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A Qualitative Assessment of Informal Caregivers and Language Loss Support for Dementia and
Alzheimer's Patients in Vermont

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Abstract

Dementia is a global concern, and rates of people with dementia are expected to triple in the next thirty years (Prince, Wimo, Guerchet, et al. 2015). In the United States particularly, the growing aging population means an increase in people with dementia and a growing need for professional care facilities. For many families, the decision to care for their loved one with dementia through professional care or informal caregiving is a very personal choice, driven by economic, geographic, and cultural motives. Whether or not a family chooses a professional care setting, informal caregivers are usually the primary caregiver for people with dementia for 1-3 years before professional help is provided, and even once in a care facility the caregiver burden does not disappear (Czekanski 2017). As dementia degenerates, language loss is common, and can be a double burden if loss of language is present (aphasia). In cases like this, communication with professional care can become challenging and the quality of life, social relationships, and daily tasks become affected (Ferris and Farlow 2013). In these cases, the caregiver burden is usually stressed as caregivers become a primary communicator with the patient as well. This study takes an anthropological approach at the experience of caregivers and language loss in elder care facilities. The experiences of informal caregivers, primarily adult children of patients with dementia, are analyzed through semi-structured interviews and analyzed in using a hermeneutic phenomenological method with the goal of seeing themes across experience. Ethnographic observations of patients in a facility will be conducted and analyzed using sociolinguistic theories and methods. This study aims to understand how informal caregivers in Vermont and New England navigate dementia in their loved one, how it affects their life, and what resources are available for patients with aphasia.

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Introduction and Significance

Dementia is an increasingly prevalent disease. Worldwide, over 46 million people live with dementia, and this number is expected to reach 131.5 million by 2050 (Prince, Wimo, Guerchet, et al. 2015). In the United States, Alzheimer's disease is the second leading cause of death in older Americans, second only to Ischemic heart disease (United States). With an aging population in the United States, this is only expected to become more significant. About two-thirds of dementia cases are classified as Alzheimer's disease, "a progressive neurodegenerative disease characterized by impairment of a number of higher cortical cognitive and affective functions" (Karger 2018). People with dementia become increasingly in dependant on the care of others as they face increased symptoms, communication challenges, and daily social activities become more difficult (Zwaanswijk, Peeters, van Beek, Meerveld, Francke 2013). The average length of the illness is seven years (Zwaanswijk et al 2013). As the population with dementia rises, however, the amount of professional care available cannot grow as fast, and other barriers such as economic, geographical, and cultural barriers may prevent someone with dementia from seeking professional care. As a result, people with dementia depend on informal caregivers such as their spouse, their child(ren), or relatives (Zwaanswijk et al 2013). In Vermont, according to 2014 data, the average monthly cost for memory care was \$5,779 (Vermont Alzheimer's and Dementia Memory Care Facilities, N.d.). Informal care is recognized to extend beyond just when the person with dementia is living at home, but when they are living in long-term care as well, meaning a long process of care is required of informal caregivers (Zwaanswijk et al 2013). "The progressive and often unpredictable course of dementia poses considerable challenges to informal caregivers" (Zwaanswijk et al 2013). Most informal caregivers receive little support, and discussions about dementia socially are also rare. As a result, informal caregivers can feel isolated, depressed, anxious and have poorer mental and physical health as a result of caring for their loved one. A challenge dementia patients and care for dementia patients face is language loss and language barriers.

Language impairment in Alzheimer's disease occurs mainly in the semantic and pragmatic language processing abilities of the patient (Ferris and Farlow 2013). The largest implication of language loss in Alzheimer's patience is the inability to express one's needs, which greatly affects life quality and social interactions on a day to day basis (Ferris and Farlow 2013). As a result, caregiving can become an increasing challenge when communication between professional caregiver and patient is impaired. When language loss occurs and patients rely more on physical and facial communication rather than verbal communication, informal caregivers face an increased burden of dependency from the dementia patient.

In this proposal, dementia and Alzheimer's are used interchangeably to mean a degenerative diseases causing memory loss and other high cognitive functions to deteriorate.

While Alzheimer's Disease (AD) makes up for only two-thirds of dementia cases, it is the most debilitating form of dementia and the most frequently studied form of dementia.

Thesis

This study looks at the care surrounding dementia in the United States, specifically informal caregivers of patients with dementia and Alzheimer's, and the additional challenges of support for patients who experience aphasia. My research will consist of semi-structured personal interviews with adult children and spouses who are informal caregivers of people who have dementia. This interview will be focused around the role of caregiver that adult children may acquire, and what their experiences are with this. I will also be completing participant observation of a nursing home memory care unit. I'll be looking at the social interactions, the communication between patients, between patient and caregiver, and between patient and family member, paying particular attention to how nurses interact with patients who use non-verbal communication. I seek to find out how informal caregivers support their loved one, what support systems exist for them, and how caregiver burden is increased when the patient becomes less verbally communicative.

Significance

This research is important because qualitative research in the realm of dementia is an asset to quality care and improved patient and caregiver help. This study will provide an important basis of the challenges that informal caregivers face in caring with their relative with dementia, focusing particularly on challenges with language loss and communication barriers. Few bodies of research look at these aspects uniquely. Qualitative research that delves into the personal experiences of individuals, as well as participant observation of patients, can help to show the more personal side of medicine and dementia care. For a rapidly growing illness worldwide, all research regarding dementia is important, particularly here in the United States as the baby boomer generation reaches old age. In an increasingly diverse (culturally, linguistically, ethnically) nation, research regarding multilingualism coupled with dementia is especially important.

This research will hopefully bring to light the need for greater intervention programs that support informal caregivers of people with Alzheimer's disease as well. It is proven that counseling and intervention programs that are aimed at improving the situation of informal caregivers result in reducing a caregiver's stress and depression, increase social support, "improves caregiver health, and delays nursing home placement for persons with ADRD (Alzheimer's disease or related disorder)" (Gaugler et al. 2018). Few programs like this exist in Vermont, so this research will help express the need for such a program.

Literature Review

Review Methodology

To find the most pertinent literature for this multidisciplinary topic, sources were drawn from the fields of anthropology, psychology, neuroscience, geriatric medicine and social work. Delimiters to the past ten years contained preferred sources, although literature from up to twenty years ago was utilized for theory and methods. The primary research databases were found through the University of Vermont Bailey Howe Library Research Databases collection. Main research databases used were AnthroSource, Anthropology Plus, PubMed, Global Health

CABI, Academic Search Premier, and Google Scholar. Main search terms followed the boolean search style, [elders] and [U.S. OR United States OR US OR America] and [languag* OR linguist* OR bilingual], and “caregivers or family members or relatives or informal caregivers AND dementia OR alzheimer’s OR memory loss” or simply “caregivers AND Alzheimer’s OR dementia”. The articles found through these sources were reviewed and examined carefully, and an in-depth reading of each was conducted for relevant and useful information, as well as additional content of importance. I synthesized the relevant literature and compared sources theme by theme in a way that could be logically followed for the best understanding of this study.

Family members as caregivers

The burden that a family member can feel from caring for a loved one who has dementia is a shared experience for many individuals. Currently, more than 15 million Americans provide unpaid care to patients with dementia or Alzheimer’s, often as family members to the patients (Czekanski 2017: 25). These unpaid caregivers face more emotional, physical and financial burden than caregivers who are paid (such as nurses, or paid aids) (Czekanski 2017: 25). Caring for a patient with Alzheimer’s or related dementia is a unique experience of care because patients often do not realize the need they have and their own limitations.

In *Caregiving: Its Role in Medicine and Society in America and China*. *Ageing International* (2010), Arthur Kleinman examines the role of caregiver to patients of Alzheimer’s. Something Kleinman asserts is the idea that caregiving, as viewed from a biomedical perspective, is a burdensome anachronism, and biomedical professionals have taken the role of a technologically skilled doctor. Kleinman sees caregiving as a vestigial aspect of training in medical school. Kleinman also describes how “moral experience is the flow of things at stake in local worlds” (100). Experience, defined day to day, is the sharing of words, interactions and emotions between each person (100). For patients and families facing serious health concerns, there is the tendency to “reframe the moral experience of suffering” as a result of the threat of pain and loss, and the main way that individuals do this is through remaking meaning and emotions through “ethical, religious, and aesthetic activities” (103). These activities change and alter the experience of the caregiver. Kleinman discusses how the notions of suffering have been transformed through the 20th century as a result of dehumanizing bloodshed and bureaucracy, suffering is no longer of religious meaning, or a soul struggle, but is now an unnecessary, preventative evil (Kleinman et al 1997). Caregiving is a rather ancient practice, that has been trivialized by increased globalization, biomedical influence, and technology dependence.

Communication with someone with dementia can be very difficult because it is a progressive neurodegenerative disease (Karger 2018). Among the hardest communication ability is a misunderstanding between patient and caregiver regarding the level of communication ability of the patient. One of the first elements of communication to be lost in patients of dementia is the inability to read other people’s emotional expressions (Karger 2018). In caring for someone with dementia, communication in both verbal and non-verbal ways is very essential (Ekman et al 1995). In Ekman et al’s study “Dimensions and Progression in the Interactions Between Bilingual/Monolingual Caregivers and Bilingual Demented Immigrants”, they determined that bilingual caregivers communicated in many different ways with patients and the relationship was overall more positive when caregivers had the multiplicity of communication methods (Ekman et al 1995: 30). When a patient is having a hard time understanding human emotions, caregivers can often become frustrated, but “the more limited the patient’s capability

is assumed to be, the greater the risk that caregivers will distance themselves from the patient and consider their own actions to be meaningless” (Akerlund & Norberg 1990). As Alzheimer’s progresses, it often happens that patients experience neuropsychiatric symptoms such as apathy (Karger 2016: 316).

One of the ways that the the experience of patients with dementia has been improved is through “Living Alliance”, or strong relationships with a diverse group of people in the community. Radda et al defines “Living alliances” as “the process of forming relationships with allies (institutions and individuals), interacting with them over time, and drawing on their skills and resources over time to enhance the quality of life of older adults...” (Radda et al 2011: 154). Close relationships are very important especially for a person with dementia because their ability to experience wholeness and meaning is very different from what it used to be, and they may lack the creativity, intimacy, or industry they used to have (Ekman et al 1993: 38).

The financial and human cost required to provide family care to someone is well-researched and well-documented, as assessed in *Process Evaluation of the NYU Caregiver Intervention-Adult Child* (Gaugler et al. 2018). This research assessed the effectiveness of counseling support programs provided for family caregivers of patients with Alzheimer’s and dementia. The programs offered by NYU were individual and family counseling, support groups, and ad hoc counseling. From the study of these counseling programs over twenty-five years, it was determined that these programs “reduced the primary caregiver’s stress and depression, improves and enhances social support, improves caregiver health, and delays nursing home placement for persons with ADRD (Alzheimer’s disease or a related disorder)” (Gauger et al. 2018). Most of these programs were only offered for spouses who are caregivers, not for adult-children, so the study sought to find out what programs were available to adult children, if any.

Interviewing informal caregivers

In interviewing informal caregivers of people with dementia, seven themes emerged in their caregiving process. These themes were “something is wrong, journey to diagnosis: ambiguity and negative emotions, shifting roles and relationships: losses and challenges, seeking knowledge and support: solutions and frustrations, adapting to the topsy-turvy world of caregiving: finding purpose, preserving self without guilt, finding a way out” (Czekanski 2017). Family members who were interviewed in various locations, of various ages, and across different studies all found these similar themes of phases of caregiving. For the caregiver, whose average age in Czekanski’s study was 66, had varied lengths of time they spent caregiving (from 1 to 13 years), but regardless of the total time had experienced these similar phases. This is a long time for the caregiver burden that is felt by family members. That is why many family members may make the hard choice to provide their loved one with a facility of care, such as a nursing home, instead of caring for them individually (Cronan et al 2016). Even when the family member with dementia is in assisted living care, the caregiver burden often does not dissolve completely, as the emotional and psychology energy spent towards, caring and worrying about their family member only get more advanced. One of the more challenging shifts that caregivers felt was the need to financially provide for their partner or family member. Alzheimer’s care is expensive, and some caregivers had to go on to disability benefits so they could afford the care (Czekanski 2017). Another strong theme across all interviewees was the need for self-care. When they were full-time, or even part-time caring for their family member, their own health and well-being often took a toll, or at least was put on stand-by. For many interviewees, the need to talk to someone was one of the most important things in self care, as explained that “a common belief

was that it was therapeutic to have someone to talk to about their situation. Several participants reported that being able to tell their story during this research study was invaluable” (Czekanski 2017: 45). Main conclusions from adult caregivers are the need for better communication between caregiver and nurses/nursing homes and access to resources.

Challenges with Aphasia care

For elders whose first language may not be the dominant language of their culture, they can feel a sense of “othering” which is exacerbated by lack of communication ability. In the U.S. elder care system, finding caregivers who are bilingual in the same language as patients is a challenge. Often, patients are led to lean on family and friends as primary communication partner even after years living in a nursing home.

There is a decent amount of research that exists surrounding bilingual aphasia. More than half of the world population is multilingual, meaning they use two or more languages or dialects in everyday life, not necessarily with perfection in each language (Fabbro 2001: 201-202). So, it follows that “multilingual individuals suffering from developmental or acquired speech or language disorders do not represent isolated and exceptional cases... but rather the majority of clinical cases” (Fabbro 2001: 202). Despite the large population of multilinguals in the world, very few research studies exist regarding therapy for multilingual aphasia patients, and the ones that do exist do not present clear information about language loss (Croft et al 2011).

Sociolinguists studying aphasia have found that ‘communicative competence’ remains while linguistic competence disappears. ‘Communicative competence’ addresses the ethnography of speaking and refers to a larger ability to communicate within a specific community (Burns et al 2008: 166).

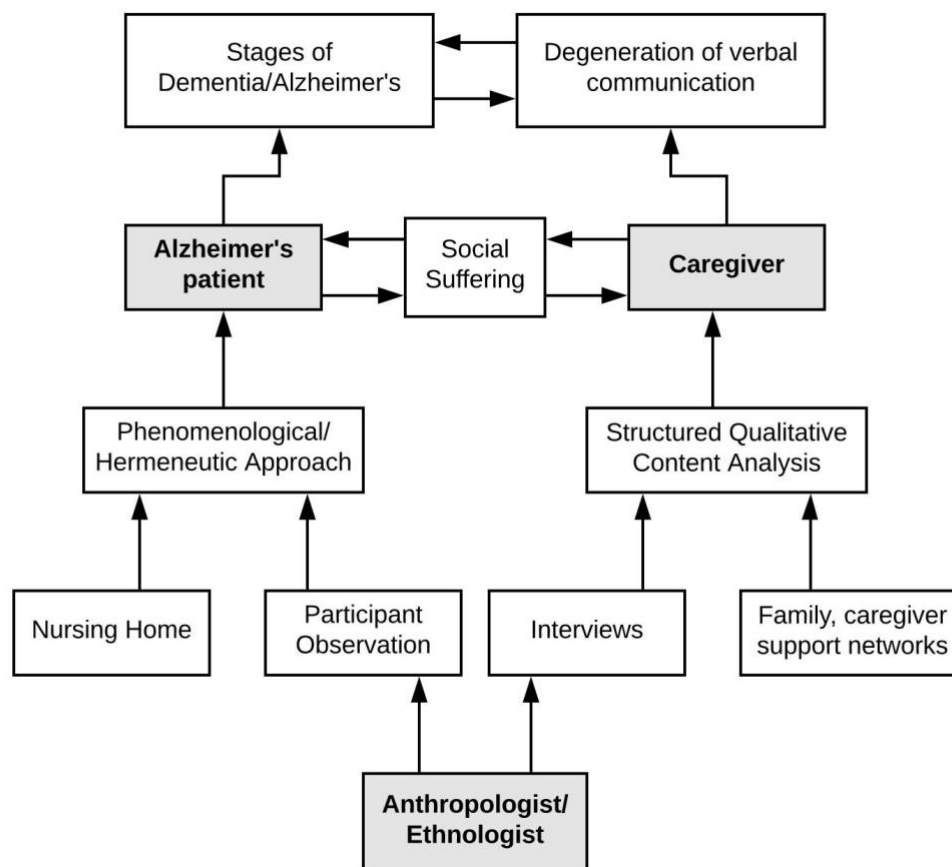
Strengths and gaps in literature

The strengths of the literature that exist are among caregiver interactions with patients with dementia. There is a lot of information of ethnographic interviewing and the psychological and emotional experience it requires to care for a loved one. It can be a financial, emotional, physical, and long term burden for someone. For some, they choose to provide their loved one with a nursing home environment. However, nursing homes are an expensive option and cannot be accommodated by all. For some people with dementia, they knew they would get dementia in old age and saved up money for care to help them through it. This can ease the strain of financial burden on a family. However, if a person has not allocated money for this specific care, it can come as a surprise to family members and be a challenge to pay for.

As Gaugler et al (2018) discusses, there is also a significant lack of research in terms of how caregiver support programs are effective, what kind of processes they use, and how caregiver support programs can be replicated.

Gaps in the literature remain in terms of a connection between caregiver roles and bilingual care. Literature exists for bilingual care and linguistic elements of aphasia. However, the connection between aphasia in patients and the way in which an informal caregiver such as a family member helps to communicate with their family member despite language loss does not have extensive.

Concept Map



Research Questions

- What role can community members and support networks play in the life of someone with dementia?
- In what ways may support of a loved one be more challenging if they are experiencing language loss?
- How are informal caregivers, particularly spouses and adult children, affected by having a relative with dementia and how does their role with this relative change?
- What does existing medical anthropology literature say about the role of caregivers for dementia and Alzheimer's patients?
- How is communication in the nursing home environment conducted among dementia patients also experiencing aphasia, and what role do nurses or caregivers play in verbal and physical communication?

Proposed Methodology

This research will follow methods of qualitative research as outlined in Joseph A. Maxwell's *Qualitative Research Design: An Interactive Approach* (2013). Maxwell, in Chapter 5, *Methods*, discusses the role of myself, as the researcher, as the research instrument in this qualitative research. The two main types of qualitative research are participant observation and interviewing, both methods that I will be using. The methods I've chosen are prestructured in

advance of my research, rather than taking a more unstructured, inductive approach (Maxwell 2013: 89).

I plan to conduct a series of in-depth semi-structured interviewing in a casual setting. I will interview 8-10 adults who have experienced being an informal caregiver or currently are an informal caregiver for a family member. The interview will take place over the first four months of my research, and the analysis of the interviews will happen in the months following the interviews. Individuals will be found through friends, family, and through the nursing home at which I will be volunteering and conducting the participant observations. I would like to get to know interviewees before the official interview, so I will ask them to a lunch or coffee during which I will formally introduce myself and explain my research project. After I explain my research project, we will plan a time to have the interview, if they decide after the lunch that they would like to be involved. It will be completely elective, and so an introductory lunch will be important in familiarizing participants in the project and providing them full information in order to make fully informed consent.

The interviews will be semi-structured. While I will come with a list of interview questions (separate) it is not imperative that I stick to this set of questions, and whatever responses the interviewee provides is valuable. Additional observational field notes will be collected. Purposeful sampling, reaching out to connections. Finding someone who feels entirely comfortable answering these questions. In-depth semi-structured interviews, along with observational field notes. Interviews be transcribed and coded and will be analyzed using structured qualitative content analysis with the goal of seeing themes across experiences. Notes will be made regarding non-verbal communication and combined with the transcripts of the interviews, a method used by Ekman et al. 1995. Participant observation notes will be analyzed using the hermeneutic phenomenological method.

I will also conduct ethnographic observation older adults with dementia in a nursing home environment. This observation will be of the social interactions, conversations, and overall experience of being in that setting. One of the main analyses of the observation data will be to see linguistic patterns and observations that happen among patients with dementia who may be experiencing language loss.

See Appendix for interview questions and ethnographic observation questions.

My analysis plans will be audio recording or videotaping, jotting down notes, notes on conversation as well as environment, examining data at the individual level, finding patterns in answers among interviewees, or possible shared experiences.

Conceptual Framework and Theoretical Approach

Through my analysis, I will examine the theory of social suffering, as proposed by Kleinman. Social suffering conveys the idea that the pain and suffering of a disorder is not limited to the individual sufferer, but can extend to family and social networks (Kleinman 2010). I will also be looking into the role changes that adult children play when they become the caregiver for their parent. This role change can be a challenge. I will also look at communicative competence.

Ultimately, through these theories and theoretical approaches, I am hoping to examine how both caregiving and the ability to communicate are given value in society. Caregiving, as I've read in my preliminary research and literature review, is a physically and emotionally taxing but morally important activity for many individuals, in which they feel the responsibility of caring for their loved one. But, caregiving is largely overlooked in the biomedical world as a

necessary form of care compared to biomedicine and high-tech facilities. Caregivers additionally are left with small support networks and they are playing an emotionally taxing role that is unpaid, and usually led only by the obligation to care and the love for the individual. In our society, we also place huge importance on communication, effective and efficient communication, and the ability to interlocate with others. This can be examined through the theory of communicative competence. When someone with dementia or Alzheimer's disease loses the ability to interlocate as effectively and consistently as others, the perception of others is the inability to communicate and thus others often decrease their communication with the patient. If someone does not feel the reciprocity of conversation, they are less likely to continue speaking to the individual, even if the barriers to communicating come from the disease they suffer from. The caregiver role is important in this because as elders lose verbal communication they are more likely to rely on physical communication, more subtle facial communication, and general body language. When this happens, if the patient has an informal caregiver, more reliance is placed on communication with this caregiver because the caregiver knows the patient well and is more likely to continue conversation with them because they understand the non-verbal communication techniques that the patient might be using. Where a nurse or health aid may be confused or frustrated, it is more likely that a family caregiver will understand the shift in communication methods and continue to communicate with the patient, just in different ways, as frequently as before.

Preliminary data from exempt research

I conducted a pilot-test of an adult child whose parent had Alzheimer's Disease. I had a semi-structured interview with my mother, Dominique Winn, who I will refer to as Dominique for purposes of this pilot-test. Dominique's father, Louis, (my grandfather) had dementia (specifically, Alzheimer's) for a number of years before he passed away in June 2017. Dominique is a mother of two college-age kids, has a husband, and works part time as a librarian at university. For the last three years of her father's illness, she spent significant amounts of time caring for him, visiting many times a week to the nursing home he lived at, Sunrise. The primary caregiver before Louis entered Sunrise was Monique, his wife and my grandmother.

The interview happened April 8, 2018 at 9am. Dominique lives in Massachusetts so the interview was conducted over Skype. The interview lasted about 40 minutes. The purpose of the interview was to learn about Dominique's experiences, how she felt about the care Louis received, if there were any language barriers during his illness, and overall how Louis' illness had an impact on her life and changed the way she was able to interact with her father. Dominique assumed a caregiver role during his illness, as well as a teacher to him when he forgot how to use tools, words, or needed help completing simple tasks. She acted as a therapist to her mother, Monique, who handled tremendous strain from Louis' illness. For the first two years in which his dementia was really affecting him, Monique took care of him alone. This was a huge challenge for her, for their relationship, and her mental health.

I did well in keeping it in the realm of exempt research. Dominique answered very focused on the questions. In fact, she had requested the questions before our Skype so that she could be prepared to answer them. Since she was prepared with the questions beforehand, the interview was more structured than it probably would be in a more casual, on the spot setting. She also answered focused on the question.

What worked well was the phrasing of the questions, and the openness they provided for the interviewee to answer in different ways. What needed work was the sequence of my

questions. The questions could go in a better order that would make more sense. Some ways I've brainstormed to better order the questions are to go from simpler information and details to deeper conversations/memories with the person, or to go chronologically, from when the interviewee first knew that their parent had dementia to present. Another sequence I could follow is discussing the parent as an individual and their best qualities, then discussing the illness separate from the person, then discussing the interviewee's feelings and reflections.

Dominique gave feedback that having a question about what her favorite quality about Louis would be a good transition into a discussion of Louis as a multidimensional person separate from the illness. She gave the feedback as well that she felt comfortable and the questions weren't too hard to answer. This was a primary concern of mine, but she said she didn't feel at all like she had to answer something if she didn't feel comfortable doing so. She reflected on a woman she'd met in the library a few weeks ago whose father also had dementia, and she felt great consolation in that. She said it is helpful when you hear someone else be sympathetic, and it helps to unpack questions like these with other people. So, she thought the interview was very helpful for putting to words some feelings she'd felt. And she appreciated someone interested in listening. She said no one really wants to hear about this topic, they don't want to learn and they don't want to deal with this issue. Someone devoting time to looking at these questions doesn't happen often, and she said it was valuable. Dominique reflected as well that the elder care system in the U.S. is okay, but we could do a lot better job in taking care of our old people. The nursing home Louis stayed at was pretty good, but the support was impersonal and sometimes he would fall or get hurt and no one would be there to help. Dominique also gave feedback that my question "what is your favorite activity to do with them?" might be too broad but could be better phrased as "what is your favorite activity to do with them when you visit?".

Moving forward, I will certainly incorporate the feedback into my interview questions. To begin, it was reassuring to know that the questions and interview setting in general will provide more comfort and empathy to the interviewee than I had expected. I will work on making the questions more sequential so they can be answered a bit more organically (moving in one of the formats I had mentioned before). The way in which I ask the interview questions, I think I may try to provide some of the questions, at least a few of the more challenging ones, to the interviewee before we sit down, so they are given a chance to reflect on the issues. In the interview space, I can ask more questions. I also think I could have included more side questions that were personal to the interviewee, so that the questions don't seem too formulaic. For example, if they say they loved to play chess with their parent, I could then ask a question that builds off that statement, such as "did they teach you to play chess?" That is just an example of a question that might happen more organically in normal conversation and I'd like to keep the feeling of in my interview.

The pilot-testing results compare with commentary about methods in the scholarly literature in that the interviewee was very interested in the project and the interviewer as much as I was interested in interviewing them. That reciprocity of curiosity is something I've read about in the literature, and is definitely the case, especially for a young person like myself interviewing middle-aged people about their parents and focusing on elder care. I also will try to do more research on aphasia and try to include the word aphasia in the questions, so that some of the questions I am asking make more sense as questions with a linguistic focus. Dominique said that Louis definitely experienced aphasia, and she said that was a significant frustration and sadness

towards the end of his life especially. So, I will give more weight to how aphasia plays in (more than just second language loss, but language loss in general).

The pilot testing helped me to improve my research design in terms of feasibility and validity because I learned the limitations of my writing abilities and felt better about the ability to conduct the interview. What I mean in the limitations of my writing abilities is that I was unable to audio record our conversation so I jotted notes, and I definitely could not jot all the notes I wanted to because I write pretty slow. So, this will be something to think about going further. Luckily, unlike this interview, the other interviews will be conducted in person, so it should be easier to audio record. This will give me more opportunity to make eye contact with the interviewee and engage with them, as I won't be focusing on what they said 15 seconds ago and trying to write it down. This interview helped me to confirm that this research is feasible and the validity threats I'd brainstormed before are appropriate.

Description of IRB Exempt Research

Interviewees' and patients' personal information and identity will remain anonymous, and possible identifiers will be removed. This form of exempt research falls under the Exemption #2 of Educational Tests, Surveys, Interviews, or Observations. The human subjects, both in the interview and participant observation portion of the research will remain confidential and any identifying information will be removed. Information gathered from the interviews and observations will be kept securely under password protection on the remote UVM server, accessible to no one but myself. This research is being reviewed as an expedited proposal by the IRB under the guidance of Professor Jeanne Shea.

Description of ethical protections

The AAA Code of Ethics summarizes the important elements of keeping ethical, open, honest, work. Of all of the different aspects, the aspect that remains the most important for my research is the first article, Do No Harm. Do No Harm explains that no aspects of any of the research should inflict harm on another human or animal. All implications of the research as well should be considered, so as resulting effects of the research will not cause any harm either. Of the most serious harms that should be avoided are harm to dignity and well-being, particularly within a group of participants that may be considered a vulnerable population. As I am conducting research with old people who have memory impairment (dementia, Alzheimer's), they are considered to be a vulnerable population, according to the IRB guidelines. Thus, any possible aspects of my research design must be thoroughly evaluated for harm they may cause on this vulnerable population. Immediate harm is an important aspect to consider, but so are "potential consequences and inadvertent impacts" (Gusterson et al 2012) of my work.

The ways in which I need to consider the "Do No Harm" principle are in my interviews, my participant observation and my analysis. In the interviews I conduct, I will be interviewing the adult children of people who have dementia or Alzheimer's. So, the interviewees will not a vulnerable population but I still need to be very mindful of their sensitivity to the topic we will discuss. For some, the person in their life who has/had dementia may no longer be living, so it can be an emotional experience to talk about their life, particularly the challenges that came later in life when they were struggling with dementia. I should also be very mindful in the interviews if an interviewee feels uncomfortable answering certain questions, and that is okay. In my pilot interviewing, I know it will be a challenge for my mother to talk about this, and she may feel uncomfortable at times. My hope is to reduce the uncomfortably that the interviewee may feel. I

will do this by creating a strong relationship with those I interview, so they feel that they can confide in me with personal, emotional details. For many adult children, they have very fond memories of who their parent was before they had dementia or Alzheimer's, so discussing this hard part of their life may bring up bad memories, or they may not want to be reminded of this very debilitating disease their parent has.

The principle of "Do No Harm" is also very important in my participant observation. I cannot stress enough how valuable this portion of my research will be, but also how thorough and careful I must be with every step of it. As people with dementia/Alzheimer's are a vulnerable population, extra precautions are necessary. For me, I know that the relationship I create with these individuals and the nursing home they are at is very important. Having a known presence, being a familiar face, and establishing myself as a kind, honest individual will be important in making sure my research can be done, and that individuals will be comfortable with my presence as a researcher. Another aspect of this is how I will spend time with individuals while also taking notes on conversation and surroundings. I do not want to come off as a cold researcher and not be interactive with patients, but I also cannot leave behind my notebook. Finding a balance is important. Another important aspect is getting signed Assent from the caretaker or family member of the individuals I will be researching. This is crucial and my research cannot continue without this step. I will need the signature of the authority figure in the nursing home, the nurse, and probably family members of the individual so that I can research them. Assent will need to be signed because they may not be in a state of mind or fully capable of signing for Consent by themselves. Another consideration that I had not previously considered until this point in my research, and was brought to my attention by Julia Goodgold, is how the disease is a degenerate one, and I may be racing the clock in my research. I consider this to be an ethical concern because if this research takes place over about 8-10 months, the chance that an individual who may have been highly communicative at the beginning could lose language abilities throughout the course of my research. There is also the chance that they may pass away. This being said, I need to be very cautious about the condition of the participants, and at what point I should stop researching if they are no longer in a state where they can socialize with others, or communicate at all. This will also have a very deep emotional effect on the family members and caretakers of the individual, and I will need to know my place and know when to leave the situation, or be a support if that is requested. This being said, I think there is an adjustment to my research that I need to make that says at what point I will stop researching them, if over the course of time there will probably be degeneration in their cognitive abilities. I think a threshold I should consider creating for my research is when an individual no longer has any desire to socialize and does not join in on activities, conversation, games, etc. If they seem to recede or are not feeling well, I will stop observing them immediately. What I can apply to my research from Hoeyer and Hogle is that regardless of how circuitous or challenging the consent process may be, consent must always be followed and moral guidelines are never exempt to the research. "When practices differ from stated intentions, it is always the practices that are supposed to change" (Hoeyer and Hogle 2014: 349). What I previously mentioned about if the condition of my participants changes, I should immediately reassess my process, and be willing to change it.

Dissemination Plans

I plan to conduct this research as a senior thesis project. I am a Sophomore this year, and the thesis will be done during the summer leading up to my Senior year and throughout my

Senior year. Thus, this proposal will become pertinent June 2019-April 2020, the period in which I will be conducting this research. I also hope to provide this research as information for the larger public. I would like to present my final findings and research to those whom I interviewed, as they will benefit from the research and feel a sense of contribution to my project. I will present my research to them through a PowerPoint and booklet/brochure, so a condensed version of the research I've found. After I present my findings to the interviewees, I would like to organize them all into a focus group, where we can discuss the findings together and they can share experiences, feelings, and commentary with one another. This focus group will require my organization of a specific event at a central, public meeting location where all the interviewees will feel comfortable attending. I will keep the interviewees informed throughout the process so they know when the project will be completed, and when to expect a presentation on the information.

Researcher Identity and Preparation

Researcher Identity

I am a student at the University of Vermont in the Anthropology Global Health track. I have very strong interests in psychology, psychiatry, social work, and languages, all of which align well with this project. The prior experience and exposure I have with nursing homes and elders with dementia all come from the experiences my grandfather had. I have experience with close family members being informal caregivers and the psychological and physical toll this had on the caregiver. My maternal grandmother and my mother were primarily caregivers for my grandfather, whose illness lasted at least seven years. I visited my grandfather every week when we brought him to the nursing home, and we would spend time together. Seeing first-hand the impact that having a loved one with Alzheimer's has on a family, and the impact that being a caregiver also has on an individual and their relationships, I am passionate about this area of study.

Assumptions I have in this research are that all the interviews I conduct will be the same, and that all informal caregivers will reflect on the same experiences between them. I know this not to be the case, from the interview I've conducted so far and conversations I've had with peers. However, this remains an assumption to be wary of. Another assumption is that of the level of cognition patients are at. I must be cautious of not assuming their communicative competence when I am in the nursing home, and recognize when their health and cognition may be deteriorating as well.

I will mitigate subjects' related impressions of me by explaining my research well, providing materials of the research and sufficient preparation information before interviews and to the supervisors before observations. I will come prepared and available to the interviews and observation, and be professional while also friendly. My identity as a college-aged female may influence subjects' perceptions of me, but my age does not change the quality of the research I will be able to conduct.

If community members are asked specific questions that they are sensitive about, they may not want to answer certain questions. Additionally, if they know I am a researcher they may make up more elaborate information about support if they feel that their response isn't vast. If I am doing participant observation for this, it may be very hard to see what is an actual "challenge" between people, and what I may be projecting to be a challenge. I will need to be careful that I am not "assigning" certain communication techniques to having dementia if they are not—a strong linguistic background will be important.

I can't assume what good communication is (Nelson et al 2014). Nelson et al. discusses how different cultures and different generations define good communication very differently. Nelson et al.'s discussion of intergenerational differences will also be important for me, as I interview adult children of people with dementia. There can be the adoption of a parent-like role for adult children if they are caring for their parents, and this can sometimes be uncomfortable.

Preparation

As a University of Vermont Anthropology student, and with my interests, it is feasible for me to do this research. This research is also feasible for me because of the timeline of my research. As a Sophomore, I have two years with which to complete this research project. I have existing skills with volunteering at nursing homes previously and I have experience and skills with interviewing people because of my background of working on the school newspaper, The Vermont Cynic. I have practice with ethnographic observation as I have done research projects at the University of Vermont before in which I record and/or take notes in an ethnographic manner of my surroundings. My plans for additional preparation are to contact and solidify a nursing home at which I will volunteer, create relationships, and conduct the participant observation. I will, through the combination of the nursing home, family networks, and advertisements at the UVM medical center, find participants who are caregivers of patients with Alzheimer's who would like to be interviewed.

Validity Concerns

The researcher will provide space and a chance for all interviewees and nursing home nurses to give feedback. This research is focused on a small number of interviewees and a short period of observation. It will look at common experiences among people.

Conclusion

This research will help add to the field of knowledge regarding caregiving, experiences, and challenges in a support network with a patient with dementia. By combined methodologies of interviewing informal caregivers and ethnographic observation of patients with dementia, this research will help to bridge the gap between caregivers, facility experiences, and help address the need for better, more holistic care for patients with dementia. Few bodies of research have looked at language loss and informal caregiving directly, so this research will provide a resource of personal accounts that point to the need for professional care facilities with more linguistic diversity, and more consideration towards communication as an important aspect of dementia later in its degenerative process. The experiences of informal caregivers have reflected the need for more personalized, accessible support, more open conversation without the cultural stigma of dementia, and a more affordable option to elder care. Further discussions and research can look into socioeconomic status and elder care accessibility, as providing professional care is expensive. Further research can also look into cultural differences that influence the decision of whether to put patients with dementia into a professional facility or depend on informal caregivers alone.

Annotated Bibliography

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2016 Caregiver Burden and Perceived Health Competence When Caring for Family Members Diagnosed with Alzheimer's Disease and Related Dementia. *Journal of the American Association of Nurse Practitioners* 28(10): 534–540.

This source is a Psychological source, created for the use of mental health specialists and nurses. This is an important source that looks at ethnography as well as interview sources. Also, it looks at the perceived impact that caregivers feel from their loved one with dementia.

Balard, Frédéric, Marie-Christine Gely-Nargeot, Aline Corvol, Olivier Saint-Jean, and Dominique Somme

2016 Case Management for the Elderly with Complex Needs: Cross-Linking the Views of Their Role Held by Elderly People, Their Informal Caregivers and the Case Managers. *BMC Health Services Research* 16: 1–10.

This is a biomedical health services source with social work perspective for best practices. This source looks at the challenges of elder care and the many different roles that those who help play. Takes a Social work perspective, which is also very interesting to look at.

Buch, Elana D.

2013 Senses of Care: Embodying Inequality and Sustaining Personhood in the Home Care of Older Adults in Chicago. *American Ethnologist* 40(4): 637–650.

This is an Anthropological source. This research article looks at elder care in Chicago and the way that health workers help elders reimagine and recreate their social and sensory worlds.

Burns, Allan & Xenakis Blonder, Lee & M. Heilman, Kenneth

2008 Sociolinguistics and Aphasia. *Journal of Linguistic Anthropology*. 1. 165 - 177. 10.1525/jlin.1991.1.2.165.

This is a sociolinguistic source and was used to look at the ways in which aphasia effects speech patterns in older people affected by it.

Cera, Maysa Luchesi, Karin Zazo Ortiz, Paulo Henrique Ferreira Bertolucci, and Thaís Minett
2018 Phonetic and Phonological Aspects of Speech in Alzheimer's Disease. *Aphasiology* 32(1): 88–102.

This is a sociolinguistic source that looks at the source of speech impairment in individuals with aphasia, used to look at the perspective of communicative competence.

Cronan, Terry, Charles Van Liew, Dhwani Kothari, Jennalee Wooldridge, and Maya Santoro

2016 "Experience Keeps a Dear School": The Effects of Ethnicity and Caregiving Experience on Hiring a Healthcare Advocate. *Journal of Cross-Cultural Gerontology* 31(4): 409–426.

This is a gerontological psychology source. This source will tap into the multilingual/multicultural aspect of my project, speaking to the role that ethnicity and identity play in one's ability to access care.

Czekanski, Kathleen

2017 The Experience of Transitioning to a Caregiving Role for a Family Member with Alzheimer's Disease or Related Dementia. *AJN American Journal of Nursing* 117(9): 24–45.

This is a nursing source. This will be an important source to help with my interview portion of research, because it looks into the transition from family member to caregiving role.

Ekman, Sirkka-Liisa, Tarja-Brita Robins Wahlin, Astrid Norberg, and Bengt Winblad
1993 Relationship between Bilingual Demented Immigrants and Bilingual/Monolingual Caregivers. *The International Journal of Aging and Human Development* 37(1): 37–54.

This is a gerontological psychology/medical Anthropology source. This will be one of my most important sources, almost perfectly resembling what I wish to study in this project. Discusses the relationship and caregiver interactions with linguistic challenges.

Ferris, Steven H, and Martin Farlow
2013 Language Impairment in Alzheimer’s Disease and Benefits of Acetylcholinesterase Inhibitors. *Clinical Interventions in Aging* 8: 1007–1014.

This is a neuroscience/psychological source that looks at aphasia and regression in language usage during the illness, which is important in my study.

Gaugler, Joseph E, Mark Reese, and Mary S Mittelman
2018 Process Evaluation of the NYU Caregiver Intervention-Adult Child. *The Gerontologist* 58(2): e107–e117.

This is a Psychology Gerontology source. This source examines the effectiveness of an intervention program for adult-child caregivers at an NYU memory care facility.

Hopper, Tammy, Michelle Bourgeois, Jane Pimentel, et al.
2013 An Evidence-Based Systematic Review on Cognitive Interventions for Individuals With Dementia. *American Journal of Speech-Language Pathology* 22(1): 126–145.

This is a speech and language pathology source examining cognitive interventions to help elders who are experiencing language loss.

Karger, Cornelia R.
2018 Emotional experience in patients with advanced Alzheimer’s disease from the perspective of families, professional caregivers, physicians, and scientists, *Aging & Mental Health*, 22:3, 316-322.

This is a psychology and nursing source. This is an interesting source in seeing the perspective of families and caregivers and looking at how an interview method is used. This will be one of my most useful sources.

Kleinman, Arthur
2010 Caregiving: Its Role in Medicine and Society in America and China. *Ageing International* 35(2): 96–108.

This is an Anthropological source that examines the caregiver role for patients with dementia from a cross-cultural perspective with elder care in China.

1997 ‘Everything That Really Matters’: Social Suffering, Subjectivity, and the Remaking of Human Experience in a Disordering World. *The Harvard Theological Review* 90(3): 315-335.

This is an Anthropological and theological source looking at social suffering and the creation of shared experience within groups of people.

Kleinman, A., Das, V., & Lock, M. (Eds.).

1997 *Social Suffering*. Berkeley: University of California.

This is an Anthropological source looking at social suffering and the creation of shared experience within groups of people.

Mccarty, Teresa L., James Collins, and Rodney K. Hopson

2011 Dell Hymes and the New Language Policy Studies: Update from an Underdeveloped Country. *Anthropology & Education Quarterly* 42(4): 335–363.

This is an Anthropological source. This source will be helpful in providing context of cultural linguistic challenges for immigrants and multilingual people in the United States. Discusses educational policies surrounding language teaching.

Morioka-Douglas, Nancy

2004 Issues in Caring for Afghan American Elders : Insights from Literature and a Focus Group. *Journal of Cross-Cultural Gerontology* 19(1): 27–40.

This is an Anthropological gerontology source. A very useful article in providing information on elder healthcare in the United States, specifically the experience of Afghan-Americans who came to the United States primarily as refugees.

Prince, Martin, Anders Wimo, Maëlen Guerchet, et al.

2015 *World Alzheimer Report 2015, The Global Impact of Dementia: An Analysis of Prevalence, Incidence, Cost and Trends*. *Alzheimer's Disease International*: 87.

This is a psychiatric/psychological source important for providing information on data around dementia, worldwide statistics, and important medical facts.

Radda, Kim E., and Jean J. Schensul

2011 BUILDING LIVING ALLIANCES: COMMUNITY ENGAGEMENT AND COMMUNITY-BASED PARTNERSHIPS TO ADDRESS THE HEALTH OF COMMUNITY ELDERS. *Annals of Anthropological Practice* 35(2): 154–173.

A Medical Anthropology article that looks at the community bonds created around elders in elder care. A very helpful article in looking at effective practices in the US surrounding elder care.

Sanders, Scott R., Lance D. Erickson, Vaughn R. A. Call, Jacob S. Rugh, and Mathew L. McKnight

2016 Healthcare Use in the Heartland: How Health Care Selection Varies Between Rural, Retirement-Age Migrants and Long-Term Residents. *Rural Sociology* 81(1): 66–98.

This is a sociological source. This is an important source in looking at a sociological perspective to aging and research. Also, it discusses health care access in the United States for elders.

Tateishi, M.

2017 Supported communication for adults with aphasia. *Journal of the National Institute of Public Health* 66(5): 512–522.

United States

2018 Institute for Health Metrics and Evaluation. <http://www.healthdata.org/united-states>, accessed April 24, 2018.

This is a grey literature source that was helpful in looking at larger metrics about rates of death due to leading diseases and finding quantifiable data about Alzheimer's in the United States.

Vermont Alzheimers and Dementia Memory Care Facilities

N.d. A Place for Mom. <https://www.aplaceformom.com/alzheimers-care/vermont>, accessed April 26, 2018.

This is a substantive source, a website for an assisted living referral service, used to find data about dementia and Alzheimer's care facilities available in Vermont, and data around this topic.

Xenakis Blonder, Lee & Deane Kort, Eva & Schmitt, Frederick

2008 Conversational Discourse in Patients with Alzheimer's Disease. *Journal of Linguistic Anthropology*. 4. 50 - 71. 10.1525/jlin.1994.4.1.50.

This is a linguistic anthropology source that looks at the speech tendencies of patients with dementia of the Alzheimer's type (DAT).

Zwaanswijk, Marieke, José M Peeters, Adriana PA van Beek, Julie HCM Meerveld, and Anneke L Francke

2013 Informal Caregivers of People with Dementia: Problems, Needs and Support in the Initial Stage and in Subsequent Stages of Dementia: A Questionnaire Survey. *The Open Nursing Journal* 7: 6–13.

This is a gerontological nursing source. This is one of the sources most important to my research. It looks at the phases of dementia and the need for caregiving at each phase, and the experiences of caregivers. Data comes from a questionnaire of 1494 informal caregivers.

Appendices

Appendix A: Sample Interview Questions

Semi-structured interview questions with adult children of people with dementia:

1. Who in your life is affected by dementia?
2. How long ago did you realize this was the case?
3. When did they come to this nursing home (except the specific name)?
4. Tell me about this experience.
5. What are some of the greatest challenges of having someone you love suffer from dementia?
6. How has the diagnosis of your (parent/sibling/friend) affected your life?
7. What kinds of activities do you enjoy doing together?
8. What challenges do you face in communicating/connecting with your (parent/sibling/friend)?
9. What do you enjoy most about spending time with them?
10. How has the support at this facility been?
11. How has it helped your (relative) the most?

12. When/if you've noticed a change in your (relative's) language and speech ability, how has it affected you? How have you accommodated?
13. Do you speak the same language as them? If not, how does that feel?
14. How has having a (relative) with dementia affected your life? How has it affected your family or the dynamics in your family?
15. What are some things you've learned about your (relative) and their experience?
16. (To a volunteer): What kinds of things do you do with the patients?
17. How do you feel after you've spent time with them? How do you think the patients feel after you've spent time with them?
18. What was/is your favorite memory with this person?

Appendix B: Sample Participant Observation Questions

Participant observation of social interactions among patients:

1. What is the frequency and pattern of using the first language, second language, and language mixing, or errors made with language?
2. Do elders choose with whom to socialize/ask for help based on their language spoken?
3. Do they try to find others who speak a similar language to them?
4. Are there any social groups or interactions that form over this?
5. How do different staff, family, friends, and volunteers connect with the elders if they are experiencing language loss?
6. What observations have I made about comfortably around language usage for all parties involved? Are there strained relationships?
7. Does the facility have the staff and volunteers required to effectively serve the linguistic needs of the patients?
8. Which interactions elicit more speech from the elder or elicit the appearance of having a good time/being more engaged?
9. How do the elders respond to activities you lead?
10. What was the overall reaction from the group?
11. Did group activities spark the interest of the participants?

Appendix C: Lay Summary

Dementia and Alzheimer's are diseases that affect millions of families each year. For many families, one of the largest challenges is finding appropriate, accessible care for their loved one. In other cases, and even if a care facility is available, a family member may still be a caregiver for their loved one with dementia. In this research I am looking at the individual experiences of adult children who are caregivers for their parent with dementia. I additionally am observing the influence that language and language loss has in the connection between elder, child, and facility caregiver. I hope in this research to find themes across experiences that will help bring attention to a challenging role that many adults play in caring for their parent, which is rarely a role that is chosen. I will interview ten adults who have been caregivers for a family member with dementia, and we will talk about their experiences. I will also be observing a nursing home environment where elders are interacting day to day, and observe how language loss can be a barrier to relationships. This research serves to fill a gap between anthropology, gerontology and sociolinguistics that currently does not exist. Qualitative, social science research also is rare for patients with dementia and experiences around people with Alzheimer's. As the United States has an aging population and more people are expected to be diagnosed with

dementia and Alzheimer's in the next few decades, this is a pertinent study in the impact dementia can play on individuals, families and the health care network. I hope to bring light to the need for linguistically diverse staff at nursing homes, the need for the accessibility and affordability of elder care, and the normalization of dementia. By looking at common experiences, the stigma against mental health and dementia can hopefully fall away, and a comfort with the topic of dementia and caregiving can help to create community.

Appendix D: Informed Consent Provisions

The informed consent provisions were created along with the UVM 2017-2018 Manual for Human Subjects Research for qualitative data collection. Consent will be obtained in written form for this project. A waiver of consent through documentation will be completed in accordance with the consent form and submitted to the IRB with other materials. The purpose of this study is provided to those involved in the lay summary.

After approval by the IRB, I will be able to begin research. For the interviews, each participant will consent to the interview through written signature on an information sheet. Participant information will be kept confidential. For participant observation, participants will need to be given consent by the nursing home.

Appendix E: Research Permissions

Approved Research Permissions:

- Support from a faculty member (Professor Jeanne Shea)

Pending Research Permissions:

- UVM Honors College Committee
- IRB full committee review
- Informal caregivers to be interviewed
- Permissions from nursing home

Appendix F: Timeline

This research will be done next year during the summer going into Senior year and Senior year. The proposal will be submitted in the Fall of my Junior year, because I will be studying abroad the Spring of my Junior year.

	<i>Oct 2018</i>	<i>Nov 2018</i>	<i>June 2019</i>	<i>Sep 2019</i>	<i>Dec 2019</i>	<i>Feb 2020</i>	<i>March 2020</i>	<i>April 2020</i>	<i>May 2020</i>
Edit and Finalize proposal	√								
Proposal Submitted		√							
Begin volunteering at nursing home, participatn observation. Reach out to people for interviews			√						
Going regularly to nursing home, meeting with interviewees				√					
Interviews and Participant Observation Complete					√				

Analysis Complete						√			
Edit, Finalize Thesis							√		
Submit and Defend Thesis								√	
Graduation from UVM									√

Appendix G: Budget and Resources:

For this research project, I will need a car with which to drive to the nursing home and meeting locations to meet with interviewees. I have a car. Financial requirements for the research will be to pay for gas for the car (estimated \$20 a month allotted to this project) and to pay for coffee or lunch if I and an interviewee decide to meet at a food location (estimated \$20 average to pay for them as well) for each interview. Housing will not be required as I will be living in Burlington and doing small day trips within Vermont. A translator is not necessary as the situation of speaking French with nursing home staff or interviewees would be comfortable for me, as I am comfortable holding conversation in French. A laptop, which I have, will be needed to analyze data and write up information on the research.