

LEAVING WORDS WHERE YOU FIND THEM;
A STORY WITH FIVE WOMEN LIVING WITH DEMENTIA
IN A RESIDENTIAL CARE-HOME IN ST. JOHN'S
NEWFOUNDLAND

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Running head: LEAVING WORDS WHERE YOU FIND THEM

Leaving Words Where You Find Them; a story with five women living with dementia in
a residential care-home in St. John's Newfoundland.

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"These stories don't mean anything, unless you've got someone to tell them to."

"You see the smile that's on my mouth; it hides the words that don't come out."

-Brandi Carlyle's song "The Story"

Introduction

For the past year I have weaved in and out of conversation with and about women living with dementia in a residential care home in St. John's Newfoundland.

This research report is my arrangement of narratives. I am attempting to convey with words, experiences and relationships, stories that were expressed to me. Within this project, there are many stories. The purpose of my research was to get to know each woman on her own terms. I wanted to know her stories, without imposing questions and without contextualizing her identity through dementia. I use the term "story" in this paper to refer to what is shared through the expression of one's lived and living experience. A "story" does not require any traditional story form. It does not need to be written or spoken. The story only requires one to share it, one to receive it, and something in-between.

Research methods are not intended to predict or define what the participants will say, but to tailor the methods so there is a positive and open space of communication for the participants to say it, even if this means a new language must be learned. Dementia does not allow the individual to live in a linear existence. Their understanding of the world and their expression of self is a story with more than traditional parts. For the researcher to hear the story from someone living with late-stage dementia, it is necessary

to think in terms of how the individual living with dementia is thinking. The participant might be able to inform the researcher about their disease, but the disease cannot define them. It can, however, contextualize how they might communicate.

During my research I sought to express the significance of sharing a story without words. While it is difficult to convey the stories I heard, it is even more difficult to imagine these women's voices, their knowledge, and their lives forgotten, because they themselves are forgetting. This paper, these pages, and the research within hold more than black lettering. Held within is a brightly lit perspective not often heard within discussions of women's knowledge, especially those living with dementia.

I sit, socked feet warmly tucked under me in an oversized chair. Sitting across from where I am is Tom wearing worn through slippers in a chair that fits him just right. "This is her home." He says. "We lived here together for sixty-five years." Paintings line the walls. A doily on the piano is barely visible due to several stacks of sheet music. Family photos sit upright against each surface.

"I go in every day for a meal...I cannot see cooking for one." Tom speaks about his wife in a soft voice, hardly audible by my tape recorder. He tells me the clothes-line story. He says that she arranged for someone to come and install a line in her back yard, but after the guy had left, she had to call him back because neither she nor Tom could reach it. "There's no sense in building something useful that is only useful for others." He says.

"Aggie always held my hand...still does, sometimes I think she just holds my hand even though she's not quite sure who I am." (Excerpt from interview with Tom)

Overview

This report is a contextualization of many voices; the women involved in the research and myself as researcher. First I will introduce you to the project, how and why it developed in the way that it did and where I locate myself and others within that development. I discuss my research questions and the ethics process concerns raised by the Human Investigation Committee (HIC). I also discuss my research as a collaborative

arts-based project that went beyond the attainment of a degree. I illustrate what is involved in thinking about research with persons living with dementia including my methods and methodology. Next, I take you through the first phase, and introduce you to five women living with dementia within a residential care-home in St. John's, Newfoundland.

The discussion of the second phase takes you through the interviews with the family members and one focus group with the care team and also my experience of the participant's articulations. I take you through a discussion of the concept of story, within the theme of women's knowledge. The final section discusses the outcomes, what happened within the research framework and what happened outside of it. I explain what was expected, unexpected and overwhelming. I explain the process of locating myself within the research after the first two phases and how I allowed that lead to the third phase. I then discuss the artistic research phase and the construction of the wall.

Background

In April of 2008 I became a member of the Newfoundland and Labrador Centre for Applied Health Research affinity group for arts and health. This group includes community members, artists, medical professionals, professors and other persons who believe that art, in its many forms, contributes to health and healing. As I was searching for a research topic, I wrote an email to the members of the group, outlining my research interests, the requirements of the program and my previous experience with community groups. Within a few hours, Anne, a recreational director at a residential care-home in St. John's, responded to my inquiry.¹ Anne expressed her interest in a project that valued the women living with dementia in her unit. She stated that through her work, she had the

¹ For the purpose of this report, all participants have been given pseudonyms to protect their privacy.

opportunity to appreciate these women for who they were. Others could not. Following this email she and I met for coffee over a period of several months and discussed possible frameworks for the project. The more conversations we had, the more I realized that conversation, in its different forms was going to be at the core of this project.

The process of applying to receive HIC approval involved considering the participants as part of a vulnerable population. HIC states that,

[...p]articipants have given free and informed consent when they have freely agreed to serve in the study on the basis of their understanding of the objectives of the research. They must be fully informed of all risks and possible benefits of their participation. The participants must have an opportunity to evaluate the relative weight of any risks and benefits of the proposed research. Continuing voluntary participation requires that participants be assured that at any time their withdrawal from the research shall not result in penalty or harm or loss of promised benefits.

http://www.mun.ca/research/researchers/human_subjects2.php#9

The women that I would be working with were not able to give me their consent, as it could not be ascertained whether they would understand what the consent meant. In this case, it was up to their families to make this decision for them. For these reasons, it was important that my project be more likely to benefit than harm, and that it be as unobtrusive as possible, because I could not ask the women themselves about my presence in their daily routine. In my application, I designed an information letter that clearly describes my purpose and what participant involvement meant. I developed one consent form for both the family member's interview and for the consent of the women in the first phase. The consent form gave the family member the opportunity to say whether they would agree to participate in an interview. I am grateful for the HIC ethics process, because it made me aware of some of the vulnerabilities of the participants. The following is a statement taken from the initial letter distributed to families by Anne:

I am doing this project as a granddaughter of an incredibly strong woman who lives with Dementia, and as a student who has spent most of her education learning different ways to listen to and value women's life stories. My own experience has taught me that communication is more than verbal language, and that in order to hear an individual's voice, sometimes, one has to look beyond what they are saying. As an artist, a musician, a woman, and a granddaughter, I feel that I have designed this project so that in using the best aspects of myself, I might help others to know a group of women whose stories are often not heard, because they live with Dementia. In spending time with your family member and in getting a chance to hear your experience, it is my hope to shed a unique and positive light on the identity of your family member. On paper I am spending time at the [home] as a researcher and as a Master's student of Women's Studies. In reality I am there drinking tea and absorbing all the adopted grandmothers I can.

I first met the women who were to be participants in my research on my initial visit to the home. This visit predated planning the phases of the research. We entered the unit just as residents were eating their dinner. Anne walked past me, greeting people and asking them how they were. I remember feeling awkward as I said to Elisa, "it is a nice day today". She laughed and stared at me. I thought perhaps that the way she was looking at me suggested that I should have more to say to her. Anne walked up to a woman sitting in a chair. Here, she is known as Grace. I could see that she was trying to form words, but I could not make any out. It was very difficult to tell what she was trying to say. Anne bent her knees so that they were eye level with each other, put her hand on Grace's and said, "you are so funny...you always tell the best jokes". Anne explained to me after, that she could tell from Grace's intonation that she had finished the joke and was waiting for the punch line to hit. When Anne acknowledged what was being communicated to her, relief and a smile were clearly visible in Grace's face. I began to realize what Anne was talking about. To value the person, where they are at right now, and how they are communicating right now, is not reliant on our satisfaction, but on theirs. Anne learned to

communicate in the space of the resident first, and because of this, she created a positive space of interaction.

After the initial visit, I began to wonder about these women. Where were their stories; were they being forgotten because they themselves were forgetting them? How were these women telling their stories and expressing their current state of self? And how could I conduct meaningful qualitative research that valued these women's voices? As Proctor (2001) outlines, it is, "...very rare for the subjective experience of the person with dementia to be considered, to be judged valid, possible to access or to be worth listening to" (p.362). I consider the voices of women living with dementia to hold more significance than they are recognized for. There are generally two types of research when working with the topic of those living with dementia: biomedical research and quality of life research. The biomedical approaches the individual from a science based medical lens. The quality of life based research looks at the individual from all perspectives of how that person's existence is affected. Although quality of life research is currently popular with persons living with early-mid stage dementia, these are still avenues to be explored with persons living with later-stage dementia.

To think about my research project and the participants, I first had to locate myself within the topic. This paper will fall into the hands of my fellow students, future students, professors, mentors, participants, friends and family and other community members. This is my second degree in Women's Studies, the first I completed at the University of Regina in Saskatchewan in 2007. Learning about what women had contributed throughout history, allowed me to appreciate what it meant that my great grandmother had her own meat market and radio show, that my Gran had been married to

an RCMP and remembers every story the family has, that my mother raised me mostly as a single mother going to university, working at a writing clinic and driving taxi, looking after a child with cancer and grieving the loss of my sister Jamie, and that I am the first person in my family to seek a PhD. All that I learned through Women's Studies was centered on strength. The strength that has not been written in our children's history books and is not depicted in the wages of many professions. For myself, the need for feminism is a visible one. It is not a need to blame or punish men, or male strength, but to demonstrate that women's strength holds our social world together just as much. My feminism is that women's experiences and knowing them, allow our world to be a more equal place. Feminism means something different for each person, and for me, it means for all of those instances where men have worked incredibly hard, and they have, there is a woman standing near-by who can teach us a unique perspective about these same things.

I was drawn to working with the women at the residence because of my conversations with Anne but also because someone in my family is living with dementia. I knew that I could contribute patience and sensitivity. I also believed that I could demonstrate these same attributes in whatever came out of the research. My supervisor Dr. Natalie Beausoleil spoke nothing but confidence in my ability to act responsibly and respectfully within my field of research. The support of my peers and mentors definitely helped me to be confident in what I was doing.

Dementia and Qualitative Research

There are close to 28 million people living with dementia (Page & Keady, 2010, p.511). There is no cure for dementia. Statistics convey a startling reality about a disease.

A disease is attached to an individual. Researchers have recognized the exclusion of the person within this research and have developed methods and studies to express the significant contribution that an individual living with mild-moderate dementia can make to knowledge about their lived experience, before and with dementia. Unfortunately, there is no "after-dementia" as later stages of dementia are also the later stages of life. As researchers we work with material to which we have access. If I want to ask someone what is important to them, it is necessary that they have an answer. In late-stage dementia, if you ask, there might not be an answer, however, innovative research and approaches to care that are enthusiastically being applied to persons living with mild to moderate dementia, should not forget those experiencing the later stages.

To discuss research involving persons living with dementia, it is important to know how the "self" has developed in theoretical discussions and in tangible practical ones. There are two key research developments that came out of research conducted in the 1990's, with regards to method and methodology when working with individuals living with dementia. The person-centered approach and dementia care mapping highlight the shift of focus from a bio-medical understanding of the individual's behaviors, to a social or external environmental based perspective. Downs (1997) cites Kitwood's work which looks at the inter-personal interactions that an individual has, which allows them an expression of self (p.604). Another study demonstrates that there are two expressions of self observable in those living with dementia. The first expression of self is the ability to refer to one's self with a first person account. And second, the embodiment of certain roles that are taken on by an individual who may not be able to

refer to themselves in first person (Small, Geldart, Gutman, & Clarke, 1998, p.292).

Recognizing how the self is expressed is a significant aspect of dementia-care.

Dementia Care Mapping is a coding system that allows researchers a method of person-centered care. It is an approach to observation that evaluates the presence of person-centred approaches in institutional settings. It is focused on improving dementia-care, and also research methods (Kelly, 2010, p.108). Within this model, there are two types of self: the “supported” self and the “unsupported” self. The supported self occurs when an individual receives encouragement, acknowledgement and enthusiasm about how they express and communicate who they are (Kelly, 2010, p.116). To improve the quality of care and life for individuals living with dementia, they must be supported in how they express their self. Kelly states, “[t]his way of viewing and interacting with people with dementia has the potential to fuel a transactional flow of positive interactions”(2010, p.119). I have formulated my method to be focused on the individual. What distinguishes my research from others, is that I started in the space of communication of individuals living with late-stage dementia. Kelly (2010) suggests that if as practitioners (and I will add researchers) we, “...are taught to recognize and support verbal and visual expressions of the self of the person with dementia, this might promote a new way of viewing and engaging with them” (p.121). These qualitative methods are important, because they push our boundaries as researchers. Richardson (2000) states that, “[u]nlike quantitative work, which can be interpreted through its tables and summaries, qualitative work carries its meaning in its entire text” (p.924). Qualitative research reminds us that the research is not only about the knowledge that we can easily access, but also the knowledge that challenges us to change our methods.

Page and Keady recently conducted an analysis spanning 18 years that examined autobiographical works of persons living with dementia. This research looks at how each individual tells their story, the message within, and what it contributes to understanding of dementia. They illustrate that in all the stories they examined, "...the sense of self was intrinsically linked to how one functions: as functioning was affected through the progression of dementia, so the senses of value, utility and purpose were undermined" (Page & Keady, 2010, p.517). They state that, "[u]nsurprisingly, all the narratives are inherently stories associated with the anticipated and actual loss of the sense of 'who one is'" (Page & Keady, 2010, p.517). Page and Keady articulate the importance of "continuity" both in their research, and in the experiences written in the autobiographical accounts. They discuss how in early stages of dementia, their research showed that maintaining "identity and presentation to others" was central in all of the stories.

The stories that individuals have about their lives are articulated in ways they can understand, and they feel others can understand as well. An individual living with late-stage dementia cannot be asked to tell their story in a way that they themselves cannot understand. The responsibility then, to hear the story, to allow a space of communication, lies with the listener, to find out what that "telling of the story" means for the individual. It is my assumption that the feelings articulated by persons in earlier stages of dementia, are not un-similar to those of individuals in late-stage dementia, they are just expressed differently. Through this project, I sought those stories. Page and Keady state that "...for people with dementia the (re)construction of a 'new identity' is maintained only in the sense that it brings change in the self with a different set of goals, assumptions and aspirations" (2010, p.512). In the paper entitled, "Personhood in dementia care..."

O'Connor et al. (2007) state that there is a "...need for researchers to consider innovative approaches to data gathering, since traditional methods could be inadequate once the dementia progresses and communication skills deteriorate" (p.126). My research embraces this perspective. I recognize the need for alternative research methods, and more sensitive, individually-focused research. Such methods support Beuscher and Grando (2009)'s conclusion that:

Future studies might involve participants with more severe [Alzheimer's Disease]. Those studies will probably require shorter but increased numbers of interviews per participant. Another suggestion is to increase observational time of participants to understand their communication abilities. To establish credibility and dependability, researchers might consider triangulation of the participant's interviews with the caregivers' interviews (p.11).

Instead of triangulation, I offer Richardson's (2000) alternative discussion of the metaphoric 'crystal'. The crystal allows for more flexibility in how we approach information collected and written about. "Crystals are prisms that reflect externalities *and* refract within themselves, creating different colors, patterns, and arrays, casting off in different directions. What we see depends on our angle of repose" (Richardson, 2000, p.934). Here there is no concept of validity, only partial knowings of what we are studying. Miller and Fox's (2005) bridge metaphor works well to describe the social spaces of the residents, family members and care-workers in this research.

Bridges link distinctive land formations, making it possible for people to traverse between them. While opening new opportunities for residents on each side, bridges do not blend the formations or otherwise make them indistinguishable (Miller & Fox, 2005, p.35).

The metaphors of crystal and bridge allow the researcher an approach to an analysis of conversation that allows them to see what kinds of dialogue are happening within the research, and what that dialogue can mean for how we understand our social worlds. The

term “social” is key here, in that reality is going to display itself differently depending on who is entering the social space. Miller and Fox (2005) illustrate, “[a] major assumption of the triangulation strategy is that sociological research is a discovery process designed to get an objective truth that may be systematized as a formal theory of social structure and process” (p.36). This previous statement suggests that it is possible to triangulate without looking for a single truth and that, “...looking at an object from more than one standpoint provides researchers and theorists with more comprehensive knowledge about the object” (Miller and Fox, 2005, p.36). The object here *is* reality. I am interested in what the social reality is for each participant, and how the individual experiences and communicates their experience of that space. In conducting research that observes persons and not objects, there is no objectivity, as we are constantly in relation with those persons; we cannot be outside of these relationships.

Beuscher and Grando (2009) state that there is, “...[a] growing interest in conducting qualitative studies that capture the personal perspective...yet few of these have been published, and very little has been written about the challenges of conducting qualitative research...” (p.6). Research with individuals living with dementia can require more of the researcher than of the participant. It can mean stepping out of one’s comfort zone, being incredibly sensitive and open-minded and it can also mean changing one’s preferred methods of communication and research. It has also been illustrated that the information gathered from qualitative research, “...is critical to researchers and clinicians who develop and test interventions for people with [Alzheimer’s disease] to reduce stress, fears, and anxieties and to improve their mental well-being and quality of life”(Beuscher and Grando, 2009, p.7). Specifically, if the research process is reflective of the

communicative process of the individual participant, the information gathered is going to more accurately represent that individual's lived experience. In addition, that particular research is not only more likely to benefit the participants, but the researcher and future research conducted with individuals living with dementia as well.

Defining dementia is difficult, as it displays itself differently depending on the individual. Knowing how dementia affects a person requires knowing the person first. If we rely on the medical texts to define dementia, we medicalize the person, this is why it is important that qualitative research contributes to the knowledge-base surrounding dementia. Despite the inability to know dementia on its own, there are a few general symptoms that appear in most persons living with dementia. It is important to know that symptoms vary according to the individual. One definition of dementia is that it is "Dementia is a syndrome consisting of a number of symptoms that include loss of memory, judgment and reasoning, and changes in mood and behaviour. These symptoms may affect a person's ability to function at work, in social relationships or in day-to-day activities" (Alzheimer's Society of Canada, 2010).

There are generally three stages of dementia, however they are often not clearly isolated and individuals might be in two stages at once. The first stage is known as early stage. This is a general forgetfulness or inability to solve some problems the individual was able to previously solve. Individuals in this stage are often aware they are experiencing new difficulties and may attempt to hide the fact (Kuhn & Verity, p. xv). Persons experiencing middle stage dementia may experience even more difficulty in saying what they want to and short term memory loss. Individuals in this stage are described as being confused about what has happened or what is happening at the

moment (p. xvi). Those experiencing late-stage dementia have a lot of difficulty communicating with words and often have a very personalized vision of what is happening at any moment. This stage of dementia demands that individuals receive a lot of assistance with basic needs and taking care of themselves (p. xviii). If one defines the person through dementia, and sees that person as being gone, this only perpetuates that they **are** their disease.

The research outcome included hearing the stories that these women living with dementia had to tell, but also finding ways of hearing them. The first research phase relied upon naturalistic observation. My method was to not ask formal questions and to not require the participant to do anything outside of their regular routine. The information gathered was collected through observation and recorded through field notes at the end of the session. The second phase was to find out how these women's families knew them. I intentionally positioned this phase second because I wanted to know the current state of self of the women who participated first. If I had met with the families first, I would have known them through other's eyes, and I would have negotiated thoughts of what I knew had happened in their lives with what they were saying. Interviews with families were semi-formal. I provided each family member with an interview guide. I not only wanted to hear who the women were, but also to find out how they communicated to each other. Although I had questions as a guide, I was completely open to hearing whatever stories emerged. I used a tape-recorder for each interview and transcribed them afterwards. In this phase I had planned to conduct interviews with the recreational care team at the home. These interviews would allow me to get to know these women on another level

entirely. I would be speaking with people who saw them everyday and yet had only known them (in most cases) since they had lived at the residence.

The final phase of the project involved an interactive and artistic wall exhibit within the residence. The purpose of this phase is three-fold. First it would allow for a symbolic representation of the spaces of communication that emerged throughout the project. Second, it would exist as an educational tool, about the identities of these women with and without dementia and about new ways of approaching one's thoughts about and interactions with women living with dementia. It would do this by engaging viewers, some by image and some by word, and by providing an example of a meaningful approach to communication with someone with late-stage dementia. Third, the wall holds a space for anyone to write or draw, thus allowing for even further dialogue to occur.

I allowed for the potential that my methods might change. Allowing for this flexibility was a benefit as it allowed for a more comfortable space for participants. When I first proposed my project, I explained to the recreational care-team and the families that their input was essential in the way the research played out. An example is that when I formed my proposal, I indicated that I would conduct individual interviews with those who wanted to participate from the recreational care team. When the project was well underway, it came up in discussion that the care team would prefer to have a focus group. There were two reasons behind this. One was that we could all sit around a table at tea-time, so it would not require them to move too far from their schedule. The other reason was that each care worker had spent different amounts of time and had conducted different activities with the women and would perhaps be able to remind each other of things if they were all present for the discussion. Another woman added they might

benefit from hearing the stories as well. Although I had planned out the phases and thought about how they might go, I left them open to be changed and provided space for conversation about them.

Reflexivity is a way of ensuring that one's research includes one's own thoughts as well as those expressed by participants. Fonow and Cooke use the term "reflexivity" to refer to, "...the tendency of feminists to reflect upon, examine critically, and explore analytically the nature of the research process" (1991, p.2). Miller and Fox suggest that, "...reflexivity refers to the ways in which our portrayals of social realities simultaneously describe and constitute the realities" (p.36). Nagy-Biber and Leckenby's definition highlights the importance of treating reflexivity as a process and not merely a state of being; they state, "...reflexivity is the process through which a researcher recognizes, examines, and understands how her social background, positionality, and assumptions affect the practice of research" (2004, p.115). Together these definitions reflect my concept of reflexivity going into this project and coming out of it.

At first I was not sure where my narrative fit in with the participants', and then it occurred to me that the entire project was in a way, my narrative. There was an ongoing dialogue that I had with myself and others about my own sensitivity and my personal experience with loved ones living with dementia. Having a relative living with dementia gave me a certain degree of distance and empathy for those I was working with. I felt as though I was the grand-daughter. I envisioned myself in this role to start the research from a position of respect, and now I felt as though I was living that role. During the process of locating myself, I took a week to reflect on the decisions I had made and whether the methods represented the goals at heart of the project. I was satisfied with my

reflections but decided to make one change. As I was having thoughts about my own family, I realized that the women at the residence were a constant comfort and although they did not know my name, they treated me as family. Whether or not it would be remembered or understood, I expressed my gratitude directly for the unconditional friendship I was receiving:

Aggie and I were sitting together like old friends. I was having a sad kind of day, mostly because I was missing my family. She kept mentioning a man by the name of Tom and said he would be home soon. Then she placed her hands over mine as if to comfort me. Although I could not make sense out of the words she spoke, the intention was clear. I said, "You are a good friend". She looked at me and took a gasp of air and said, "Really". I returned with, "Yes...you have a good heart". Aggie smiled and continued to rock in her chair while telling me stories. However, on that particular day, the only story I heard was friendship between two people who didn't know each other, because of their efforts to communicate. (Journal Entry Day 15)

As I was making decisions about how my research phases would operate, I kept a journal and I spoke regularly with Anne at the residence. I also met every couple weeks with my graduate supervisor. My supervisor informed me that research with persons with dementia had not been allowed for a period of time because of the difficulty of attaining consent. As Helstrom et al. state, "...exclusion of people with dementia is itself an affront to their dignity, and that inclusion, if appropriately handled, would enhance their dignity of personal identity" (2007, p.609). This was a contributing factor to choosing naturalistic observation as my method.

A researcher can never really stand outside of what they are looking at or who they are speaking with, as the way we articulate what we see and the reasons we see it that way is as much a part of the context as it is a part of the content. It is important to recognize that, "[o]ur descriptions of social realities, then, cannot be separated from the

objects, persons, or circumstances that they describe or the languages that we use to describe them" (2007, p.36).

Eliza reached out and levered herself out of the chair, using my arm. My first thought, was what would happen if she fell, what would I do. I know that I can't be confident that simply asking, "Are you alright?" will relieve my anxiety. I have to pay attention to more than words to figure out if she is steady on her feet. We walk out of the building and into a sunny day with a cool wind. Still using my arm she gestures to look several times. I can't be sure what it is she wants me to see. I can tell she needs to sit down for a moment as she is taking jagged breathes. We sit and she holds my hand and closes her eyes with the sun directly on her face. A bench is a few pieces of wood and some nails and yet at this moment it represents a rest in the sun that Eliza may not have known she needed, but is happy she is there. (Journal Entry Day 3)

Phase One: The Women.

The ritual that I started my day with was as important as the dedication I gave to my field notes. Each day I went to the home, it was a forty-five minute walk. I found it therapeutic. I passed through neighborhoods and along streets that I had not seen before. It was a chance to clear my thoughts and gather a sense of peace before entering into the women's residence. Once I arrived at the residence, the recreational care team invited me to have tea with them. I was surprised at how much that tea meant to me. If I was running late and thought I had missed tea, it was a relief when I saw them there, still having tea. After tea-time, Anne would take me onto the floor. I remember the first time I walked into the unit.

On my left, there were patients' rooms. My immediate reaction was not to look. It felt a little like a hospital and so I felt it inappropriate to be looking in patient's rooms. On my right, a nursing station and in front were several residents staring at me from their chairs. Aggie walked briskly up and down the hallway pointing and counting what seemed to be random numbers. Eliza fixed the collar of the woman beside her. I took a deep breath and sat beside Grace. It was very quiet, not a lot of talking except from myself and Anne. Grace started talking to me. It was as if she was telling me about this incredibly busy day. I could not make out what she was saying, and it made me feel really awkward. This would be my first

challenge. I would have to find a way to get used to not being able to introduce myself and get to know someone with the communicative strategies I was used to. (Journal Entry Day 1)

Depending on the day of the week and the general mood and energy level of the residents, Anne picked a group activity. The first I refer to as 'feeling useful'. On this day, we filled a cart with things that the residents could help get accomplished. There was laundry to be folded, coins to be rolled, nuts and bolts to be sorted, knitting to be done, and buttons to be packaged. The second type of activity is a tea-time which I call "feeling community". For this activity, we sat around a table, and everyone received a piece of china and a cookie. We either sang traditional Newfoundland songs, or Anne discussed pictures. The "feeling active" activity involved batting a beach ball around in a circle using flotation foam sticks. On some days, residents became particularly involved in this activity. The last activity that I was a part of was taking a resident outside for a walk.

At one point she looked out the window and asked me what that big hill out the window was. The funny thing is that I have no idea, so I said that. She said (a little panicked) "We're not going to do that hill are we?" and I said "no we are not hiking today...do you like to hike?" To which she said "Do I cook?" and I went with it repeating "do you cook?" She took a little pause and said, "well it depends I have all that laundry to do first." (Journal Entry Day 20)

Within the walls of the home, there are stories that are told about things that have happened and things that have not. There are also stories that are kept inside because the words are not there to tell them; inside walls and sometimes inside the self. The purpose of this research project was to demonstrate that the stories being told and not being told are both significant, even if no-one else knows the story, and even if it did not actually happen. As I was planning the project, I was also completing a course on qualitative research methods. It was in this course that I was exposed to the idea that the voice of the individual, the voice of the community, and the voice of the participants were more

important than the voice of the researcher. I struggled with how I would express this. In asking how would I gather these women's voices and how would I hear their stories, I realized that I had been defining identity and story in my own terms, not theirs. To provide an idea of how I define the notion of identity in this context, I refer to Crichton and Koch. They state that

[c]urrent diagnosis, treatment and care of people living with dementia often neglects their changing identities and particular biographical, historical and relational contexts. Whilst some aspects of identity like age, gender or ethnicity tend to be fixed 'in advance', others reflecting personal qualities are more fluid and potentially subject to negotiation during interaction. Hence, identity is a dynamic process that evolves from ongoing interactions between the individual and more or less negotiable aspects of her social environment (2007, p.365).

At this moment, phase one emerged. I asked myself what the outcome would be if I knew absolutely nothing about these women and just sat with them. What would I learn about who they are? What if I stopped asking questions and was just there? This then formed the basis for phase one of this research. I planned to go to the care home as regularly as I could to participate in group activities and interact with the residents on their own terms. Then at the end of the day I set aside time to sit and write about my interactions. These field notes were then the only visible part of my role as researcher.

I went into phase one with an awareness of specific power dynamics that are associated with being a researcher. In choosing naturalistic observation, I decreased the possibility that I would appear as an authoritative figure. I was not interviewing the women, therefore they would be more likely to feel free to communicate in their own time or not at all. It was important to me that these women did not have to leave their daily routine. I tried to remain aware that I was in *their* home, and that I was a guest.

There is laundry to fold. Dish cloths, baby clothes, and a bra. I sit down in-between two women. Winifred holds up a blue sleeper, tracing her fingers along

the snaps and the lace and says, "This one's mine" The woman next to her says, "that is your baby". I smile and she turns to me and asks, "You want one?" Winifred leans over and says, "Sure, she'll have ten of them". It wasn't my sleeper and it didn't belong to any of them, literally, but symbolically, it was all of ours and it represented a conversation about sentiment and family. Ten babies is a lot of babies, though (Journal Entry Day 12).

Five women's families had turned in consent forms, and so there were five that I could write field notes about at the end of the day. Within the first few days I felt I was really getting to know these women. It surprised me, the relationships I felt developing despite what I initially saw as a lack of communication. Perhaps I was never really going to find the stories they had before, because they were so busy telling the stories of what was happening at that moment.

It is late March and the snow has melted and the ground is beginning to thaw. I walk outside to the patio hand in hand with Aggie. There are raised planters there, and she is running her hands across the dirt as we walk. There are perennials and there are weeds. I ask, "Do you garden?" she says, "I don't think so" I then watch as she pulls all the weeds and leaves the perennials. Here I have learned something about what this woman knows, even though she could not tell me that she knows it. Aggie's knowledge does not disappear because she is no longer able to articulate it, it disappears when those around her stop paying attention (Journal Entry Day 28).

This first phase was beyond our voices as I heard more than words. As these women communicated to me, they were sharing their knowledge. As we stood beside each other, I was shown how to fold articles of clothing differently, how to slow my walking pace, and how to balance another person while they held my arm. It felt no different developing a sense of who they were than if they had been telling me their entire life story. In many ways it was a more close relationship than had I conducted interviews with them.

Interviews operated in a specific space for a certain amount of time and are useful when that space is designated by the participant as one where they are wanting to communicate

something. The spaces where the women communicated to me were spread out and unpredictable, and I felt my being there allowed me to be a part of many moments where we connected. The relationships I developed with the women evolved from moments chosen by them, but that they themselves could not predict to me. Each day I went into the residence, things had changed. One thing that remained a constant was that each day we got to know each other we had to start over again the next day. Not once did anyone speak my name or ask for it, and yet the whole time I was there, I felt appreciated.

I am sitting on the side of an armchair in the common room watching Aggie while she knits beside me. Our interactions are brief but meaningful. I've hardly heard a sentence from her and it has been several weeks. I start humming the song *Amazing Grace* and then after the first verse, I stop. She continues humming, the song her and I both know. This is shared knowledge. She then hands over her knitting and states sternly, "I don't know how to do this." I take the knitting and knit for a minute and drop a stitch. Aggie takes it back, fixes the stitch and repeats, "I don't know how to do this" (Journal Entry Day 29).

One of the care workers described interactions with residents like a puzzle. She expressed that it was as though we had the puzzle pieces but just did not know what the end picture was supposed to look like. One day, I sat with Eliza and she told me things with disjointed words and body language that did not seem to fit the words. I could see her anxiety building as she became more and more upset that she could not find the words. Sometimes her facial expressions did not seem to match what she was saying. I went home feeling frustrated. It was difficult to watch someone really want to say something and not be able to find the words. I wrote for several hours that night thinking about the puzzle concept. I decided to print out my field notes from that day and cut them into puzzle pieces. I then deleted them from my files. At the public presentation of my Master's research at the Women's Studies Speakers Series, I scattered the pieces on the

floor. My thoughts and emotions for that particular day would never be known. The pieces lay on the floor and although they were physically near, you could only guess at what they said when they fit together. I was hoping that this might give me some sense of what it was like to not be able to share my own frustrations. Even now, long after the event, I still feel that I have shared this feeling, with the women and with those I have shared my story with.

Due to the nature of my project and the community I was working with, it was not possible or desirable for me to predict or control the level at which I would get to know the women in the first phase. I tried to have very little expectation going into this phase, and it developed more shared knowledge than I could have imagined. Aggie was probably the woman I spent the most time interacting with. Although we were mostly always in a group, there was something that allowed me to connect with her so that I could hold her attention longer. My first impression of her was that she was busy. She always had to get up and go. This made the moments where she sat down and relaxed beside me, more meaningful. Most times, Aggie was walking and counting and although I did not understand why she was always counting, I understood that it was important to her. There was one instance where the nurses were trying to get her to go and eat her breakfast, and she would not budge. Comments were made about how she was not moving and I was told it might be better to just leave her. Being stubborn and perhaps overstepping I said to Aggie, "Would you come have tea with me?" She looked at me and said, "Alright I'll try...I'll give it a go". Perhaps she recognized our similar degrees of stubbornness, or perhaps she merely appreciated being asked at that particular moment. Aggie has this way of expressing herself when she is feeling something strong, whether it

is positive or negative. She rubs her hands together as though they are cold and makes really big eyes and says, "oh oh oh." Each time I saw this reaction I felt like she was completely aware of everything that was going on and just had no bank of words to choose from. Perhaps the reason I felt most connected to Aggie was that she was always up and about. Every single day I was there...so was Aggie.

Eliza seemed as though she would be the type to keep to her self and have a strong feeling of personal space. Eliza seemed really nervous about forming sentences. The first while I visited, she did not really pay a lot of attention to me, and did not use words, but took my hand and lead me to show me things; if there was a mess of carrots on the table, if someone was sleeping upside down in their bed, or if someone only had one slipper on. She never stuck around me for too long though, Eliza was clearly independent. From the beginning to the very last day I felt like she was hesitant to warm up to me. She was kind and entertained me but there was something in her that did not want to be social. This was not just with me, but with everyone. During one of my visits during the first month, I asked her to come into the tea room with me. She said "ok" and walked holding my arm down the hallways. When we arrived at the tearoom everyone was already seated. I pulled out a chair for Eliza and I, she motioned for me to sit and then whispered "thank you" and left again. I felt as though she wanted me to know that she saw my efforts to include her, but was not in the mood for tea. On one of my last days at the home, I was sitting with my back to Eliza speaking to Anne. I had just taken her for a walk outside and I still had my jacket on. I felt something on my neck and turned to see Eliza fixing my collar. She then dusted off my shoulders. Eliza was always bundling

things up or fixing things. If there was anything to be put in a neat pile, her hands were there.

Grace and I got along right from the first day. I honestly could not understand a word she said, and yet I heard more jokes and stories from her than from anyone. Her face was always full of life and she was mostly always in a really joyous mood. She was always giving Anne and I cheek kisses. It seemed as though Grace was able to let go of inhibitions, she was still stubborn about some things, but she was really ok about talking despite not forming words. Grace, like Aggie had a unique way of communicating strong feeling. It is difficult to describe with words, but it was a sound she would make with her tongue and she sang a little at the same time. It was always followed by a giant smile. Anne has a particularly strong relationship with Grace and I could tell it was really difficult for her not to tell me all about her. About a month after visiting with Grace and the other women, she fell and fractured her hip. This meant that I did not see her for several weeks, and when she did come back she could not participate as often because of her health needs and also they had her in a wheel chair bed for most the time. Grace seemed to be a very strong and opinionated woman, but not afraid to laugh.

Winifred is a woman who felt like a grandmother to me. She adopted me from the moment I met her. With all of the hugs I received, she seemed to be a positive and radiant person. When she held my hand, there was no letting go. Winifred loves babies and anything child related. She carries around a doll which she took care of just as well as if it had been real to someone else. When we were folding laundry, anytime there was a baby's sleeper or socks, she held them up and appeared so happy. Winifred found the friend in each fellow resident. She held hands with residents and walked down the hall as

if she had known them forever. There was one woman who was anxious a lot of time and it seemed that holding Winifred's hand comforted her. When she needed to get up and go, Winifred went with her. Winifred's family requested that she be moved to a more comfortable floor, so once this happened, I was not able to interact with her as often. I did however run into her at events which included all of the home's residents, and occasionally in the hallways with her husband. There was one occasion where she was sitting quietly and then all of a sudden she went and gave hugs and kisses to several people in the room. "I loves ya" was something she was not afraid to say or show.

The only narratives I have for Mavis are her own, and that of those who know her like I do. Her family was not able to give an interview, and based on the sentiments expressed in the other women's family interviews, this made me feel incomplete. What I gathered from the first phase, however, was no less than with the other participants. Mavis was always up for tea and usually participated in the group activities. She seemed to be an excellent listener; I always felt she was interested when I told her things. Sometimes she mentioned going home. She said that her mom was waiting for her in Harbor Grace. Mavis was constantly helping out the other residents. I remember her bringing a resident a sweater, and telling a staff member about another resident feeling ill.

Mavis came over and told me she was hungry. I had noticed while we were playing games in the lunch room that she was sitting with another resident up at the table and had given him her toast. Then she asked for more toast, and he ate that too. I commented on this to her, "well you gave your toast away, of course you are hungry" and she said. "Aw how could I not, the poor thing" (Journal Entry Day 15).

I have found that the things I thought I might focus on and the things I thought I might learn are not as forefront as I had expected. All of the residents on the floor are taking care of each other in some way, even if it is to provide an interaction or

acknowledgement where there otherwise might not be any. I am not visiting with individuals in individual spaces, but with relationships and people interconnected in a community. These women bring the people around them into their story, sometimes in a verbal and visible way (holding hands, giving toast) and sometimes in a symbolic way (a story about someone). Comfort seems to be found in reassurance, even the assertive “yes” response. To know that someone is responding and interacting with you, even if you do not really hear or understand each other, imbues your words with meaning. Perhaps if one was always around flowers in life, the ability to name some of the flowers while standing in a garden might bring pleasure. However if you do not remember, are the flowers still visible? Is it necessary to even ask if they remember?

Phase Two: The Families (Interviews and Focus Group)

In the first part of phase two I met with five family member participants. Two participants were from the same family and one of the women who participated in phase one did not have a family member available for an interview. I contacted the family members and held the interviews at locations that were convenient for them. Three interviews were held in their family home and two were held in the care-home.

I first interviewed Winifred’s husband. Bruce told me the story about when they first met. He was wandering through a fairground with a friend and saw a “gorgeous woman” standing near him. He took her up on the Ferris wheel and that was it...they were together. The following passage from my interview contextualized the perception I had of Winifred from the first phase,

We had a lot of friends on the street and this one lady was at Woolco...what it was called then, that was a while back, She asked her to come to work with her,

ya know, for company driving back and forth. She was the head cashier at the store. So she got a job in the children's department. I knew that was going to come, it wouldn't be in the cutlery or the women's department. It was gonna be children. I used to drive sometimes, it be a stormy night, I used to drive in our four wheel truck. They had the car in there. I'd go in and pick them up and she'd be working late. Everyone was going home at ten o'clock...the store closed and she'd be still working there (Bruce).

When I initially called Bruce for an interview, he could hardly let me off the phone. He was eager to tell me all about this wonderful woman in his life. He goes to the residence every day and eats a meal with her.

I just comes in and I has a candy (reaches in pocket to find it). So when I go up....she's changed. When I used to go up first, the doctor told me...she'll reject you. I used to go in there and say, "Come on let's go downstairs and let's go for a walk" and that "nope...don't touch me...you're cold, your hands are cold" She have all excuses not to come with me. Now...she's changes...she says. I goes in there and she says, "I love ya you know". I love you too. "Oh ya" she says (Bruce).

He buys her new clothes and takes her out sometimes. For him, Winifred will never be anyone other than the woman he married. This said, he loves her as she is now. Bruce mentioned that one of the positive things that dementia had brought for him, was that now Winifred does not remember that he cannot dance. He explained that he had two left feet, and that Winifred was a wonderful dancer. Bruce's stories are not without sadness. His eyes teared as he told me about how he missed her but he had found ways of appreciating Winifred through finding methods of different communication.

And every Tuesday when they were playing [cards] down there she would bring muffins...two kinds of muffins. I used to put tags, type up tags on the computer and put them on. Blueberry or partridgeberry. Every week we'd bring them down. Finally some of the ladies said to me. "[Winifred]...used to be a good card player, and now she's playing the wrong cards" (Bruce).

Bruce explained to me that there is something in her eyes that lets him know that she knows who he is. He makes sure he always says her name and hands her a candy when he

comes in. If he behaves lovingly just as he would before her diagnosis, then she will assume that he is someone who loves her. Whether she is making muffins or folding babies' clothes, their communication allows for her self, as she is, to be present and embraced. After the interview, Bruce mailed me an envelope. Inside, there was a single piece of paper with a poem typed on it. There was no explanation. It was a poem that highlighted his loss and love of Winifred.

The second interview was with Eliza's daughter in law, Donna. This conversation happened with a different tone than the previous interview. She invited me to her home, which was also Eliza's home. I was sitting at the kitchen table with Donna and I could hear from the very beginning before I had even asked her anything, that she was tired. Not the kind of tired that follows you after a long day, but the kind of tired that exists consistently after years of taking care of other people before your self. She told me that Eliza was widowed at a young age, in her early twenties, and that from that point on she worked multiple jobs to support her family. There was one name that Eliza would mention randomly sometimes when we were doing something in the kitchen at the home, when I asked Donna about it, she said it was her sister. She also said that if there was one person Eliza really remembered, it was her sister.

She uh basically she was a clerk in clothing stores, fashion stores. And uh she worked in dry cleaning. There used to be really nice clothing stores down here on Water St. one was Simon Levitz and she worked in jewelry stores. And she worked at the Royal stores. In the states the last place she worked was Empire wasn't it. Which was a really nice upscale clothing store. And she just absolutely loved to dress up. She wouldn't go up to the door unless she was.... She really enjoyed putting outfits together and criticizing what we had on. But she was very fastidious about herself...very. No she worked hard (Donna).

After hearing this statement, I immediately reminded myself not to let my mind wander off. When Donna mentioned fashion, I began to think about how Eliza fixes things,

especially magazines and shirt or jacket collars. She told me that before she moved Eliza into the home, that she was ripping up and bundling things. She found bundles of papers everywhere.

The last five or six months she was here. You don't know how much paper I cleaned up after she went into the hospital. She would sit there on the floor and tie up bundles of paper. She'd tear up the catalogue shed tear up the bible...anything she could get her hands on. Bundle it, wrap it, and tie it. You name it. And she had every one tied in the radiator. She had papers pushed in there. I was picking up paper for...I won't say weeks I'll say months after. No-one knows what she had bundled up. Everything you could think of. Flyers...she destroyed a couple of beautiful books. Photograph albums. You name it. And she'd spend hours sitting over there on the floor or on the chesterfield wrapping up these bundles. So, I was not as good as I should have been because she was quiet and I let her stay there doing it. She'd get upset if you interrupted her and I figured she's not doing any harm. Let her stay there and wrap up her papers. But I had a time...oh what a time we had going through everything after. She didn't read a lot. She liked magazines (Donna).

This statement allowed me to see connections between her behavior in the home and in her own home. I was in the room where this happened, and the way she was at the home was not a lot different in terms of wanting to be fixing everything. For Donna, Eliza's behavior is symbolic of exhaustion and loss, when you have the memory of a different woman to compare it with. I was able to appreciate the privilege of knowing Eliza without knowing anything else about her, then what she communicated to me.

The interview with Grace's daughter happened next. This interview provided an example of how the current state of a woman with dementia does not have to mean she is gone, just because she has forgotten, but can in fact be completely embraced for the new elements of who she is, combined with the old elements of who she has always been.

If you put your face down close to her, she'll be very affectionate. She may very well kiss ya...which is not something she...well I shouldn't say that she was never loving, cause she was loving, but demonstrative...like to be kissing while other people are watching. That was not Mom at all...no. No....alright in family situations. I guess she feels if people know her, maybe you are family to her. Now

at this point. Where as before, if there were strangers around, you wouldn't hug or kiss, it's not for show. But, you know we'd always kiss each other before we went to bed. Kissed her when my sister went away and came home and you know it was expected. And you know Mom was very loving like that. It's funny that she would be more-so here, but maybe she feels that everybody that comes up to her, talks to her, and is nice to her that it's a family type of feeling maybe (Deb).

My interview with Deb was one of the longest, and after hearing her talk about her mother, I saw yet another perspective on the identity of women living with dementia. Here was this woman who had in some ways lost her mother, but in other ways had elements of a mother she had always wanted. Grace was pleasant anyways, always chatting at you and radiating positive energy, but when her daughter came in, she lit up even more. Some of these women were recognizing people that symbolized family, and some were recognizing people that were actually related. Both interactions demonstrated how having positive and familiar interactions allow for us as outsiders to really see the personality and knowledge of someone who cannot use words all the time. This is the response I received from Deb after telling her that I had heard Grace singing a few times.

Really...I thought that was gone, cause that was a part of mom's life right from childhood. Oh yes...choir...she was always in a choir. She was in a choir for years. She was in a glee club up here in St. John's and then when she moved to Cornerbrook, it was in the Glee club out there. The church choir and the church choir in here. And always, it was a big part. Her father was in it, and her aunt was in it. Her brother was a tenor...he sang. So music was always a big part of us growing up and Mom's growing up herself. So I'm glad she is still, cause I thought that part was gone.

Cause I played the piano and Mom played the piano as well and when I would come in first when she was in here, I would take her down to the gathering square and I would always play, and she would really perk up. You know...so...I'm hoping that's the last thing that goes. Yah...cause she has always been a music lover (Deb).

The next interview was with Aggie's husband Tom. As I walked up the pathway towards the door, there was a lamppost on my left. I could see sections where flower beds

had been, and I could envision her smile as Tom invited me into the living room. Tom told me about how they always held hands and that now, even though she does not always know who he is, she comments on how nice it feels to hold his hand. Tom tells me about how Aggie and he worked in one of the first shops downtown, and that she was always in charge of inventory. She kept the books and did the counting. All of a sudden, Aggie was no longer pacing the hallways counting random numbers, she was making sure the proper numbers were there, because this is what she was used to.

Tom told me about their daughter and how she had really put a lot of time into understanding what her mother was going through. He said that Aggie was a very busy and dedicated mother.

I'll give you an example of what an argument was like for us. If she [the daughter] needed to be driven somewhere. She'd say, well I'll take her. No you just got home, you relax and I'll take her. Well I can take her. Well why don't we go together? (Tom).

A few days after my interview with Tom, his daughter, Beth, was visiting from out of town and called requesting her own interview. We met all three of us at the family home. Beth recalled one of the times that she sat with Aggie, looking at family photos.

"Now that's you, now who do you think that is? That's Aunt Fern, that's your sister, Fern. She [Aggie] said, "This has all vanished." It made the hair on the back of my neck stand up, cause to me it is so profound. It's like I know I should know" (Beth).

This moment that Beth shared, demonstrated the approach she first took to communicating with Aggie. She then shared another moment that occurred in the family home:

I could set up in the kitchen, a little area with the potatoes and you know a peeler. Call her in, because part of the problem is she couldn't do an activity if she couldn't remember how to start the activity. So I could call her in, while I was

peeling. I would call her in while I was peeling. So she could see. So she could have a visual, and hand it to her. I would put the potato and the peeler in her hand and she would just carry on. Granted if there was a ten pound bag of potatoes, she would peel all of them (Beth).

It was conversation of stories, where if Beth could not remember, Tom filled in. It occurred to me, that perhaps all of our knowledge is a puzzle. How often does any one person remember everything that ever happened to them in the form of a story? For these women living with dementia, they held the edge pieces of the puzzle. Everything they did or said would be connected, but their families were able to bring more to the picture. It did not make my interactions with the residents any less informative, just different.

Having felt the closest to Aggie in my visits, being in her home with her family was at times overwhelming. I had to take some time to myself away from my work after this interview. The interviews allowed me to think about communication and how important it is in our relationships and for our health and well-being. The extent that families go to, to re-negotiate their relationships really impressed me. It amazed me to hear from a man who had spent more than fifty years loving a woman who now was not sure who he was, and yet he spoke about her as if nothing had changed. Aggie's daughter and husband did not speak as though she was gone, but as if it was just a relationship that required a lot more from them. It seemed like their perspective was that she had spent so much of her life giving to them, that this was the least they could do.

When mom first went in, he (Tom) was so broken hearted that they had to be separated. He would go upset and just distressed all the time and I'd say, "Dad, you have to realize that when you are there with mom, you have the ability to make her happy, and that's wonderful. How you go in and how you go out and the people that you meet each way, it is the smile on your face and the greeting that's going to impact them. So, by going in and saying "hello Tim...good morning, how are you today?" Even if what he says does not make any sense, or even if he doesn't respond, somebody has called him by name, and someone has a smile on their face, and the tone in their voice that they are happy to

see them. Your presence in five or ten seconds can have a really positive effect, and not just on mom" (Beth).

Aggie was no stranger to me at this point, she was my mother, my grandmother, and my sister. She not only connected her own fragments of narrative, but she connected parts of my own.

The second part of phase two consisted of a focus group held with the recreational care-team at the home. Initially, I planned to hold individuals interviews. When I had made that decision, it was because I could see no particular benefit to holding a focus group. I learned more about these women's jobs, the more I attended the home. One of the first things I noticed was that each member of the care staff had a different schedule, and so some of them did not know the residents as well as others, or had not worked on that particular floor recently. This was the primary reason that these participants suggested a focus group. They stated that the conversation would be a lot easier for them if they could all sit together and remind each other different events that they might not otherwise recall. A secondary reason that I had not thought of was that this group received their coffee break at the same time. This meaning that it was less of an imposition on their schedule if they could all attend during this "free-time". Although I had tentative questions to ask the focus group participants, the conversation went in its own directions following the first question. I chose the following section of the dialogue to represent communication and sentiment in the ways the four members of the care team were relating to the residents. Each number represents a different participant and the letter M refers to myself.

M: What comes to mind when you think of Aggie?

1: I find her funny.

2: She has a funny sense of humor.

3: She's obviously a very bright woman. Inquisitive about life and people.

4: Busy.

3: Very committed to her family...her husband...her children. She has a bit of a sarcastic sense of humor (everyone agrees and there is laughter).

1: You know when she's mad.

4: When she rubs her hands together you can tell.

3: She's always one to go go go.

(Focus Group)

Although these are short phrases, they are quite meaningful. I was surprised at how much they encapsulated exactly what I had learned about this woman. They expressed her identity in her own terms. They had seen her on a daily basis and without too much previous knowledge and so could express the meanings behind the expressions, in addition to the expressions themselves. The dialogue that followed was a conversation among and about friends. As they spoke about the women's lives, it was clear to me that they were also speaking about their own lives. Their words were infused with respect and appreciation. I was amazed at how they were able to talk about these women. The themes present in the sample of focus group discussion provided for the purpose of this paper are: personality traits (past and present), connections to family, and physical communication. In addition to these themes, the participants identified only positive traits. They represented the residents with a very positive perspective.

One woman told me about her first day as a recreational therapist. She said that there was a resident getting really upset in the hallway because a nurse wanted him to walk and he would not go because of the river. The blue floor tiles represented a river to this man. She said she just stood there and watched as the nurse told him, "now see that white part there? That is the bridge...so come over to this side of the river" The patient walked over, turned around and waved and said, "I'm ok now". She said that she was not

sure she was going back another day, until this happened; it made her understand. Communication in this instance was made so much easier by accepting the resident's reality as reality...period.

Phase Three: The Wall

For the third phase of my project, I constructed an interactive and artistic wall exhibit within the residence of the women. I wanted the wall to represent and outline the symbolic and literal spaces of communication of the residents, their families, and the care staff according to my perception. On the left would be four frames. These frames hold four black and white images of places where I remember feeling like I had gotten to a space of communication belonging to the residents. These images are of places that did not hold any special meaning until I met these women. The meaning that they brought to these spaces is represented by bits of color attached to the photograph.²

The first photograph is of a walkway. There are leaves on the trees and the path ahead is paved. Attached to the path are small translucent bits of blue stone. Seeing a pathway as a possible body of water was something I learned to see. There is a walkway that runs around the back of the residence, and one can see hills from there. When I was walking with Mavis one day, she commented on them. The hills were something familiar to her. What was familiar to Mavis became familiar to me as I let her direct where we walked and where the conversation went if there was any. I learned to appreciate a simple walk as a method of communication, as a way of learning things about a person. Even though I was not able to hear stories about Mavis' life from her family, there were things I could learn from her directly that benefited those working with her, about what made her comfortable and what made her happy.

² The resulting layout of the wall appears differently, however takes on the same symbolic meaning.

The second black and white photograph is of a flowerbox. This image has little vinyl cloth flowers attached to it. I chose this image because in each of the interviews, family members talked about gardening. When the weather got to be nicer last spring, Anne and I took the residents out into the courtyard to bag up old leaves and to pull weeds. All of the women seemed to enjoy at least one aspect of this type of work. Some had their hands right in the soil, placing the seeds and others sat and talked about the weather. In each situation the courtyard is a space of communication.

The third framed image is of a bench with a lamp-post beside it. Inside the black frame of the lamp is gold glitter paint. As I walked up to the door of Aggie's house for the interview with Tom, the lamp-post caught my attention. I had already chosen the image of a lamp-post to be one of the images because it represents light in a metaphorical darkness. The lamp-post that I imagined was the same as the one in their yard. A wooden bench had always been something I saw as an accessory, it never really meant anything to me. When I was outside with the women, the bench was a place we were both safe and relaxed, and it was when we were both doing the exact same thing; yet another shared space of communication. Therefore I combined the two images for this frame.

The third photograph is of two poles. There is a line attached to the photo and colored pegs with babies' clothes attached to look as though they are hanging. All of the women involved were mothers at some point. Some of them had communicated this to me on their own, and others I heard it from their family. The way the women participated in the folding of laundry, it did not seem as though it was too much of a chore, but an opportunity to remember feelings attached to seeing and feeling the clothing belonging to babies.

I chose to represent our interactions with images, so that it is just as accessible for the residents. I realized that each time Aggie and I sat together, we were sitting on her front step. When I watched Winifred hold up babies' clothes and hold them close to her heart, she was out in her backyard hanging them in the sunlight, and I was watching. Every time Eliza held onto my arm in the hallway, we were heading out for a brisk walk outdoors. When Grace told me story after story, we were just sitting having tea. I had spent time with each of the women sitting, walking, and placing our hands in dirt. For the most part these images are representative of the things that have not been lost, and the feelings that are still there, represented by simple and yet colorful moments.

The concept of 'home' is something most people can relate to, and if it is a positive feeling, it can be a positive space of communication. Getting to know and love them feels positive when I am not comparing or feeling at a loss because of what I knew them to be. They are extravagant women, not because they have changed the world, but because the world has changed them and they continue to desire to contribute to it. The recreational care team does an amazing job of creating a sense of home for these women. The residents may not recognize their own personal possessions or their own homes (should they visit), but they notice the feelings associated with home. In this case, and in most cases, perhaps home cannot be put into words. All of these images are attached in black and white in the appendix. If you as the reader wish to see the colors that these women have shown to me then I welcome you to experience as I have, or imagine as they do.

On the other side are four plaques representing the space of communication of the families and the care-workers. There are three with phrases and one with a poem. They read as follows:

Plaque one:

She may not know how many times she made you stop and sit at that lamppost.
 She may not remember how hard she worked and the paths she walked.
 She may not be able to count the babies she held or the times she hung their clothes.
 She may not be able to tell you which are per-annuals and which are weeds.

However...

She knows it feels nice when you sit beside her.
 She appreciates when there are things for her to do.
 She feels love when you treat her like family.
 She will gladly pull the weeds, if you walk with her to the flower box and put her hands
 in the soil.

Plaque two:

Her first day working, she thought she wasn't coming back.
 The resident thought the blue floor-tiles were a river.
 If we cannot tell them there is no river, we can at least help them across it.
 The woman and the river...
 Are still there.

Plaque three:

She doesn't [Communicate.
 I find it difficult to [Talk to her.
 I just [Take her hands.

Plaque four:

The lamp-post...

Light...warm and welcoming...as I walk the stairway to a giant house surrounded by
 flowers.....the light is gone from it now, but this evening you will remember as though it
 is there,
 and when he looks out your window he will see the same light...
 reflecting from your eyes and off your face just the same as before
 ...without words.

The paintings...
Your hands still hold that brush that painted these pieces...

They line your walls.
A layer of strength that will never be stripped down.

It is not so much what they are of, or how they were painted, but who painted them.
The colors you chose now fill his days with longing to see you.
You painted colors he'd never seen. Now you paint them in his dreams.

The Routine...
He tells me of his days. Your days.
He comes for a meal every day.
There is no trace of exhaustion or resentment...only commitment and adoration.

The Words...
Words or no words, you are both telling me of your connection.
Words or no words....I would have known.

Richardson discusses writing as a way of discovering something new. The aim is not to write about something one has learned, but to continue the learning process when writing. She states,

Writing is always partial, local, and situational, and...our Self is always present, no matter how much we try to suppress it – but only partially present, for in our writing we repress parts of ourselves, too. Working from that premise frees us to write material in a variety of ways: to tell and retell. There is no such thing as 'getting it right' only 'getting it' differently contoured and nuanced (2000, pp. 930-931).

For this paper, I am working within a traditional academic format, however I have "contoured" it so that the writing reflects a creative research process and myself within it. Richardson writes, "[s]ettling words together in new configurations lets us hear, see, and feel the world in new dimensions" (2000, p.933). In-between the framed photos and the plaques is an interactive space to write or draw one's thoughts. A rolling pin of ideas and a sculpture of hands will also be there. The idea for these hands came from Anne. She

highlighted that in most of her interactions, she feels it is easier to establish a comfortable interaction with a resident if you reach out to them. Anne also pointed out that the residents use their hands to express affection. She said that it would be nice if there was something for the residents to touch, that was comforting, and she suggested the hands. This is a story belonging to everyone, of hands and told through hands themselves. This project has encouraged me to step outside of what I knew to be communication. I was challenged in seeing how their gestures could communicate a story, but also in seeing how my own could do the same.

Women's Knowledge

"The Story Began Long Ago"

This is the world in which I move uninvited, profane on a sacred land, neither me nor mine, but me nonetheless. The story began long ago...it is old. Older than my body, my mother's, my grandmother's. As old as my me, Old Sontaneous me, the world. For years we have been passing it on, so that our daughters and granddaughters may continue to pass it on. So that it may become larger than its proper measure, always larger than its own in-significance. The story never really ends, even though there is a beginning and an end to every story, just as there is a beginning and an end to every teller. One can date it back to the immermorial days when a group of mighty men attributed to itself a central, dominating position vis-à-vis other groups; overvalued its particularities and achievements; adopted a projective attitude toward those it classifies among the out-groups; and wrapped itself up in its own thinking, interpreting the out-group through the in-group mode of reasoning while claiming to speak the minds of both the in-group and the out-group (Minh-ha, T.T., *Woman Native Other*, 1989, p.1).

Women's stories hold high regard in feminist circles. We choose what categories to fit different groups of women into. This is a way of maintaining difference.

Acknowledging that women not only hold different stories, but different ways of telling those stories, highlights that different listening skills and research methods are necessary.

There is much to be learned from categories that demonstrate difference, as they allow for insight into someone else's experience, but also into our own understanding of that

person and where our understanding has come from. If one considers the category of identity, can dementia be discussed without it, and can identity be discussed without dementia? Dorothy Smith's discussion of categories of difference and how they maintain each other is useful in thinking about dementia and identity. She argues that,

There is no discrete category that does not contain internally the other from which it is differentiated. So there is no way in which concept or category can function purely representationally, no exact or reproducible correspondence between term and object. We must always mean more and other than we mean to say/write (1999, p.103).

I have been confronted with the category of 'other' in many instances, and in this case, I believe that acknowledging the category of other allows myself and others to acknowledge our categorizing of 'other'. In discussing women living with dementia, I am maintaining my status as the 'we'. However, every woman is a part of a 'we', as is every man. *Our* collective voice does not mean anything if it is not inclusive of the voices unlike us. I am not supposed to write with the word 'you' because I cannot assume I know the reader. What if my assumption was the only opportunity 'you' had to tell 'your' story? What if my writing, 'you', was the only way I could tell my own? I engage with Smith and Minh-ha's discussions briefly to shed light on the theoretical discussions that occur surrounding identity and difference. In this project, the academic preparation for my methods and my thinking were invaluable, but they have also expanded. Our identities as women are not in the labels that describe our health status, but in the way we experience life and how we convey that experience. The women in this project have taught me about relationships and how we communicate with one another, not as one person with dementia and one person without, but as two people who seek to communicate to each other.

My story has been about and with the women involved in this research and their families. I sought to collect multiple stories and I intended to learn about women's lives. But in the end, the most significant aspect of this work was the space(s) I walked through as the story became less about the details and more about its transmission. As I was standing in front of Aggie or Mavis, or Eliza or Winifred or Grace, they were no longer individuals with dementia, they were just individuals. Just as I was watching these women experience communicating with someone who knows absolutely nothing about them, and to whom they cannot speak too comfortably, I realized that here I was in the same position. The following quotation encapsulates what this position felt like for me. "A conversation of "us" with "us" about "them" is a conversation in which "them" is silenced" (Minh-ha, 1989, p.67).

A woman's knowledge is not forgotten just because the woman forgets it. The woman does not cease to exist because she cannot tell you who she is. This project has been an attempt to demonstrate that elderly women living with dementia have a narrative, but it cannot be the narrative that you are looking for, no-matter who *you* are. The value of this narrative is only exposed if the research method used to reach it reflects a person-centered method that begins within the communicative space of the woman, and not the researcher. The person-centered approach is a relatively new approach to working with persons with dementia. It is attributed to Dr. Kitwood who developed England's Bradford Dementia Research Group. Kitwood described the experience of someone living with dementia as one that was greatly influenced by the communication strategies and care from those around them (Kuhn and Verity, 2007, p.6-7). This method encourages researchers, care-givers, and care-workers to see the individual who is living with

dementia, before their disease. This method suggests that questions about experiences of dementia, in mild to moderate cases, should be asked of those who are living with it. The Alzheimer's society of Canada states that to create a better quality of life for those living with dementia, researchers should,

...recognize each person as an individual who deserves to be treated with dignity respect; presume the person's competency; acknowledge the person's right to autonomy and self-determination; take into account the person's personality, life experiences, support systems, and ways of coping; understand that people with dementia are capable of learning and adjusting to their illness, contributing to their own care, and living meaningful lives ("Enhancing care", 2009, p.5).

Researchers that use this approach have found that individuals living with dementia have a unique perspective that is not only first-hand knowledge, but first-hand lived experience. The researcher is not only hearing about the disease from someone who has been through it, but from someone who is currently living with it. Studies convey that persons living with mild to moderate dementia, "[w]hen asked...place emphasis on being useful, contributing to the world and to others, on having privacy and security and on self-determination and choice" (p.5). I received these same responses from the women in my research and as well from their families. I found that these expressions of what is important to them was available to me, once I allowed myself to just listen, and stop asking questions. In the population of my research, the women are living with late-stage dementia, which means that they might be excluded from this type of approach to dementia research. This is not to say that the care they receive does not use this same person-centered approach to care, but in terms of asking questions, one may not, where the traditional interview responses are not available.

If research methods exclude certain women, then their knowledge is excluded from the information gathered regarding women's lives. In women's studies, feminist

theory can include the discussion of marginalized women's voices, however, women living with late-dementia, are more than a voice existing on the margins. Braithwaite states that,

Feminist theory or theorizing, in this formulation, is not a matter (only) of learning and using terms and concepts that have been passed on from elsewhere. It is also—and this is the double project part—about the necessity of always examining what and how something is being passed on in the name of or as the theory; it is about the necessity—to put in other words—to always “think about how we think about” whatever term or concept is being used (2004, p.97).

It is important to think about the categories that surround women's knowledge and its organization in discussions of such. If we are to be discussing the significance of women's lived experiences, we must first tailor our research methods to find out what those experiences are, and how women are articulating them. Richardson illustrates, “The researcher's self-knowledge and knowledge of the topic develop through experimentation with point of view, tone, texture, sequencing, metaphor, and so on” (2000, p.936).

Within the field of Women's studies there are multiple diverse feminist voices. For each feminist voice, there is a woman whose story is either being heard or re-told. Sometimes, the only opportunity for others to hear her story is for someone else to tell it. A woman's identity is comprised of her knowledge and experience. A woman's voice, however she expresses it constructs a narrative which allows others to acknowledge the value of her life. Feminism addresses how and why women's identities and therefore their lives are forgotten. To achieve this, we look at the spoken story and the written one. Sometimes, there is a story from someone who is no longer living, but it is still in a linear story form. It is difficult to re-tell a story that we are not sure we have heard correctly or that we cannot understand. In this project, I have accepted two things as a researcher and as a feminist. The first is that I may never really know if I have benefited these women as

it is my story that I am telling and I cannot ask them their experience of my telling it. The second is that sometimes to create a more positive representation of a woman's voice, their knowledge and their identity, they must be more than the subject or the participant, they must be our educator.

The stories of a woman living with dementia can be told in a way that informs on communicative and research strategy, and also in a way that remembers the significance of how she lived before, but does not forget the significance of how she lives now. These stories will inform feminist knowledge of the diversity of women's lives and the diversity required in feminist research methods. These two parts of her narrative serve different purposes and yet tell one story; her life may not make sense when you walk past, but it will if you sit down beside her. Smith discusses the importance of human interaction and the recognition that social relations are research. Smith highlights that from a woman's standpoint, the act of inquiring about their lives, must also be an act of inquiring *for* the women themselves. Smith writes, "[t]he aim of inquiry is not, as in established sociologies, to explain people's behavior, but to explain to people the social – or society – as it enters into and shapes their lives and activities" (1999, p.96).

Dementia is a disease that gets worse over time and for which there is no cure. Most people know dementia by the characteristic of memory-loss or a confused mental state. Because of this, this is also the way that most people with dementia are known. Naue and Kroll write that, "...this prevailing image of dementia as a loss of self and a change of identity leads to the situation that demented persons represent difference and otherness" (2009, p.26). It does not matter what a woman has accomplished or experienced in her life before dementia or what she experiences while currently living

with it, her identity is now known through the language of dementia. She has an alternating and alternative voice. Her voice is sometimes filled with vocabulary and sometimes it is only facial gestures. At times I can sense she is in the same moment I am in, and other times, she speaks from a memory as if it is right now. My research demonstrates that if we make the effort to contextualize how they alternate, her identity has a chance of not being seen as alternative. Naue and Kroll suggest, that, "[o]n the one hand, identity is something flexible which can change in different spatial and chronological contexts. On the other hand, identity is a rather static concept, comparing one person with others in a certain space or moment" (p.28). A woman living with dementia has a narrative which expresses her experience of the world. It does not require approval or validity. It requires patience.

Knowledge Translation

The greatest outcome of this project has been an increase in dialogue about living with dementia. The project spanned a time period of a year and half, including the planning phase. During this time, I found myself telling the story of my research. In every circle, my story has elicited stories about family members and friends with dementia. To date, I have given five presentations about my research, all for different communities. The first was for the Eastern Edge art marathon, where, using story and songs that I wrote, I expressed the importance of feeling loved in a community in my life, and in my research. The second presentation of my research was the requirement to present at the Women's Studies Speakers Series. At this presentation, one of the husbands I interviewed was present. From the conversation afterwards, I could tell that this was an opportunity for him to talk about his experience some more. It meant that my

research had reached a community outside of my own, and was accessible to different listeners. Following the presentation, I was invited to present a third time to the therapeutic recreation staff from eight residential homes in St. John's. I also presented my research in the form of a poster at the NLCAHR Symposium, "New Directions in Health Research" and as a background poster at "Aging Gracefully; Plugging into health research". I gave a presentation at The Blue Castle discussion group at the Ship Inn, which included blues songs that I wrote about the relationships within my research. I am scheduled to present twice more, one to the Newfoundland and Labrador Association of Gerontological Nursing, and the second for a specific staff of nurses at a residential home. The feedback from these presentations, and the community networking they have created, are the greatest and most visible outcome of my project. My impression from these experiences is that no-one wants to talk about dementia, but everyone has a story they would like to tell about a person living with or near it. In each of the interviews and in conversations not held in interviews, there were similar sentiments. The people we love who are living with or who have passed from dementia, are people we love. The stories we have to tell are not about dementia, even as it might be a part of them, the stories are about our lives.

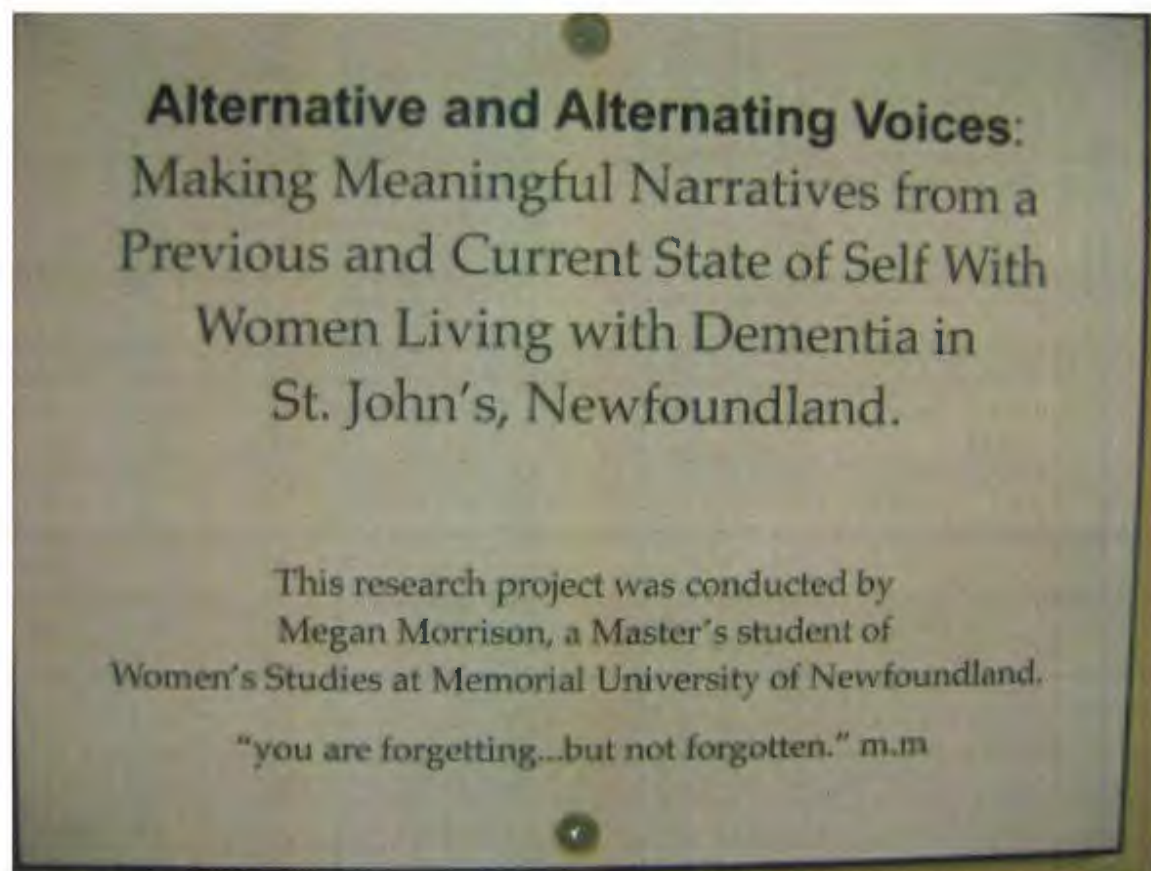
Conclusion

I hope that wherever I leave my words, others will find them. If these words contribute to the conversations surrounding dementia in an academic and community circle, then I will have achieved my goal. In a more tangible way, the permanent pieces upon the wall also encourage others to leave their words. There were some things that I was prepared for in my experiences in this project, and other things that I could never

have prepared for. Creating more possibility for healthy and positive experiences of aging for elderly persons, and specifically for the purpose of this research project, those living with dementia, means paying attention to our interactions when we are physically there as researchers and health care workers, but also when we are interacting through the words we write afterwards. O'Connor et al. illustrate this well, stating that to have a greater understanding of what "personhood" means for those living with dementia, researchers must look beyond the immediate environment, as these individuals are social beings, and their identities and knowledge is what shapes their experience and their context. Also, that this is a component of multiple environments; dementia and the individual's experience of it is only a fragment, a puzzle piece, and a single component of multiple factors affecting their lived experience (2007, p.130).

The hands within this project are responsible for everything that has been learned. Through these women's literal hands I have learned how to knit, how to help someone out of a chair, how to keep a clapping rhythm to a Newfoundland song, and how to turn the soil over. Through their symbolic hands, I have learned how to tell someone that they mean a lot to me, how to demonstrate who I am, and how to share things I thought I could only share with words. With my own hands I have constructed an art project, a research project, and a Master's project, and I place all of those things in yours. If we forget the stories, we will forget the people who still tell them.

Appendix A



Appendix B



Appendix C

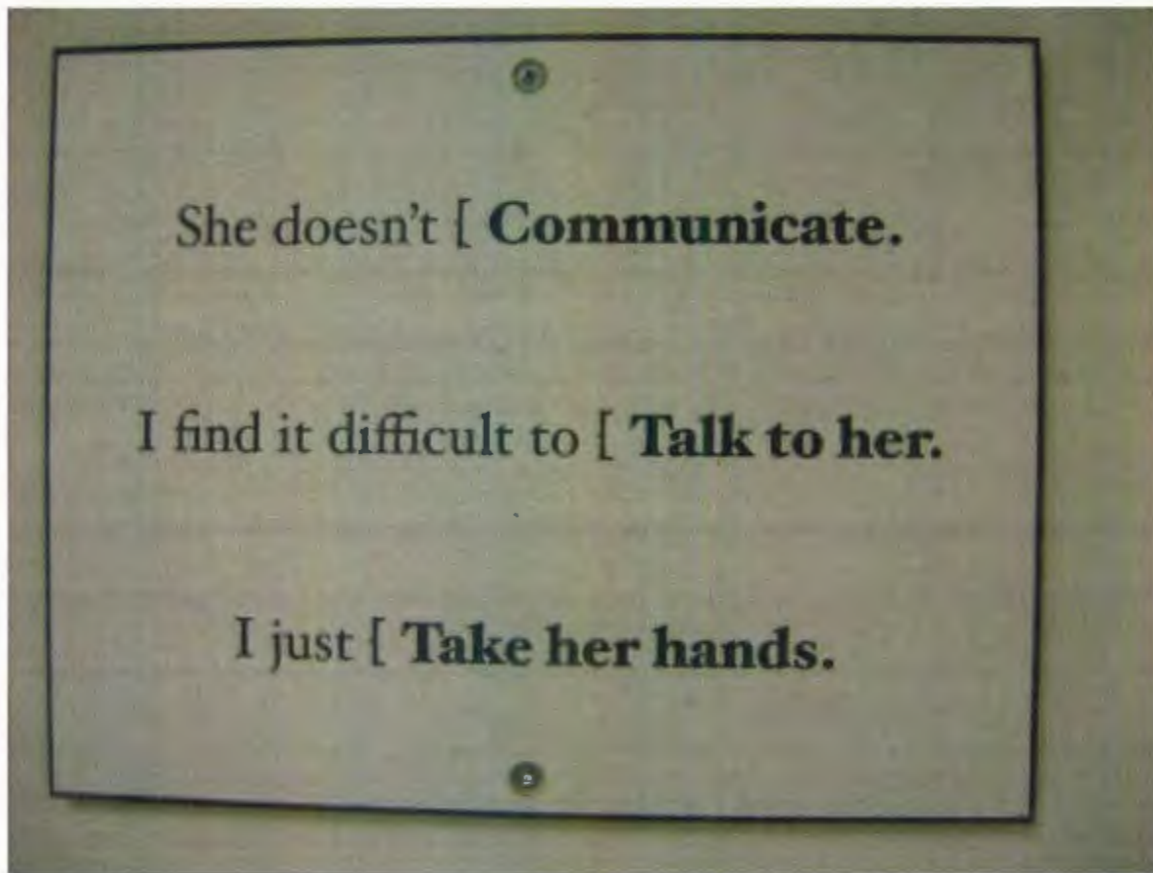
Her first day working, she thought she
wasn't coming back.

The resident thought the blue
floor-tiles were a river.

If we can't tell them there is no river, we
can at least help them across it.

The woman and the river...are still there.

Appendix D



Appendix E



Appendix F



Appendix G



Appendix H



Appendix I

February 2009

To Whom It May Concern:

In this package you will find an introduction to a project that you are invited to participate in. The information should fully inform you on what the project is about, who the researcher is, and what your participation would mean. These letters are being distributed by [Anne], because of the nature of the project. The researcher is only able to include participants who contact her with an interest in being a part of the project. The contact information is so that you can clarify any questions you may have. There is no obligation or consequence involved in contacting the researcher.

I look forward to hearing from you!

Sincerely,

Megan Morrison
Masters Student in Women's Studies
Memorial University of Newfoundland

Participant Consent Form

Consent to Take Part in Research Project

Title: Alternative and Alternating Voices:

Making meaningful narratives from a previous and current state of self with women living with Dementia at in St. John's, Newfoundland.

Potential Participant:

You and your family have been invited to take part in a research study. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

The researcher will:

- Discuss the research project with you.
- Answer any questions you may have and discuss your concerns.
- Keep all possible identifying information confidential. This means that the researcher would be the only one to know who is actually participating.
- Be available throughout the project to address any further concerns or questions.

If you decide not to take part or to leave the study this will not affect your family member's health care in any way.

1. Introduction/Background

I am doing this project as a granddaughter of an incredibly strong woman who lives with Dementia, and as a student who has spent most of her education learning different ways to listen to and value women's life stories. My own experience has taught me that communication is more than verbal language, and that in order to hear an individual's voice, sometimes, one has to look beyond what they are saying. As an artist, a musician, a woman, and a granddaughter, I feel that I have designed this project so that in using the best aspects of myself, I might help others to know a group of women whose stories are often not heard, because they live with Dementia. In spending time with your family member and in getting a chance to hear your experience, it is my hope to shed a unique and positive light on the identity of your family member. On paper I am spending time at the Home as a researcher and as a Master's student of Women's Studies. In reality I am there drinking tea and absorbing all the adopted grandmothers I can.

2. Purpose of the Study

Within the walls of the home, there are stories that are told about things that have happened and things that have not. There are also stories that are kept inside because the words are not there to tell them. The purpose of this project is to demonstrate that the stories being told and not being told are significant, even if no-one else knows the story, and even if it didn't actually happen. Through this project I want to know in what ways women with Dementia are communicating their stories? What is it like to get to know these women initially just by being around them, without the background information from staff and family? What is important to them now, and what kinds of symbolism exist? What are their family member's experiences with having a loved one with Dementia? What are family member's experiences with communicating with their loved one? What are the experiences of staff members with communication with women with Dementia? The last part of this project will be to create a wall within the home that displays the value of having an identity that has multiple stories and multiple forms of communicating voice.

3. Description of the Study

Your family member's participation would not require that they do anything outside of their normal daily routine at the home. Basically, I will be spending time with them in a group setting while they are participating in activities that they would normally participate in. I will be taking notes on our interactions; however, these notes will not be taken until after I go home.

Your participation would involve a discussion with me concerning the project and your family member at the home. There will be no formal interview questions, however possible discussion topics include:

- interacting with your family member
- communication with your family member
- your family member's identity
- your perspective on Dementia

4. Length of Project

The project will start in February and will be completed by the Winter 2009. The length of individual interviews will depend on each individual discussion. There will be no set minimum; however a general maximum length of two hours is expected.

5. Possible Risks and Discomforts:

The following information is provided for you not because these things are expected to happen, but because I cannot guarantee that they will not. By giving you this information

I am hoping that you are as informed as possible about the project and about my respect for you as a potential participant.

Common:

1. **As a researcher I hear or witness information that is not related or non-disclosable to my project.**

You and your family member will be referred to with a different name in all notes. Although I cannot guarantee that you will be anonymous, I will do my best to exclude any identifying information about those who participate.

Uncommon:

1. **A participant becomes emotionally upset in my presence.**

I will always be in the presence of either the Social Worker and/or [Anne] during all of my interactions with residents and family members.

2. **Residents or care-workers ask me to share information about other residents or care workers.**

I will explain to them that it is my role as researcher to keep each person's words confidential.

3. **I hear of or witness physical abuse of a resident or care-worker.**

For this risk I will be taking the instruction of both the Ethics Committee and the Social Worker at the home. I will abide with the guidelines that the home follows in conjunction with Eastern Health.

6. **Benefit:**

There is no guarantee that this project will benefit you or your family.

7. **Liability Statement:**

Signing this form gives us your consent and consent for your family member at the home to be in this study. When you sign this form you do not give up yours or your family member's legal rights. The researcher and agencies involved in this research project still have their legal and professional responsibilities.

8. **Confidentiality:**

If you decide to participate, every effort will be made by the researcher to respect you and your family member by keeping all identifying details confidential. At **no point** in this project or after will the researcher disclose identifying information about you or your family member. Throughout the project confidentiality will be maintained by respecting the guidelines set out in this consent form. Should you have any questions regarding clarification of this matter, there is contact information at the bottom of this form.

9. **Questions:**

If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution. That person is:

Name: Megan Morrison

Phone number: (709) 749 1867

Email: m.morrison@mun.ca

Another Contact is the investigator's supervisor:

Name: Dr. Natalie Beausoleil

Phone number: 777-8483

Email: nbeausol@mun.ca

***You also have the right to ask questions about your potential participation and your rights as a participant in a research study. This can be done by contacting:**

The Office of the Human Investigation Committee (HIC)

Phone: (709) 777-6974

Email: hic@mun.ca

Study title: Alternative and Alternating Voices: Making meaningful narratives from a previous and current state of self with women living with Dementia in St. John's, Newfoundland.

Name of principal investigator:

MeganMorrison

To be filled out and signed by the participant:

Please check as appropriate:

I have read the consent [and information sheet].	Yes { }	No { }
I have had the opportunity to ask questions/to discuss this study.	Yes { }	No { }
I have received satisfactory answers to all of my questions.	Yes { }	No { }
I have received enough information about the study.	Yes { }	No { }
I have spoken to _____ and he/she has answered my questions	Yes { }	No { }
I understand that I am free to withdraw from the study	Yes { }	No { }
• at any time		
• without having to give a reason		
• without affecting my family member's future care [health care, treatment etc.]		

I understand that it is my choice for myself and my family member to be in the study and that we may not benefit.

Yes { } No { }

I agree to have the interview audio taped

Yes { } No { }

I agree to take part in this study.

Yes { } No { }

I agree for my family member to take part in this study.

Yes { } No { }

Name of Family Member I am giving consent for: _____

Signature of participant/Family Member

Date

Signature of witness

Date

To be signed by the investigator:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

Signature of investigator

Date

Telephone number:

Assent of minor participant (if appropriate):

Signature of minor participant: _____ Date: _____

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