sing. After the Chaplain retired the singing was no longer offered. They re-established the group and as an added benefit the group was extended into an art session. The staff commented on the benefits they had

experienced in the clients. There were problems at one point with the dining manager when he felt that his staff was impeded from doing their work. Anne Marie felt because of this experience that she would not pursue employment in a hospital setting. For holistic patient centered care many times there can be misunderstandings and miss- communication.

Also while Anne Marie was a CPE student she worked along with the music therapist and gave a CD of a client's favorite songs to the family when she passed away. The holding environment provided the family with the woman's voice talking and sometimes singing to the music. This was also done when Judith's mother was in long-term care. The lasting memento of music or art-work as with Josephine is heart- felt and honors everybody involved.

Barry, a spiritual/pastoral care provider, played music for the clients when he was in CPE. The holding environment for him involved clients and staff together in the day room where he played. He witnessed the nurses dancing with the clients. Never before had he seen such interaction. He was honored to witness the clients "come alive" with singing, clapping their hands and dancing."

Roger stated his hospital had a "snoezelen room" established for clients living with dementia. This holding environment provided a space for recreation and is beneficial for people with sensory, cognitive and physical disabilities. The clients are accompanied and it has special lighting and has tactile things to touch. He also noted that sometimes during Chapel many clients also sleep because the service put them in a "calming zone." Many clients, who mostly cannot sit for long, sit for the chapel service.

(e) Prayer, symbols and spirituality

Laura stated that religion accesses a different part of the brain and gave an example of when she visited a non-verbal man living with Alzheimer's. On more than one occasion when she sat down she greeted him and said "the Lord be with you." He would then respond and she learned to bring the prayer book with her when he would recite the whole book from memory she followed in the book with him.

Marilyn also related an experience with her mother when she called her one day. She recounted this happened while her mother could still reach to answer the phone. It had been some time that her mother did not remember who she was. That day on the phone Marilyn started to sing hymns. Her mother started to sing as well and they went through several together. A grace filled moment occurred when her mother stated "we were good together weren't we?" The singing helped to reconnect them together and "opened the door of recognition, reality and meaning."

Judith stated that "Monarch Moments" in Massachusetts and Iowa is a service that was created for healing and remembrance. The butterfly is used as a symbol of "beauty of living in the moment." Instead of now releasing butterflies, Judith uses candles, flowers and stones. Judith quoted Stephen Post in the statement, "the person with Alzheimer's is eventually swept away, while caregivers look back and feel forever changed by their experiences." She stated just as the butterfly is released it is a brief moment and like the client the beautiful moments of recognition are brief and are honored and this "loving memory rests with us."

Robert, a spiritual health practitioner, said that while growing up he played liturgical music in the church and for his large family. He said that because of grief in his childhood that

he played music that touched people in very emotional ways and helped them to grieve. He said he does not shy away from working with people and that the staff draws on the "goodness of his music" and calls on him to sing and play his guitar or wheels a portable piano into the client's rooms. He engages and supports clients and families and says the spiritual value is "a mystery to us." His "faith and friends" weekly session has over 30 clients, family and staff attend. He uses music to help clients to find love and joy by changing the routine of praying using scripture to shifting to music and song by using the Psalms. Many families have stated they have not heard their loved ones sing in years. He is intrigued with clients on the Alzheimer's units and is "happy to see people through to experience some wellness."

Samuel recounted how the music that the clients produced was played in the evening service of the Jewish Day of Atonement (Yom Kippur) and the Jewish New Year to give honor and thanks to God for the gifts. He said that anything that captures the imagination triggers an emotion. He said that "spirituality is not the same as emotion but is central to the spiritual experience." Art, creativity and music clearly opens up people's feelings and is used for the "opening for a larger discussion." He felt that clients sitting in groups learn from one another and develop friendships. He felt that his mentoring to the clients was "self-taught" and his love for poetry came from translating the Hebrew Bible and poetry. He felt that the most important work was done when they gathered in the synagogue.

Samuel's clients produced cards and sold them. They were invited many times to the largest synagogue to the art exhibits that included many of the clients from his hospital. He discovered early on in his work to invite creativity of all kinds also from family and volunteers to enable people "to have what they need to live better lives."

Joshua, a chaplain, studied fine art before going into seminary. His message is to encourage the client and to reach the client in creative ways. He said that because he is a visual person he also tries visual or tactile things with the client. He believed that because Jesus used word pictures to illustrate such as "through the eye of the needle; talking to a tree that has not provided good fruit; the breaking of bread; the Sermon on the Mount; and seeing things in everyday life then applying spiritual meaning, is what one should do in caregiving. Whatever is invisible becomes visible. He does not believe in coloring books that have someone else's viewpoint but wants to assess and really get to know the client's individuality. He noted that women liked to draw.

Roger said that if you mention meditation some people back away from the term because it "sounds too Christian." Roger said that spiritual care touches the client's memories of how they were raised. Marilyn stated that although some of the adult children do not know the Lord's Prayer or have heard their loved ones recite it does not mean that the parent is not spiritual. When asking them if they want to pray, they say yes and she asks if they want the Lord's Prayer. People that were thought to be in a coma when hearing the Lord's prayer started to awaken when it was prayed and by reciting it at the same time. She felt that seeds were planted in early life and even non-spiritual children then witness their parent's spirituality.

Symbols used to reach out to this population include leaves, rocks, candles, sand, hand prints, words such as believe; truth, hope and the psalms. Many of the Chaplains and spiritual/pastoral care providers have songs that utilize many symbols and resonated with particular clients when they share their stories. Contemplation and meditation were fitting for this population where so many of them have started to lose their use of language. Art became the

language for many and Fiona discovered that as the clients become less able to do art, she assists and becomes their hands and she loves their smiles and sense of accomplishment and shared stories. In the 2 years that Fiona has been there she has seen some “go downhill” but even the smallest reaction is “great and she likes doing it.” Fiona would like to finger paint with the clients and said, “my God can you imagine the clean up!”

Many spiritual/pastoral providers have witnessed families that have not seen their family members sing, pray or do art. This is part of the “mystery” that Robert mentioned No one know what to do all the time and it is the “spirit” that leads them into being able to provide care with sometimes just using a phone to google and play someone’s favorite song from their era or a hymn.

By working with this population care was extended to caregivers, families and staff members. Creative art crosses boundaries and reaches people’s spirits. Whether encouraged by family or not, it reaches the true self of the client and “thou” which is God.

(f) Education, training and needs

Many of the chaplains and spiritual/pastoral care providers want to continue their education. Many have branched out, for example, Joshua taking courses in pharmacology, gerontology and thanatology to enable him to provide care. I interviewed Marilyn who had just completed her Masters in Counselling. Because of regulations in Ontario many have to prove they have qualifications to enable them to work.

Some of the participants want more creative arts therapy training at the Master’s level while others are seeking to attend workshops and conferences. Bruce who is a CASC specialist

would like to teach students who could benefit from learning about his specialized way of reaching various populations by using creative arts. Lila would like chaplains and spiritual/pastoral care providers to use a "consistent vocabulary."

Most of the participants shared many techniques with me. Many references and resources such as the latest books and methods were shared. Some of these participants are spiritual care leaders within hospital settings that have the authority to care for the Alzheimer's population and on a rotation every other week. The chaplains have time constraints, one said he often gathers patients and starts playing music, and then the staff starts to bring others into the common area.

Spiritual care is spread thin in some areas and Barry works at 3 part-time jobs to be able to earn a living. Joshua stated his place of employment went from 90 beds to over 500 which stretches him very thin.

3.2 Summary

This thematic analysis revealed 6 different themes which included: breaking down barriers; multiculturalism and connection; resourcefulness and different programs created; holding environment; education, training and needs; and prayer, symbols and spirituality.

In the theme of breaking down barriers it was noted that creative arts were used for people living with dementia in many hospitals such as with the veterans, dialysis units and with those patients needing advanced care. New ways of communicating with this population have been established and spiritual break- through occurred with people remembering complete prayers and songs. Having sensory stimulation has broken down barriers of having people living with dementia secluded and put away from other populations within the hospital setting.

Barriers were also broken down when it was found that poems and songs were written by people living with dementia. It was also found that this population functions well at the chapel services when tactile things were included to touch and reflect upon to encourage spiritual connections.

Multiculturalism and connection was evident with the spiritual/pastoral care providers because in Canada there are many immigrants. Some of the participants noted they had to immerse themselves into learning songs that related to their culture and era. Some learned some songs from other religions and connected with them by using nature pictures and Psalms.

Participants shared stories of what programs and references they used to facilitate creative arts with the patents. Innovative ways of creating were established and volunteers and other health care professionals have asked to share the materials so they can also provide care. Some participants have encouraged the use of T.V's for other purposes other than watching the news and not being able to process the events.

The holding environment is important in providing care. Some of the participants were able to provide care by working with the patients on a one to one basis and others worked with them in groups. The holding environment resulted in spiritual break- through of patients awakening to song and singing when they had not been verbal for some time. Patients also experienced joy, creativity and peace when music was utilized as well as poetry, pray and art. Lasting mementos were also created and passed to the family in memory of their loved ones. The chapels and synagogues were also holding environments and provided places for worship, singing and reflection.

Prayer, symbols and spirituality was evident and singing hymns would sometimes provide spiritual/pastoral care providers with grace filled moments. Some symbols associated with people living with dementia include butterflies, candles, handprints, prayer, songs and words such as faith, and believe.

Most of the participants that were interviewed wanted additional education and training to provide additional creative arts. Some have continued to train to enable them to be able to provide care to many diverse populations as well as the staff. Some of the participants want a consistent language taught to them when they take CPE.

In chapter 4, I will discuss the challenges, limitations, recommendations for further research and conclusions.

CHAPTER FOUR: DISCUSSION

4.1 INTRODUCTION

I interviewed 22 participants that worked in the spiritual/pastoral care departments of many hospitals and long-term facilities in Canada and in 2 major cities in the United States. I noted that there was agreement of all of those that were interviewed in sharing the work and assessments with other staff. The participants were mainly chaplains, pastoral/spiritual care providers, and students just completing CPE that came from many diverse backgrounds. Many loved the creative arts before entering ministry and found time to facilitate creative arts and spiritual care with all hospitalized populations. Many that provide care to the Alzheimer's population also provide grief services or work with hospice or palliative care.

Many of the interviews featured the work of the spiritual/pastoral care providers, chaplains and others over the span of their working careers. Most of them provide care with all populations within the hospital settings. Those that specialize with the Alzheimer's population want them to be spoken of in a positive light. Although there are challenges in providing care to this population, it was mentioned on several occasions that it was because of boredom and lack of stimulation of the patients.

Types of creative arts utilized included music therapy, art therapy, poetry therapy, movement and somatic therapy, improvisation, life review, praying and singing with the psalms, sensory stimulation, meditation, and the utilization of many programs. Many of the participants shared in the joy when the person with dementia remembered songs, prayers and for the first time spoke and said they liked something. All found there was a sacredness and mystery and working with the spiritual aspects that revealed grace-filled moments.

4.2 LIMITATIONS

I found that there were few participants in the U.S. that wanted to be interviewed. Although some of the spiritual/pastoral care providers corresponded, many could not take time away for an interview. Some participants had just completed CPE training and when they completed their advanced training it was not working with the Alzheimer's population but with Palliative care, hospice or providing grief support to clients and families. Some of their recollection of the experience was brief because it happened years before. Some of the interviews were short because they could not relate any personal stories due to the fact that they had worked in groups and did not interact with the senior population. Some of the spiritual/pastoral care providers work in the evening or on a casual on- call basis. They were not present during the day when most creative art programs were facilitated. Their interactions were varied and some used "reading" for the client, use of recorded music, reflective prayer, cards and life review.

I have not attended any conferences provided by the "Canadian Association of Spiritual Care" (CASC) and had no way of knowing whom to contact. Many spiritual/pastoral care providers were surveyed recently whether they supported research and some responded without reading the directive for the "Alzheimer's population." Most of the participants except for those that worked with the veterans found they supplied their own materials from their funds designated for spiritual care. One participant did not want to interfere with the art therapist on staff and devised a program that incorporated looking at art rather than creating it although she worked in a different population. Some spiritual care/pastoral care providers still believed that clients living with Alzheimer's cannot or are not capable of doing creative arts. This was a limitation because they were not fully aware of what lies below the surface of what "they see" or

believe a senior is capable of. According to a participant there were limitations to where in the hospital creative arts could be held. From her experience she decided that she would apply to work in a long term care facility rather than the hospital because her program was cut back. Creative arts advancement had been tremendous with the population then scaled back.

4.3 RECOMMENDATIONS FOR SPIRITUAL CARE PRACTICES & RESEARCH

The themes of my research support the use of creative arts therapies with people living with dementia and involved many theories: The theory of hope is important because all human beings need hope to survive and creativity sparks all people. The concept of redemptive re-making was evident when spiritual/pastoral care providers branched out from singing hymns to include folk music and songs from the patient's eras. The notion of Nouwen's wounded healer was evident when participants talked about their lives that included processing grief, sickness, being widowed and having their own health issues. Barth's elements of encounter were evident when participants collected patients to participate and found them in hallways or T.V. lounges and found creative ways to interact with them. Winnicott's potential space theory was utilized when any connection was made between the patient and the spiritual/pastoral care provider and the families. Patients require more than just their physiological needs met and Maslow's hierarchy of needs was utilized by the participants assisting them with self-actualization by the patient singing, writing poetry and by doing or enjoying art. It was evident in the research that Erikson's stage reversed to some of the patients needing to be cared for, just as they were in infancy. The late stage of aging does not have to focus on despair and loss but can focus on

creativity and leaving something of themselves behind. Life review was evident in having the patient tell someone what they like or dislike and having the family share their loved one's history and put it where others can learn about them as well. Catholic social teaching themes were revealed by the participants in their use of providing dignity; family participation; respecting their rights; providing care for the vulnerable; working with health-care professionals and caring for those that live with dementia by providing creative arts, using nature and symbols. Sabat's social model of the self, described the 3 stages of the self and spiritual/pastoral care providers can work alongside family members to assist them to push aside the negative identity, by showing them they can still pray, be creative and still be in a spiritual community. The theory of paternalism and autonomy was apparent when a patient was assessed and was asked what she wanted in her final days. When this patient asked to study with the Rabbi she lived for another five years. And finally the theory or feminism capabilities perspective included 10 capabilities and some feature the need to move freely around; be able to imagine; express and enjoy themselves; be able to socialize; be able to continue to pray and go to go to chapel; still recognize nature and symbols; and have meaningful relationships with others.

I would encourage more study into the field of the body and remembered emotions. I have witnessed what negative emotions do to this population with after effects lasting many days. What are the remembered positive emotions from doing creative arts and how long do they last? Are there any other examples as with Samuel's client that lived for 5 years longer? Negative and positive emotions are felt by the staff and studies may be done on how this affects them?

Pierre stated that when the staff called him to play cribbage that it was the only time that the client did not think of dying. Laura stated the emotion was the last to go in the Alzheimer's population. The client will remember how you made them feel. She stated the mindfulness accesses peace and resides on our bodies. She did body mapping with the staff and monitored physiological responses. Robert stated that he stays with the emotion until it subsides and said "that's where healing occurs." Sally stayed with the emotion when she showed a picture of a Saskatchewan landscape which showed a stormy sky with an opening of light shining over a grain field. This was the 4th picture that she had showed to a woman with dementia and she cried out that "she couldn't stand the pain" and died a few days afterwards. If grief and trauma can reside in our bodies for many years, how does it resolve itself in the person living with Alzheimer's? More research can be utilized in the study of how the "body has stored memories."

4.4 CONCLUSIONS

My participants had varying levels of experience in caring for persons with dementia. Many participants only had experience with the Alzheimer's population when they were Clinical Pastoral Education (CPE) students and the experience for some was from as long as 5 years previous to the interview. Some of the male participants when entering into the setting where they were to play their instruments recall the population sitting together not conversing and many sleeping in their chairs. These musicians recall avidly the reaction of the population to the music by them awakening, clapping, singing, toe-tapping, swaying and more. Many of these students have gone to work with other populations but wanted to share their experiences.

In this thesis I offer art therapy as one possible means of caring for person with dementia. I would turn off the recorder after the interview and share various creative ideas with some

participants to encourage them. I interviewed two Canadian art therapists that were also spiritual/pastoral care providers. Their input was important because in the beginning stages of dementia when people are removed from their homes because they are angry, despondent and the families seek assistance. The input of the art therapists was important because they provide a holding environment that allows the patient to create and let out varied emotions. As well it was important in learning that Sister Fiona provided art therapy for chaplains to de-brief after providing care to populations that live with dementia and become palliative.

It became clear that there is enough work for art therapists, music therapists, along with spiritual/pastoral care providers, chaplains, students and volunteers. It was helpful to learn that a spiritual/pastoral care provider used “body mapping” to debrief and check-in with her staff as a way of using a non-verbal technique. It was also beneficial to learn of an art therapist asking to utilize a booklet of activities, poems and art, designed by a spiritual/pastoral care provider because she had patients that were spiritual and would benefit from her Biblical messages. Lila also worked together with a student art therapist during her practicum at her hospital.

Several spiritual/pastoral care providers used photographs of art-work and cards that featured Psalm passages. It was important to learn of Samuel’s work that had people living with Alzheimer’s write poetry and then produce songs from psalms, revealing a wealth of hidden talent. Writing accompanied with music was very beneficial with this population. Many of the spiritual/pastoral care providers remember the clients from what songs they preferred to sing and listen to. Many of these providers were also mourning those that had just passed away or their health had quickly deteriorated. The creative arts used by these providers by- passed language and cultural issued and connected many into small communities within the acute care settings.

Judith provides improvisation training for all hospital staff and caregivers. She noted that come chaplains felt they could not "lie," but should follow the client's story-line accepting what the client had to say and adding to it. Too many times in a day the person living with Alzheimer's is corrected, re-orientated and some of the language is "no, don't, wait, that's not true" and more causing frustration and negativity. Creative arts therapies enable the client and the staff to relax, create, play and learn about the feelings of the person that sits or stands before them.

Most of my participants stated they would like to continue their education by either attending workshops or studying creative arts at the master's level. Many do not have the funds to do so and the hospital will not finance attending conferences. It is imperative that articles be published in pastoral/spiritual care magazines. During the interview process it was mentioned several times that the hospital administrators wanted the chaplain to start to write in the monthly newsletters to enable the hospital staff to learn more about spiritual care and what creative arts were being implemented. It was with surprise when I interviewed a CPE student who had just completed her studies in April 2016 when she talked about an art project that she had devised and it had been devised by another CPE student in "2001" and had just been submitted and published by the Pastoral Care Magazine in April 2016. How many people living with Alzheimer's would have been assisted if the CPE student would have published her findings in "2001?" To be able to have therapies practiced and used to facilitate research, the works must be published in a timely fashion.

The growing ratios and work-load did not deter some spiritual/pastoral care providers from sharing with me. One participant stated that because she was also a researcher and that she

was blessed with double the participants for her study that any researcher that requested assistance would be aided by her. Many participants referred me to others in the field as well. Someone critiqued my use of the term pastoral because this population, although many of them were church goers, many were not physically able to go to church. It was explained to me that spiritual care is a term that is more widely accepted. Many of the providers also stated that to be more readily accepted was also to state that they were part of the "hospital supportive team." Many of the spiritual/pastoral care providers that provide music do not want to be labelled as the "guitar guy" or one that provides recreation.

Although I noted there are hospitals that have teams that work closely together to provide care there are spiritual/pastoral care providers that work on call/evening hours and there are no creative arts given during their shift. It is these providers that read to clients, pray, play music from their i-pods and try to assist those that have no visitors or family present. A participant noted that when it was too quiet that many of those living with Alzheimer's are anxious and are not at rest.

Because I work with long-term care I did not know of the recent therapies that are offered within the hospital setting. It was with surprise that I learned that there are centers that provide ceramics, sculpture, tai-chi, meditation, "spa-days," "snoezelen rooms" and even some therapies that were offered one on one are now given in groups. The exchange of information was helpful as well and inventive such as how life-review is promoted by the staff by having a paper sheet attached to the clients locker to enable themselves and family to write their likes and dislikes, hobbies, past job experience, favorite music, T.V. shows and more. I also learned of

Remembrance Day activities and other rituals that I never knew existed in hospitals and are offered by the Alzheimer's associations throughout the continent.

The spiritual/pastoral caregivers that work within this population are welcoming and shared their wealth of knowledge with me. I hope this thesis revealed that there is room for all health care providers and spiritual/pastoral care providers to continue to work together. It was my experience by working in health care to include everybody in the spiritual healing process. I learned from the interviews that to provide spiritual care using the creative art therapies means sometimes alternating clients so that everybody gets a chance to participate and that if it is one/week that that is considered "a good week." Some participants wished that there were more like themselves. I agree! Given the effectiveness of the therapies as reported here, I would recommend that spiritual/pastoral care providers should be introduced to using creative arts during the CPE training process no matter what the population is and to be able to also facilitate creative arts on the geriatric-psych unit.

My research question was answered by learning about how spiritual/pastoral care providers implement a variety of creative arts to the Alzheimer's population. Music and art was used interchangeably by many spiritual/pastoral care providers. Why the implementation of creative arts is not documented was found to be because of high client ratios. The beginning of documentation using creative arts was starting to be implemented by many of the hospital newsletters. I found people like me that believe in the grace filled moments and the uniqueness of every individual. Culturally creative arts reached the clients whose language fluctuates sometimes with 3 languages for example Italian, Latin and English. Spiritual/pastoral care providers claim that God is present in these encounters, and person living with dementia benefit.

It is a means of fulfilling the biblical mandate to love one's neighbor, to care for the needy and to honor the elders. People living with Alzheimer's are persons and belong to the religious community. They are Mothers, Fathers, Aunts, Uncles and more and remain so, the disease did not take that away from them. They remain the beloved children of God, and to not visit, care and keep them in community, is to ignore God. Grace does not require cognition. In Matthew 25: 45, Jesus states that "refusing to help one of these least important ones you refused to help me." The church has a role through teaching and preaching that counters the notion that one has to be productive, active and successful and the anthropology that person's with Alzheimer's are somehow less human. Further research into spiritual/pastoral care with dementia patients is warranted and could be useful for soliciting support from government, hospitals and medical providers.

APPENDIX

(a) Information

Dear (participant),

My name is Debbie Theriault I am a student in the Master of Arts in Theology at the Atlantic School of Theology (AST). As part of my program, I am undertaking a study of creative arts used by pastoral care providers in the hospital setting. Creative arts are defined as the use of art, music, drama, dance/movement, poetry, creative writing/ life review and more.

This is important because of the increased numbers of seniors awaiting placement this population needs pastoral /spiritual care. I'm hoping that the results of my research will serve as a resource for the hospital faith communities that would like to use creative arts to facilitate communication. This research project will be conducted under the supervision of Dr. Susan Willhauck, and my plans have been reviewed and approved by the AST Research Ethics Board.

I am contacting you because of your experience as part of a hospital pastoral/spiritual care community that has used creative arts and I would like to ask you to be a participant in my study. If you were to agree to be part of this project, it would mean being interviewed (by Skype) about your experience at a time that is convenient for you. For research purposes, an audio recording will be made of the interview, but your identity and that of your hospital will be kept confidential. Should you be interested in becoming a participant, I will provide you with a more detailed account of how materials related to this project will be securely stored and destroyed.

Thank you in advance for considering my request. I would be happy to answer any questions you might have about this project. I can be reached at this email address: heavenly@nbnet.nb.ca and by phone: 506-855-0810.

Sincerely,

Debbie Theriault

(b) Invitation to Participate and consent form

Debbie Theriault

Atlantic School of Theology

660 Francklyn Street

Halifax, N.S. B3H 3B5

heavenly@nbnet.nb.ca, 506-855-0810

I am a student enrolled in the Master of Arts in Theology at the Atlantic School of Theology. As part of my coursework under the supervision of Dr. Susan Willhauck, I am conducting a study of pastoral care providers that provide pastoral/spiritual care by using creative arts to the Alzheimer's population within the hospital setting which includes (art, music, poetry, creative writing/life review, improvisation, drama, dance /movement and more.) I will be interviewing people who have been closely involved in the provision of pastoral/spiritual care. I am inviting you to participate in my study.

The purpose of this work is twofold: first to increase the body of knowledge that we have on the topic of pastoral care providers using creative arts to facilitate communication with the Alzheimer's population; and second, to explore how this experience might impact the patient.

The research relies on the perception and impact of spiritual care providers as to any benefits noted from this type of care with people experiencing dementia. The questions and the project are designed to study the perceived benefits noted by pastoral care providers that use creative arts. The researcher will take notes and digitally record the conversation. The audio files and transcript will be held in a secure environment until the completion of this course of study, at which time they will be destroyed. This project will be completed by the first of September 2016.

If you are willing to participate in this project, please read the following and indicate your willingness to be involved by giving your signature at the bottom of this page:

I acknowledge that the research procedures outlined and of which I have a copy have been explained to me. Any questions I had have been answered to my satisfaction. I know that I can contact the researcher at any time should I have further questions. I am aware that my participation in this study is purely voluntary and I understand that I am free to withdraw from this study at any time. I understand that the personal record relating to this study will be kept confidential and anonymous as possible. Names and potentially revealing facts will be changed, this affording me anonymity. To further protect individual

identities, this consent form will be sealed in an envelope and stored separately. Furthermore, the results of this study will be aggregated and no individual participant will be identified.

The following is a time line for the storage and destruction of data:

1. Upon receiving a signed Informed Consent form from each research participant, I will:

a) Provide one copy to the participant.
b) Keep one copy for myself, which I will place in an envelope separate from all other materials and store in a locked file cabinet in my home office.
c) Provide one copy to my supervisor (Dr. Willhauck), also placed in a separated envelop, who will store it in a locked file cabinet in her office at AST.

2. Audio recordings of interviews will be recorded on a digital recording device. These digital audio files will be stored on a password-protected computer and secures at all times during data collection from the time of Informed Consent through the defense of the Theses and until deleted permanently from my device, no later than September 25/2016.

3. Within two weeks of each interview, I will transcribe the interview onto a Word document. The Word Document transcripts will be kept on a password protected computer from the time of data collection until the defense of the Theses (September 2016).

4. In September 2016, I will bring my recording device to my supervisor who will check to make sure the interviews have been deleted. I will delete the interview material from my home computer.

5. When the Thesis is submitted to my supervisor in September, 2016, The Word Document transcripts of interviews will also be submitted to her, either printed as hard copies or disposable CDs and deleted from my computer and trash bin.

6. Dr. Willhauck will store transcripts of interviews in a locked file cabinet in her office at AST for one year and all data materials will be destroyed by shredding or crushing in September 2017.

If you have any question, please contact the student researcher, Debbie Theriault at 506-855-0810 or heavenly@nbnet.nb.ca

This research has been reviewed and approved by the Research Ethics Board of Atlantic School of Theology. If you have any questions or concerns about the study, you may contact Dr. Alyda Faber at afaber@astheology.ns.ca Chair, Research Ethics Board.

By signing this consent form, you are indicating that you fully understand the above information and agree to participate in this study.

Participant's Signature: ______________________________ Date: ____________________________

(c) Thank you

Dear (Participant),

I wish to extend to you my sincerest thanks for your participation in my study on the experiences of pastoral care providers that provide care utilizing creative arts to the Alzheimer population. I appreciate the time that you set aside for out interview about your experiences and the candidness of your responses. By participating in this study you have expanded what we know about how your work impacts the life of the patient and your contribution to my study will benefit other pastoral care providers by helping them to communicate to this expanding population.

This project has been an important part of my education and training for providing pastoral/spiritual care to the Alzheimer's population in the hospital setting. I sincerely thank you for your participation. If you have any further questions about this study, or to request a copy of my final paper, please contact me at 506-855-0810 or heavenly@nbnet.nb.ca

With warmest regards,

Debbie Theriault

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