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Evelyn Saru Jimmy
The University of Texas at El Paso

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RETHINKING METAPHOR IN THE RHETORIC

OF ALZHEIMER'S DISEASE

EVELYN SARU JIMMY

Doctoral Program in Rhetoric and Composition

APPROVED:

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Lauren Rosenberg, Ph.D., Chair

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Lucia Dura, Ph.D.

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Iva Ivanova, Ph.D.

_____

Stephen L. Crites, Jr., Ph.D.
Dean of the Graduate School

DEDICATION

I dedicate this dissertation to my husband Jimmer, and our children, Jaime, and Joy. They have all diligently stood beside me as I walked the path toward completing my doctoral degree. They have held me up and pushed me forward when I wanted to give up, and they never let me use them as an excuse for not meeting my deadlines. They refused to let me give up even when I felt like I couldn't do it anymore. My husband has listened to my ideas just as much as my children, and while they never really commented, their being my sounding boards is what got me this far.

I also must acknowledge my American family Dr. Garber and his wonderful wife Shirley. Without your unwavering financial and moral support, I would not have made it this far. Dr. Garber, you are a true inspiration. You have shown me that nothing is impossible, and that all the things in life worth having require hard work, time, commitment, and sacrifice. Little did they know how much of their sacrifice and confidence in my ability has allowed me to persevere even when I seem to think that there is no hope in my future. Thank you so much for being there for me when I am overwhelmed. The many telephone calls we shared, whether it was to allow me to vent my frustrations, or to help me understand my research questions better, was priceless. I knew I could always count on you to help me make the journey.

To my late dad, I wish you were still alive to witness this moment. To my mom and my two wonderful sisters, thank you for pushing me and telling me that I can do it. Thank you for the unconditional love and hours of laughter and prayers. Thank you for always believing in me and never doubting my ability. Your love and your prayers have carried me through. I love you all.

RETHINKING METAPHOR IN THE RHETORIC

OF ALZHEIMER'S DISEASE

by

EVELYN SARU JIMMY

DISSERTATION

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I would like to thank Dr. Lucia Dura, and Dr. Iva Ivanova for serving as my committee members and offering comments, suggestions, and encouragement during this dissertation journey.

ABSTRACT

This dissertation examines the metaphors that early onset Alzheimer's blog authors use to make meaning of their experiences living with Alzheimer's disease (AD). To complicate the study, I also compare whether early onset Alzheimer's blog authors use the same metaphors with those who serve as caregiver to late-stage AD patients. This research project is situated within the overlap fields of Disability Studies (Dolmage, 2006; Lewiecki-Welson, 2003; Yergeau, 2014; Kerschbaum, 2014), Rhetoric of Health and Medicine (Segal, 1997: Price, 2011; Molloy, 2015) Rhetoric of Mental Health (Chrisman, 2008; Uttapha, 2017, Reynold, 2008), and Technical Communication (Meloncon, 2014). Following the principles of these fields, this project deconstructs the bio-medical model of Alzheimer's disease and provides a critical metaphorical analysis of the metaphors that these two groups of blog authors use to construct and make meaning of their experiences with AD. The prevalent use of metaphors in the narratives of both early onset AD blog authors and caregiver blog authors, shows just how integral metaphor is in conceptualizing, conveying, and expressing meaning. The practice of medicine has advanced dramatically in recent years, but the language, especially the use of metaphors that were used to discuss and talk about illness by medical practitioners, caregivers, and the public as a whole has not kept pace. Paying attention to and analyzing these problematic metaphors could help provide healthcare professionals with a tool that can afford better empathy for people with dementia.

TABLE OF CONTENTS

viii

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1

RETHINKING METAPHORS IN THE RHETORIC OF ALZHEIMER'S' DISEASE

> I have Alzheimer's, and I'm still here. When I was diagnosed in 2012, I took a positive approach and said, "Okay, this is who I am; it's part of my life." I decided to maximize what I've got rather than be depressed about it.
>
> I also chose to be physically active because early in life I learned that physical activity raises my spirits. I got back on my bike, and I even ride in the winter – it's exhilarating! I can honestly say that giving up my driver's license enriched my life because I became more aware of the seasons and the large-scale openness of the landscape.
>
> With other people, I use candor. If someone doesn't know me, it helps to put my cards on the table and tell them I have Alzheimer's disease – then they won't feel snubbed if I forget their name. My attitude is, if there's a problem, don't pretend it's not there. Let's analyze it and find coping strategies and cures. The Alzheimer Society is doing a really good job of getting the word out, so people understand.
>
> I had a lifetime teaching career, and I have supportive friends who I taught with for years. I meet them and we go for coffee or bike rides. These outings keep me in touch with other people and get me out. I want to stay open and see all the possibilities; my goal is to live life to the fullest as best I can.
>
> Anonymous, Alzheimer society, Manitoba

Online storytelling on social media platforms like the one posted by an anonymous author on the Manitoba Alzheimer Society website above is fast becoming a popular way for lay people including patients and caregivers to share health information, connect with others, and share personal experiences of living with a terminal illness. In the telling of his or her story wrote Frank (1995) "the ill person who turns illness into story transforms fate into experience; the disease that sets the body apart from others, in the story becomes the common bond of suffering that joins bodies in their shared vulnerability" (p. i). Virtual support groups in virtual space have the potential to modify how individuals perceive their situation, how they manage their illnesses, and how they communicate within the doctor-patient relationship. The information shared on

blogs not only benefits the writer and his/her prospective audiences, but it could potentially be the missing piece of information a healthcare professional needs in order to better understand the terminally ill person that may become his or her future patient. This shift toward a more interactive online environment, not only changes how information is shared and communicated, accessed, circulated; it has transformed how health care is practiced. Social media platforms like blogs, therefore, provide a unique location to read narratives of people living with terminal illness experiences. In the case of Alzheimer's disease, reading patients' narratives and tracking the metaphor choices that they use to communicate their experience can help uncover how Alzheimer patients frame their dementia experiences. Moreover, it can be useful to identify strategies that help reframe their experiences in a more positive light and foster their well-being and coping responses.

Approaching the study of Alzheimer's disease (AD) through narratives composed by the people who live with it and experience it daily make it possible to study human reasoning, emotions, and experience in an everyday context, as well to consider major events in a particular culturally defined context (Paal, 2010). Kleinman (1988) proposed two reasons for studying illness narratives: 1) patients with chronic illness need to have "a witness to suffering;" (2) illness narratives can help ill individuals—and I add family members who often serve as volunteer caregivers—address the questions that relate to: Why me, why my family? What is next, and what can be done from this point? In other words, illness narratives provide spaces to express these feelings of the transcending illness experience to society, which modern medical models often find difficult to address.

For scholars in Rhetoric and Writing Studies and specifically scholars of Rhetoric of Health and Medicine, illness narratives provide a fertile ground to read how contemporary

writers construct and make meaning of their personal experience living with illnesses in order to better understand their perspectives, address their concerns and make their voices more visible. Yet, despite an increasing number of studies conducted on first person narrative and use of metaphors in narrating lived experiences living with chronic illness such as cancer, the study of first-person narrative and use of metaphors in narrating the lived experience of those who are living with Alzheimer disease remains understudied in the field of rhetoric and writing studies and the overlapping subfield of rhetoric of health and medicine. This dissertation hopes to fill that gap and contribute to interdisciplinary conversations about public health from Rhetoric and Writing Studies and Rhetoric of Health and Medicine.

Why Alzheimer's Disease and Metaphor?

Prior to pursuing my education in the United States, I had never heard of the term dementia or Alzheimer's disease (AD). My first encounter with AD or dementia related AD was in my Anatomy and Physiology (A&P) I and II classes back in my pre-med/pre-nursing undergraduate years in the United States. Compared to what I know now, although I find the biomedical model useful in explaining the state of mental health and the pathology of the brain, the lack of attention given to the social reality or the meaning of illness from the sufferer's perspective has always troubled me. Just as disease causes physical illness, the biomedical model posits that cognitive disorders including AD are brain diseases and emphasizes pharmacological treatment as a fix to presumed biological abnormalities. Psychiatrist George Engel (1977) eloquently described and criticized the biomedical model:

> The dominant, model of disease today is biomedical, with molecular biology its basic scientific discipline. It assumes diseases to be fully accounted for by deviations from the norm of measurable biological (somatic) variables. It leaves no room within its framework for the social, psychological, and behavioral dimensions of illness. The biomedical model not only requires that disease be dealt with as an entity independent of social behavior, it also demands that behavioral aberrations be explained on the basis of

3

disordered somatic (biochemical or neurophysiological) processes (p. 130).

Engel's (1997) portrayal of the medical model aptly described the predominant approach to mental disorder in the United States for the last three decades including approaches to Alzheimer related dementia. The problem with biomedical approach is, it triumphs cure over care. Given the dominance of the biomedical model in the United States, it is, however, not surprising that the public has embraced this approach to understanding mental disorders. While these relatively monocultural understandings of mental health practices have provided powerful conceptual tools and frameworks for the alleviation of mental problems in many settings, such practices can be problematic. For a start, it is important to remember that each person is an individual, and each individual even within a given culture may not hold the same views or opinions about a disease or even have the same amount of knowledge about the condition. In her book *The Body Multiple*, Mol (2002), describes how in different practices, "illnesses are 'done 'differently, or, in her terms, 'enacted.' For instance, arteriosclerosis in the consulting room with a patient is something else than the entity derived from X-ray pictures of a radiologist" (pp. 30 - 36).

My interest in the study of AD narratives was rekindled when I visited Malaysia in the summer of 2019. While in Malaysia, I had the opportunity to engage in deep conversation about AD with family members and friends who were medical professionals and were directly involved with patient care. From the many conversations that I had with them, I not only learned different narratives about dementia, but I also discovered that the metaphors that people in Malaysia used to construct narratives about AD often conflict with how people in the United States talk about AD. It was during this trip that I was also introduced to the concept of 'nyanyuk' which serves as a powerful framework for my interest in the study of metaphor in dementia narratives. Culture can influence how people make meaning and interpret the reality

around their world. And the languages that people speak are connected to their culture. Kövecses (2009) argues that both culture and language are about meaning making. The view of culture that I embraced in this study is the definition of culture that was proposed by Geertz (1973), wherein he wrote "man is an animal suspended in webs of significance he himself spun" (p. 5). Like Kövecses (2009), I take the meaning of culture that Geertz (1973) proposed "as one not as experimental science in search of law but an interpretative one in search of meaning. In this way, we can, as Kövecses (2009) suggests, "approach both culture and language as a web of significance that people both create and understand" (p. 135). People who are able to successfully participate in meaning making are said to belong to the same culture. This meaning-based approach to culture and language can be found in Lakoff's (1996) theory of metaphor. Depending on who is using it and how it is used, meanings of language, can be interpreted differently. The same can be said about the metaphorical language that people use to make meaning about illness experience including illness experiences connected to a diagnosis of dementia.

Much of the conflicting cultural representations of AD are also intertwined with other social meanings, such as social expectations of aging (Hulko, 2009). Western cultures, for example, see memory loss like dementia as a terrifying event. Yet, Eastern cultures like Malaysia where I grew up see memory loss as a normal process of growing old. As a matter of fact, the culture that I grew up in doesn't even have a label to describe AD; instead, what we have is a local cultural idiom 'nyanyuk' to describe someone who behaves like a child or is senile due to memory lost. Some public hospitals in Malaysia do not even have any special units that cater for dementia care or diagnosis. Interestingly local cultural idioms associated with dementia have also been documented in other Asian countries. In China for example, mental function is not

equated with cognitive capacity. Instead, in Chinese culture, as long as a person is behaving in a socially acceptable manner and not posing a threat to the society, he/she is considered normal (Ikel, 1998). Meanwhile in Japan, a decline in functional mental ability is said to be due to lack of daily physical activities and social engagement (Traphagan, 1998). As a solution to the problem, the Japanese believe that daily physical activities and mental exertion conducted within the framework of social gatherings should be prioritized, hence the term 'boke bôshe,' which literally means 'as dementia prevention' (Cipriani & Borin, 2014). The fact that these Asian countries do not share similar illness constructs about what AD is with Western biomedical models suggests a gap in meaning making as well as how healthcare or medicine is practiced in different parts of the world. This suggests a need for further investigation. One reason for this gap in research about AD especially in Rhetoric and Writing Studies is perhaps related to the challenges in accruing participants for the study. Many AD patients may have multiple cognitive impairment and may lack the capacity to provide informed consent (Grill & Karlawish, 2010).

Yet, what is obvious is that for decades, the framing of diseases and how medicine and health care ought to be practiced have centered solely upon Western points of view. We need a new model of thinking about dementia. For me, this is where the concept of nyanyuk becomes relevant. What I find significant and powerful about the concept of nyanyuk where AD is concerned is that it offers us a new possibility of thinking about AD. Unlike the term dementia which denotes a negative label, the concept of nyanyuk carries a more sympathetic tone. It focuses on the language of respect and empathy.

The language that we use to talk about dementia is powerful and can influence how we view dementia. Innes & Manthrope (2013) stress that "how we approach dementia…. will impact on how we 'see' the problem; how we might try to approach it, and how we might try and

respond to or look for a solution" (p. 88). Because the language used to describe dementia is powerful in its impact on how the disease is understood and experienced, the extent to which metaphors and narratives are common or different to individuals and groups is important to examine. Drawing from the concept of nyanyuk, the goal of this study therefore is to propose that we change the metaphorical language we use to describe and talk about dementia as not everyone considers AD as a disease. Changing the metaphorical language, we use to describe and talk about AD might potentially shift public attention away from the biomedical model of responding to the challenges of AD. Moreover, doing so can move the focus from individual symptoms and management to a more holistic, situated view of a person with dementia.

What I hoped to discover through the study of metaphors and illness narrative in the discourse of AD was how early onset Alzheimer bloggers and those who served as caregivers to late onset Alzheimer disease used metaphor to frame the experience of living with the disease. I believe that composition studies can serve as an ideal disciplinary space to approach this kind of study. Unfortunately, until recently, literacy research—and I add composition studies as a whole—focused myopically on literacy instruction alone (Purcell-Gate, 2009, p. ix). Calls for attention to digital literacies or multiple literacies (Moje, 2008) or engagement in contemporary practices (Selfe, 2004) often needed to be justified. Limiting literacy research to literacy instruction only may limit the researchers' ability of writing practices going on in research sites (Thomas & Tokayoshi, 2016) and real life (my own emphasis). We need therefore to examine literacy practices in different settings like the literacy of the sick and the disabled lives which this dissertation aspires to accomplish. Literacy events, argues Health (1993), "must be viewed in larger socio-cultural patterns which they may exemplify or reflect" (p. 74). Ruth Ray (2000)

7

suggests that there is power in storytelling, in that it can empower both the writers themselves and others (p. 105).

My approach to the dissertation is threefold. First, I seek to examine the dominant medical metaphors that dominate public rhetoric about Alzheimer's disease (AD) or dementia. Specifically, I am interested in examining the ways in which metaphors shape and frame the written accounts of people with early onset AD. Second, I seek to explore the counter narratives and metaphorical expressions that two groups of people—early onset Alzheimer rhetors and those rhetors who serve as caregivers—use to counter, confront, and communicate their experience with living with AD by paying special attention to those metaphors that help them frame and communicate the impact of dementia on their psychological coping response to the emotional and psychological consequences of disease and stigma. Third, I seek to provide a comparative rhetorical analysis of these metaphors and analyze the narrative strategies that early onset AD bloggers employ to maintain their identity and sustain their continued agency. To further complicate the study, I will also discuss the persistence of negative stereotypes associated with dementia and aging. In paying attention to the disabling metaphors and stereotypes commonly used in the rhetoric of AD, I hope to bring to the forefront the issue of neuro-cognitive disability resulting from AD making it more visible to the public in addition to highlighting how neuro-cognitive disability is routinely understood as an ethos problem. Additionally, in paying attention to these disability metaphors, I hope to disrupt and alter the social order and lessen the stigma and the continued omission of bodies associated with cognitive disability. By understanding how representation of neuro-cognitive disability is problematic, I hope to advocate for greater awareness and more sensitive communication strategies that can reframe and change the continued negative narratives about AD. This is important to rhetoric and

writing studies as it can inform us of the complex and myriad ways in which writers use writing to communicate their experiences as well as sustain their individual agency and identity.

In addressing the different arguments and goals that I made above, this dissertation contributes to, to borrow from Miller (2016), "a recent move in writing studies to bring the social and material aspects of literacy into closer conversation" (p.35). Literacy activity theory as articulated by Pior & Shipka (2003), which sees materiality as "the dispersed, fluid chains of place, time, people, and artifacts that come to be tied together in trajectories of literate action" (p. 180), perfectly encapsulates the social nature of writing that I envision. Theorizing literacy as "social material" can help expose how social values, expectations, and trends are imbricated in the very material of literacy and how the two "interanimate each other" (Vieira, 2010, p. 423). Failure to account for how writing is enabled by a range of material realities keeps us from fully articulating the social nature of literacy (Micciche, 2014; Brandt & Clinton, 2002; Shipka, 2011). The social and material aspects of literacy, argues Miller (2016), are inseparable; however, in order to account for the social dynamics and consequences of literacy, we must attend to the material as well as the body (Miller (2016). Framing the dissertation through the lenses of literacy as social material, can also help writing studies sharpen and broaden its understanding of how writers' bodies matter (Hass & White, 2001; Owen & Ittersum, 2013), specifically by drawing our attention to embodied experience as a way of knowing—as theory in and itself (Siebers, 2010, p. 14).

This research project also hopes to contribute to the conversation about disability and dementia in disability studies. The history of disability demonstrates that social practices continue to maintain and reinforce disability as a category of the marginalized other. The problem with the process of othering is that it set the stage for discrimination by zeroing on

difference and using difference to create division between people. Conventionally, such practices have serious implications not only for how we view and treat people with disabilities, but also for how we understand the limits of the human body. Through their embodied literate practices, disabled writers "challenge our assumptions about literacy and cal[l] attention to the physicality of literate acts" (Lindgren, 2007 p. 99). The work done on disability in rhetoric and writing studies not only overlaps and intersects with the work done in disability studies but in technical communication as well. The field of rhetoric and writing studies, like both disability studies and technical communication, supports the need to bring rhetorical analysis to bear on understanding the construction of disability through a study of "the social meanings, symbols, and stigma attached to disable identity" (Sieber. 2008, p. 31). For example, the Conference on College Composition and Communication (CCCC) in their statement on Policy and Best Practices, touts the need to promote inclusive approaches and praxes responsive to the needs and experiences of disabled people (Policy on Disability, 2006, Reaffirmed April 2011, para, 1). Disability, whether it is invisible or visible, should not only invite us to rethink language, the body, environment, identity, culture, power, and the nature of knowledge itself, but it should inspire us to reconsider and interrogate its complexities and its impact on the affected individuals.

Additionally, this dissertation contributes to the conversation on accessibility in technical communication. Meloncon (2014) suggests that "when we filter our understanding of accessibility through the diverse and growing body of literature in disability studies, our attention is drawn to the ways in which technologies enable and include disable people and exclude both users and practices" (p. 5). Unfortunately, although disability studies have grown into a robust and theoretically rich field, current scholarship in technical communication notes Meloncon (2014) "has yet to fully engage the complex intersections of technology and disability" (p. 5).

This dissertation is a step forward toward that goal. As Meloncon (2014) accurately points out "with the growing use of technology in our daily lives and the ongoing changes of writing through and with technology, technical communicators need to be accurately aware of issues involved with accessibility and disability" (p. 5). In addressing the issue of disability and accessibility, I focus on the complex nature of language. Specifically, I argue that we need to change the language that we use to talk about AD to language that represents the preference of the groups. The discussion I present in the literature review will provide some of the theoretical grounding of this project as well as its positioning among the work of other scholars before me in Rhetoric and Writing Studies and the overlapping field of Rhetoric of Health and Medicine including the subfield of Technical Communication.

Key Concepts and Definitions

Before delving into the literature review section, I would like to provide some working definitions that will help frame this research project. These definitions will be expanded and complicated as I move and understand the orientation of the study, but introducing these definitions now will allow readers to start at the same place:

Neuro-cognitive disability: A term I made up to describe the cognitive impairment and disability caused by the progressive degeneration of the brain cells that affect a person's memory, thinking, and behavior.

Nyanyuk: A local cultural idiom used by the Land Dayak and Sea Dayak community of Sarawak, Malaysia to describe someone who is childlike and senile due to memory lost.

Dementia: A term I used to describe loss of neuro-cognitive disability due to Alzheimer's related disease. In this dissertation project, the term dementia will be used alternately with Alzheimer disease.

Alzheimer's disease: Progressive cognitive deterioration that occurs due to the degeneration of the brain (alz.org).

Front Temporal Dementia: Frontotemporal dementia (FTD) is one of the less common types of dementia. The term covers a wide range of different conditions. It is sometimes called Pick's disease or frontal lobe dementia (alz.org).

In the 21st Century market driven healthcare, the empathy that Hippocrates aimed for increasingly slipped away as business practices and not the art of medicine shaped medicine. For those people who are diagnosed with terminal illness like AD, their existence is nothing more than a numerical statistic. Writing about the decline of doctor-patient relationship, health and science journalist, De Vita (1995) writes, "ask just about anybody and you will hear a doctor-patient horror story, a tale that reflects the indignation with which Americans have come to view their healers" (p. 63). The once sacred relationship between the doctor and the individual has devolved into a mechanized, industrialized conveyor belt practice. Franks (1995) writes of this loss of voice in *The Wounded Storyteller* that "in post-modern times, pressures of clinical practice, including the cost of physicians' time and even greater use of technologies, less time is available for patients to speak" (p. 13). For much of modern medicine's history, the traditional role of the physician has been that of paternalistic authority over the patient (Wilson, 1980). Talcott Parson's work in the late 1970s noted that the physician was becoming "responsible more to professional codes than individual patients" (Franks, 1995, p. 15). The health care professional in the latter part of the twentieth century placed more emphasis on "adherence to the profession before the particular demands of any individual patient" (Franks, 1995, p. 15).

Illness discourses outside the medical setting and the development of online spaces like blogs thus become an important virtual space for the terminally ill to search illness information, find support whether it is during the early aftermath of their diagnosis or throughout their journey with their illness, stay inspired, stay connected or to educate others and make them aware of their illness. Caregivers also find similar reasons to use social media outlets like blogs to their advantage. There is much to learn about illness narratives and the language that they use to make meaning and create meaning created in virtual space through social media.

Summary of Chapter Overview

Chapter 1 has provided a rationale for why I am interested in studying the metaphors that early onset bloggers and those who served as caregivers to late onset dementia patients used to construct and make meaning of their experiences living with and coping with AD. The chapter also proposes that reading illness narratives and tracking the metaphor choices that early onset Alzheimer bloggers and those who serve as caregivers use to communicate their experience can help uncover how they frame their dementia experience. Moreover, it can be useful to identify strategies that help reframe their experience in a more positive light and foster their well-being and coping responses. I then proceed by contextualizing the absence of neuro-cognitive disabled perspectives in reference to mental health issues related to dementia in AD in the history of rhetoric as well as the field of Rhetoric and Writing Studies. By demonstrating that the logic of neuro-cognitive disability as an ethos problem embedded as metaphors in illness narrative that warrant examination, I hope to denaturalize discourses that assume neuro-cognitively disabled rhetors have ethos problems. In chapter one I also argue that cognitive metaphor can serve as important linguistic contributions towards a theory of rhetoric and persuasion in health communication and health literacy as it can illustrate how rhetoric is used for the purpose of

13

legitimization of ideas and thought. Chapter 2 will review the theoretical framework and gaps in the relationship between blogs, illness narrative metaphor, disability studies as well as its positioning among the work of other scholars before me in Rhetoric of Health and Medicine. Chapter 3 will discuss the methodology used in this study. Chapter 4 provides descriptive information about the blog authors and their blogs as well as addresses my findings and weaves them with elements from my theoretical framework. Chapter 5 provides conclusion to the study. It will further offer suggestions for future research on metaphors. In this chapter I also explore the implications of my findings for rhetoric of writing studies, rhetoric of health and medicine and disability studies.

CHAPTER 2

LITERATURE REVIEW

This chapter presents a comprehensive review of the literature that situates this project within the field of Disability Studies and Rhetoric of Health and Medicine, and the emerging field of Rhetoric of Mental Health. First, I make the case for why the field of rhetoric need to study the metaphors that are used in the construction of dementia narratives. I then provide an overview of the research in the fields of Disability Studies and Rhetoric of Health and Medicine that serves as the foundation for the research in this project. Last, but not least, I present a summary of the research that has been done surrounding metaphors within and outside of the field of RWS. The research discussed in this chapter presents the theoretical grounding of this dissertation as well as its positioning among the work of other scholars.

Illness Narrative and the Gaps in Rhetoric and Writing Studies

For many people, being diagnosed with AD is the adult equivalent of the monster in the closet that comes to steal your memories and independence in the middle of the night. So feared is the disease that for many people, being diagnosed with AD is like a death sentence. A 2011 survey conducted by MetLife foundation on over 1000 participants discovered that 75 percent of millennials, Generation Xers, and baby boomers worry about what would happen if their memory failed them. Some studies found that the fear of developing AD heightens as people grow older (Cutler, 2015; Cutler & Brăgaru, 2015; Roberts et al., 2014), while other study (Yeo, Horan, Jones, & Pendleton, 2007) found no differences in worry across age groups.

People fear AD because they see what the disease can do to their loved ones. They saw a parent, a grandparent or other beloved relative slip away in the twilight of their lives through the steady erosion of memory, cognition, and identity as the disease progresses. People also fear AD

disease because of the stereotype and stigma in the form of negative attitude and inaccurate beliefs toward people with AD. Some of the myths and stereotypes include dementia as an inevitable part of ageing (Mendez & Cummings, 2003). Another example of stereotypes or myths about dementia is that once someone has dementia the person you knew will eventually disappear. People with dementia are like children (and probably worse) and should be cared for as such. These myths have not only too common and circulating well within the public sphere (Devlin et al., 2007), but amongst healthcare professionals as well (Baste & Ghate, 2015) despite a wealth of evidence demonstrating their inaccuracy (Nelson et al., 2011; Markova et al., 2014; Peel et al., 2014). The stigma and stereotypes about AD are not just attached to the diagnostic label but to the assumed experiences people will have post diagnosis. Such assumption of course is grossly irresponsible and unacceptable as it does not recognize the continuing future of people living with AD particularly those with early onset AD.

Being diagnosed with any kind of illness, let alone a terminal illness, is certainly a terrifying event. As part of coping mechanisms and in an attempt to make sense as well as derive meaning from their diagnosis and illness experience, people turn to the healing power of illness narrative to conceptualize the subjective experience of their suffering. Illness, whether it is acute or chronic, may cause us to question and re-evaluate our lives in the light of our own frailty. It is in this context that narratives become particularly useful. Narratives provide the space for presenting, discussing, and negotiating how we relate to illness. Charron (2006) defines illness narrative as a form of health care that "recognizes suffering, provides comfort, and honors the stories of illness" (p. 17).

Illness narratives according to Frank (1994, 1995), are not just a form of meaning making; they can provide insights into how patients understand the why and how of illness

causation and treatment, including how illness are linked to broader and structural contexts of patients and their community. The book, *The Spirit Catches You and You Fall Down: A Hmong Child, her American Doctors, and the Collision of Two Cultures by* (Fadiman, 1997), for example, provides us with a profound insight into how, despite a medical team's best efforts, inadequate care can arise from miscommunication, failure among clinicians and health professionals to reflect on their own cultural assumption and economic positions, rigid institutional policies and procedures, and systemic inequities. For researchers and scholars of Rhetoric and Writing studies and Rhetoric of Health and Medicine, the proliferation of online illness narrative provides an ideal ground to study metaphor in the construction of illness experience.

As a means by which thought is structured and a means by which meaning is constructed, it is important to examine the metaphors that individual used and produced in the construction of illness as it can provide insights into how these individuals understand the world around them and make meaning of their subjective experience including the course of action they take. A metaphorical structure of human thought suggests that metaphors are capable of providing new meaning to the past, to daily activity, and to what is hoped for in the future. Thus, metaphors have the ability to generate new realities. Lakoff and Johnson (1980) labeled this phenomenon "embodied metaphor," and it influences the way individuals think and act. My dissertation understands embodiment as the way in which one's emotions and experiential knowledge affects how one understands the reality of one's world. Lakoff and Johnson's (1980) critical theory of metaphor (CMT) thus is central to my research.

Segal (1994), one leading medical rhetorician in the subfield of Rhetoric and Writing Studies, drew our attention for the need to study medicine because of its position of power in our

society (p. 92). In recent years, more and more, both science and medicine have come to occupy a position of power in society by becoming the leading authorities in our understanding of health and the human body including their subjective experience. Although science and medicine are important for our understandings of the physical world including the understanding of disease, it is important to note that these understandings are culturally infused and socially constructed and therefore are subjected to different interpretations and understandings. Lisa Keränen (2007) has argued that as a field, we are missing a "comprehensive account of medical discourse arising squarely from rhetorical tradition" (p. 442). I believe indeed it is important for the issues of medical discourses particularly the study of metaphors to be approached from members of different disciplines in order to encompass the wide range of impact of medical discourse on our constructions and understanding of health and disability. And as an interdisciplinary field, we are positioned to identify the gaps in the field of RWS and use our scholarships to serve as an important site for critical analysis and the deconstructions of disability, health, and the human body. Although the study of metaphors particularly metaphors in cancer have already been undertaken by a variety of scholars ranging from anthropology to bioethics to rhetoric and composition studies, no research in the use of metaphor in the construction of illness experience among early onset AD blog authors that I know of has been conducted in the field of Rhetoric and Writing Studies including its subfield of Rhetoric of Health and Medicine, Disability Studies as well as Technical Communication. This study serves to fill that gap in research. In the next section, I introduce what conceptual metaphor is and the role that it plays in the understanding of illness experience.

Conceptual Metaphor and Illness experience

The classic treatment of metaphor can be traced back to Aristotle whose treatment of metaphor set and influenced the course of Western thought on metaphor for the last two thousand years. In *Poetics*, Aristotle defines metaphor as "the application of name that belongs to something else, either from genus to species, species to genus, species to species or by analogy, that is proportion." (Poetics 21 1457b, p. 9-10 as translated by Coughlin, 2013). This classic view of metaphor has been strongly criticized by proponents of contemporary metaphors because it suggests that metaphor is nothing more than a stylistic extension to language, a rhetorical device or, at best, a mechanism for filling lexical gaps in the language. For proponents of a contemporary view of metaphors, such a representation of metaphor is utterly a mistake, for them, metaphor is integral to language and cannot be divorced from it.

The emergence of theories that associate metaphor with a cognitive function changed the dynamics of the study of metaphor apart from its communicative function, hence the theory Conceptual Metaphor Theory (CMT). Metaphor, wrote (Lakoff & Johnson, 1980) in their famous book *Metaphors We Live By*, permeates the everyday existence of human beings:

> Not just in language but in terms of which we both think and act, is fundamentally metaphorical in nature. The concepts that govern our thoughts are not just matters of the intellect. They also govern our everyday functioning, down to the most mundane details. Our concept structures what we perceive, how we get around in the world, and how we relate to other people (p. 3).

Studies on conceptual metaphors across languages and cultures have shown that metaphors are not only essential but an unavoidable part of language use, and that people use metaphors in their everyday communication with each other about their feelings, thoughts, and life experiences (Lakoff & Johnson, 1999; Charteris-Black, 2004; Kövecses, 2005). Pain undermines mind-body dichotomies: the cry "it hurts, here!" is both an assertation about the

localization of pain in the body and a testimony to amorphous suffering. Metaphors are particularly useful when people are attempting to convey experience most resistance to expression. A diagnosis of dementia at any age is devastating but diagnosis in younger patients also known as early onset Alzheimer' disease presents a particular challenge. Those recently being diagnosed with dementia therefore are likely to experience a range of emotions. These may include grief, anger, shock, fear, and disbelief. Some may struggle to deal with these emotions, and they may move between emotions as they adjust and make meaning out of their diagnoses. In the face of chaos, complexity, and incomprehensible life events, metaphors are a fundamental mechanism through which our minds conceptualize the world around us. As Bourke (2014), suggests, metaphors can bring interior sensations of the body and mind into a knowable external world, where they can be communicated, and processed so that meaning can be created. So, it may be described that our stomach pain is like the stabbing of knives, or our throat feels like a burning sensation. On the cognitive "heuristic" characteristic of narrative and metaphor, Bougher (2015) writes:

> Metaphor and narrative provide psychological structures that allow us to piece fragments of information together into a cohesive whole. With metaphor, we piece together bits of information by relying on our existing knowledge structures in other domains; with narrative, we use embedded knowledge structures, grounded in everyday life, to make sense of our social world (p. 251).

The relationship between narrative and metaphor runs deep and can be described as follows. Narrative uses metaphor to express or illustrate its message and metaphor finds expression through narrative (Hansen, 2018). Both metaphor and narrative can function independently but when present in the same message, the interaction should be studied and merit critique. The study of metaphor in discourse, particularly illness discourse can reveal information about the

speakers/rhetors such as their thought, social cultural norms, and practices, along with their emotions, attitudes, values, and beliefs (Cameron, 2010).

Metaphors in Illness Experience

The role of metaphor at the level of conceptual processing mechanisms and the making of meaning is an idea that has been explored for decades. Metaphors are important in human communication and cognition because they express, reflect, and reinforce different ways of making sense of particular aspects of our lives. In a medical context, the frequent use of metaphor comes as no surprise. Since the publication of *Metaphors We Live By*, by Johnson & Lakoff (1980), metaphor has been not only viewed as a linguistic phenomenon but as an essential tool with which we come to understand the world or being in the world. By relating a complex, abstract and intangible concept (target domain) to another that is perceived as more concrete, familiar, and well-structured (source domain) metaphor makes abstract, complex experiences more imaginable, comprehensible, and easier to communicate (Gibbs, 2008; Lakoff & Johnson, 1980). As a powerful framing device that has the propensity to shape the way a situation or event is perceived, metaphor choices in illness narratives are not trivial, rather they reveal particular ways of thinking about an issue and stress the aspects of that issue that the speaker considers most important. Explaining the role metaphors play in experiences of illness, Broyard (1993) in Intoxicated by my illness: And other writing on life and death wrote:

> [M]etaphors may be as necessary to illness as they are to literature, as comforting to the patient as his own bathrobe and slippers. At the very least, they are a relief from medical terminology. If laughter has healing power, so, too, may metaphor. Perhaps only metaphor can express the bafflement, the panic combined with beatitude, of the threatened person.

The statement above reflects the powerful nature of metaphor in conceiving complex ideas and experiences that would otherwise be difficult to articulate. In illness narratives,

metaphors make the experience more intelligible and "connect individual illness to collective experience" (Skott, 2002, p. 234). Thus, what is deemed difficult for the patients to express, is made fathomable through the use of metaphors.

Since the publication of *Illness as Metaphor* (Sontag, 1977), a long list of studies has been conducted from a metaphorical point of view. For example, in an ethnographic study conducted by Peterson and Sterling (2009) on asthma, they found that children used metaphors such as "troll," "jellyfish," "cracker," and "guardian angel" to make sense of their condition. Of these four metaphors, the "troll" and the" cracker" metaphors are classified as internal while the "jellyfish" and the "guardian angel" metaphors are external to the child's body. The internal metaphors are significant for indicating that the child is aware of his/her own illness in terms of early symptoms. As one child described, the troll is the one who controls the airflow into her lungs if she wakes him up with activities while another child described the experience of asthma similar to chewing a cracker whereby the tiny pieces would fly around and cause him to cough and make a "crumbly" sound.

Another study conducted by (Plug et al., 2009) on epilepsy patients also highlights the important contribution of metaphors in medical practice. In their interviews with epilepsy and psychogenic non-epilepsy patients (PNES), Plug et al., (2009) found that there is a significant difference in the way two categories of patients conceptualize seizure. Epilepsy patients tend to use metaphors deriving from the agent/force (seizure is an agent/force) or event/situation (seizure is an event or situation), while PNES patients use the space/place (seizure is a space/place). The metaphorical conceptualization of seizure by epilepsy patients places the patients as the experience of seizure, which is represented as an event happening to them, whereas PNES patients experience seizure as a state or place that they have to pass through. These findings have

important practical implications for healthcare practices as the type of metaphor used by patients can help medical professionals distinguish between the two conditions when diagnosing patients suffering from either epilepsy or PNES. For scholars of rhetoric and writing studies, these findings highlight the potent framing power of language and the direct effect of language upon the way ill people perceive and deal with their condition. The use of metaphors in illness framing are diverse and wide encompassing complex medical conditions including cancer, motor neuron disease, diabetes, mental health, among others (Gibbs & Franks, 2002; Locock, Manzanderani & Powell, 2012; Palmer-Wackerly, and Krieger, 2015). All in all, these studies have shown the importance of metaphors not only in describing their symptoms but also as a tool in articulating their emotions and the impact of illness on their expectations and psychological well-being.

In the case of Alzheimer's related dementia, only a handful of studies have explored the patients' perspective from a metaphorical point of view. The bulk of the most recent research on metaphors in Alzheimer related dementia comes for Zimmerman (2017a, 2017b). Her analysis highlights how despite their awareness of the degenerative and incurable effects of the disease in their future undertaking, Alzheimer patients still find meaning to continue living productively. The other study comes for Cãstano (2020). Her study provides useful insights into in-group language choices that early onset Alzheimer bloggers made to communicate about their experience with dementia. While Castano's (2020) study focuses on how metaphor is mobilized to frame and describe the lived experience of dementia patients, I am interested in looking at how both early onset Alzheimer patients and those who served as caregivers to late-stage AD patients constructs and make meaning of their experience living with AD. Reading their narratives and tracking the metaphor choices that they use to communicate their experience can help uncover how early onset AD patients frame their dementia experiences, maintain their

identity and sustain their agency. Moreover, it can be useful to identify strategies that help reframe their experiences in a more positive light and foster their well-being and coping responses.

Understanding metaphors can present a unique challenge. While many metaphorical images are used because of their cultural familiarity (Rancour, 2008; Skott, 2002), the individual reasons behind choosing a metaphor are context-specific, which means they are open to misinterpretation (Byrne, 2008; Harrow et al., 2008; Reisfield & Wison, 2004). For example, the phrase "to fight cancer" may carry different meanings depending on patient' prior experiences, prognoses, belief systems, and values (Penson et al., 2004). "Medicine is war" is yet another example of a metaphor that invites misrepresentation. In the war metaphor, the word war, not only portrays illness as an act of war, involving weapons (medicine), but the term 'war' also connects an act that is negative in nature, something which we are not fully in control of and must let the doctors win (Hodgkin, 1985). What if you fail to win the war especially in terminal illness like AD? In fact, AD is the only disease in which patients are told to go home and put their life together (Swaffer, 2016). This could lead the patient to feel a lack of control in their situation resulting in heightened negative experience (Semino et al., 2015). Although there is a pitfall in metaphors used especially when illness experience is concerned, still metaphors are fundamental to both individual and collective experience. As such, they must be further interrogated because they can reveal something about illness experience that we don't already know.

Metaphor, Thought, and Ideology

As both cultural entities and culturally loaded linguistic phenomena (Kovecses, 2003), metaphors are not only political, but they are also associated with issues of power, hegemony,

and ideology. As Dutta (2008) notes, "those who have access to power also determine the stories that circulate within the discursive space of the culture" (p. 111). For example, the dominance of the narratives and metaphors of biomedicine can be argued to privilege those who understand them, and ideas associated with them such as the mechanical concept of the body, self-reliance, individualism, marginalizing and excluding alternative perspectives of health and healing (Dutta, 2008). In *Writing Science: Literacy and Discursive Power,* Halliday and Martin (1993), for example, describe how the language of science, "sets apart those who understand it and shields them from those who do not" (p. 21). Obliviously, this results in a cultural divide between health professionals and lay worlds, and where illness is concerned this can be problematic.

As a socially motivated phenomenon, different metaphors may have different ideological loadings (Fairclough,1995b). And when we see the world through the lens of a particular metaphor, it then forms the basis of our action and ideology. Understanding this power of metaphor is essential as people can interpret social reality in accordance with their ideology. Although the interpretation is one of the many possibilities, dominant groups may take advantage of their social resources and make their metaphor the dominant one. Acceptance of these metaphors means the approval of their construction power. And when a particular metaphor is accepted by more people, it becomes social cognition. Lakoff and Turner (1989) forewarned us when they stated that the metaphors we rely on constantly, unconsciously, and automatically is so much part of us that they cannot be easily resisted, in large measure because they are barely even noticed. We don't always notice these metaphors because they have become part of our ideology. That is, we live by them without even noticing them. I. this way, controlling metaphors maintain hegemony. Where health communication is concerned, careful consideration needs to be given to what meaning people make of the metaphors and narratives used, and how health

information is framed for a particular audience. A move toward new metaphors, however, is still possible through achieving recognition for the power and resisting and recreating them, a goal which this dissertation seeks to achieve.

Psychiatric Discourse, Metaphors, and Disability Studies

Medical accounts of dementia and the language used to describe the disease tend to evoke frightening thoughts and images. Representations of dementia in the media also tend to focus on the extremes of the disease, making dementia freakish, something that happens to "them" rather than "us" (Zeilig, 2014). According to the Online Etymology Dictionary, the word dementia comes from the Latin word *demens* which means "out of mind or crazy." Worldwide, it is estimated that 44.4 million people live with AD and that number is expected to increase to 135. 5 million by 2050 (Prince, Guerchet & Prina, 2013). That is a lot of people to be unjustly labeled as crazy. The ethical implication of this is that once a person is being diagnosed or labeled as having mental problems, this label carries with it an entire set of values. In the case of a neuro-cognitive disability as in AD, this use of label automatically becomes a comprehensive reason for individuals to be regarded as unreliable or lacking ethos. The label dementia self explains the ethos problem and provides a framework in which their unreliability makes sense to a presumably neurotypical audience/readership. As Prendergast (2003) accurately explains, a diagnosis as mentally ill "necessarily supplants one position as rhetor" (p. 191). Those with mental disabilities exist in what Prendergast calls a "rhetorical black hole" (p. 198). We speak, she claims, "from positions that are assumed to be subhuman, even nonhuman; and therefore, when we speak, our words go unheeded" (p. 198). In concrete terms, what Prendergast (2003) means is that the failure to make sense, as measured against and by those with "normal" minds, means a loss of personhood or self-identity.

Speaking of mental illness, Price (2011) writes that mentally disabled people are "presumed not to be competent, nor understandable, nor valuable, nor whole" (p. 26). Molloy (2015) discovered that participants in her study reported nostalgic regard for loss of credibility due to mental health conditions. Uthappa (2017) writes that the challenge to a rhetors credibility begins the minute the person reveals his/her mental condition. When these rhetoricians frame mental disability as a rhetorical problem, they do so in large part to take an unstated assumption out of the shadows. The observation and concern that neurocognitive disability is a rhetorical problem is not only a concern for individuals who have been labeled as such; it is also an issue for the field of rhetoric, which so far has devoted little attention to the issue of neurocognitive disability.

Lunsford (2005) warns us that we must not take for granted terms like handicapped or differently abled within our own scholarship (p. 330). These words, claim Lunsford, create realities thus making it useful that we pay attention to them (p. 330). As such, she argues that we need to complicate these terms within ourselves and as a field so that we not only are aware of the implications of those words but become sensitive to their uses. I take this statement to apply to metaphors that we use to talk about AD as well. The work done by Kershbaum (2014) on recognizing differences is also useful in the discussion of how to make disability more visible especially in institutions of higher learning. Her ethical attention to the changing dynamics of the self-witnessed and experienced by students in writing classrooms—especially those in first year contexts—impressively captures the following core tenet often shared by scholars in this field: "when people write and read, they wrestle with not just texts but also selves" (p. 67) is particularly relevant to the argument made in this dissertation. Doing so can help us understand and ask proper questions about "how people are different from one another and what those

differences means" (Kershbaum, 2014, p. 67). M. Remi Yergeau's (2018) work on

neurodiversity is also applicable here. In their book *Authoring Autism: On Rhetoric and*

Neurological Queerness, they point out that both theories of autism and theories of rhetoric,

"privilege restrictive notions of what it means to interact and interrelate" (p. 12). For Yergeau,

the solution, is not just to pick out a few autistic people to single out as effective rhetors, but to

disrupt, to queer, what we mean by rhetoric (by autism) in the first place. Instead of excluding

autistic people from rhetoric, Yergeau asks, what if we consider the generative potential of a

rhetoric that embraces the non-symbolic, bodily material? What if we consider the rhetorical

potential of "awkward gestures, crip time, dysfluency, obsession and perseveration" (p. 68)?

Failure to question the language we use surrounding disability, argues Lunsford (2005),

would slip us back into "hegemonic unawareness" (p. 330) that leads to taking for granted the

terms and labels we apply to people we perceive as disabled. The key is, according to Lunsford

(2005), we "cannot stop questioning authority" (p. 332), which serves as critical advice to follow

when exploring not only issues of disability in general, but also issues of neuro-cognitive

disability as in Alzheimer related dementia.

Paying attention to portrayals of disability metaphors thus become critical not only

because representation matters but because disability language has long been used to exclude and

demean marginalized groups everywhere even in rhetoric and writing classroom. Furthermore,

failure to include an entire category of people with mental disability like those with AD is not

only unethical, but it creates an incomplete understanding and picture of the diversity of

communication practices both in academic and non-academic cultures particularly in the rhetoric

and writing classroom. In the next section of this chapter, I will explain why Rhetoric and

Writing Studies must be involve in discussion and research about health issues.

Public Health, Alzheimer's Disease and Rhetoric and Writing Studies

Public health is an umbrella term used to describe the various ways that stakeholders communicate about and respond to issues of health that affect the entire population. A large part of the public health mission is promoting healthcare equity, quality, and accessibility (CDC foundation.org). As a discipline, Rhetoric and Writing Studies (including the overlapping field of rhetoric of Health and Medicine) can play a major role in championing the public health effort. In their paper *The Rhetoric of Public Health for RHM Scholarship and Beyond*, Malkowski & Meloncon (2019) accurately state that, "with increased access to and speed of information due to Internet and mobile technologies, an increased exigency exists to understand more fully the persuasive dimensions and capabilities of communication practices related to public health" (p. iv).

What about the academic classroom? Does the study of AD matter in a Rhetoric and Writing classroom? Of course, it does. As Matalene (1989) observed in her book, *Worlds of Writing: Teaching and Learning in Discourse Communities of Work*, rhetoric and composition specialists in university English departments have increasingly recognized the importance of studying all uses of language not just literary uses, of offering direction and insights to all users of English not just to freshmen and poets and literary critics, of building better bridges between the academy and the public, of learning and teaching in the many worlds of writing other than their own. A key point to remember is that, as medical rhetorician Reynold (2008) aptly reminds us, even if we think we are not personally affected by a mental disorder like AD, we have a family member, friend, colleague, student (p. 150) who is affected. This is where Rhetoric and Disability studies fit in. Rhetoric writes Dolmage (2014) "needs disability studies as a reminder to pay critical and careful attention to the body. Disability studies need rhetoric as a reminder to

better understand and negotiate the way that discourse represents and impacts the experience of disability" (p. 3). Here the critical contribution of Dolmage's (2014) work on Disability Rhetoric particularly the concept of *métis* reading which I will employ in this study is certainly powerful in shifting and creating generative possibilities that disability theory has for rethinking the norms that our disciplines have been built on as well as a fruitful lens to look and trace prevailing attitudes and language use toward disability. Dolmage (2014) called *métis* the sort of reading in the way that is cunning and tactical, looking for points throughout the rhetorical tradition of rhetoric in which mental disability may have been imagined, even implicitly.

Cultural Framing of Dementia and the Diagnostic and Statistical Manual of Mental Disorders

The cultural framing of dementia in both public and scientific discourse in the Western culture no doubt has resulted in a putative understanding of dementia and AD as something that is deadly and incredibly frightening. But how does that ideology start in the place? In order to answer that question, it is imperative that we understand the ways that psychiatric discourse itself facilitates this thinking. *The Diagnostic and Statistical Manual of Mental Disorders* (DSM), commonly known as the "Psychiatry Bible" because it guides all psychiatry assessment, holds enormous power over a person's life. When questions about a defendant's mental capacities, internal states, or cognitive abilities are raised in the judicial system, the DSM manual is what experts will refer to. The DSM, remarked psychiatrist Frances (2013):

> determines all sorts of important things that have an enormous impact on people's lives—like who is considered well and who is sick; what treatment is offered; who pays for it; who gets disability benefits; who gets to be hired for a job, can adopt a child, or pilot a plane, or qualifies for health insurance; whether a murderer is a criminal or a mental patient; what should be the damages awarded in a lawsuit; and much, much more (p. xii).

As a powerful tool, the DSM is often considered a "necessary evil" as it can both encourage (through labeling) and discourage (through normalizing) prejudice and discrimination. In clinical settings, mental health professionals rely on diagnostic labels to classify individuals for both treatment and research purposes. This allows them to assume that all members of a group are generally homogeneous in the underlying nature of illness, regardless of whether there is some variability in the presentation of symptoms or circumstances surrounding illness onset. In other words, diagnostic labels help health professionals distinguish patient groups by a set of definable boundaries (APA, 2000). Diagnostic labelling in clinical settings serves two purposes. The first is, it provides an efficient way for clinicians and researchers alike to understand a large amount of information (Frances, et. al, 1990). This method also allows for convenient means of describing patients including presentation of symptoms as well as expected course and prognosis. Secondly, diagnostic labels may suggest etiology as well as point the way toward specific interventions that may prevent the consequences of the condition being diagnosed (Corrigan, 2007). Yet, despite clear benefits of diagnostic labels, such labels often serve as cues to signal stereotypes and stigma.

The negative impacts of labeling appear to arise through two social psychological processes. First, when an individual is diagnosed with a neuropsychiatric disorder, cultural ideas associated with those with mental illness (e.g., demented, dangerous) become personally relevant and foster negative feelings of the self. Second, these personal cultural meanings transform into expectations that others will reject the individual, and these expectations will then trigger defensive behavior aimed at preventing that rejection (Link, 1987; Link, et. al., 1989). The stigma associated with labeling does not only affect the individual affected with the disease, but it also tends to spread and extend to the person's close connections (Goffman, 1963).

When dementia is considered part of a natural aging process (as in Malaysia and other nonwestern cultures), rather than a pathological condition, part of the stigma associated with it may include the notion that the condition is untreatable. This can lead the individual affected and his/her family members to believe that medical intervention is not necessary. Such belief will also limit the individual's access to useful resources. In certain instances, dementia diagnosis is used to exclude individuals from receiving some form of health care benefit. Consequently, the inability and failure to obtain treatment reinforces patterns of low self-esteem, isolation, and hopelessness (Graham et al., 2003). The latest effort to replace the term dementia with major and minor neurocognitive disorders from DSM-5 says a lot about how egregious the impact of labels is on individual mental health. Different cultural understanding can add complicity to this already murky situation. Already the diagnostic guidelines have been heavily criticized as having a fundamentally European American outlook. This is problematic because it represents a myopic view of mental health. Also, these are perfect recipes for misinterpretation and misrepresentation and add to the suffering and disability of those who are diagnosed with AD.

The brief criticism of the DSM presented above is only the tip of the iceberg, but it merits our attention because it exposes not only the rhetorical nature of psychiatry and the dubious agendas of the rhetors who compose its key texts, but beyond that, it highlights the power of language in disease representation. And these linguistic choices which are usually metaphorical in nature and have a direct effect upon the way in which ill people deal with their condition and how the public views the condition. I mention the DSM here to help us understand how language is used to construct reality albeit a distorted reality in the case of AD. Nonetheless, the medical metaphor used in the DSM to talk about dementia is influential in shaping public understanding of dementia. These metaphors and the stories that they animate become subconsciously ingested

and inform how we feel about dementia and how we interact with people with dementia. Metaphors claimed (Zeilig, 2014) "have dual relevance when considering dementia because they innate to linguistic expression, and they also influence the ways in which our thoughts are patterned" (p. 265). Rhetorical examination does become necessary. Understanding the wider stories that condition our responses toward those with dementia is one way of ensuring that negative attitudes and practices are questioned rather than accepted. Past research in Rhetoric and Disability studies have indicated that rhetorical theory has not adequately incorporated neuro-cognitively disabled people into its theories of what it means to be persuasive rhetors.

Disability Studies and Metaphor

The use of disability as metaphor is well recognized. Susan Sontag's (1978) treatise on the rhetoric of cancer, *Illness as Metaphor* attests to the power of language to influence how people perceive and describe illness and disability. While undergoing treatment for cancer in 1978, Sontag lamented that unlike other maladies, cancer was viewed as a unique and highly symbolic disease, often accompanied by rhetoric that compared cancer to an invading army. This discourse she claims resulted in a specific kind of victim blaming, and many patients, feeling personally responsible or weak in some ways, asked themselves, "why me?" – as if some personal failing had brought this punishment to them. Instead of cancer simply existing as a basic malfunction of the body, the rhetoric of cancer caused people to internalize the metaphors surrounding disability. People recovering from cancer then had to deal not only with the disease itself but with all its social and emotional entanglements. Here I argue that the same situation applies to AD.

The language we choose to describe and talk about illness is powerful. As Gibbon (1999) writes, "[M]etaphor is always significant" because "when we use language, we make choices and

choices are not always innocent, but determined by belief systems which underlie them" (p. 3).

These belief systems (or ideologies) provide justification for what people do and how they

represent what they do in language. Paying attention to portrayals of disability metaphor thus

become critical not only because representation matters but because the language of disability

has long been used to exclude and demean marginalized groups everywhere even in the rhetoric

and writing classroom. We cannot live without metaphors, but we can certainly pay attention to

which ones we choose and how they sculpt our worldview. By being aware of the metaphors we

use, we can act upon and expand or even change the frame of problem setting. This can be

achieved through what Schön (1979) call "generative metaphors" (p. 255). A generative

metaphor contends Hansen (2018), is a metaphor that allows for new ways of thinking about a

problem or topic and for restructuring the frames for problem setting.

Moving Toward a New Metaphor

One of the goals of this dissertation is to argue that while the medical community root's

metaphors of control (e.g., the much-used military metaphor of battle or war) still dominate

public imagination about AD, counter-metaphors can serve as a tool to empower and resist such

notions. After all, many patients or individuals may prefer not to view their illness as battle or

war. Indeed, it seems strange that the language of healing remains so interwoven with the

language of warfare, especially in the era of chronic disease like AD, where the condition can

only be controlled and managed, not eradicated or annihilated. Examining the metaphors

Alzheimer patients construct and use, rather than those constructed for them by the media or the

medical community, claimed (Radley, 1993, p. 121), "reconstitutes the patient as a subject; that

is as someone who has the sense of power to signify about his or her condition."

In particular, studying metaphor in situ thus becomes necessary as it can address the need to center the disabled experience (Linton, 2006). Instead of looking at disability as a signifier, I draw on Brueggemann's (2009) view of disability as a space for critical insight that opens up a range of new rhetorical possibilities and practices as it pushes the field of Rhetoric and Writing Studies as well as the subfield of Rhetoric of Health and Medicine to rethink their normative assumptions and histories. Building on the foundational work that has been laid out by Beresford (2000), Brueggemann (2009), Dolmage (2014), Prendergast (2003), and Price (2010), I seek the stories of what I term people with neuro-cognitive disability in online spaces–specifically blogs to understand how their disability can be regarded as more than an ethos problem, and can be seen as critical knowledge that creates new terministic screens Burke (1965) and influences how the public and individuals affected by the disease see themselves. As rhetoric and writing studies expands its writing locations, modalities, and practices within its purview of study, in this dissertation, I push the field to expand the people it recognizes as part of the discipline by recognizing their stories as an important source of new knowledge of meaning making about a particular illness, experiences or diseases. What I hope to demonstrate in this dissertation is that, when Rhetoric and Writing Studies interrogates and critiques the medical model of neurocognitive disability and is open to other models, we are bound to find examples of neurocognitively disabled people like Alzheimer's patient as skilled, reflective, and passionate rhetors. More importantly, I intend to demonstrate how the linguistic metaphor we use in talking about illness can be destructive to the people affected by the illness. The medical model continues to dominate public thinking and imagination about illnesses and diseases in a negative manner. By studying blogs produced by people with AD, we can learn from these authors how to create new metaphors that are more life affirming and meaningful. Further, I will demonstrate

how the use of metaphors, while sometimes harmful and counterproductive, patients have a choice to recreate new metaphors and alternative stories to reclaim and recreate their new identities.

Failure to represent positive characteristics of the roles occupied by people considered to be disabled can result in minimal expectations about them as colleagues, neighbors, and members of their communities. As Wilson (2000) explains, the legacy of discrimination resonates in the metaphor. Unless the roots of exclusionary disabling metaphorical language are examined, new and more positive metaphorical concepts will be eclipsed by or tangled in them. Inclusion of people who are different from us requires the recognition of and intentionally conscious participation in meaning making as a social process, characterized by on-going questioning and flux. Rhetoricians in rhetoric and writing studies have significant opportunities and responsibilities to create inclusive everyday experience through language.

A wealth of studies from different fields of studies have been done to analyze illness-related discourse from metaphorical perspective (see e.g., Camus, 2009; George, 2010; Gallagher, Zimmerman, 2017a & 2017b; Castaño, 2020). Studying illness narratives and metaphors from rhetoric and writing studies can provide a richer understanding of how knowledge is created, codified, shared, revised, contested, and enacted. Rhetorical criticism and rhetorical analysis, which form the foundation of rhetorical study in the field of rhetoric and writing studies are concerned with more than persuasive language. Rhetorical studies can help us know what language does and how it moves people to action. Rhetorical analysis combined with discourse analysis and critical metaphor analysis—two key approaches that I employ in this dissertation—can also help us identify and expose embedded ideologies in a variety of discourse and situations including AD discourse. In paying attention to the use of metaphors in the rhetoric

of AD, my study hopes to disrupt and alter the social order and lessen the stigma and the continued omission of bodies associated with chronic illness and cognitive disability like AD.

Aging, Alzheimer's Disease and Rhetoric and Writing Studies

In the industrialized West, being able to stay active and vital well into one's seventies or early eighties is not uncommon. The introduction of improved pension systems in all Western capitalist countries coupled with advancement in Western medicine have without a doubt generated a class of elderly that live autonomously often until the end of their lives. As more people live longer, the prevalence of Alzheimer's disease also has skyrocketed. By 2050, the number of Americans living with AD is projected to rise to nearly 13 million (Alzheimer.org). Cultural representations of aging, whether subtle or blatant, have real-word impacts on individuals. They shape the way individuals think and imagine the course of their lives as well as the ways they enact and experience aging (Thane, 2005; Cruikshank, 2009). This is especially true with terminal illnesses like AD. When the only available representations of aging crushingly suggest that later life is primarily about body failure and the ever shrinking social, spiritual, intellectual, and physical body decline, it becomes difficult to imagine old age in any better terms. As modern medicine flourished and the meaning of old age was reduced to biomedical terms, the medical and cultural battle against aging is growing stronger than ever. As Cole (1992) writes, "Americans have come to view aging not as a fated aspect of our individual and social existence but as one of life's problems to be solved through willpower, aided by science, technology, and expertise" (p. xxii). In other words, in today's capitalist America, the role of old people, notes age studies scholar Cruikshank (2009) is to be sick, providing massive revenues for the medical-industrial complex (p. 38-42). This declining narrative of old age is then produced and reproduced everywhere making it the new normal to think about old age

(Gullette, 1997). What is discerning about this whole issue of old age and decline is that literate acts are fully implicated in the decline narrative of aging, both in the way literacy as a condition and as a set of practice is represented in age-based terms as well as in the way literate activity is experienced by people who age. Notably, as with seemingly every aspect of later life (Bowen, 2012), literacies are also read through the lens of an aging body.

As new literacy technologies proliferate alongside the growing population of older adults, researchers and scholars argue for the (Bowen, 2012), "need to include considerations of old age and aging in their in their agendas—not only because senior faculty need to be prepared to navigate literacy scapes but also because literacy must be understood from a lifelong perspective" (p. 3). Indeed, if we recognize that literate activity is "nothing less than ways of being in the world, forms of life" as articulated by (Prior & Shipka, 2003, p. 181), it makes sense to pay attention to how ways of being shift and adapt over the course of a lifetime, how they are experienced bodily and materially, and how they interact with age ideology. Hence, an approach to literacy that is "agewise" (Gullette, 1997) seems relevant to this dissertation as it can aid in resisting and countering reductive ideas about what literacy—and old age—can mean in the age of technology.

Configuring aging as chiefly a body problem, also ignores an opportunity to examine how bodies actually participate in the lives of older people. Surely there is more to later life than body problems. Further, this dissertation seeks to direct attention to the emergence and perpetuation of ideologies that create that system of oppression in the first place, even as they identify opportunities for resistance to, appropriation of, or confirmation of dominant ideologies through literate acts.

Although scholars in both age studies and writing studies are copiously aware that the rhetorics that contribute to the creation of oppression as well as opportunities for change are all located in the material world, still it remains too easy to disembody studies of literacy. Even in everyday experience, our own bodies, explains Bowen (2012), can continue to remain strangers to us, ever fading into the margin of awareness. Part of the reason we so easily lose sight of physical bodies, notes Bowen (2012) "is that the postmodernist rejection of the mind/body split brings other problematic binaries that, once again, relegate real, live bodies to the margin" (p. 17). Similarly, Selzer (1999) in his introductory essay for *Rhetorical Bodies* observes that, in rhetorical studies following the expansion of social constructionism, "Things in themselves…. are sometimes being reduced to a function of language; genes, genders, jeans, and genetic have all be reconceived recently through the prism of language. Words have been mattering more than matter." The result, he adds, is a failure of a field dedicated to understanding literate acts within situated contexts to actually articulate "the relationship of rhetorical events to the material world that sustains and produces them" (p. 4). Critiquing the lack of attention to body Fleckenstein (1999) writes, "In sacrificing bodies to some illusion of either transcendent truth or culturally constituted textuality, we cut ourselves adrift from any organic anchoring in the material reality of flesh. She further adds that we need an embodied discourse, one that interprets the body as neither a passive tabula rasa on which meanings are inscribed nor an inescapable animal that must be subdued before pure knowing can be achieved" (p. 281).

To resist the beliefs that certain bodily functions or actions can predict literate potential, literacy researchers, argues Bowen (2012), "cannot overlook the centrality of the body's role in literacy. A dismissal of the lived body in literacy and writing, she, further contents would not only fail to address the body as a site of power struggle but doing so might actually contribute to

further subjugation of marginalized identities" (p. 17). Marvin (1994) points out that, when we ignore the moving breathing body, it becomes easy to use the physical body discriminatorily in our scholarships such as suppressing it from discussions of literacy among privileged classes of readers and writers (pp. 130-131).

Bodies certainly matter, including in old age. The question becomes, how can we bring the body back as an important element of literate practice? Though literacy cannot be taught or practiced without bodies, according to Marvin (1994), bodies "have rarely been considered as a relevant dimension of literacy theory" (p. 129). Even popular and specialist notions of literacy conceive of the human body as physically and socially detached from literate practice. To direct attention to the importance of bodies, some scholars of literacy and writing have taken up the body as a central object of research on literacy and pedagogy by reading it as a site of literacy and learning. Others look to examinations of the long history of bodies in pedagogical contexts (see e.g., Hawhee, 2004). Yet some others look to studies of young children and the political implications of disciplining their literate bodies through language in school (see e.g., Luke, 1992). In an effort to refocus our attention to the importance of bodies and bringing back the centrality of the body in literacy and in our research, I look to bodies of Alzheimer patients in order to capture their embodied experience with AD. This study is very much in line with Grosz's (1994) assertion that our research should place the "body in direct relations with the flows and particles of other bodies and things, as a way to understand how the body experiences health and illness individually and/or within larger systems" (p. 168).

Central to all of these studies is the desire to explore the relationship between ageing, illness, and disability. In particular, I am interested in exploring the age-based stigma of and against people with dementia. Past research suggests that people with late-onset AD experience

greater amounts of stigma due to the 'double stigma' of being an older adult and having

Alzheimer's disease (Nolan et al., 2006). Alternatively, Chaston (2010) argues that people with

early-onset AD may be more predisposed to stigma than people with late-onset AD. The

conflicting hypotheses around age-based stigma allude to differences in public perceptions and

expectations. The conflicting view of how stigma is perceived between early-onset and late-onset

AD needs further exploration. In problematizing and refocusing our attention to the body through

the study of the Alzheimer's body, I hope to contribute to the conversation on aging and age

studies and hopefully to the developing theories of literacy and the body within the field of

rhetoric and writing studies as well as the field of rhetoric of health and medicine.

Embodied Writing, Metaphors and Rhetoric and Writing Studies

For anyone who is ill, the telling of one's illness story is one way to piece together the

disrupted pieces of one's life experience. Embodiment therefore is an essential part of the

perceptual and cognitive processes by which we make sense of our experiences in the world

(Gibbs, 2005). And embodied writing seeks to relay the living experience of the body from the

point of view of the lived body, Leib rather than Körper Husserl's (1989) sense. Metaphors, by

establishing correspondences between different entities, become a vehicle for understanding this

feeling, and "invite people to understand one thing in terms of the other" (Steen, 2008, p. 213).

This malleability puts metaphor in a unique position as a linguistic vehicle to achieve a variety of

communicative purposes. It can be argued that narratives are extended metaphors. An extended

metaphors is a literary device that writers use to break down complex ideas or compares

unrelated objects in more details using different subjects, ideas, images, or situations so that the

audience can comprehend the complex ideas in simpler and more compelling terms. Extended

metaphors are important because they help readers make complex connection with your story in

addition to giving readers a thought-provoking way to think about something. Understanding

metaphors can help us analyze narratives, and narrative analysis can help us reveal underlying

metaphors. Until now, the rhetorical and communicative functions of metaphorical language in

Alzheimer disease discourse have remained understudied in rhetoric and writing study, therefore,

my dissertation is a step forward toward the study of metaphors in creation of meaning in illness

experience. By studying metaphors in illness narratives, rhetoric and writing studies can benefit

from the powerful communicative function of metaphors in conveying logos and pathos and in

establishing a persuasive appeal in a range of academic writings.

In thinking about the relationship between texts, thought, words and ideas and the

experience of illness, I think Dolmage (2012), in *Writing against Normal* is fairly accurate in his

assessment that we in the field of composition and rhetoric, "have not acknowledged that we

have a body, bodies: we cannot admit that our prevailing metaphors and tropes should be read

across the body, or that our work has material, corporeal bases, effects and affects" (p. 2).

Knoblauch (2012) suggests that we need embodied knowledge that is knowledge that is clearly

connected to the body. Embodied knowledge claim Knoblauch (2012) is "knowledge that begins

with bodily response—or what we might call [gut reactions]" p. 54). Characterizing the

embodied concept, Franklin (2003) writes, "As I listen to someone's powerful story, the hair on

my arms stands up. When I am held captive in a meeting listening to the droning of endless

cover stories, I feel a deadening tension in my lower back" (p. 18). Sarah Ahmed (2004) further

reflects this embodied concept by writing that "knowledge cannot be separated from the bodily

world of feeling, and sensation; knowledge is bound up with what makes us sweat, shudder,

tremble, all those feelings that are crucially felt on the bodily surface, the skin surface where we

touched and are touched by the world" (p. 17). A question that we scholars in Rhetoric and

42

Writing Studies should reflect on is what does this conceptualization means for bodies like AD?

Like Dolmage (2012), I argue that ignoring the body has serious consequences. As Dolmage (2012) accurately captures what I have in mind, that is when we compose media, we must also—always—compose embodiment. And that we need to be careful about which body we conceptualize (p. 2).

What I hope to be able to achieve with my current study is to argue that we can learn from the writing of early onset AD patients. This entails recognizing and paying attention more to writing that not only affirms the body but that affirms all bodies. This also means questioning our assumption about bodily norms. Norms as Dolmage (2012) describes them can be seen as either passive or active. Recognizing and paying attention to bodies also means scrutinizing how we filter our norms through language use. Disability theories Lennard Davis (2002) has written that "language usage, which is as much as physical function as any other somatic, has become subject to an enforcement of normalcy" (p. 100). In other words what Davis is saying is that "An economy of the body [dictates] our own metaphors about language and knowledge," these metaphors in turn "support the illusion of the ideal body" (p. 103). A writing pedagogy and curriculum that ignores the body might actually limit our ability to make meaning. Perhaps the argument that I am interested to make is that in order to bring back the body centrality to our teaching and discourse, like Dolmage (2012) suggests, we need to examine the body, the body-image, the thinking of the body—not only as implied, normative inversions of a range of Other, wrong bodies and not as a default ideal. As Dolmage (2012) aptly suggests, "To [compose]the body is to examine the shadows and scissions that differentially constitute embodiment. Likewise, if we want to truly understand embodied writing, perhaps what we need to most

closely study are not ideal, complete texts, but the messy and recursive process of composing, as we break our ideas apart through language" p. 24).

Metaphors in Rhetoric and Medicine

Medicine claim (Charon, 2001; Montgomery, 1991) is basically about storytelling and interpretation, and narrative, metaphor, and symbol are fundamental tools of the trade. Patients understand their illnesses in a narrative way, that is they see themselves as characters in a life narrative. This reliance on metaphor is partly due to the lack of linguistic expression for effectively conveying body feelings (Lupton, 2012). For example, in his essay, *Othello: An Essay to Illustrate a Method Burke* (1951) sheds light on the roots of medical metaphor in his theory of tragedy. Catharsis, he notes, is derived from the Greek word Katharma. Greek society saw Catharsis, as a sort of medical purification, a cure. By explaining the roots of Catharsis, Burke alludes to the belief of some Greek thinkers that rhetoric was an ambivalent drug that both causes and cures disease. Burke (1969) considers metaphor as "a device for seeing something in terms of something else. It brings out the thisness of a that, or thatness of this" (p. 503). Charron (2006) in *Narrative Medicine: Honoring the Stories of Illness*, writes that metaphor help readers "identify…governing image[s] in a work" and this "often help to orient the reader toward its [the works] figural or figurative meaning" (p. 119). Metaphor, argues Angeli (2012), is one device that the media, the medical world and even individuals use to convey certain meanings of disease, e.g., AIDs as a plague or dementia as a monster. Johnson-Sheehan (1999) suggests that rhetoricians should take "a rhetorical view of metaphor" to understand how people use it (p. 48). They further contend that the meaning of metaphors is created by an "interpreter's prior experiences and belief" (p. 47) and uses contemporary hermeneutics to examine the interpreter's role in metaphor. Elaborating on the nature of contemporary hermeneutics, Johnson-Sheehan

44

(1999) asserts that an interpreter always makes meaning within a context and, therefore, creates a "contextual narrative" while interpreting a metaphor (p. 57). According to Johnson-Sheehan (1999), the contextual narrative contains three stages: identification, invention, and narration. In the identification stage, the interpreter identifies a metaphor within any given narrative, and the interpretation depends on the context in which the interpreter resides. The context also plays a role in invention which is the second stage, in which the interpreter creates a meaning of the narrative that aligns the metaphor with the context overall narrative. Finally, the interpreter understands the metaphor through and with metanarratives that are constructed by human experience. Therefore, according to Johnson-Sheehan (1999), it is the interpreter and the interpreter's context that play a vital role in assigning meaning to a metaphor.

Building off Johnson-Sheehan (1999), Baake (2003) discusses how metaphor functions in and with science. He suggests that words do not have literal meaning: rather, they are assigned meaning based on the context in which they are used. Because the word "metaphor" states Baake (2003) has its roots in the Greek terms epiphor, which loosely translates as "transference" and "locomotion," meaning shifts across term (p. 62). This movement and shifting, suggests that truth cannot be "fixed in language" and instead "must be constantly renegotiated as new metaphors appear (p. 62). Sontag (1989) who wrote about illness and metaphor offers an example of how metaphor plays a strong role in public understanding of illness. She uses two pandemics to show the relationship between illness and metaphor: tuberculosis (TB) and cancer. Sontag (1989) states that cancer is the new TB of 1977, as both diseases were mysterious, feared, and "morally if not literally, contagious" (p. 6), and that TB "was—typologically—cancer" and cancer, like TB, was described "as a process in which the body was consumed" (p. 10). Metaphorically, the diseases differ based on their symptoms and characteristics. TB is a disease

of liquids and "speed up life," it is a disease of time, and the metaphors surrounding the disease reflect the disease characterization (pp. 13-14). Cancer on the other hand, has stages and is slow compared to TB, therefore, metaphorically, cancer is "a disease or pathology of space," as cancer "spreads," "proliferates," and is "diffused" (pp. 14 – 15). What can be deduced from Sontag's (1989) illustration is that metaphors surrounding illness including illness like AD aid the interpreter in understanding how a disease "works," and metaphors continue to be used over time, though contexts in which metaphors are used may change.

Metaphors in Rhetoric of Health and Medicine

Writing in her groundbreaking book, *Health and the Rhetoric of Health and Medicine*, Judy Segal (2005) eloquently reiterated a claim made by a number of scholars – that the metaphor is "the most rhetorical of figures" and citing Kirmayer (1988), argued that "rhetoric uses metaphor to smuggle values into discourses that proclaim itself rational, even-handed, and value-free" (p. 115). Writing in her essay on *Values, Metaphors and Health Policy*, Segal (2005), argues that the outcomes of health-policy debate are constrained in part by biomedical terms and metaphors in which the debate takes place. Her purpose for the essay is not to suggest an exchange of old metaphors for new ones but rather to take up Emily Martin's (1991) call to wake up sleeping metaphors, especially in science. Since Segal's (2005) groundbreaking book, a handful of other rhetoricians in the field of Rhetoric of Health and Medicine have made concerted effort to frame and address healthcare topics and the study of disease and illness through the lens of metaphor.

In Metaphors in *The Rhetoric of Pandemic Flu: Electronic Media Coverage of H1N1 and Swine Flu*, Angeli (2012) uses rhetorical analysis to examine and move toward understanding the metaphors surrounding H1N1 and swine flu. To understand the metaphors connected to the two

pandemics, she created Google Alerts for the terms "H1N1" and "Swine flu" and collected data

using Google Alerts from November 10, 2009, to December 10, 2009. She then examined the

headline and content found in new articles, blogs, and websites from Google Alerts and grouped

the metaphors used in the headlines and content thematically. Her work sheds light on how

metaphors used in electronic media create meaning for health concerns. Metaphors are not only

useful lenses for thinking about the flu, but it also provides a powerful framework to understand

inclusive language.

In *Supercrips* Gutsell and Hulgin (2014), made clear that inclusive language means more

than "politically correct," and it involves more than being inclusive of race and gender.

According to Gutsell and Hulgin (2014), the "supercrips" is a metaphor used to describe people

who have "overcome" their disability. Because this metaphor identifies them as being abnormal

or problematic, the solution is for them to overcome or to fix themselves or to remediate their

condition in order to make it possible to participate in daily activities. A remedy to the problem

Gutsell and Hulgin (2014) argues is to move the conversation forward by offering a definition of

inclusive language that recognizes the full identity of people with disabilities. Their research is a

much-needed summary and reminder that we must be meta-aware of the language we use

because that language can be disempowering or empowering.

Drawing on critical analysis theory, Arduser (2014), examines the use of metaphor by

members of diabetic social networking sites. Most research on metaphors related to disability

and chronic illness have been framed from the perspective of the health care community, the

media, and other "abled entities." Arduser (2014) has shown that metaphors that have attached

themselves to certain diseases have influenced attitudes toward those who experience the

disease. She argues that even though the disease is still framed by the medical community's root

metaphor of "control," the way these counter metaphors are used by this particular community empowers people living with the disease. Because the metaphor used within online diabetes narratives can help uncover the conceptual framework of people living with diabetes, understanding such a patient-generated metaphor can give medical practitioners a clear understanding of the lived experience of the disease, which she said can lead to better patient care. This understanding she claims is constructive to both disability scholars and technical communicators. From a disability studies perspective, paying attention to and understanding counter narratives, claimed Arduser (2014), can help lessen the stigma associated with popular illness and disabilities, while attention to narrative constructed by disabled users moves technical communication closer to meeting the goal of user-centered environments. Beyond basic cognitive consideration, metaphors as we see them are relevant to discourse and culture in health context. Understanding how metaphors are used and their influence in public perceptions of disease and health information thus becomes necessary. Even more important we need to pay attention to the counter narrative as it can help minimize the impact of stigma associated with the disease. One of the proposed goals of this dissertation therefore is to locate a means of using counter-narratives by early-onset AD patients and those who serve as caregivers to reconstruct the ways we understand/relate to AD.

Rhetoric of Mental Health

The growing field of Rhetoric of Health and Medicine (RHM) serves as an umbrella to the studies of the mental health rhetoric research (MHRR). Scholars who focus their studies on mental health also often find themselves engaged in disability studies as there is substantial overlap in both areas. Reynolds (2008) examines the *American Psychological Association's diagnostic manual* and its construction of mental illness, arguing that "clinical diagnosis is a

form of rhetorical definition based on diagnostic criteria used in conjunction with technical

labeling, both of which are social constructions, and as such, are deeply rooted in contexts and

biases" (p. 152-153). Using disability studies as a framework, Chrisman (2008), invites scholars

of rhetoric to engage more in the rhetoric of mental health studies arguing that "mental health

studies do not receive the same attention as other disabilities" (p. 2). By taking up the question of

rhetoric of mental health in her dissertation, Powell (2018) sheds light on the myriad problematic

ways in which mental health is medicalized, stigmatized, shaped, framed, and stereotyped. To

disrupt these harmful stereotypes and stigmas, she argues that "ideological constructions of

mental illness health must shift and change to embrace non-normative ways of being" (p. 207).

Elsa Bonilla-Martin (2017) explores how the way we talk about mental health can have a deep

impact on the lives of people afflicted by the disorder. Uthappa (2017) looked at the impact of

cultural stigmatization of mental disability arguing that "the cultural stigmatization of mental

disability guarantees that the challenge to a speaker's credibility begins the minute she reveals

her condition" (p. 164). Collectively, this robust body of scholarship throughout the literature

review constitutes the foundational texts that inform my dissertation by offering models of how

to effectively use rhetorical lenses to meaningfully engage with health and medical phenomena

in ways that add important insights and richer understanding of mental health issues like AD.

It is widely recognized that language has a direct impact on the behavior and identity of

the individual. Growing up, I am sure we were all familiar with the phrase "Sticks and stones

may break my bones, but words will never hurt me." But our words can and do hurt, in ways we

are not aware and cannot always anticipate. To be called a name claimed Butler (1997) "is one

form of linguistic injury that one learns. Being called a name she further argued is one of the

conditions by which a subject is constituted in language" (p. 2). Althusser (1971) introduced the

term interpellation to explain how ideas are socially constructed and produced, and how these ideas manifest themselves into our identity. For Althusser (1971), the process of interpellation begins when a person is being hailed (like calling them out in the street), and the hailing works best when it functions in an invisible manner unknown to the individual being interpellated. Interpellation argued Althusser works in two ways—through repressive means (force) and ideological means. Either way both these two sources of power provide us with certain attitudes, behaviors, and feelings. This holds true in health and medicine, wherein our prevalent, ever-evolving metaphors of disease have the social power to literally position people and resources in a culture.

Metaphors claimed Segal (2005) operates lavishly in health and medicine. Metaphor is also one means by which biomedicine controls the debate about mental health issues like AD. While framing health issues through metaphor can motivate efforts to deal with the issue, framing or using war metaphors for conditions that may not be fully treatable like AD and cancer may cause more harm than good. The relationship between metaphors, disability studies, and neuro-cognitive disability in the rhetoric of AD remains an untapped region of RHM study. By arguing for an alternative metaphor that invites positive ways to talk and think about AD, I hope to contribute to conversations of mental health in RHM and bring us closer to the concept of universal design in health literacy as well as health communication.

Medicine, Illness Narrative and Self-Representation

Medicine, notes Jurecic (2012), "has become a big business." Once upon a time, it used to be that physicians had time to talk to their patients and know the details of their lives. More doctors today don't have time or inclination to listen to their patient's stories. The examination room claims Frank (1995) silences many individuals who are "wounded not just in body but in

voice" (p. xx). The physician's narrative always revolves around a person's symptoms and diagnosis and the patients are treated as nothing more than clinical notations of symptoms and billing codes. Writing on medical records, Monsted et al., (2011) states:

> These documents have a strong narrative aspect because narratives supply a workable medium for representing knowledge that is time- and context- dependent—and often uncertain or ambiguous as well. They are created to organize, record, and capture practical experience (p. 81).

Similarly, well-known neurologist and author, Sacks (1984) writes on case notes that they

> tell[s] us nothing about the individual and his history…. nothing of the person, the experience of the person as he faces and struggles to survive his disease. There is no 'subject' in a narrow case history… To restore the human subject as the center—the suffering, afflicted, fighting subject—we must deepen case history to a narrative or tale; only then do we have a 'who' as well as a 'what', a real person, a patient, in relation to disease [or disorder]" (p. vii).

The sad state of how healthcare is practiced is staggering. Frank (1995) writes of the patients' loss of voice explaining, "In post-modern times, pressures of clinical practice, including the cost of physician's time and even greater use of technologies, less time is available for patients to speak" (p. 15). In an article about the decline of the doctor–patient relationship, DeVita (1995) writes, "ask just about anybody and you will hear a doctor-patient horror story, a tale that reflects the indignation with which American's have come to view their healers" (p. 63). Arthur Kleinman (1988), in *The Illness Narratives writes,* "the care of chronic illness is not one of the great success stories of contemporary medicine" (pp. 143 of 5441, preface). Kleinman believes that modern medicine is flawed because "one intended outcome of modern medicine is that it does just about everything to drive the practitioner's attention away from the experience of illness … to the alienation of the chronically ill...……" (pp. 135 of 5441).

When patients' stories no longer have a place in the doctor's office, they emerge elsewhere — in memoirs, storybooks, and private journals and with the presence of the Internet,

stories emerge in abundance in social media. Chronic illness narratives thus are a means to reclaim the patient voice, to make sense out of the chaos of life (Charmaz 1990, p. 1161) and virtual support groups whether it is Facebook, blog or twitter to name a few provide the vehicle by which otherwise silent stories, autobiographical narratives, can be expressed as a way to borrow from Goffman (1963) "preserve face" and to manage "potentially spoiled identities" (p. 80). Illness narrative as Charon (2006) aptly puts it is a form of health care that "recognizes suffering, provides comfort, and honors the stories of illness (p. 17)."

Social Media and Blogging as a Way Out

The Internet has made it possible for people to tell their stories in ways that were not possible more than ten years ago. Instead of turning to diaries and personal journals, people are now writing blogs and commenting on discussion boards about their struggles with disease and disabilities. Because of their accessibility and readability, blogs have become one of the most popular mediums for social networking utilized by individuals with chronic disease (Fox & Purcell, 2010). Blogs are websites that contain a series of often updated, reverse-chronologically ordered posts, usually written by single authors (Hookway, 2008). Miller and Pole (2010) call blogs the "quintessential Web 2.0 application" (p. 1514) and credit the user-generated content for rapid growth in health-related content online. Literature on health blogs (see e.g., Sundar et al., 2007), suggests three reasons for why people blog: social connectedness, coping and identity formation. Similarly, an online survey conducted on cancer support groups, also listed three communicative reasons for why people blog: information sharing, personal reflection, and interaction with others (Page, 2013). What remains unknown is, why do early onset Alzheimer bloggers/authors and those who serve as caregivers blog to late onset Alzheimer disease blog? What is the motive behind their social media presence? Could it be that because blogs are less

retrospective than narrative interviews and autobiography, and are usually written in discontinuous, episodic posts, that it may offer those diagnosed with early onset Alzheimer an alternative context in which to express the fluctuating and fragmented voice of the turmoil that they are going through? To find what the answers are to these questions, and to study as well as identify the metaphors that they used to frame and counter-frame their experience living with Alzheimer's disease, in the discussion that follows, I analyze ten blogs written by early onset dementia authors and six blogs written by those who serve as caregivers to late onset dementia patients.

CHAPTER 3

MATERIALS AND METHODS

Rationale for Studying Blogs and Metaphor

I came to this dissertation project with two simple goals in mind. To examine the metaphors that people with early onset Alzheimer's disease used to make sense of their diagnosis and their experiences living with Alzheimer's disease and to explore if those who serve as caregivers to late-stage AD patients share the same metaphors in making sense of their world living and taking care of their loved ones. Prior to doing actual research, I spent about four months (February to May 2021) just observing the walls of blogs written by early onset AD patients and those who served as caregivers. During this period, all I did was take notes of what I observed. One aspect of social media, particularly blogs that I had overlooked until I started my dissertation project was how powerful a platform it is for people to make their voices heard. Social media also affects the way information is accessed and circulated. According to a study conducted by McKinsey Global Institute, almost one in five online hours is spent on social networks particularly through mobile devices (Chui et. al., 2012). Undoubtedly, social networking has not only transformed the way how information is accessed and shared; it has transformed how healthcare is practiced. Past studies (e.g., Kotenko, 2013) indicates that more and more hospitals and medical professionals are embracing and utilizing social media as a means to convey general health information, and sometimes even personalized help. The benefit of using social networks also extends to the public. Consumers in healthcare now have places to have their voices heard. For example, some social networking sites let patients evaluate the care services provided by the hospital that they use. Other social networks sites like PatientsLikeMe

and MedHelp encourage the formation of online communities which allow participants to upload detailed information about their condition and receive information from similar patients.

Blogs, I noted, are one example of a powerful social network platform where individuals can share their experience, voice, sight, and obtain support from friends during their medical journey. DeSalvo (1999) and Hunt (2000) have called writing about one's physical illness the *Wounded Body Narrative* and *Illness Narratives* respectively. Narrative, according to Garro and Mattingly (2000), is a fundamental human way of giving meaning to experience. One of the first blogs that caught my attention was the blog written by Wendy. In her blog she wrote:

> "I started this blog to allow me, in the first instance, to write all my thoughts before they're lost. Luckily the part of my brain that allows me to type hasn't broken yet and I find that easier than talking. I have calendars that take care of the future, but this blog serves as a reminder of what I've done and said in the past – it now serves as my memory. If anyone chooses to follow my ramblings it will serve as a way of raising awareness."

This statement by Wendy caught me by surprise as it spoke boldly of the importance of social media as a way for the blogger to preserve their soon to be gone memory and raise awareness of their disease. In the opening of her blog, Wendy also wrote how her involvement in blogs writing was geared at reminding people that, although she was diagnosed with early onset AD, people like her still have a substantial contribution to make. We she wrote:

> Still have a sense of humor; we still have feelings. I am hoping to "show the reality of trying to cope on a day-to-day basis with the ever-changing environment that dementia throws at those diagnosed with the condition. Living as well as you can with dementia is all about adapting. Adapting to new ways to enable us to live better for longer with dementia. I can type as though dementia never entered, I can type as though dementia never entered my world as that part of my brain has not yet been affected, but that often works against me as people question my diagnosis. All I can say is, live a day in my shoes and I'm sure the reality will dawn. What I want is not sympathy. What I want is simply to raise awareness. I'm now, the proud author of the Sunday Times Best Seller, Somebody I Used to Know, which just goes to show, you should never give up on yourself.

Reading Wendy's blog was an eye-opening moment for me considering that people with dementia are often ignored as thinkers and writers because they are believed to have lost cognitive functioning. What I observed showed otherwise. Reading Wendy's blogs also made me think about what literacy is to a blog author like her, and how her literacy practices and understanding of its purposes might be altered as she changes, both cognitively and as an author. The rise of digital literacy certainly complicates how we understand what literacy is, especially as it relates to people who are cognitively challenged like early onset dementia patients. What I recognized and learned from Wendy' blog was that digital literacy through blog reaps the value of being able to make personal connections that traditional published narrative might not be able to accomplish. As I read Wendy's blog I was also thinking about how older bodies and disabled bodies are marked. The question that came to my mind was: how do bodies function within this complex system of writing? In thinking about writing and the meaning of digital literacy, I was also drawn to Bobby's blog. Bobby was diagnosed with early onset dementia at the age of 54. His mother died from AD. One thing that stood out in my reading of his blogs was how well organized and well thought out his writing was. The narratives that he produced totally blew me off as they contradict assumptions people generally make about those living with AD. A powerful statement in his blog that is difficult to ignore was: "I have Alzheimer's Disease BUT…..., I don't allow it to define who I am." Like Wendy, Bobby's blog was written not to solicit sympathy or pity but to ask for support. What I found unique about Bobby's blog, is that all his blog entries end with "I have Alzheimer's BUT……It DOESN'T Have ME!!!"

Bobby's words are worth reflecting on in terms of his invoking a readership. To me it almost seems that he wrote his blogs expecting others to read them. Which is the case. Something I also noticed in the observation phase of my dissertation that many early onsets blog

writers have very strong advocacy goals for why they blog. Rockie, for example was very

explicit about why he blogged. He wrote:

> So here is my blog. I want people to know my story so it may influence change. If I keep
> quiet no one will know what it is like to hear those words. Look into the abyss and out
> again, upwards. To welcome each day and hope it is good and make it good. Cos one day
> before long it won't be. And then my Jane will be my comforter. Till then listen to me
> and others. And take action to make living better for people with dementia.

It turned out Rockie was not alone in his mission to advocate and create awareness about

the disease. Both Wilma and Bobby shared similar goals for engaging in blog writing, and so did

Lindsay. Lindsay wrote a very powerful statement about the need for people with dementia to

speak about their disease and how their experience can serve as a teachable moment for others as

well for those who have recently been diagnosed. She wrote:

> Recently, when I set out to do a blog of over 200 "famous people" with dementia, I found
> exactly 5 who did something to make a difference. The others kept their diagnosis hidden
> until after their death or care facility placement, when the family announced they had
> been suffering for years. These five individuals promoted dementia awareness, fought for
> legislative changes, wrote a book or song and /or became an Alzheimer's advocate. So, I
> say THANK YOU for being a "Dementia Doer."

In another blog entry Lindsay wrote:

> Why do I write about living with dementia? Through the muzzy, I learned that there is
> more joy and happiness in focusing on others rather than our own illness. With every
> article I write, I pray that God will use my challenges, emotions, and symptoms to teach
> someone in a special way. To provide caregivers some insight on what their loved one
> may be feeling. To encourage a person with dementia that life does not end after
> diagnosis – clutch every moment you can. To increase awareness of the profession and
> challenges of dementia – it starts with confusion and frustration and is so much more than
> memory loss. I find joy in every comment from a caregiver saying how much a post
> helped them relate to their loved one, in every comment from a person with dementia
> saying how much it means to them and with every blog that is shared. As I pray for each
> person who comments about the struggles – I am happy to know I can still make a
> difference.

Lindsay's remark highlights the powerful influence her writing can have in helping others as

well as herself to cope with the burden of her illness. Brandt (2001) writing on the power of

literacy in *Literacy in American Lives* is relevant here, she wrote "what people are able to do with their writing or reading in any time and place — as well as what others do to them with their writing and reading—contribute to their sense of identity, normality, possibility" (p. 11). For Lindsey, Bobby, Wilma, and Rockie, writing not only gives them voices to their struggles and tools for advocacy and awareness about dementia, but writing also contributes to their sense of identity, normality, and possibility.

Alzheimer's disease I observed truly does not discriminate based on skin color, nationality, ethnicity, profession, education, gender, age, or whether one is rich or poor. A diagnosis of dementia at any age is devastating, but diagnosis in younger patients presents a particular challenge. Those recently being diagnosed with dementia therefore are likely to experience a range of emotions. These may include grief, anger, shock, fear, and disbelief. Some may struggle to deal with these emotions, and they may move between emotions as they adjust and make meaning out of their diagnoses. What is also true about terminal illness, especially a terminal illness like dementia, is that it is difficult to put into language the grief, the anger, the shock, fear, the disbelief that came with the diagnosis. Many early onset AD bloggers that were included in this study who were writers before the fact, also struggled to find the language that could represent their frustration as well as their experience living with the disease. Dementia discourse therefore abounds with imaginative tropes such as metaphors. I cannot help but notice how pervasive the use of metaphors was in each of the blogger's narratives. Describing the impact of her diagnosis with early onset AD, MaryAnne wrote about her daughter:

> The disease is a curse that has robbed our happiness as a mom and daughter. When she is
> with me now, our roles are reversed, and she acts like the mom.

MaryAnne was not the only blogger whose narratives were replete with metaphors. Hunter's blog was loaded with metaphors. He described his journey with AD the following way:

> The road can crush you and leave you along the way if you let it. I get bruised and scratched along the way, but I try to deal with it. If the problem is too hard for me to handle, I ignore it. I wear a smile and a skip in my step. I seem to have no worries or care.

Cherry captured what it was like living with Frontotemporal Dementia (a type of early onset AD) as being in a black hole. She wrote:

> When I am in that black hole, while struggling to get back to make sense of something, anything, my reaction is to lash out.

Even the most controversial war metaphor was useful at times to describe the unspeakable grief and pain, and anger that comes with the burden of having to live with Alzheimer's disease. For example, Mabel wrote:

> Every single day, I want to stop fighting to stay as positive as possible for as long as possible and stop fighting to retain as many levels of independence as possible, by developing new strategies and working hard to accommodate my increasing cognitive and other neurological and spinal disability. Sorry also for the war metaphors……... advocacy feels like being at war most days.

Based on my observation, without resorting to metaphor, it would have been very difficult for MaryAnne, Hunter, Cherry, and Mabel to represent their experience adequately. Metaphor, I noticed, gave them that language to conceptualize their experiences. Elaine Scarry (1985) described the move from unspeakable pain to speech as the birth of language. The texts and metaphors and the metaphors in the texts can reveal a writer's general orientation towards the body and self, illness, life, and death. This is what I hope to probe and the rationale for studying metaphors and illness narrative blogs. The methods and materials section that follows describes the process and procedures for my study.

Methodologies and Research Questions

In this section, I discuss the rationale for the methodologies used in this study. I also discuss the participants and procedures, the data collection and the coding and analysis of information collected during this study. The following research questions guided this study:

1. What metaphors are commonly used to characterize Alzheimer's Disease (AD) and how do these metaphors operate in the dominant discourse of illness narratives that includes AD in blogs?

2. Specifically, what can rhetoric and writing studies (RWS) gain through, and contribute to, the study of the narratives and metaphors surrounding Alzheimer's disease, and how are these narratives and metaphors negotiated by the early onset Alzheimer's blog authors as well as caregiver blog authors who serve as caregivers to late onset Alzheimer patients?

3. How might the ideologies of the narratives surrounding disease shed light on how individuals and groups produce knowledge, meanings, understandings, identities, and the courses of action they take about health and illness?

4. What can rhetoricians learn from and contribute to the study of ideologies embedded in AD metaphors and narratives?

The objective of my study was to examine the metaphors that early onset AD patients and those who served as caregivers to late-stage AD patients used to construct and make meaning of their experiences living and coping with AD. To answer the four research questions above, I used a mixed methods design with the intent of mixing quantitative and qualitative data in a single study to develop a richer understanding of the research questions (Creswell, 2003. p. 208). Using mixed methods reflects "the situation today [that] is less quantitative versus qualitative

and more [about] how research practices lie somewhere on a continuum between the two (Creswell, 2003, p.4). Mixed methods also provided room for multiple points of view and varying levels of insights (Creswell, 2003, p. 16). According to Creswell (2003), they are advantages and disadvantages to using a mixed methods approach. The advantages of mixed methods are, they are increasingly familiar to researchers and "can result in well validated and substantiated finding" (p. 217) in a much shorter time period. Secondly, mixed methods may also allow for multiple perspectives within one study or may allow two types of data collection whether of equal or unequal priority to the study (Creswell, 2003, p. 218). On the other hand, this type of research requires more effort and expertise because of the use of different methods for data collection and analysis. In this research, I collected data using observation and analysis of blogs posted online by early onset AD bloggers and those who serve as caregivers to late-stage AD patients.

Ethics and Research in Online Spaces

As the Internet becomes an increasing part of our daily lives, so does its use for health and medical information exchange of all kinds including for sharing illness experiences and gaining social support. Like any other research that involves human subjects, online research comes with many ethical challenges. Even though all the blogs that I included in this study are publicly available online and can be accessed by anyone without permission. Researchers in digital spaces are just as obligated to demonstrate "respect for persons, beneficence, and autonomy" (Banks &Eble, 2007, p. 3) as any researcher. Too often, "digital spaces…. are often referred to as 'virtual,' suggesting 'not real, 'yet we cannot always agree about the ramifications of this real-ness, nor are we clear about what constitute public or private space in environment" (Banks & Eble, 2007, p. 36). As a result, according to (Bank & Eble, 2007), "researchers must

go to great lengths to articulate possible risks to human participants and must justify their

interactions with participants in ways that will reduce these risks as much as possible" (p. 36).

Throughout the research process, the selected blog authors for the study were never far

from my mind. The Institutional Review Board exempt review for conducting research was

obtained before any research or observation were conducted. All participants were identified by

pseudonyms. All information recorded was kept confidential in a secured word document files.

Rationale for Theoretical Framework

This mixed methods study was framed through multiple theoretical frameworks. My

methods were foremost emergent; this means they began with observations of blog activities.

Charmaz (2008) explains that emergent methods are inductive, contingent, or dynamic

phenomena" (p. 155). Emergent methodologies are particularly appropriate for studying topics

like mine where little research has been done. I choose emergent methodologies because of the

value they place on participants and on the data. This means that in my study, the blog authors

were truly the experts on their online communities and the rhetorical framing of their

experiences. My job was to report and provide analysis based on their writings. By valuing the

insights of the blog authors and analyzing the online narratives that they write, I aligned my

methods with the politics of the disability rights movement, of which the motto is "nothing about

us without us" and with approaches in rhetoric, writing studies, and literacy studies that engage

with the situated knowledge of underrepresented groups (Clifton, Long & Roen, 2013).

Rhetorical Analysis

Where appropriate, I utilized rhetorical analysis to explain and draw upon data salient to

the disciplinary conversation taking place in the narratives of the blogs that I analyzed. I also

drew from different rhetorical theories like Bakhtin's (1981) theory of dialogism and the creation

of meaning, Burke's (1966) theory of symbolic action, and Althusser (1971) theory of ideology

to name a few. Bakhtin's theory (1981) of dialogism for example, was crucial in my research to

understand the relationships between metaphors. Dialogism is itself based on a metaphor, that of

a conversation, but goes beyond the ordinary everyday usage of the word 'dialogue,' although

Bakhtin himself did not use the expression explicitly. Dialogism emphasizes the importance of

relationships and intersubjectivity for establishing meaning (Holquist, 2002). From Bakhtin's

point of view, it is the relationship between things that generate meaning. The 'things' in

question, whether they may be individual human talking, a person reading a text or institutions

interacting in some ways, derive their meaning from the relations, the intersubjectivities, that

exist between them.

<div align="center">**Critical Metaphor Analysis (CMA)**</div>

In addition to using emergent theory and grounded theory as well as drawing from

rhetorical theory where appropriate, I also adopted the critical metaphor analysis framework

(Cameron & Low, 1999 & Charteris-Black, 2004). Cameron and Low (1999) describe 3 stages in

the methodology of metaphor analysis:

> The methodology of metaphor analysis typically proceeds by collecting examples of linguistic metaphors used to talk about the topic…. generalizing from them to the conceptual metaphors that exemplify and using the results to understandings or thought patterns which construct or constrain people's beliefs and actions. (p. 80).

Coincidently, these steps are very similar to Fairclough's (1995a, p. 6) three stages of

identification, interpretation and explanation that are in turn, based on Halliday's (1985)

functional linguistics and comprise of critical discourse analysis (CDA). That said, what made

critical metaphor analysis (CMA) an ideal framework of analysis for this study was that it

combines critical discourse analysis, corpus linguistics, pragmatics, and cognitive linguistics to

explore the implicit speaker intentions and the covert power relations within the social and

<div align="center">63</div>

cultural context. As an approach to metaphor analysis, the main objective of the CMA, argued

(Charteris-Black, 2004, p. 34) is to "reveal the covert (and possibly)" the unconscious intentions

of the language users. Moreover, CMA does not deny the conceptual nature of metaphor, rather,

it is built upon the very claim of conceptual metaphor theory (CMT) that metaphor governs

cognitive thinking. Additionally, this approach to metaphor brings metaphor back into the

traditional view of metaphor except now it accounts for the semantic view and context of

metaphor use. Charteris-Black (2004) argues that metaphor analysis must combine the linguistic

component, the cognitive component as well as the pragmatic criteria since any one component

itself is not sufficient to give a comprehensive explanation of metaphoric expressions. I argue

that cognitive semantics and CMA, can serve as important linguistic contributions towards a

theory of rhetoric and persuasion in health communication and health literacy as well as more

generally within rhetoric and composition as they illustrate how rhetoric is used for the purpose

of legitimization of ideas and thought. By integrating CDA into CMA, CMA advances the

theoretical framework of metaphor analysis by providing researchers with the tool for the study

of meaning making within a virtual social support group that was established online by early

onset AD blog authors as well as those who serve as caregivers to late-stage AD. The virtual

support groups are spaces in which stories collide not only because participants' need to tell the

stories and be heard but also because they need to hear another's stories as a means of validating

their own. Besides using the virtual social support group to share their stories, participants must

also accept that their stories often may be disrupted by the stories of others. Santos (2011, p. 1)

argues that "digital technologies awake a desire for something that is missing in the atomistic

Modern life: they rekindle a desire for others." The CDA component of CMA is a tool by which

to examine the space where this disruption of the narratives occurs. For the participants selected

in this study, the disruption is the AD that the participants are diagnosed with. CMA also has similar goals with CDA and disability studies in that it focuses on altering the social order which my study hoped to achieve as the overarching goal.

Disability Studies Theories

This study was also framed through the lenses of disability studies theory. I adopt Dolmage's (2014) disability rhetoric theory particularly the concept of *metis* which Dolmage defines as the rhetorical art of cunning, the use of embodied strategies to transform rhetorical situations. In particular, Dolmage's (2006) argument that "all rhetoric is embodied" (p. 2) is particularly relevant to my study and analysis on metaphors. Like Dolmage, I used disability theory to expose the tropes and stereotypes about disability that shape the stories that our culture continues to hold on to. I also adopted a critical disability theory framework to argue about how language influences the concept of disability and status of disabled people. Like Schalk (2013), and May & Ferri (2005), I contend that the use of disability metaphors promotes an ideology of impairment as a negative form of embodiment (para. 7) and my own emphasis othering. And like Vidali (2010), I argue that it is important for the theory of metaphor to include not just disability but diverse forms of disability.

The New London Group Theory of Multiliteracies (NLG) and New Literacies Theory

I also framed this study through the theoretical view of the New London Group theory of multiliteracies (1996), which argues that the multiplicity of communications channels and increasing cultural and linguistic diversity in the world today call for a much broader view of literacy than portrayed by traditional language-based approaches. Traditionally, literacy approach has been restricted to formalized, monolingual, monocultural, and ruled-governed forms of language. But, with the exponential increase in local diversity and global

65

connectedness, such a view of literacy is short sighted. In particular, when technologies of meaning are changing so rapidly, there cannot be one set of standards or skills that constitute the ends of literacy learning and acquisition, however taught. The concept of "multiliteracies" was thus introduced by the New London Group in an attempt to broaden and enrich the definition of literacy to accommodate new practices in peoples' working, public and private lives, and I would add, in their sick lives. A major characteristic of a pedagogy of multiliteracies theory, which is relevant to this study is, it is multimodal, situated and has a social purpose (Olthouse, 2013). Literacy is situated because literacy practices are different in different contexts, just as the literacy practices of early onset Alzheimer authors/bloggers as well as those who serve as caregivers. In addition to the New London Group theory of multiliteracy, this study was also framed through the lenses of New Literacies theory which views literacy as socially embedded process that is used in specific ways by specific people who operate within social contexts (Cook-Gumperz 1986; Gee, 2012; Scribner & Cole, 1981; Street, 2003; Szwed, 1981). Combining these two theories provided theoretical innovation in response to the rapid change in people's economic, social, and cultural life. In the following section I explained how I found and selected the metaphors in the blogs that I included in the study.

Metaphor Identification

Identifying metaphors in a discourse can be tricky, to simplify the process, I used the Pragglejaz Identification Procedure (MIP). To illustrate the procedure, take the word journey in the sentence below:

> It started me thinking about the strengths that I have that would/has already enabled me, so far, to get me through my Alzheimer's Journey.

As an example, the contextual meaning of the word 'journey,' as something which you go through in an attempt to regain health, can be understood in comparison with the basic meaning of journey, as the person is going through their illness hoping to go from being sick to becoming better again. The contextual meaning contrasts with the basic meaning, but can be understood in comparison with it, therefore in this context the word journey is metaphorical. The next section explains how I selected the blogs for this study.

Data Collection Procedures

All the blogs that were included for analysis in this study were easily accessible to the public without a password. Because these blogs are publicly available documents online, I did not have to ask the bloggers for permission to include their blogs in my study. I identified the blogs that I wanted for this study in two stages. In the first stage, I conducted general keywords searches in Google and Bing search engines. Two criteria were developed for the blog search, first, blogs must be self-initiated by people diagnosed with an early onset form of dementia, which contained personal demographic details about the author (e.g., age at time of diagnosis or dementia type), were written in English, and focus on personal experience living with AD. The ages of the early onset blog authors that I included in this study were between the age of forty and early sixties. Because language was one inclusion factor in this study, all the blogs that I selected came from English speaking countries such as the United Kingdom, Australia, and the United States. The second criteria that I established was that the blog must be updated regularly and must have been around for at least five years since the time of diagnosis. This was important for me as it allows me to trace the progression of their disease and to see how they manage their agency and identity as their disease progresses. Because the searches brought up more unrelated than related websites, I decided this was not an efficient way to complete a comprehensive

search. Once I had identified several that fit the criteria, I developed a snowball sample from

blogrolls. I then visited each linked site to determine if it fit the criteria that I have established.

Many of the blogs linked to each other and to the same blogs that were clearly inactive (i.e.,

showing an error screen) as well as blogs that were not narrative-based descriptions of their lives,

such as blogs that only featured videos, or blogs that were primarily a record of the blogger'

medication or diet. Once the list of active blogs meeting the criteria has been selected, I

identified and tracked blog characteristics, including descriptive statistics such as the number of

entries and any information about the bloggers that I could glean from their user profiles. I also

took note of visual elements, such as graphics, images, and video. All of this information was

recorded on a schema I created in the Word document.

In the second stage of blog selection, I read each blog in detail over the course of three

months (June to August 2021) and took extensive field notes. I created a separate document for

each blog that I selected and gave each blogger that I included in my study a new pseudonym to

protect their identity. As the purpose of this study was to gain insight into the perspectives and

personal experiences of individuals living with early onset Alzheimer related dementia,

exclusion criteria were also established to eliminate blogs that were not reflective of the focus

that was stated in the criteria above. In order to complicate the study and to compare whether

those who serve as caregiver to late-stage AD patients share the same metaphors with early onset

AD blog authors to make sense out of their experiences with AD, I also included 6 blogs written

by caregivers who are either daughters or spouses of late-stage AD patients. The selection of

caregiver blogs was also based on an established set of criteria, which I established for early

onset AD bloggers. Like early onset AD blogs selection, all caregiver blogs that were included in

this study are publicly accessible without password. The search resulted in 16 sets of blogs which

comprised a total of 1920 posts (326.579 words) which ranged in length from 150 per to 1500

words.

Coding and Data Analysis

Once blogs were selected, a line-by-line open coding of notable themes was conducted.

Four themes were selected to represent the nine categories of metaphors that were identified.

The four themes were: diagnosis stage, what is like to live with AD disease stage, transition

stage, and post transition stage. I identified the four themes based on how the metaphor was used

and when the metaphor was used in the bloggers' narratives. For example, I noticed that the

death sentence metaphor which often was metaphorically worded in different ways was

frequently used to reference the frustration that early onset bloggers have with the onset of their

diagnosis. Whereas with the journey metaphor, I noticed that early onset dementia bloggers

frequently use it to describe what it is like to live with AD. This gives me an idea to create a

theme that is relevant to the context in which it is used.

To manage the high volume of metaphors found in the bloggers' narratives, I group the

metaphors into categories based on how common they were used in the blogs. The 9 categories

of commonly use metaphors were: Journey metaphor; Loss and Transformation metaphor; Death

sentence metaphor; Disability metaphor; War metaphor; Robbery metaphor; Monster metaphor:

Storm metaphor; Game metaphor. I manually coded each metaphor and grouped them under the

9 major categories and save them in a Microsoft words document. I then utilized MAXQDA

Analytics Pro 2020 (Version 20.4.2) research software to quantify the frequencies of metaphors

used across the blogs by both early onset AD bloggers and those who serve as caregiver to late-

stage dementia patients and to analyze the documents and materials. The process involved

uploading each document into the program and using various commenting and coding features to

document the items in the research protocol. The protocol was copy/pasted into commenting box for each document and filled out. Using the software features, I created a set of coding categories based on the research protocol that were used to highlight specific places within the documents. MAXQDA also supports in-vivo coding, which was necessary to track emerging patterns and concepts throughout the analysis. The coding capabilities allowed me to create groups of codes which functioned easily as a way to categorize and organize codes. MAXQDA was also used to analyze the relationships between certain groups and individual codes. The following section outlines the procedure used to identify the metaphorical expressions that I glean from the bloggers' narratives.

Demographic Characteristics of Bloggers Included in the Study

The initial search for suitable blogs for the study resulted in the identification of 20 blogs written by early onset AD patients and 10 blogs written by those who serve as caregivers to late-stage AD patients. The blogs were then screened against the inclusion/exclusion criteria that I established in the beginning of my data process. Blogs that failed to meet the criteria for content and demographic requirements based on an established set of criteria were eliminated. As a result, a total of 10 blogs written by early onset Alzheimer authors which consisted of 5 males (n=5), 5 females (n=5), and 6 blogs written by caregiver authors which consisted of 1 male (n=1) and 5 females (n=5) were included in this study. Of the 10 early onset Alzheimer authors selected, five were from the United States (n=5), four were from the United Kingdom (n=4), and 1 from Australia (n=1). Five caregiver authors were from the United States (n=5) and 1 caregiver author was from the United Kingdom (n=1). Three of the 6 caregiver authors were spouses/husband/wife (n=3) and 3 were daughters/mothers (n=3).

The methodologies discussed in this chapter informed my decision-making processes as the researcher for this study and different aspects from multiple methodologies were utilized as the project developed. In chapter 4, I discuss the findings of the research, in chapter 5, I discuss the conclusion and contributions of the study to the field of Rhetoric and Writing Studies.

CHAPTER 4

RESULTS AND DATA ANALYSIS

In this chapter, I report the study's findings and data analysis of the findings. Data from this study were gleaned from blogs written by early onset AD bloggers and from those who served as caregiver to late-stage AD patients that I selected for the study. My original intention for the study of AD was to critique the biomedical model of AD and to compare how different cultures understand the disease. Reading through the blog posts written by early onset AD bloggers shifted this goal. Given the pervasiveness of metaphor in dementia discourse, it was important to examine how these tropes are used in the struggle for meaning. The central focus of this project then was to examine the metaphors that early onset AD bloggers use to make meaning of their experiences living with dementia. To complicate the study, I also compared whether those who served as caregivers to late-stage dementia patients used similar metaphors to make sense of their experiences taking care of their loved ones. This was important as it can provide insight of their needs for tailored support and help.

What I was looking for when I ran the analysis was to identify the salient metaphors that both early onset bloggers and those who serve as caregivers used to make meaning of their experiences living with dementia. To be more accurate, what I was interested to find were metaphors that were related to freedom of choice to live, sense of control over the disease, self-efficacy, and personal relationship. Deci and Ryan (2000) called these psychological needs factors tightly linked to human well-being. My analysis of the 16 blog narratives included in this study resulted in 339 different metaphorical concepts that shape the talk of, and thoughts about AD experience. In order to manage the high numbers of metaphorical concepts that were identified from the data, I grouped the metaphors into 9 categories.
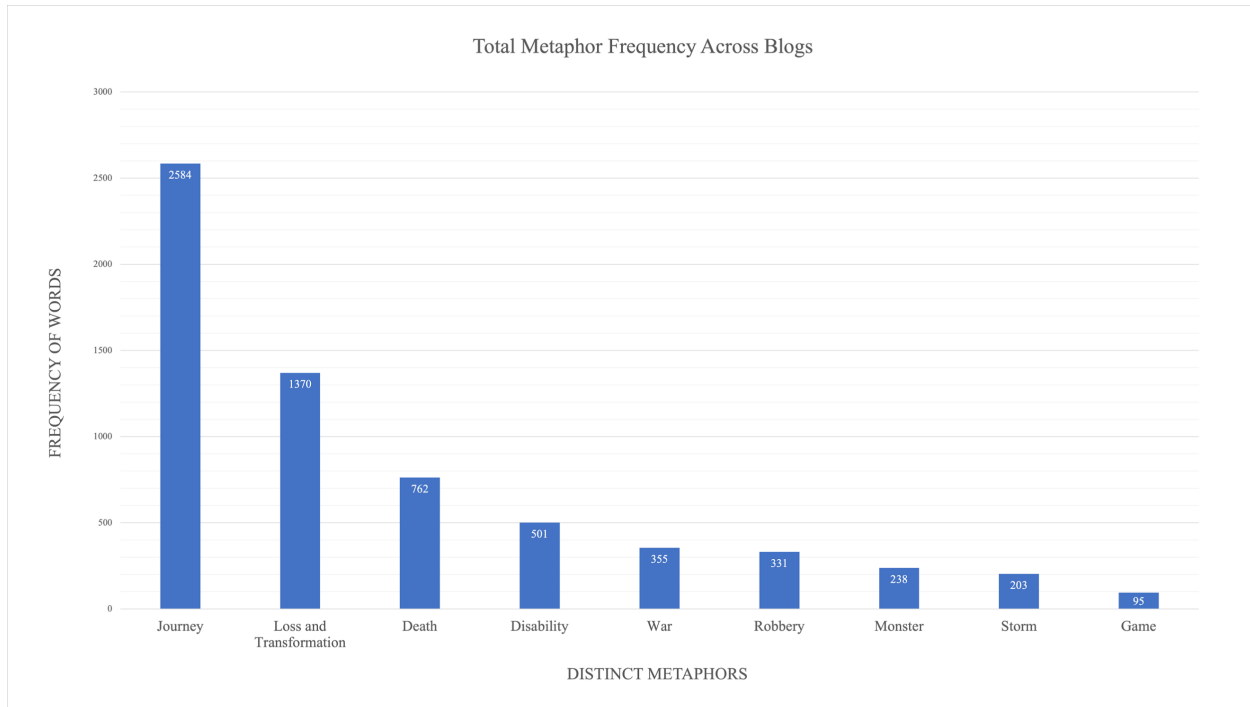
Figure 4.1: Categories of metaphors that were identified

Figure 4.1 shows examples of the 9 categories of metaphors ranging from the most frequently used metaphor to the least frequently used metaphor that I identified after I ran the analysis. The horizontal axis represents the frequency of metaphor usage by both early onset AD patients and those who serve as caregivers to late-stage AD patients. The vertical axis represents the distinct metaphor words that were used by both groups to make sense of their experiences with AD. As the figure shows, the most frequently used metaphor category is the journey metaphor, the second category is the loss and transformation metaphor, the third category is the death sentence metaphor, the fourth category is the disability metaphor, the fifth category is the war metaphor, the sixth category is the robbery metaphor, the seventh category is the monster metaphor, the eight category is the storm metaphor, and the last category is the game metaphor. Four themes were selected to represent how the 9 categories of metaphors were used by the bloggers in their dementia discourse. These themes were used to reflect the timeline of the stages the bloggers

went through before accepting their fate with the diagnosis of AD. The four themes used to

reflect these timelines were diagnosis stage, what is like to live with AD, transition stage and

post transition stage. In the following paragraph I explained how these themes were used.

Diagnosis Stage

Table 4.1 Examples of death sentence metaphors and monster metaphors

Metaphor Groups	Examples
Death Sentence	An AD diagnosis is quite literally a death sentence
	I refuse to be put into the end stages of Dementia until I am ready.
	Nobody should have a secret dementia as a dark hole in our life
Monster Metaphor	The disease is a monster (to me).
	Walking in the pits of Hell is what it is like at times living with dementia
	The world of dementia is cruel and ugly and meant to be read about and not lived in.

In the diagnosis stage, two categories of metaphors that were commonly used are the

death sentence and the monster metaphors. Table 4.1 above shows different examples of how the

death sentence and monster metaphors are used by the bloggers. It is important to note that the

bloggers may use different terms to describe the metaphors that they use. For example, the death

sentence metaphor was alternatively described as end stages or a dark hole. The same can be said

about all the categories of metaphors that were identified in this study.

For many early onset Alzheimer's patients, the onset of their diagnosis is the most

defining moment of their life. It comes as no surprise therefore that the death sentence metaphor

category and the monster metaphor category become the main choices of metaphors to depict

this shocking and devastating moment. And for many AD patients, the confirmation of their diagnosis after a long period of tests and visits to specialists and the lack of future verdict that comes with the diagnosis is likened to being given a death sentence. For example, Conway wrote:

"Having Alzheimer's wasn't, isn't the end, it was a bloody shock!"

Given the untreatable nature of AD, the use of the death sentence metaphor to depict the bleak outlook of being diagnosed with AD above is fairly accurate. In this regard, I must say that I disagree with Sontag's (1978) claims "that the most truthful way of regarding illness and the healthiest of being ill—is one most purified of, most resistant to, metaphoric thinking" (p. 3). For the ill, especially in the case of terminal illness like AD, metaphors prove especially useful because they reify meanings that help foster communities of shared experience and support (Beakley et al., 2014; Skott, 2002). Just as patients are the deciders of the character and duration of their treatment, they deserve to be the keepers of the lens through which they view and make meaning out of their illness.

The evaluation of death by default is negative based on the assumption that being alive is preferable to being dead. Interestingly, while the onset of the diagnoses tends to garner a poor reception among the affected individuals initially, if the timeline of their disease's progression is revealed to be longer than once believed, they can remain content with their results and start to move on with their life. This is reflected in Mabel's as well as Rockie's narratives below.

Mabel: Don't let the fear of dementia, Kill your dreaming, or stop you from living.

Rockie: In the month since my dementia diagnosis I have taken even more notice of what I see, smell, and hear around me. I know it's not a death sentence, as is sometimes said, but knowing that at some stage I am going to be less able to go out and see the countryside, meet people, walk up a hill or along a canal, makes me regard every day as potentially the last time I will do things.

75

The reactions that Mabel and Rockie portrayed above are consistent with past research findings (see e.g., Zimmerman, 2017a; Castaño, 2020; Locook et al., 2012) in that they show a certain conformity in the way people react to their terminal diagnosis. This conformity can be either positive or negative. In Mabel and Rockie's case they resist that conformity by refusing to take on the metaphor of death sentence. Their responses draw our attention to the powerful ways people use life-affirming metaphors to counter the negative narrative about dementia as well as to quell their own anxiety about the disease.

The second category of metaphor that was widely used in the diagnosis stage was the monster metaphors. This metaphor is used to highlight the perceived tragedies and cruelty of the disease. Below are some examples of how the monster metaphor was early onset bloggers.

> Cherry: Frontotemporal Dementia (FTD) is a horrible disease. It steals so much from you and from everyone who loves you. Most of all, it sometimes steals your happiness.

> Bobby: This disease robbed me from working, took away the ability to provide for my family, took away memories, made people who I thought were my friends disappear and many other things associated with having a Disease that is not only invisible but so very, very cruel.

Note how Cherry used the term "horrible," and Bobby used the term "cruel" to express the monster nature of the impact of the diseases on them. The account of AD as a monster suggests without a doubt how horrific the disease is to the sufferer. Yet, what I found interesting is that when patients learn more about the disease, the fear of the disease is gradually replaced by a desire to educate others. For example, Wilma wrote:

> I've started this blog to allow me, in the first instance, to write all my thoughts before they're lost. If anyone chooses to follow my ramblings it will serve as a way of raising awareness on the lack of research into Alzheimer's.

An important observation with the above statement is AD is not a monster striking at random that one is powerless to prevent. Perhaps the desire to educate was one way for the early onset bloggers to counter the monster striking at random.

What Is Like to Live with Alzheimer's Disease Stage

Under the theme "What is like to live with AD," five categories of metaphors were. They were the journey metaphor, robbery metaphor, war metaphor, storm metaphor, and game metaphor. These metaphors were grouped under the "what is like to live with AD" because the recurring narrative patterns in the blogs were centered on the bloggers' experiences with dementia. The notion of a journey is common to many societies and resonates well with individual and collective experiences of living with a terminal illness, especially a terminal illness like AD. This is because the metaphor journey has universal appeal, people can relate to the physical journey with the body as the vehicle. In this study, the use of journey metaphors can be summarized as: i) conceptualizing the confirmation of a dementia diagnosis as the beginning of journey ii) presenting the blog author as sometimes lone, reluctant, or still on the road travelers iii) express powerlessness and lack of control over the situation. A majority of the bloggers in this study described their diagnosis with dementia as the beginning of a journey. For example, Bobby wrote about his diagnosis with dementia as traveling on a journey:

> To me, we are explorers, traveling on a journey, making new discoveries each and every day, never knowing what is waiting for us around each bend.

Others used the journey metaphors to emphasize the overwhelming challenges that they went through with the disease journey as demonstrated in Cherry's narrative:

> I have found that many people don't understand me or what I am going through, and don't care to make an effort to find out. People that I thought I could count on have disappointed me, but others who I never expected to help or understand have really surprised me in a good way. I do not harbor any ill will against those who have disappointed me. Frontotemporal Dementia (FTD) is a difficult concept to comprehend,

77

especially when most people automatically think "Alzheimer's" when they hear "dementia."

With dementia, as with other terminal illnesses, the journey is not always voluntarily chosen. However, what is clear from the data, is that the journey metaphor served as a powerful instrument for early onset blog authors not only to present their major concerns about the disease, but it was also used to express understanding of their prognosis and depict the sometimes powerlessness and the lack of control over their situation. Yet, despite feeling powerless and feeling a lack of control over their situation, as they get adjusted to their diagnosis, they are able to experience a sense of choice and purpose. As Bobby wrote:

> I've said from the beginning of my Alzheimer's Journey, I would not allow my Alzheimer's to define who I am as a person. I would live my life the way I want to live it.

> The idea of movement forward in spatial terms was also described using complex

extended metaphorical expressions such as: "roads," "very rocky," "roller coaster ride of my life" as can be discerned from Mabel's blog.

> But the road has been very rocky, definitely 'the' roller coaster ride of my life, and one that has highlighted so many breaches of the most basic of my human rights. It has also highlighted quite profoundly, and with incredibly thunderous clarity, exactly who were my true friends. Dementia has also brought me a very large group of new friends, who I love as much as my pre dementia friends, and who are people I often refer to as my 'Dementia family.'

> A useful feature of the journey metaphor is that it encompasses possibility: for

exploration, struggle, hope, discovery, and even change. And its main benefit is that it comprises the idea of companions, and of people with earlier diagnoses' acting as guides. It also makes room for the idea that diseases can come with some positive outlook as Bobby illustrated in his narrative:

So, I start my day and end my day acknowledging how fortunate I am for the many ways I am loved and cared for. I'm lucky to have some very special people on my Support Team and I'm thankful that I still know what it feels like to be loved. As an Alzheimer's Advocate, I plan on continuing my Alzheimer's Advocacy, educating, updating and sharing my personal journey to anyone wanting or willing to listen. I don't want our sons and daughters, or their children, or their children to have to live with this horrific disease known as Alzheimer's!

Some bloggers describe their journey as a tourist to dementia land. As MaryAnne wrote: "I'm an Alzheimer's tourist visiting the land of Alzheimer's and dementia." Of course, not everyone is a fan of the journey metaphor, especially those who think of a journey as a fun vacation. Dementia, to some, especially caregivers, is more like a bad dream than a hike in the Grand Canyon. As caregiver Hilda wrote:

> What I experience is hollow and empty, like a bad dream where crazy things happen. Things that have no logic or reason, nightmarish events that stick around when woken. For my mom, what I'm observing is her nightmares are coming alive, she's awake but asleep. She walks between both worlds when she's in a demented state of being. Not sure if the ground is before her or a big hole, she walks with calculated steps, cautious not to fall.

Surprisingly in this study, all 10 early onset blog authors use the journey metaphor in an empowering way with some sense of control over their experience. This is demonstrated in the table 4.2 below.

Table 4.2 Example of positive use of journey metaphor by early onset AD patients

Journey Metaphor	Examples
	I love the word bebop. I don't even know if there is such a word, but it describes my life to a tee. I go through life just bopping around. I try not to take every bump in the road seriously. I see the good in everyone and live the fantasy we are all WORKING TOGETHER.
	This road can crush you and leave you along the way if you let it. I get bruised and scratched along the way, but I try to deal with it. If the problem is too hard for me to handle, I ignore it. I wear a smile and a skip in my step. I seem to have no worries or cares.

	I know I am going to be faced with more vulnerabilities as I travel along on my Alzheimer's Journey but having Macy as my "Travel Partner" (I guess I'm going to have to add that to her Titles) I feel confident that she will help get me over any hurdles that we face.
	There's a lot of power in having knowledge and I think most people are scared of dementia because it's the 'monster under the bed' that you know nothing about. The more you know, the more you can understand your diagnosis and accept it – and even embrace it and move forward.

Table 4.2 above provides different examples of how early onset AD bloggers in this study used the journey metaphor in a positive way despite the disappointment they faced being diagnosed with AD. An emerging theme that was apparent in the data was the employment of counternarratives metaphors by the bloggers. By employing counternarratives metaphors that are positive, these bloggers not only were able disrupt the storyline that colludes the ideas of AD as something that is negative, but by employing counternarratives, the bloggers were able to resist the all-too-common view of people with dementia as people who should be ignored as thinkers, writers, or even decision makers because they are thought to have lost their cognitive functioning. Nelson (2001) argues that master narratives are often "archetypal consisting of stock plots and readily recognizable character types" (p. 6) and they are used not only to make sense of experience but to "justify what we do" (p. 6). In contrast to master narratives, counterstories are narratives that "constitute a revised understanding of a person or social group" (Nelson, 2001, p. 8). These stories she claims are "developed for the express purpose of resisting and undermining an oppressive master narrative" (p. 8). Counterstories, then, as Nelson (2001) argues, are "narratives act of insubordination" (p. 8). For early onset AD patients counterstories are useful tools not only to repair the damaged that had been imposed on them by the negative metaphors and narratives about AD that circulated in public discourse, counterstories provide early onset

bloggers with the metaphorical tool to change the oppressive yet commonly held understanding, knowledge, or assumption manifest in the master narrative about AD.

The second category of metaphor commonly used under theme two, is the war metaphor. The use of military metaphors in describing dementia has gained traction over the years. Previously the military metaphor was used widely in the "battle against" cancer. The war against Alzheimer's made headlines internationally when President Obama declared war on Alzheimer's disease in 2012:

> Proclamation 8745—National Alzheimer's Disease Awareness Month, 2011
>
> In January, I signed the National Alzheimer's Project Act, which calls for an aggressive and coordinated national strategy to enable earlier diagnosis of the disease, improve strategies for long-term care, and accelerate the search for a cure by promoting collaboration among researchers. The Act also establishes an Advisory Council on Alzheimer's Research, Care, and Services, which brings together some of our Nation's foremost experts on Alzheimer's disease to ensure our efforts do the most good for patients and their families.
>
> My Administration, in collaboration with a variety of private and public partners, is making headway in the fight to eliminate Alzheimer's disease. Research funded by the National Institutes of Health has identified genetic markers that may indicate increased risk of developing Alzheimer's, and researchers across our Nation and around the world continue to shed new light on the disease. These discoveries bring us closer than ever to lifting the immense physical, emotional, and financial burdens that Alzheimer's disease imposes upon aging Americans and their families (alz.org).

Although debate about the usefulness of the military metaphor remains ongoing to this day, military metaphors can be useful if used with care. For example, military metaphors can be effective in raising the profile of health issues, for fundraising, and bringing them to public and media attention (Lane et al., 2013). At the individual level, metaphors can aid in understanding, meaning making, and communication. In this study, some early onset bloggers use the war metaphors to depict themselves as being at war with dementia while they acknowledged that

given its lack of treatment, fighting dementia is a choice they need to make. This is elaborated in

Hunter's blog as well as Mabel's:

> Hunter: Next time you look at me, be proud that I am fighting this hard and still trying to make you happy. I need to stand tall and be proud I made it through another day. Tomorrow when I wake up, I will fight the same battle, I get no relief, I cannot cry.

> Mabel: Living well at any time of our life is probably what everyone wants, but add in the diagnosis of dementia, and the Disengagement, and many of us think we can no longer live well, so we might as well die now, in the sense that many just give up fighting for their lives. Although it requires a lot of hard work to support ourselves with non-pharmacological interventions, and on remaining positive, and meaningfully engaged is not a cure, 'fighting for our lives' in any way we can think of, does improve our quality of life and perceived well-being.

The examples above highlighted not only the strong determination that many early onsets

blog authors possessed to fight the disease as long as they were able to, but a further analysis on

the blog texts shows how dementia is also portrayed as an unquestionable threat to their

autonomy. Interestingly, although the initial shock of diagnosis was difficult for them to accept

at first, all of the early onset AD blog authors included in this study were determined to fight

back. In adopting the role of the fighter and conqueror in the war against AD, they gain a sense

of perceived autonomy over their illness.

The third category of metaphor commonly used to characterize AD under the theme,

"What is like to live with AD," is the robbery metaphor. Memories are what make a person. If

you strip someone of their memories, what is left is a skeleton devoid of memories and identity.

At least that was what Rockie said in his blog: "my body will be here, but I will be gone." Others

like Bobby characterized dementia as the robber who robbed him of his future:

> This disease robbed me from working, took away the ability to provide for my family, took away memories, made people who I thought were my friends disappear and many other things associated with having a Disease that is not only invisible but so very, very cruel.

As the disease progressed, concern about losing memories and being unable to take control of their life is not uncommon. Most, however, have learned to gain acceptance of their diagnosis and have turned to online blogging as a means of prolonging, retaining, and preserving whatever memories they have left as detailed in Wilma's blog below:

> That's the advantage of having Dementia Diaries. How many valuable nuggets of gold would be lost if we didn't record our thoughts as and when they popped into our heads? How many voices, views and feelings would be lost as they float away from our mind? Even when I no longer liked using the phone, we found a way round. I now record mine via a recording app on my iPad …. there's always a way…...
> The same for my blog. How lucky am I to be able to type? Because I'm sure I wouldn't remember most of what I'd done or said each day if I didn't type in real time.

The fourth category of metaphor that is commonly used to characterize AD in the "What is like to live with AD" theme is the storm metaphor. While the storm metaphor is quite common in mental illness that is not the case with dementia. In this study, the storm metaphor is used to describe the unpredictable nature of AD. For instance, Hunter wrote:

> My life is like the weather, I can have a violent storm one day and the next, a calm sunny day. Last night we had some severe storms pass over and today is sunny with a beautiful clear blue sky. Maybe like the weather, nature is cleansing my body of unwanted things. It seems to me that I have a string of good days and then a bad day slips in, reminding me that I am taking on more than I can handle. I am forced to slow down and relax then the sun returns once again. I call this my cycle of life and it's something I cannot change.

Storms are incredibly powerful, so is AD. It can destroy everything from marriages, relationships, families, to the individual themselves. While storms don't last forever, AD does. Some early onset bloggers described a bad day with AD as living in a fog. This is detailed in Lindsay's narrative:

> Experiencing Dementia Daze is like digging for a coin in a muddy swamp on a foggy day – everything is murky and unclear. The more you move around, the deeper you and your goal sink. The deeper you sink, the more difficult it is to get back out. The best thing to do is sit back and let the water settle and the fog clear.

83

The two very different metaphorical ways of structuring one's idea about illness

experience make perfect sense in light of the diversity of thoughts and emotions that people have

in understanding illness. These very different ways of talking about experience are not specific

rhetorical devices selected just for communicative purposes because of a lack of appropriate

literal language. Rather, these very different ways of making meaning reflect alternative

conceptualizations of the individual complex experience.

Commonly used in cancer narratives, the last commonly used metaphor under the 'What

is like to live with AD' theme is the game metaphor category. In the game metaphor, having

dementia is likened to a game that you play. As with any game, sometimes you win, sometimes

you lose, sometimes you get sick, but as a true sportsman you must learn to accept whatever the

outcome is with grace. Such an attitude is demonstrated in Hunter's narrative when it comes to

dealing with the game of dementia.

> It is going to rain today, but that is ok because I know eventually the sun will shine. That
> is actually how I view DEMENTIA, it makes our life miserable but in the end we all win.

Like a game of cards. A vital part of life is that there is time for joy, sorrow, happiness,

defeat or even heartbreak. The decks of cards are the different choices and strategies to choose

from. In the game 'life' you don't always know what card you are going to draw. Whatever cards

you choose, there is no redraw, you just need to make the best out of whatever you get. But you

can choose to use your experience to move forward and guide others. The same can be said about

living with and dealing with illnesses like AD, as elaborated in Mabel's narrative:

> My brain continues to allow me to make sense of my world, to have insight into what is
> happening to me and to my family, and to speak out about it. Because of this I feel
> obligated to speak out, to make up for those who can't. Speaking out has also helped me
> make sense of this disease, to feel as if there is a positive reason, I have been dealt this
> deck of cards.

In the next paragraph, I provide analysis and example of the metaphors that are commonly use the transition stage based on the data analysis.

Transition Stage

In the transition stage one frequently used category of metaphor is the loss and transformation metaphors. The loss and transformation metaphors imply the feeling of loss as a result of recent diagnosis and the realization that a transformation of self from the old capable and competent self to a new less able self is necessary. In this context, the focus is about the struggle to adjust to their new selves, while reclaiming the continuity of their old selves. As Hunter wrote:

> Have you ever said to yourself, I hate my life? This is the year that you find out what you hate and change it. Changing might just be the way you think about it. I hate my disease, but I cannot change the fact that I have Alzheimer's, but I can change the grip it has on me. I can make sure that Alzheimer's doesn't control me. I'm getting the hang of turning pens and having a blast. Living with dementia is not all bad. the year we stop saying, I Can't do that. This is especially true if you never tried it. I may not be able to rock climb, but I can take a walk in the park. I can't hunt anymore but I can take my camera to photograph wildlife. I refuse to be put into the end stages of Dementia until I am ready.

Coping with any illness, especially a terminal illness like AD is not easy. In this situation, individuals must decide what they want to do about their situation. What I find interesting in the data is that many early onset dementia bloggers choose to find hope in their suffering. I find it interesting because it takes courage to be positive especially when you know there is no cure for your illness. Being brave for them means taking a leap of faith. This is apparent in Kenneth's narrative:

> Finding "Hope" is a means of coping with this illness, and what is happening in our lives, and Professionals need to be aware that even when "Hope" is unrealistic people must find their own meaning to life. Although I am struggling to cope with my faith these days, I still have "Hope." I know that even though I lose the ability to do some things, I "HOPE" to fight on, enjoying my family for a bit longer, and enjoying the hobbies I can still do without assistance.

85

In solidarity with Kenneth, Lindsey also employs a life affirming metaphor to focus on

the positive side of life with AD. On living positively beyond dementia diagnosis, she wrote:

> "Accept what you cannot change. Change what you cannot accept." After a period of grief, anger, and denial, I began to seek my old self. I found that once I accepted the changes my life was going to take, I began to appreciate the joy and beauty around me. As my stress lessened – my confusion lessened, and my energy level increased. The more I embraced the change with a positive attitude, the more Roy and I were able to discover ways to reduce the amount of "dementia daze" (the state of confusion and disorientation) and the more I was able to feel joy again.

The examples above exemplify the brilliant ways early onset AD bloggers used positive

life affirming metaphors to counteract the negative predicament that they are in. The application

of metaphors from one that is negative to one that is positive shows the transformative power

that metaphors have for people to reshape their understanding of their situation. In the next

paragraph I talk about my observation and analysis of the post transition stage

Post Transition Stage

One category of metaphor that is pervasive in the post transition stage is the disability

metaphor. Scholarship in disability studies shows that language and rhetoric shape our attitudes

toward disabled people and that those attitudes in turn, affect how we deal with matters of

access and inclusion in education, workplace, culture, and society as a whole (see e.g.,

Dolmage, 2017; Price, 2011; Cedillo, 2018; McMahon & Shaw, 2005). My findings confirm the

distressing effect of negative metaphorical language on individuals. This is highlighted in

Hunter's narrative below:

> Stigma is the use of negative labels to identify a person with a disability or illness. When you live with Alzheimer's you are labeled with so many different labels.
> A diagnosis may test friendships. Friends may refuse to believe your diagnosis or withdraw from your life, leaving a feeling of abandonment or isolation.

We are constantly compared with each other. If we are not on our deathbed, we are considered lucky. Everywhere you look we are assumed to be in our latter stages of this disease. Many see us as going from diagnosis to late stage in one giant leap.

When a disability isn't obvious, others sometimes doubt it exists and accuse those who suffer from invisible conditions of simply angling for special treatment. The invisible nature of early onset AD left many AD patients in a conundrum. Often, they are singled out or not given the due support that they desperately need to live a productive and meaningful life. This is highlighted in Mabel's narrative:

If we get used to a second label or D-word – i.e., disability – soon after the diagnosis, we can and will have hope again, as we then realize dementia is not only the death sentence we are advised, but we have rights to disability support that all others with acquired disabilities receive, to maintain independence for longer. If my university was able to proactively provide disability assessment and support to enable me to keep living my life, then why won't the health care sector get on board? This remains a continuing conundrum for me……. People with dementia are still being systematically denied equal inclusion, equal disability assessment and disability support, and equal Universal Health Coverage, including rehabilitation. Sadly, the lives of more than 50 million people, and each newly diagnosed person (there is a new diagnosis every 3 seconds), are also being negatively impacted because of this denial of dementia as a disability…

The lack of attention given to invisible disabilities and the failure to provide equal inclusion of the needs of people with dementia just because their impairment is not visible enough is disturbing. Overall, the data in this study highlighted and provided me with powerful examples of how language and beliefs about AD can impact how the person afflicted by the condition feels about themselves. Disabilities, whether invisible or visible, invite us to rethink language, the body, the environment, identity, culture, power, and the nature of knowledge itself. Nobody likes to be called names, especially disrespectful labels. As Mabel points out in her narrative:

> Personally, I dislike being labeled by anything, including, or especially by a disease. Being labeled to my height, my skin color, etc. is also offensive, and I simply prefer to be referred to by my name (the one I chose).

In the next section I report the result of the finding for distribution of metaphors based on frequency of its use across blogs between early onset AD bloggers and those who serve as caregivers to late-stage AD patients and how they were negotiated by these two groups
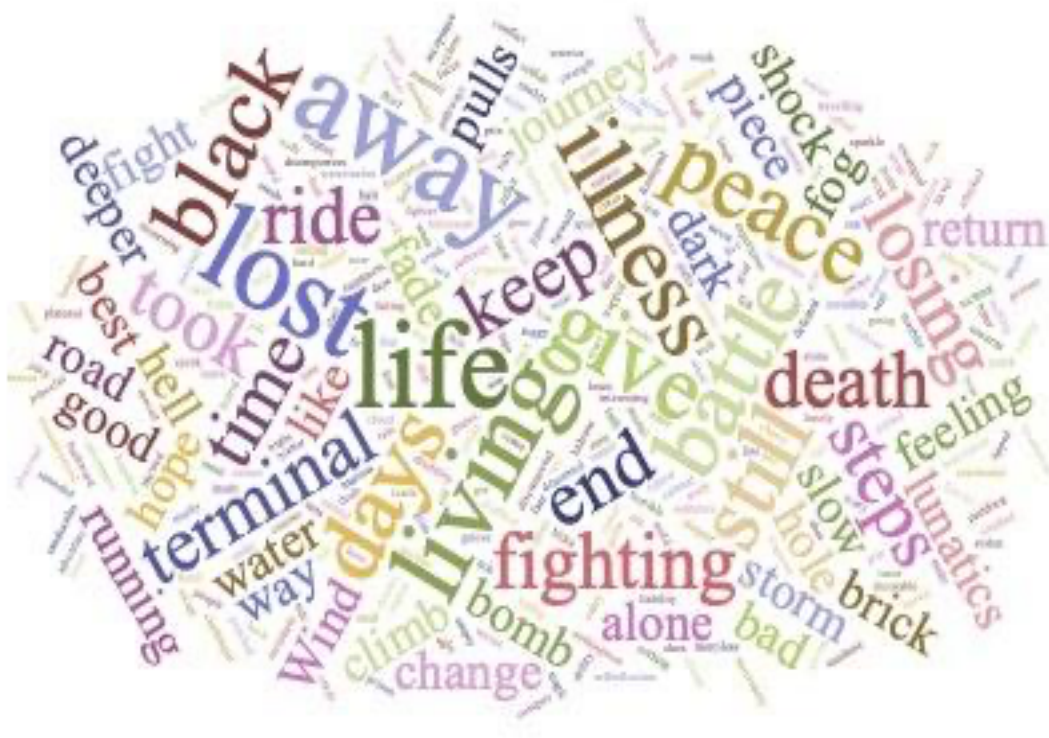
Figure 4.2 Representation of metaphorical terms use to describe AD.
Created using wordclouds.com

It should be noted that both early onset bloggers and caregiver bloggers employed a wide range of metaphorical expressions to capture their experience. Figure 4.2 shows 339 metaphorical utterances that were coded from16 blog narratives that were included in this study. They range in order from the most frequently use category of metaphors to the least frequently use category of metaphor (see figure 4.1); the top most frequently category of metaphor is the journey metaphor, the second frequently used category of metaphor is the loss and

transformation, the third is the death sentence metaphor, the fourth is the disability metaphor, the fifth is the war metaphor, the sixth is the robbery metaphor, the seventh is the monster metaphor, the eight is the storm metaphor and the last is the game metaphor. It is important to quantify the metaphors into frequency because it allows us to see which metaphor is frequently used in the discourse and which metaphor is the least used metaphor and how there used it. This helps us to follow through how these bloggers use metaphors make sense of their experiences. For example, the metaphor journey can be described as a path, a road, something that they go through, the ups of life or the downs of life. It is important to quantify the metaphors into frequency because it allows us to see which metaphor is frequently used in the discourse and which metaphor is the least used metaphor and how they used it. In the paragraph below I provide reports of the frequency of metaphors beginning from the most frequently used metaphors and how they are negotiated by both early onset bloggers and those who serve as caregivers to late-stage dementia patients.

JOURNEY METAPHOR

Based on the data, the most frequently used metaphor across blogs is the journey. The conceptual metaphor "dementia is an obstacle on life's journey" is based on higher level mapping of "life is a journey" (Lakoff & Johnson, 1990), which refer to the idea that we all are travelers navigating through life. Based on this conceptual knowledge of journeys, it is assumed that similar to a journey, life has a beginning (birth) and an ending (death). Both early onset dementia bloggers and caregiver bloggers in this study view their diagnosis with dementia as a journey. Hunter, for instance, depicts the obstacles that he encounters with his dementia journey as a bend in the road. Although he was not certain of his future, he still has high hopes things will get better. This was detailed in his narrative below:

There is a bend in the road, and I can no longer see what is ahead of me. I have faith that this will clear up and once again I will be on a straight path.

Rockie characterized his journey with dementia as routes for example, he wrote:

But is a dementia journey linear? Probably not. Dementia is a terminal illness, so we know where we are going. But we all take different routes, Some quick, many slow.

Journeys can be fun if we do it with friends or families. Some journeys have to be ventured on our own. In illness, the journey is often undertaken alone, which can lead to a sense of isolation, lost and alone. As Kenneth described in his blog below:

Getting people with dementia to talk about their illness, and their problems is a major step forward, and it's one that can do so much to help others who have just been diagnosed and feel lost and isolated. They feel so alone and tend to ask why it's them who have the illness.

Others like Lindsey portray her dementia journey as something that she goes through. For example, she wrote:

I am so blessed to have a wonderful husband to walk beside me through this journey and family to give us both support.

Apparently early onset AD bloggers are not the only people that mapped their experience with dementia as a journey. Based on the data at hand, caregivers actually employ the journey metaphor similar to how early onset patients employ it. For example, caregiver Stephen wrote of his journey with dementia as caregiver to his wife as a bumpy road.

After Clare passed away, it took me nearly 4 years to get past my depression and sadness to allow me to fully move on with the rest of my life. I have written and posted a series of Personal Blog columns describing my bumpy road to move on, and I hope these columns have been helpful to those readers also having difficulties moving on after losing their loved ones.

The blogger's narratives above illustrated the different ways that dementia is seen either as part of a trip or as an obstacle in the journey of life. Based on this framing, dementia is something one "starts" and "finishes" just like any journey. Although both groups used the same

90

metaphor to communicate their experience, what sets them apart where journey is concerned is their positionality. One is receiving care and one is giving care.

THE LOSS AND TRANSFORMATION METAPHOR

The second most frequently used category of metaphor is the loss and transformation metaphor. For most people, if not for all people, the self is the most valued possession. Alzheimer's disease takes the ability for individuals affected by the disease to take control of their life. The loss and transformation metaphors thus are used to convey a sense of loss of control over the impact of dementia. What is interesting to note is that while those who are not affected by dementia tend to focus on what a person with dementia cannot do, individuals with dementia focus on what they can do with their remaining abilities. Despite feeling loss most early onset dementia patients in this study have learned to accept the change and transformation that comes with their diagnosis. This cue is reflected in Hunter's narrative below:

> The next battle is one of the hardest and that is acceptance of your dementia and learning to live within your new world. You will find you are changing into this new person that at times, you don't like. It doesn't happen overnight, but you find the strength and belief that there is life beyond your diagnosis. You are slowly moving towards your inner peace where you can live in the now and present. The world is brightening, and you find hope. You no longer think too much about the future and you are not so afraid.
>
> You find your inner peace and believe it is what it is and there is nothing to be done to change it. You find peace with this life and start enjoying the world around you. You actually stop and smell the roses and listen to the birds singing their songs. The sun is shining brightly, and you heart is full of happiness. You have no idea how you got here but you are thankful. You realize you are walking toward a better life, and you are no longer scared and very hopeful for the future.
>
> Looking back, you realize you climbed your mountain and found happiness living with dementia.

By focusing on positivity, individuals with dementia are able to manage and preserve a positive sense of self while living with dementia. Embracing change instead of mourning over the loss of the old self has also been the mantra that was adopted by Lindsey:

"Accept what you cannot change. Change what you cannot accept". After a period of grief, anger, and denial, I began to seek my old self. I found that once I accepted the changes my life was going to take, I began to appreciate the joy and beauty around me. As my stress lessened – my confusion lessened, and my energy level increased. The more I embraced the change with a positive attitude, the more Roy and I were able to discover ways to reduce the amount of "dementia daze" (the state of confusion and disorientation) and the more I was able to feel joy again.

To me, embracing change means accepting that it is inescapable and with a positive disposition determining how to make the best of it. Together, Roy and I are learning to embrace our challenges and modify our objectives and our lifestyle. We are finding some of the things that trigger confusion and figuring out ways to overcome the hurdles that prevented me from enjoying life. "I can't" has become "How CAN I?"

Yes, I still have challenges and days of confusion, disorientation, fear, and emotions. However, most of my days are full of purpose and love. While embracing the challenges of change, we are also embracing every moment with joy.

Evidently focusing not on what they had lost but abilities retained enabled early onset bloggers to preserve their self-esteem and maintain their identity. As Conway points out in his blog:

There's a lot of power in having knowledge and I think most people are scared of dementia because it's the 'monster under the bed' that you know nothing about. The more you know, the more you can understand your diagnosis and accept it – and even embrace it and move forward.

Acceptance and transformation are also strategies that caregivers have employed in their experience with taking care of their loved ones. This is detailed in caregiver Luna's blog:

Of course, as dementia changed the entire fabric of our lives, mornings sometimes started with Jim pouring water into the pot without a carafe to catch the coffee. Or I might wake up and find him missing, jump in the car and drive down the road looking for him. Relaxation changed to stress, and I discovered that for a person without patience, I learned to accept our life's changes remarkably well. The Serenity Prayer became more than a plaque on my wall.

Similar acceptance strategy can also be discerned in caregiver Stephen's blog narrative:

One of the many things I have learned through these years is that each new AD decline in behavior and/or skills always leads to a "new normal" period for us. Each decline requires an adjustment to my wife's inability to do something she had previously been able to do. Social workers and other health care professionals can help prepare caregivers accept these new declines and learn how to deal with what lies ahead.

92

Terminal illness can influence the meaning of time, with some people adopting a strategy of living one day at a time to gain a sense of control over their situation. Such attitude was demonstrated in Hunter's blog:

> The next battle is one of the hardest and that is acceptance of your dementia and learning to live within your new world. You will find you are changing into this new person that at times, you don't like. It doesn't happen overnight, but you find the strength and belief that there is life beyond your diagnosis. You are slowly moving towards your inner peace where you can live in the now and present. The world is brightening, and you find hope. You no longer think too much about the future and you are not so afraid.

Although I had anticipated that people with early onset dementia might experience a change in time perspective like pinning for the past or avoiding thoughts of the future or dwelling on anticipated fears, instead what I found was that most of the blog writers had chosen to focus on the present. As Conway showed:

> I concentrate on what I can do now, not what I can't. That was just causing me stress before, which would lead to anxiety and make my dementia worse. I've taken the attitude that I'm living with the diagnosis of dementia and not dying from it.

Because uncertainty about the future can make it difficult for people with dementia to maintain a sense of self, adopting a present time orientation can be a way of keeping thoughts of possible future selves at bay in managing identity.

DEATH SENTENCE METAPHOR

The third frequently used metaphor across blogs is the death sentence metaphor. A challenging fact about Alzheimer's disease is that it is terminal. This means that a diagnosis with dementia, especially early onset dementia is not always received well by those affected by the disease. While older people with dementia may be retired with married children, younger onset dementia patients are more likely to have younger children and are often at their prime career which means that their diagnosis poses a strong challenge not only for the families, but the

individual affected. Because the end is inevitable, the quality of life is increasingly becoming

important for people with AD and those who serve as caregivers. Yet, instead of dwelling on the

'inevitable end,' many like Wilma turned to writing and blogging as a way of coping and

preserving what is left of herself.

> In July 2014 I was diagnosed with early onset Alzheimer's. I may not have much of a
> short-term memory anymore, but that date is one I'll never forget. I'm 58 years young,
> live happily alone in Yorkshire, have 2 daughters and I'm currently still in full time
> employment in the National Health Services (NHS). However, I'm now in the process of
> taking early retirement to give me a chance of enjoying life while I'm still me. I've started
> this blog to allow me, in the first instance, to write all my thoughts before they're lost. If
> anyone chooses to follow my ramblings it will serve as a way of raising awareness on the
> lack of research into Alzheimer's. It will hopefully convey the helplessness of those
> diagnosed with dementia, as there is no cure – the end is inevitable. However, I'm also
> hoping I can convey that, although we've been diagnosed, people like me still have a
> substantial contribution to make; we still have a sense of humor; we still have feelings.
> I'm hoping to show the reality of trying to cope on a day-to-day basis with the ever-
> changing environment that dementia throws at those diagnosed with the condition.

Others like Rockie have learned to pay more attention to things that he never really paid

attention to before. He wrote:

> In the month since my dementia diagnosis I have taken even more notice of what I see,
> smell and hear around me. I know it's not a death sentence, as is sometimes said, but
> knowing that at some stage I am going to be less able to go out and see the countryside,
> meet people, walk up a hill or along a canal, makes me regard every day as potentially
> the last time I will do things.

Evidently, early onset AD patients are not the only ones that described diagnosis with AD

as a death sentence, some caregivers like Stephen, for example, employ the same metaphor to

describe what it was like with his wife's early onset diagnosis. "An AD diagnosis is quite

literally a death sentence," he wrote. If anything, the death sentence is a fitting metaphor to

express the powerful emotion that people go through on receiving a diagnosis of AD. In the

midst of these powerful emotions, people can be defined by deficit narratives about their

condition. Not surprisingly in this scenario, a crushing sense of defeat and 'anticipatory

helplessness' can overwhelm pre-existing coping strategies as any hopes for the future evaporate (Bryden, 2015, p, 262). Conversely, some people see the benefit of their diagnosis as illustrated in the different examples above, even if their initial diagnosis was upsetting. Notable in this study is that many early onset bloggers actually found that acceptance of a diagnosis opens opportunities for agency and embracing of new identity.

DISABILITY METAPHOR

The fourth frequently used category of metaphor is the disability metaphor. The metaphors we use to think and talk about dementia are powerful in that they influence the way we perceive people with dementia and this in turn can impact how people with dementia view themselves. On metaphor, feminist Margaret Gibbons (1999), writes, "[m]etaphor is always significant" because "when we use language, we make choices and choices are not always innocent, but is determined by belief systems which underlie them" (p. 3). The problem with these belief systems argues (Schalk, 2013) is that they "provide justification for what people do and how they represent what they do in language (para 13). Because metaphor is always significant, it is also a powerful tool for oppression and control. Hunter wrote of the destructive impact of disability metaphor in his blog below:

> For me, the hardest part of living with Dementia is the emotional side of this disease. I realize that a cure will not be found in my lifetime, and I made peace with that. I know that my memories will be lost but there is nothing I can do about that. The thing that bothers me the most about this disease is the nasty slurs that are used against us. We are called names and the user thinks they are being funny. Living with this disease for nine years, I can assure you, I don't think they are funny. When you respond to these slurs, you are described as an angry little man. My response does not make me little, but your attitude makes you one. These slurs make you feel superior because you know we no longer have the mental capacity to respond. PEOPLE living with Dementia do get bullied and there is nothing we can do about it. Everyone around the user thinks they are being funny or that the way they are and means nothing by it. They never feel the hurt or pain they inflict, nor do they ever apologize for their comments. You may not be able to find a cure, but you certainly can help bring a better QUALITY of life for us. You may not like the way we are, but that doesn't give you an excuse to show your insecurities.

The narrative above draws our attention to the serious implication of the ableist metaphor that we use and how it affects individuals and their sense of identity. Aside from being called names and slurs, dementia patients are considered as burdens both by families and the public. This is detailed in caregiver Hilda's blog:

> First there was Walter, then Aggie and Tommy; folks who I believe prepared me to be a caregiver for my mother with Lewy Bodies Dementia. Countless co-workers along my journey of life, warned me about the burden of caring for an aging parent. I will never forget my friend Mary Lou's reaction when I told her in 1998 that I was buying a house; one big enough for me to move my mom in with me... "Sue!? Are you out of your mind?!" Yes, Lu, I am. Blinded by my desire for approval, I willingly entered into what would later become my personal Twilight Zone, raising Mom.
> Caregiver Hilda is not alone in describing the burden of taking care of their loved ones

with dementia. Caregiver Sheila shared the heartbreaking testimony of what life is like taking care of her husband who has dementia:

> Sheila tells her story to the unknown each day, but thankfully someone is listening to what she has to say. She draws strength and courage from the comments you share, because maybe your burden is too much to bear. Maybe like Sheila this day makes you feel sad, hearts, hugs, and kisses... (she may cry, just a tad). But she will remember that God's love kisses her life, His heart keeps her focused and His arms hold her tight.

The danger of characterizing dementia patients as a burden is that this image seeped into public imagination. And they are being picked up by the patient themselves as discerned in Bobby's blog:

> Until then, I will keep on keeping on, trying not to burden Shannon and the kids too much and continue doing what I do, and I do it in honor of YOU!

This image of having dementia as a burden to the family is also reflected in MaryAnne's blog:

> I am sad for him having to be my caregiver now. I feel so useless in this disease. Feel that I am a burden. I am unable to contribute much to what was an equal partnership. I am so sad about this. I am so sad for him being trapped by my decline).

96

Language as I have noted from the examples above provides powerful means of defining individuals and social groups and can have a powerful normative effect on social identity. Despite multiple attempts to abandon the medical model of disability for a more holistic and environmental and social interactive view of disability, slurs, fear, and burden responses to disability are disturbingly well and alive. We make choices about the word we use and have a responsibility to understand both the denotation and connotation of the words we choose. Khullar (2014) in his article entitled, *The Trouble with Medicines' Metaphors* wrote of the danger of the metaphors that we choose to describe illness:

> *The words we choose to describe illness are powerful. They carry weight and valence, creating the milieu in which goals of care are discussed and treatment plans designed. In medicine, the use of metaphor is pervasive. Antibiotics clog up bacterial machinery by disrupting the supply chain. Diabetes coats red blood cells with sugar until they're little glazed donuts. Life with chronic disease is a marathon, not a sprint, with bumps on the road and frequent detours... Military metaphors are among the oldest in medicine and they remain among the most common. Long before Louis Pasteur deployed imagery of invaders to explain germ theory in the 1860s, John Donne ruminated on the "miserable condition of man," describing illness as a "siege...a rebellious heat, [that] will blow up the heart, like a Myne" and a "Canon [that] batters all, overthrows all, demolishes all...destroys us in an instant."*

Because we have internalized these metaphors so much, often we fail to recognize how they influence us. Thus, we must interrogate metaphors and other forms of speech, and rhetoricians and writing scholars need to play a front role in exposing and interrogating ableist metaphors that constantly dominate public imagination.

WAR METAPHOR

The fifth frequently used category of metaphor and perhaps the most controversial metaphor is the war metaphor. While many medical metaphors have been maligned, no class of metaphors has been denounced as much as those of the war metaphor. One of the biggest arguments about the use of military metaphors is that they are dangerous, disparaging, and

harmful (see e.g., Jing-Bao Nie et al., 2016). Susan Sontag (1990) famously denounces the use of

all metaphors in medical discourse—especially metaphors used to illustrate the experience of

having cancer. Based on the data of my current study, war metaphors are, however, useful as

they can serve as a key source for resilience and hope in the fight against dementia. A great

example is the narrative written by Hunter below:

> I am not waiting on a cure or a magical pill to make it all better, I will face anything that Alzheimer's throws at me and shove it back. It is not easy and without tears, but I will not let my Alzheimer's control me without a fight. I need to stand tall and be proud I made it through another day. Tomorrow when I wake up, I will fight the same battle, I get no relief, I can't cry.

Hunter is not the only ones that used the war metaphors as a key source of resilience and

hope. Below are some concrete examples of how war metaphors are used in a positive and

empowering manner to build their confidence in managing dementia by early onset bloggers in

this study.

> Conway: We pick ourselves up and fight together, we become a team.

> Mabel: I believe it is important I make every effort to live beyond the diagnosis, and say to myself every single day; Why die upon diagnosis, when I wouldn't have given up [told to fight for my life] with any other terminal or chronic progressive disease?

> MaryAnne: Another day to battle this, with the realization that every day it gets harder.

> Wilma: The fighting dementia in the mind goes on long after it's seeped deep into our brains, and when, for a moment we win, the screaming emerges, just as it would from me…

> Cherry: This may seem like a trivial thing to be doing, but it is one of the most difficult things I have done since being diagnosed six or seven years ago. It is really tough for me to admit I need assistance. Admitting that seems to be like giving in to the disease, this disease I have been fighting tooth and nail.

Kenneth: I do feel that it's up to us all to keep fighting for as long as we can, because the thought of giving up is a step too far.

What is notable in the examples above is that war metaphors abound, and these metaphors are often viewed and used in positive and constructive ways. War metaphors are also widely used by caregivers although the motive may be different from that of early onset dementia patients. Below are some examples of how the war metaphors are used positively by caregivers.

Caregiver Luna: My new hope is that someday I'll go to D.C. and won't have anything on my agenda except sight-seeing. Until then, I'll wear my purple sash and continue to fight the war against Alzheimer's.

Caregiver Stephen: Everyone recognizes we must fight a war against Alzheimer's, but we are spending money as if we are fighting a backyard skirmish. $100 million more for Alzheimer's research and programs is simply not enough.

Caregiver Hilda: Constantly, we need to modify our treatment plan. It changes like the wind. One day something will work and the next day, it won't. It's becoming more and more difficult; fighting the battle with Lewy Bodies Dementia has compromised my health.

Certainly, there are disconcerting features of metaphorical language. Metaphors may objectify and dehumanize (e.g., body as machine or as battleground) or metaphors may confuse, deceive, and offend. Yet, what is undeniable is that metaphors also open up valuable new perspectives and conceptual language for patients and caregivers alike to talk about ideas and negotiate and manage emotionally frightening situations.

ROBBERY METAPHOR

The sixth frequently used category of metaphor is the robbery metaphor. In this study, the robbery metaphor is conveniently used to cast the blame on what dementia has done to their memories and life as a whole. For example, Rockie described how dementia has left him with a body, but his memory is gone.

My body will be here, but I will be gone.

Dementia is also depicted as the disease that takes away everything. For example, Hunter wrote:

> I love my world and I'm happy living here. I no longer get angry at what Alzheimer's has taken from me and how miserable my life is supposed to be. When you visit, don't get upset because I found happiness living with dementia.

Bobby characterizes dementia as the robber that has robbed him of everything.

> This disease robbed me from working, took away the ability to provide for my family, took away memories, made people who I thought were my friends disappear and many other things associated with having a Disease that is not only invisible but so very, very cruel.

Alzheimer's disease is also personified as a thief. For example, Bobby wrote:

> You're a thief, a thief of the worst kind.
> You rob innocent people, not of material things, but of their most precious memories. You take away their ability to reminisce, to memorize, and not recognize the faces of their spouse, their children, their grandchildren, and friends. You even go as far as taking away their ability to recognize themselves.

Dementia is also regarded as the thief that stole a person's dream as Mabel wrote:

> Dementia stole many of my (our) dreams.

All the metaphors used above "gone," "robber," "taken," "thief," "stole" are examples where the bloggers (in this case, early onset bloggers) feel that they do not have control of the situation. Lack of control is common in loss experiences, especially when the loss was unexpected. It turns out that early onset bloggers were not the only ones using the robbery metaphor. Caregivers also employ similar robbery metaphors to speak about how dementia has stolen their loved ones from them. For example, caregiver Luna wrote:

> When Jim developed dementia at forty-nine, we knew life would never be the same. Our memories eventually became my memories. The disease stole Jim from me, but it could not steal the indelible mark he left behind.

For caregiver Sheila, AD is not only a robber but a thief that robbed the world of innocent

people's lives. She wrote:

> Alzheimer's disease is no less of a robber, just because the victim was much older than
> Bob and "Al." The disease is a thief of life, it robbed the world of a beautiful, God filled,
> servant filled, life.

Monster Metaphor

The seventh frequently used category of metaphor is the monster metaphor. This

metaphor is typically used to describe the dark side of life with dementia. This was demonstrated

in Hunter's blog:

> We try to stay positive and stay away from reporting the ugly dark secrets of dementia
> but when you come in contact with the hopeless faces living with dementia, I feel we are
> not helping the very people that experience the same things I do, that are unwilling or
> unable to talk about it.

The monster metaphor is also used to depict the horrible nature of the disease as

illustrated in Cherry's blog: "Laughing While I Still Can. Frontotemporal Dementia is a horrible

disease." The same monster metaphor is also used by caregivers to expose the dark side of the

disease and the impact it has on their emotional well-being. As caregiver Stephen detailed in his

blog:

> I must make changes in my life to lead a healthier and more productive lifestyle and I
> cannot let myself dwell in those "dark places" to think about what might have been, or
> should have been, or what will no longer be. I now must fully internalize 5 words I have
> said so often these past few years ... "it is what it is."

The notion of dementia as a monster captures the sinister nature of the AD. Indeed, AD is

 a monster because it deprives those afflicted by the disease a chance to live a normal life.

STORM METAPHOR

The eighth frequently used category of metaphor is the storm metaphor. A number of the

early onset AD bloggers in this study identify with the storm metaphor because it allows them to

capture the unpredictability nature of dementia. As demonstrated in Hunter's blog:

> My life is like the weather, I can have a violent storm one day and the next, a calm sunny
> day.

Storms are incredibly powerful and unpredictable. Some storms are worse than the

others. One thing that is sure about storms is that they don't last forever, the same can be said

about dementia attacks. There is always hope and there are always blue skies ahead, and

dementia patients just have to keep going. This determination to keep going despite the storm

was exhibited in Mabel's blog below:

> In between the sadness and the deterioration of symptoms, many people with dementia
> continue to live reasonably well, in spite of dementia. With any terminal disease or
> chronic illness, there are bad days, but not every single day is always like that.

> Storm metaphor was also found in the caregiver's blog. For example, caregiver Luna

identified with the storm metaphor wherein she wrote:

> Caregivers have a lot of rainy days. It seems that down days come in clusters.
> Rain, and bad days, may seem like they are going to last forty days and forty nights. Just
> about the time you think you should get started on that Ark; the rainbow brings the
> promise that everything is going to be alright. Next thing you know, the sun pops through
> and dares those dark clouds to show their frowning gray faces.

> Alzheimer's disease is the perfect storm that can strike anyone without warning.

Awareness is key to help those who are afflicted with the storm.

GAME METAPHOR

The least frequently used category of metaphor is the game metaphor. The outcome of a

game is that there is a loser and a winner. To play a game, one must be willing to accept the

circumstances imposed by the game. The same can be said about AD. Dementia, wrote Conway:

> It's just a waiting game, with a bit of life thrown in just to remind you what the illness is doing to you!

For Bobby, having AD is like playing a game of cards. He wrote:

> Living with Alzheimer's is not the way I wanted to spend my retirement; however, I've made the decision to play the cards I've been dealt. Although the cards are not stacked in my favor, I'm still going to bet on the positive.

Surprisingly, I could not find any evidence of game metaphors being used by caregivers

in this study. The findings of this study highlight how important metaphors were in framing of

illness and in making sense of experience living with AD. While it is undeniable that they are

potential pitfalls of metaphorical language in illness, carefulness about language can be

confining when it comes to describing actual experience. Wishing to find metaphors powerful

enough to capture the emotional experience of illness and disability, some bloggers in this study

even embraced language that is often dismissed as demeaning and prejudicial. What these

bloggers are interested in is the language that conveys the reality of physical damage and the

intensity of the experience of illness and disability. And in the face of wordlessness, metaphors

give them the language to capture these realities.

CHAPTER 5

DISCUSSIONS AND CONCLUSIONS

This chapter discusses the key findings of the study as it relates to the research questions presented in chapter 3. Addressing these research questions helps to fill a research gap that includes our understanding of the use of social media by early onset bloggers and those who serve as caregiver to late-stage AD patients, the use of language especially metaphors in meaning making process in the discourse of AD, and healthcare communication practices. The gap exists in part because of the quickly changing technological advancements of social media platforms like blogs, cultural differences in meaning making especially as it relates to AD, and the increasingly market driven, clinically distant health care practices which privileges science of a diagnosis that often times are far removed from individual experience and lacks an empathetic understanding of the individual sufferer's voice.

Metaphors in the Discourse of AD and its Contribution to RWS

The prominent use of metaphors in the narratives of both early onset AD bloggers and caregiver bloggers in this study, notably shows just how important and integral metaphor is in conceptualizing, conveying, and expressing meaning. On average, each participant in this study produced 403 metaphorical expressions in their narratives. The key finding presented here is consistent with arguments of many scholars and health professionals who note the essential importance of metaphor in how people talk about and cope with the emotional and psychological struggle with terminal illness. A discourse analysis of all 10 early onset blog narratives included in this study, suggests that all 10 bloggers view dementia not as a random, meaningless event, but rather as an event holding significance, meaning, and potential for intellectual and emotional growth as expressed in their blog narratives. The deployment of metaphors in both language and

thought enable these early onset bloggers to find that deep meaning in a deeply personal way, yet

also in a manner that can be easily understood by those who suffer from the disease as well as

those who have not suffered the same disruption in their lives.

A thorough analysis of the metaphors that appear in the blog narratives of those early

onset bloggers included in this study also revealed how sometimes contradictory metaphors are

also employed to transform illness into meaningful experience. Simply put, no single metaphor

alone can capture the complexity of the individual's thinking and experience with dementia. This

is elaborated in Mabel's narrative:

> Every single day, I want to stop fighting to stay as positive as possible for as long as possible, and stop fighting to remain as many levels of independence as possible, by developing new strategies and working hard to accommodate my increasing cognitive and other neurological and spinal disabilities. Sorry also for the war metaphors… advocacy feels like being at war most days. If I gave up focusing on remaining positive and independent, I'd sit down and cry all day.

> Every day. So would my husband. In fact, he said to a friend recently, that when people ask him what it's like to live with a wife with dementia, he simply says, "you really don't want to know." But then, if we did that, we would fit the stereotype of dementia from the 20th Century, rather than the new and emerging 21st century way of living more positively and speaking publicly about it, because we are not ashamed of this condition, and in many cases, we choose to see the gifts of dementia instead.

As can be seen from the above example, multiple metaphors are used to make sense of

the different aspects of adapting and learning about being ill, treating disease, and healing. An

important observation about conceptual metaphors that should be noted here is that many of their

source domains are grounded in patterns of bodily experience hence the term embodied

experience. For example, the way we talk about life as a kind of journey refers to the very

embodied experience of people moving from starting point, along a path, to reach, or attempt to

reach some destination. In other words, the metaphor that people used to talk about their

experience is not just random, but rather, the metaphors emerge from concurrent activation of bodily sensation combined with cognitive concepts which guide people's concept.

Another key finding of this study is that the use of disability metaphors promotes the idea of impairment as a negative form of embodiment and othering. Disability as metaphor can take several forms. A classic example of disability metaphor is the term dementia itself. Coming from the Latin word *demens*, meaning "without mind" the term dementia evokes a negative connotation (Merriam Webster online dictionary). This negative connotation in turn gives cue to stigma and stereotypes. The findings of this study testify to the destructive impact of negative metaphors on individuals. For instance, Hunter wrote concerning stigma and labels:

> Stigma is the use of negative labels to identify a person with a disability or illness. When you live with Alzheimer's you are labeled with so many different labels
> A diagnosis may test friendships. Friends may refuse to believe your diagnosis or withdraw from your life, leaving a feeling of abandonment or isolation.

Because language is a powerful tool that can be used to oppress and marginalize others, it is important that we pay attention to the language we use when talking about dementia as our metaphors not only can influence how we treat or view people with dementia, but it also has the propensity to influence how people with dementia view themselves. Subjective words like "burden" and "victim" are also demeaning and derogatory and position people with dementia as difficult people to deal with. Rhetoricians and writing scholars alike have a responsibility to strive to develop ways to write and talk and rescript the negotiation of norms related to disability, especially disability related to dementia. We should, as Dolmage (2006) recommended employ *metis* that is the rhetorical art of cunning, the use of embodied strategies, what Certeau (1984), calls everyday arts, to transform rhetorical situations (p. 2). In a world of change and chance, *metis* is according to Dolmage (2006), is what allows us to craft available means of persuasion. Filtering our understanding of disability through the concept of *metis* points Dolmage (2020) can

106

"provide a model for the ways we might repurpose tensions around bodily values, recognizing the stigmatization and effacement of bodily difference, yet also mobilizing new stories and new expressive possibilities" (para 10).

Far from being just a mere embellishment, the use of metaphors in the bloggers' narratives, I observed, present meaning and help them make meaning. This current finding is consistent with Sontag's (1991) finding. In her seminal work, '*Illness as a metaphor and AIDS and its metaphors,*' Sontag (1991), explored the meanings that have been ascribed to TB, cancer and AIDS and the attendant psychological, social, and cultural impact of that meaning making. She observed that public discourses surrounding the disease powerfully shape the experience of those illnesses, including the dread created by the metaphorical language used to characterize those diseases. This powerful language she claimed divides those diagnosed, from the rest of society, the inhabitants of the "kingdom of the well" from the "kingdom of the sick" (Sontag, 1991, p. 3). Deepening this divide are symptoms that instill fear and confront us with the unpredictability and uncertainty of the human condition (Kleinman, 1988, p. 20).

Meaning making processes relating to illness Sontag (1991) has observed, are forged in social and cultural contexts, and consequently have strong relational elements. As meaning is shaped by connections with others, (Bryden, 2018; Robertson, 2014), a person's search for meaning as they live with dementia is impacted by their community in significant ways. That is why it matters that we become aware of the role of language around dementia. For example, in this study, Mabel, a prominent advocate for dementia friendly language, asks us to reconsider the phrase "suffering from" dementia versus "diagnosed with dementia" dementia. She wrote:

> Living with dementia, means I, and about 50 million others with dementia, regularly have to put up with a great many negative and disrespectful labels, including:
> Sufferer of / Suffering from dementia (I suffer from many things, but dislike being described as a sufferer of any of them.

The phrase "suffering from" she wrote is negative and disempowering. While we do not find out why being diagnosed with is presumably empowering, it is clear that the term "suffering" is an unwelcome term in the dementia context. Byrden (2015), also an advocate who herself was diagnosed with early onset dementia in 1995, similarly asserts that the term "sufferer" is "depersonalizing" and threatens the person with dementia's "dignity" (p. 224). This general concern with depicting an individual as suffering and sufferer is also reflected in the international guidelines, example, Alzheimer Society of Ireland, 2015. Regardless of the appropriateness of the language used in the discourse of dementia, the insights derived from the findings of this study represent a substantial contribution to our understanding of how conceptual metaphors work and how meanings are negotiated. Metaphorical visualizations of disease in this study provide unique insights, both psychologically and biologically into what people experience when they are ill. Notably, this study also found that culture can play a big role in shaping the particular metaphors employed to express one's thoughts about illness and different healing rituals. My findings are consistent with past studies conducted by (Kirmayer, 2004; Kimayer & Ramstead, 2017; Pritzker, 2007).

A significant reason why metaphor emerges in illness narrative is because people ordinarily reason via embodied simulation processes in which they imaginatively project themselves into different real-world situations, such as imagining one's struggle as a storm or as running against the wind. These simulations can play a critical role in therapeutic interventions to help those who are sick and in distress. The rich data accrued through the blog narratives included in this study contribute to our deeper understanding of how metaphors are used in meaning making and the powerful pragmatic nature of metaphor in conceptualizing human experience. I believe one very important contribution that this study offers us is that it sheds light

on what motivated early onset dementia patients and those who serve as caregivers to write and

to keep blogs. For Wilma for example, blogging was one way for her to record her thoughts

before they are lost and to create awareness about dementia:

> I've started this blog to allow me, in the first instance, to write all my thoughts before they're lost. If anyone chooses to follow my ramblings it will serve as a way of raising awareness on the lack of research into Alzheimer's. It will hopefully convey the helplessness of those diagnosed with dementia, as there is no cure – the end is inevitable. However, I'm also hoping I can convey that, although we've been diagnosed, people like me still have a substantial contribution to make; we still have a sense of humor; we still have feelings. I'm hoping to show the reality of trying to cope on a day-to-day basis with the ever-changing environment that dementia throws at those diagnosed with the condition. What I want is not sympathy. What I want is simply to raise awareness.

Blogs are frequently described as "distinctly social" (Lomborg, 2014, p. 15). Much like

phones, they are direct facilitators of interaction, but unlike other social media (for example

Facebook, where users can connect with friends with whom they have an offline contact)

interaction on blogs does not build on pre-established relationships. Instead, interaction occurs

between strangers whose interests overlap. The most obvious form of interactivity is when blog

authors enable commenting and respond to readers' contributions as reported by Lindsey:

> I find joy in every comment from a caregiver saying how much a post helped them relate to their loved one, in every comment from a PWD saying how much it means to them and also with every blog that is shared. As I pray for each person who comments about the struggles – I am happy to know I can still make a difference.

Aside from the interactivity features, blogging can also offer the individual a sense of

control and connection as well as a tool to track the individual's progress. As Mabel detailed in

her blog:

> I know my husband and some of my family and friends also use my blogs as a way of keeping track of what is happening, and how I am doing. It is not always truly indicative of my daily reality, as often I post blogs I've been working on for days, weeks or months, and therefore they don't necessarily tell the reality of my lived experience of dementia that day. However, this blog does act as a thermometer for me, as it quickly tells me in a tangible way how much I have to paddle to get through my day. Perhaps blogging (or writing/voice

109

recording) could be used in dementia units and respite programs to better inform staff and families how someone is coping or managing, and as a way of gauging, to better assist with care, where a person is at on any given day. It would be wonderfully therapeutic for the person with dementia too.

Regardless of the reasons behind why early onset dementia patients' blogs are significant, one important value of studying blogs is that it gives writing researchers direct access to bloggers' voices. The examples above highlight the complex ways that writing sustains individuals and how writing allows them to reclaim their voices from the biomedical narratives imposed upon them by modern medicine (Charron, 2006: Frank, 1995). This study also contributes to a deeper understanding of how writers' bodies matter (Hass & White, 2001; Owen & Ittersum, 2013) specifically by drawing our attention to "embodied experience as a way of knowing—as theory in and of itself" (Siebers, 2010, p. 14).

Metaphor, Knowledge Production, and Individual Course of Action

One of the most powerful forms for expressing suffering and experiences related to suffering is narrative. When people become ill, they question and respond to the world in a way that they did not before. Thus, for the writer, the creation of an illness narrative is a way of synthesizing the illness experience. Nussbaum (1990) wrote that literature can provide important questions about what it means to be a human being and live a human life:

> A view of life is told. The telling itself - the selection of genre, formal structures, sentences, vocabulary, of the whole manner of addressing the reader's sense of self - all of this expresses a sense of life and of value, a sense of what matters and what does not, of what learning and communicating are, of life's relations and connections. Life is never simply presented by a text; it is always represented as something. This "as" can and must be seen not only in the paraphrasable content, but also in the style, which itself expresses choices and selections, and sets up, in the reader, certain activities and transactions rather than others. (pp. 5-6).

Writing about their illness not only allows the bloggers to use their texts to represent what they have gone through, in writing about their experience, they come to recognize and make sense of what they know. In the process of writing, knowledge is transformed into understanding as the individual is forced to confront and rationalize an aspect of his/her world.

Metaphor is a significant part of how people talk about their lives and the world around them. In illness experience, conceptual metaphor provides "the intellectual and linguistic tools for communication about senseless suffering, and yet also offers a plan for personal transformation in coping with illness" (Gibbs & Franks, 2002, p. 141). The key finding of the present study strongly supports this claim. This is detailed in the narratives of the bloggers. Consider the narrative written by one early onset blogger below:

> Reliving the actual moment of any painful experience is agonizing, and takes a lot of energy, and Metzger recommends writing as a way to heal. I have found this to be true and have been 'writing for my life' for almost 50 years. When I was a child, I often used to hide in the bathroom to write on toilet paper, as it was a way for me to express myself, something that was not encouraged, but rather frowned upon. We were told to be "seen and not heard" as children. Writing meant I could get out what was upsetting me, and then flush it away so there was no chance of my words hurting others. Writing does heal, and it has allowed me to manage every difficult experience, to navigate my way around it and through it in order to not only understand it, but to find ways for it to make me stronger and more resilient.

> Writing about the painful stuff does not mean you have to share it with others, although doing that helps healing as a shared burden is one that is reduced through the act of sharing. The expression of pain is what helps and writing about it privately allows you to sift through things and heal, and sometimes you won't need to share at all. Sharing burdens, as well as the good times is what I had once thought my really good friends and family would want to do, but this is not always so.

> Therefore, healing yourself must be your responsibility. Finding ways to heal is difficult, even accepting there are things we have been through that need revisiting and healing is confronting. I liken writing about your inner pain to having a badly infected wound, and the only way to heal is to get the pus out. If I had not written throughout my life, the "silence" would have hampered my existence, hindered my ability to get up every time I fell over, or my chance of "healing the pus."

Metaphor in illness narratives notes Scott (2002) makes the experience intelligible and "connect individual illness to collective experience" (p. 234). Thus, what is difficult to express, is made expressible through the use of metaphors. People tend to conceptualize their metaphors based on things they know, value, and are familiar with and are thus able to arrange and order their experiences in personally meaningful ways. Language propagates ideology; therefore, language is ideological. Metaphor shares the socio-cognitive aspect of ideology by reproducing it through discourse. Fairclough (1995, p. 73) argues that "language is a material form of ideology, and language is invested by ideology." He locates ideology in language in lexical meanings, pre-supposition, implicatures, metaphors, and coherence (p. 74). Similarly, Wolf & Polzenhagen (2003, p. 268) conclude from a study of the ideological basis of metaphor that "global ideological patterns may rise from the application of a particular metaphor and the neglect of alternative ones." Lakoff & Johnson (1980) state that metaphor is not mere language and literary devices, as metaphorical descriptions reveal important insights regarding our thoughts, feelings, and actions. The findings of this study also strongly support that claim. In particular, I found that the ideological metaphors used in the narrative shed light on how individuals and groups produce knowledge, meaning, understanding, identities and the courses of action they take about health and illness. Consider the blog narrative written by one early onset writer:

> I try to wear a smile and stay positive. I want to be an example of someone fighting this disease and never giving a thought to giving up. I want to help others get through the rough times and help them carry their load. I am not a martyr or looking for praise. I feel it is the right thing to do and I need to pay back for having such a blessed life.

> When I started out on this journey, I never thought I would have to look at myself and see the real me. At times I don't like the person looking back but that only reminds me that I have not learned my life lesson and need to try harder. I feel I am in training for the late stages of my disease. Before I reach the point of no return and I am lost forever, I need to reach the plateau of complete inner peace. I need to like and be proud of the person I have become. I could never find peace with how much money I make or how many kudos or trophies I have. I will find my peace when I am able to look in someone's eyes and see my hard work looking back.

112

I know I am losing my battle and slipping away but I also realize my plateau is within my reach. When I fall into my valley of despair, it takes me longer to climb out and I don't climb as high as I used to. Don't feel sad for me because I am ok with this.

I see the signs and denying them will not help me. I will continue to learn about finding my inner peace and when I finally achieve it, you may not notice it, but look into my eyes and you will see.

The narrative above offers a rich description and detailed insights about the blogger's experience with dementia. In the first paragraph of his blog narrative, the blogger narrates how he wants to stay positive in spite of the fact that he knew his condition was untreatable, he spoke about his desires to advocate for others which indicates that he is fully aware of his condition and the course of action that he is taking. In the second paragraph, he illustrated how he understands his diagnosis as a journey and how his disease forces him to re-evaluate who he is and the priority in his life and how those experiences have shaped him to be a wiser person and how the experience in itself becomes a lesson for him to prepare for his next journey with dementia. In the third paragraph, he spoke about his journey as a point of no return which suggested that he understands that there are no signs of improvement, that he will eventually succumb to the disease. But what matters to him is that the impression that he has left on those he has taught is a positive one. The fourth paragraph is so poignant, he repeated how he is losing the battle and slipping away but giving up is not an option. The repetitive use of finding inner peace is not accidental but a deliberate rhetorical strategy to draw our attention to the core idea of his message. Lakoff and Johnson (1980) state that conceptual schemas organize our knowledge about perception of reality. Our minds contain models about some aspect of the world that we use to comprehend our experience and reason about it. The central insight of conceptual metaphor theory is that schemas and cognitive models that organize our perceptions grow out of structures developed in relationship to our bodies: bodily experiences are projected into mental

operations hence embodied knowledge. Each linguistic expression above refers to a different correspondence that arises from mapping of familiar understanding of spiritual journeys into a more abstract idea of inner peace relationship. The journey to inner peace is the journey into yourself and to your spirit. It is a journey that requires you to learn how to quiet your mind. In the process of cultivating inner peace you cultivate mental strength, will power, self-discipline, and control of your thoughts. The journey is not without obstacles but when you know its importance and the benefit it can bring you, the journey becomes bearable and pleasant. Here, we can clearly see how critical conceptual knowledge is conceived through the reflection process.

Dementia frequently challenges the path the early onset bloggers travel, but when one's life journey is challenged by illness, alternative pathways sometimes open up to help individuals move forward and accept what they cannot change. While people who do not have dementia focus on what people with dementia cannot do, those who live with dementia focus on what they can do, and this makes a big difference in how they manage their shortcomings and identity. The bloggers' creative use of writing and the way they spun different metaphors to describe and capture different facets of their illness experience and the road to acceptance provide insights into our understanding of how knowledge, understandings and meanings are produced as well as how identities are sustained and managed. Here the narrative becomes an essence in the world which enables the ill person to take that part of the self– the illness – and place it beyond the whole self where it can be objectively perceived by the writer. Writing about the illness and placing it out in the world gives the writer the ability to perceive the illness as a thing in the world. As Merleau-Ponty (1989) in *Phenomenology of Perception* points out:

> Our own body is in the world as the heart is in the organism: it keeps the visible spectacle constantly alive; it breathes life into it and sustains it inwardly, and with it forms a system. When I walk around my flat, the various aspects in which it presents itself to me could not possibly appear as views of one and the same thing if I did not know that each

of them represents the flat seen from one spot or another and if I were unaware of my own movements, and of my body as retaining its identity through the stages of those movements. I can of course take a mental bird's eye view of the flat, visualize it or draw a plan of it on paper, but in that case too I could not grasp the unity of the object without the mediation of bodily experience ... (p. 203).

Through the process of writing and putting it out there for the world to see and witness, the ill person also gains more integrity of the self because the fragmentation is being mediated by the order of the narrative. The illness becomes synthesized and visualized into something new (a narrative). Ultimately this is not to say that the illness suddenly goes away. What has changed is the perception about the illness and the suffering.

In her book, *Narrative Medicine: Honoring the Stories of Illness*, Charron (2006), confronts the issue of the body and its relationship with the world:

> The body defines the self from the inside, but the body does not define the self to the outside. There are two bodies; the one lived in and the one lived through. One body absorbs the world, and one body emits the self. Poised between the world and self, the body simultaneously undergoes the world while emanating to that world itself. Or again, the body is simultaneously a receiver with which the self collects all sensate and cognate information about what lies exterior to it and a projector with which the body declares the self who lives in it. The body is in the copulative position between the world and the self. (p. 88-89).

The significance of what Charron (2006) is trying to say with the statement above is that if there is a give and take between the world and the self that uses the body as mediator, then an ill or injured body would break down this system. The self and its relationship to the world become disrupted. The telling of the story through illness narrative is one way for the self to put order back into this relationship of self, body, and the world. Narratives order one's life because they have a specific beginning, middle, as well as an ending. Narrative also shapes identity by allowing people to reconstruct the disrupted life. The stories that people tell — to each other, to themselves — shape the meanings that they give to their own lives and the communities. This

shaping of identity is intimately tied to the storylines that a particular society makes available and desirable to its members.

What is clear from the findings of this study is that if we strip off metaphors away from the language in the conceptualization of illness, we deprive humans of self-awareness, meaning, emotional comfort, and potential growth (Kirmayer, 1993). Metaphors as I have asserted early on in this dissertation, are indispensable modes of communication. They are crucial to the way we discern insights about ourselves, produce knowledge, understanding and meaning making, learn to better relate and interact with others, and feel a sense of control over our lives. The use of metaphor, as this study attests, may help the sick to heal because "healing may occur not because a conflict is accurately represented, or even symbolically resolved, but because the metaphorization of distress gives the person room to maneuver, imaginative possibilities, behavioral options, and rhetorical supplies" (Kirmayer, 1993, p. 195). The findings of this study provide strong support for a deeper understanding of metaphor's role in human thought, feeling, understanding, and action, including experience of illness and healing as well as the shaping of identity and the courses of action that they take in illnesses. In particular, the metaphorical descriptions, and visual depictions, of body and bodily disturbances reveal important insights about people's understanding of their illness and bodily disorders. Each person has their own subjective experience of being ill and listening to patients speak in their own terms and in the confines of their environment and are critical to recognizing their unique understanding about what is happening to them.

Lesson learned from Ideologies that are Expressed Through Metaphors

Based on the findings of the study, it is fair to say that metaphoric expression offers early onset bloggers and those who serve as caregivers to late-stage dementia patients a highly

116

evocative and effective means of expressing bodily felt emotions that are inchoate and otherwise

not easily rendered by literal communication. Simply put, without metaphor it is nearly

impossible to adequately render the emotional richness and complexity of our life experiences as

told stories, especially in moments of crises and distress. This is especially true when patients

first learn that they have been diagnosed with terminal illness like AD, as can be discerned in

Conway's blog narratives.

> The worry through the diagnosis procedure, the worry about what was happening to me.
> The Worry I had trying not to worry about the worry!
> When the diagnosis did come, that was the biggest worry, but not for me.
> My poor wife and children are going to have to deal with the worst! The late stages when
> I won't remember, when I might not know them or even care!

Receiving this kind of diagnostic news, certainly can have a devastating impact on the

individual's basic feelings of security and safety in the world and may directly challenge core

assumptions about who they are, the kind of lives they live, and what their future will be. It is as

if the trajectory of their own self-identity narratives has been hijacked and shattered by a

menacing and unpredictable life force that has plunged them into an unfamiliar world of medical

uncertainty, difficult treatment, and courses of action, and imminent death. Sontag (1978, p. 3)

captures this profound impact on identity when she states: "We all hold dual citizenship in the

kingdom of the well and the kingdom of the sick. Although we all prefer to use only the good

passport, sooner or later each of us is obliged, at least for a spell. To identify ourselves as

citizens of that other place."

The significance of metaphors in expressing complex emotional states, especially

emotional and physical pain is well documented in past research (see e.g., Sontag 1978; Gibbs,

2004, Deng et. al., 2021) as well as in my present study. In particular, my research found that

metaphors provide important insights on how individuals and groups produce knowledge,

meaning, understandings, identities and the courses of action they take about health and illness. It is beyond the scope of this study to list all the examples of what rhetoricians can learn by studying the ideologies as they are expressed through the narratives and metaphors used by authors with early onset AD patients as well as those who serve as caregivers to late onset Alzheimer's patients. In this study, I focus on two specific examples of what rhetoricians can learn from the ideologies as they are expressed through the narratives and metaphors used by authors with early onset AD as well as those who serve as caregivers to late onset Alzheimer's patients:

I. Rhetoricians can learn how early onset AD patients and caregivers construct their world of illness through the metaphors that they used.

II. Rhetoricians can learn from the bloggers' narratives what lies outside the domain of the biomedical voice in addition to the rhetorical strategies that they employ to tell their stories.

Rhetorician can learn how AD patients and caregivers construct their world of illness through the metaphors that they used.

METAPHOR AND THE LANGUAGE OF PAIN

Paying attention to the language used by patients and caregivers and, in particular, the use of metaphorical language, allows rhetoricians to understand their world and have a wider understanding of not only the biological aspect of the disease, but also the illness experience and the social aspect of the sickness. When patients and caregivers tell their stories of their experience and suffering, they assume an active role. As their narratives unfold, they gain a better understanding of their own situations, which become more comprehensible, more explainable, and therefore more acceptable. Coulehan (1997) wrote, "In medicine we think we

live in a world of facts, something that simply happens, but the world of humans is actually a world of symbols. Care cannot be deprived of metaphor, image, symbol, meaning and interpretation. People experience meaning in their lives and illnesses; they (like all of us) experience themselves as characters in a life narrative; they seek patterns of meaning and symbols to make them complete" (pp. 99-110).

In the quest to find a word powerful enough to capture the true emotional experience of illness, many writers, including early onset dementia bloggers as well as those who serve as caregivers, embrace metaphorical language that is often dismissed as prejudicial or demeaning. For instance, one early onset blogger in this study called AD as a "grim reaper;" another blogger describes AD as the "pits of hell;" one other male blogger describes having AD as a "jolt of lightning, that just went bang and comes out from nowhere;" yet another male blogger describes dementia as a "slow burn." While these metaphorical terms may sound unrealistic, they provide the individuals the means to convey the reality, physical damage, and intensity of the experience of illness and disability that they feel. The examples above are illustrative of the situation that many early onset dementia patients find themselves in when describing their bodily experience. Lost in translation, metaphors became the only means to describe bodily sensation and experience that ordinary language otherwise fails to adequately provide.

METAPHOR PROVIDES THE LANGUAGE TO NAME THE UNNAMABLE

Elaine Scarry (1987) explores why physical pain so eludes description. She attributes the extreme dissonance that exists between the person who is suffering and other people due not to the self-absorption caused by pain, but to something in the nature of pain itself, namely, that one person's pain cannot be seen by the other. It is simply not available to any of the other senses. She wrote "When one hears about another person's physical pain, the events happening within

the interior of that person's body may seem to have the remote character of some deep subterranean fact, belonging to an invisible geography that, however portentous, has no reality because it has not yet manifested itself on the visible surface of the earth" (p. 41). While people feel love or hate for someone, that is not the case with pain. Scarry (1987) argues that "it is precisely because it takes no object that it, more than any other phenomenon, resists objectification in language" (p. 41). When words are inadequate to express suffering, metaphors can fill the void.

METAPHOR FUNCTIONS AS LANGUAGE FOR EMOTIONAL SUFFERING

In her essay *On Being Ill*, Woolf (1993) reflects on the question of language and the limitation of language in illness. She explains that a person who is ill, "is forced to coin word himself, and, taking his pain in one hand, and a brand-new word in the end drops out" (p. 52). Woolf's observation seems to hold true. In this study, I observed that both early onset dementia patients as well as those who served as caregivers to late-stage AD patients often come up with unthinkable metaphors to express their emotional experience with the disease. For instance, one female early onset blogger coined the term "fickle disease" to describe what having Frontotemporal dementia is like. Another female blogger came up with the term "watermelon" to describe her life after being diagnosed with dementia. Why 'fickle disease," and why "watermelon?" I believe that it is because those words hold significant emotional meaning to the experience of the individual.

METAPHORS AS CONNECTION BETWEEN BODY AND SELF

Because of its ability to suggest both literal and figurative meanings at once, some writers use metaphors to depict the interplay between experience of the body and of the self in illness and disability. In her blog, Mabel refers to dementia as the invisible disability because people

with dementia are still being excluded from the various rights that other disabled people are

entitled to. Dementia is literally an invisible disease because it does not have a physical marking.

But just because it is not marked, it doesn't mean the disease is not there or the effect of the

disease is not there. When you say you are invisible, metaphorically you are saying you are being

ignored. In the context of dementia, because of the invisible nature of the disease, the experience

is often dismissed and excluded. The expression "invisible disease" when used alongside

dementia point to the literal and metaphorical descriptive of the emotional situation of the

disease. The famous doctor and author, Oliver Sacks (1998), titled his book *A Leg to Stand On*

because the metaphor provides a powerful description of the literal reality of his physical states.

Both Mabel and Sacks chose metaphors that points to their actual physical situation and then

moves from there to suggest something about their experience living in the body.

METAPHOR AND THE LANGUAGE OF THE DYING

Being diagnosed with a terminal illness like AD where death is imminent certainly

involves confrontation with the limits of language. Overwhelmed with anguish at the prospect of

dying, many early dementia bloggers rely on metaphors to describe their suffering. As one

blogger wrote:

> People turn cold when dealing with Alzheimer's. Spouses abandon their loved ones.
> Friends abandon friends. Why are people so cruel?
>
> I know that everyone who has Alzheimer's is different and declines differently and at
> different rates and speed. I know that the brain atrophies in this disease, and that is the
> reason for the changes. Two years ago, I had a mild cognitive impairment. It has
> progressed to full blown Alzheimer's and progressed rapidly. I am scared. I know that I
> am dying. This is a new year, and I've been experiencing the changes that come with late
> moderate stage. Nonsensical speaking, talking to myself, great difficulty walking, I
> lumber along and often shuffle, difficulty chewing and swallowing. Now I have difficulty
> getting up from a seated position and often need help to stand up.
>
> I try to think, but most thoughts are gone, the ability to think things through is gone.
> There is mainly emotion. And now I am devastated because the only friend I had will

never see me again. The only relief is when I am asleep, but I don't sleep for over 5 hours, and often 3. The last time I had 7 or 8 hours of sleep was over 3 years ago. I have prayed to God to take me, and then been so scared when it feels like I am actually dying. When it's been hard to breathe, when tight bands constrict around my chest and I feel like I'm having a heart attack (this happened the other night in bed and I cried to God, "can't you take me without causing pain?" I get scared. I'm gradually regressing to an infantile state of mind. Babies don't think, they feel.

Descriptions of dying can be powerfully evocative. Such descriptions, however, are highly dependent on the images created by the words and not the words themselves to convey a feeling about death and dying. Nonetheless, as writers struggle to find language for their pain and suffering, we learn from the ideology as expressed through their metaphors and narratives a great deal not only about the difficulty in communicating pain in the face of death, but also the nature of illness itself. As Scarry (1987) makes so clear the pain of one is not readily accessible to another. Words can fail us in the face of suffering. It is for this very reason that some of the bloggers (both early onset and those who served as caregivers) in this study turn to Biblical texts and other literary passages while others resort to metaphors to express their feeling and communicate their experience. In the very act of struggling with language they do something very important: They bring to us through their narratives and metaphors the experience of frustration, loneliness, fear, and futility that the ill feel when they cannot communicate. And in those very moments, they soar beyond those limits by the very act of putting into words this very experience of limitation. As can be seen from the many examples presented throughout this dissertation, bloggers employed excessive metaphorical language which conveyed their meaning through powerful visual imagery and the evocation of strong feelings. By these means they are able to dramatically represent deeper experiences of living with dementia. The same can be said about those who served as caregivers to those with late-stage dementia. Looking beyond the literal meaning of a person's communication is very important.

122

Kitwood (1997b) argues that researchers and clinicians need to employ imaginative and intuitive sensibilities in their work in order to understand the important and overlooked aspects of a person's communication. This, he maintained, would be possible when we paid attention to "metaphor, oblique allusion as well as verbal and nonverbal registers" (p. 15). In this way, we can move beyond neurological issues and literal meanings to a more complex understanding of the person's experience with dementia.

Scholars in rhetoric and writing studies in particular need to pay more attention to metaphors because the ideologies expressed through these metaphors carry meaning. We do not simply talk in metaphors; metaphorical expressions impact our conceptions of reality and guide our thinking and actions. As such, they provide a rich insight into key aspects of an individual's life and cultural process, which Johnson and Lakoff (2003) highlight when they say our whole thinking is metaphorical in nature. This is especially true for the person with early onset dementia patients/blog authors. In moments of chaos and uncertainty, metaphorical language helps them convey feelings—and I add emotions—that are "authentic," and "raw" when insights and powers of expression converge (Killick, 2005, p. 22). In other words, metaphors serve an important meaning making function.

For many blog authors in this study, including those who served as caregivers to late-stage dementia patients, the use of evocative metaphorical references to the nature of dementia, such as the examples provided below, served as a powerful image that conveyed the deep sense of life as they knew before it was being abruptly and irrevocably severed.

> How dementia is causing me chaos with numbers….; Experiencing Dementia Daze is like digging for a coin in a muddy swamp on a foggy day – everything is murky and unclear; FTD is a fickle disease. It is fickle in many ways which makes it worse. It also chooses when to make the symptoms flare up with no discretion. The symptoms often conflict with each other, and I never know which one is going to win the fight to control

me each day; My life is like the weather, I can have a violent storm one day and the next, a calm sunny day.

Drawing on the theory of rhetorical listening as proposed by Ratcliffe (2006), I implore scholars and teachers of rhetoric and writing studies to engage in rhetorical listening where illness metaphors and narrative are concerned. This more interpretive approach to listening to an individual as they seek to find meaning in their narratives through symbolism and metaphor can yield a richer picture of a person's illness experience. This form of communication has limits though. It is only useful if the listener is able to apprehend how the story acts as a metaphor and the meaning of those metaphors. The stories and narratives need to be understood within their contexts, and attention needs to be paid to repeated themes. It is important to note that any analysis by listeners should be tentative and guided by the narrator and their experiences so that it is a truly shared act of meaning making (Cheston, 1996, 598). To apply the rhetorical listening as proposed by Ratcliffe (2006), the reviewer shifts from competing for mastery to an open apprenticeship with the author. The first step in such an effort—promoting understanding of self and other— ''means first, acknowledging the existence of [the other's] discourse; second, listening for (un)conscious presences, absences, and unknowns; and third, consciously integrating this information into our world views and decision making'' (p. 29). Rhetorical listening encourages recognition of such different discursive locations and requires receptivity and conscious consideration. In considering how people with dementia communicate their meaningful insights, such performance of narratives conveys potential information and additional meanings that are important to note and interrogate (Hyden, 2013).

Rhetoricians can learn from the bloggers' narratives what lies outside the domain of the biomedical voice in addition to the rhetorical strategies that they employ to tell their stories.

Just as writers struggle to find the language to describe the experience of illness, they search for ways to tell their story that capture the permanent disruption that illness brings to their lives. One powerful form for expressing suffering and experience related to suffering is illness narrative. Contemporary scholars of rhetoric note that all language seeks to persuade—even when it appears on the surface to seek only to inform. Consider one blogger's text below:

> The goal to contribute at least one post to my Daily Blog is being realized. I have written and published something for the last eleven days and feel blessed to be able to do so. Daily thoughts turned into daily blogs; short stories, poems, or sayings, some singing loudly of who I am and what I believe in, others offering softly whispered sentiments. They offer me a corporeal way to remember something each day. My mind travels along roads and highways, weaving and sweeping through villages and towns interspersed with stunning landscapes and perfect milieus. Thoughts fade in and out with some details of my memories lost, maybe somewhere in cyberspace. Perhaps one day I'll retrieve them. Who knows? Who cares? Well, I care, which means I need to find ways to repossess them, in some form or shape. Colors and smells may increase my ability to grab onto them again; talking to others, looking at old photos may help. Making sense of them might be lost to me but retrieving them is important. My memories form the basis of my own private social history, will tell my children and their children who I was; without writing them down now, this will be lost. Talking with others, visiting the places my mind tries to travel along might just be enough to bring about a response that surely will be followed by words. I can still think well enough to write down my thoughts, at least as long as I write them down at the exact moment they appear. The vicissitudes I now face can be thwarted through my words, as I realize now my travels through the past must be with pen and paper in hand, or dictaphone in tow, no longer just in my mind.

The narrative that the blogger shared above provides rich insights about why she engages in writing and how writing helped her make sense of her journey with dementia. These emotionally charged texts are not just random statements, rather, they convey specific information and additional meanings that are important to note and interrogate. As a window into the complex, often painful and distressing world of patient experience, illness narratives provide

a fertile ground for rhetorical inquiry. Yet, while narrative is embraced in health studies or medical humanities, these published accounts as Jurecic (2012) notes present a particular challenge to criticism, especially from literary scholars who too often display disdain for them, and, in enacting Ricoeur's (1970) "hermeneutics of suspicion," decided in advance that autobiographical writing on illness fails both as testimony and literature (p. 3 - 11). "Because illness narratives provoke affective and intimate engagement… they disrupt critical engagement and typical standard judgment" (p. 10). This disruption, however, notes Nielsen (2018), is part of what constitutes illness narratives as complicated, compelling, and even more worthy of critical engagement to which I concur.

Segal (2007) stresses that we must fully integrate narrative inquiry into health research because of what might be lost without stories of patient experiences. She further argues for a valuing of the complex textures of patient narratives impart because they add needed humanity to what could be reduced to simple case studies chronicling manifestation of disease. Because as (Giroux, 1997) points out, writings are inherently political, I argue that we must attend to the meanings and practice in engaging with metaphors in illness narrative in order to reveal the sentimentalism and ideology that are expressed through the metaphors in the narratives and help marginalized groups to preserve their identities and give voice to their struggles. Rhetoric and composition various methods of analysis, theories as well as histories, can aid to this goal. Charron (2006) says that we must honor the stories of the sick people; this entails paying tribute to the experience of teaching patients by being attentive and providing the appropriate space and time for listening and reflection. For rhetoricians, we can honor the stories of people with dementia by providing them the platform to bring to the forefront their voices. By sharing their

stories, we create awareness about their struggles and challenge the negative perceptions about their illness.

Contributions and Limitation of The Study

In this final chapter of my dissertation, I discuss my study's contributions, limitations, and the need for further discussion within the field of rhetoric and writing studies, the field of rhetoric of health of medicine, and technical communication. Disability, mental health, and language scholars have studied how language affects individuals' social status and what it means to be ill. It has been argued and widely accepted that disease is defined by language, particularly the metaphors which my study illustrates. Furthermore, my study demonstrates how conversation is rhetorically and socially constructed and is influenced by different factors including the doctor's and his/her patients' responses as well as cultural perception and understanding of the disease.

One key finding and contribution of this study is that it provides strong evidence that metaphors are essential communicative and conceptual tools for early onset dementia patients as well as those who serve as caregivers to late-stage AD patients to make meaning and communicate their illness experience. This finding is consistent with past findings (see e.g., Gibb and Frank, 2002, Castaño 2020, Semino et al., 2018) who note the crucial importance of metaphor in how people make sense and cope with the emotional and psychological struggles with terminal illness. Worthy of attention in this study is that all 10 early onset bloggers in this study viewed dementia not as random, meaningless event, but rather as an event holding significance, meaning, and potential for intellectual and emotional growth. The deployment of metaphors in both language and thought enable these bloggers to find deep meaning in a deeply

personal way, yet also in a manner that is relatable to those who suffered from the disease as well as audiences who have not experienced the same disruption in their lives.

A second key finding of this study is that people with dementia share a relatively stable set of conceptual metaphors to describe the impact of their disease on their lives and that most of the metaphors are conventional metaphors commonly used in everyday language (Gibbs and Franks, 2002). At the same time, data also reveals that early onset AD bloggers sometimes employ contradictory metaphors to transform their illness experience into meaningful experience, highlighting that no single metaphor alone can capture the complexity of the individual's thinking and experience with the disease. This finding adds to the literature on metaphors by showing that connotations associated with metaphors are not stable, rather they vary and are dependent on the contextual factors such as individuals' attitude and the nature of the disease. Contrary to the arguments about the use of military metaphors as dangerous, disparaging, and harmful (see e.g., Jing-Bao Nie et al., 2016; Sontag, 1990) this study found that while it is true that war metaphors are dangerous if used in the wrong way, war metaphors can serve as key source for resilience and hope against the dementia for many early onset bloggers and even to those who serve as caregivers to late-stage AD patients.

A third key finding of this study is that the use of disability metaphors in AD discourse can foster the idea of cognitive impairment as a negative form of embodiment and promote othering. My study adds to disability studies by highlighting the importance of language, especially metaphors in the way we think and talk about AD. The study also extends work done with written illness narratives in disability studies by illustrating ways in which illness is told and understood between patients, the public, and health professionals

A fourth key finding, and contribution of this research is how blogs provides the new normal embodied space for both early onset AD bloggers and those who served as caregivers to late-stage AD patients to seek knowledge, gain social virtual support, and a powerful platform to give voices and to create social awareness about AD. The blogs I studied, provide a site of possible liberation from problematic social norms and power structures (Herring et. al., 2004; Plant, 1997) and potential stigmas of illness (Berger et. al., 2005) via an un-mediated democratic realm where gender, race, class, body, and other identities are neutralized. Both through and by blogging, the writers in my study socially-produce and co-construct a location in which they generate and participate in community across geographical and social divides. My study of blog narratives also extends research on life writing, and digital literacy of mid-life to older writers.

The fifth, and one of the most important findings and contribution of this study, is that metaphors provide important insights on how individuals and groups produce knowledge, meaning, understandings, identities, and the courses of action they take about health and illness. The bloggers' creative use of writing and the way they spun different metaphors to describe and capture different facets of their illness experience and the road to acceptance provide insights into our understanding of how knowledge, understandings and meanings are produced as well as how identities are sustained and managed. I add to literature in rhetoric of Rhetoric and Writing Studies and the subfield of Rhetoric of Health and Medicine as well as Technical Communication that the patients' embodied experiences as told through their metaphors are valuable and telling. As Mabel powerfully points out in her blog:

> It seems the 'experts', namely those people who work in a field, but may not have any personal experience in that field, are always considered and called the experts, and the patients or consumers who are living with the experience or disease are often treated like morons or idiots, as if they have no expert insight or understanding of that topic or sector. This of course, has happened in the dementia sector, even though people without dementia have no idea what the lived experience is actually like. I am regularly asked to

contribute to state, national and international work on dementia, and most of the time, my previous knowledge and current qualifications are ignored, and I am written up in the final report or communique as a patient, person with dementia, or consumer.

This is totally unreasonable, and offensive, and it is time all people with dementia started to request their qualifications, pre dementia experience, knowledge and careers are recognized, in the same way as everyone else if they are providing expert advice to anyone else. In fact, we should start charging a fee for it! We are no longer willing to be someone's 'tick box' so they can say they have included us, and instead want an equal place at the table.

Patients should be encouraged and empowered to give voices to their thoughts, their feelings, and their emotions that arise from their embodied experiences. By examining metaphorical expressions that tell what one thinks, feels, and how one conceptualizes AD in and as a body, I also contribute to investigations on how patient's embodied illness experience is expressed, received, perceived, and responded to by the people who are afflicted with the disease, the public, and health professionals. Overall, my study of metaphors in the rhetoric of AD has shown how the language we use to conceptualize AD disease can influence how we viewed people with AD. Similarly, in the field of medicine, the metaphor that health professionals use and to talk about AD can lead to a particular way they treat and work with their AD patients.

Study Limitation and Further Research

One limitation of this study is the sample size, which is not reflective of the wider population of people affected with early onset dementia although the blog participants come from three different English-speaking countries: the United States, England, and Australia. The sample for bloggers who served as caregivers included in this study is also small. This limits the analytic power of this research. On a positive note, the small number of bloggers included in this study allows an in-depth analysis of a large number of posts which span a 5-year average. The other limit of this dissertation is the short duration of the study. A longer duration of the study

would allow me to better track their progress to see how they fare as their disease progresses into the advanced stage.

There is certainly a need for further study of metaphors in illness experience. Rhetoricians in Rhetoric and Writing Studies may extend my study by exploring how metaphors are used across contexts and cultures and evaluate its impact on individuals' coping mechanisms. Instead of using blogs, this study could be conducted through different media such as face-to-face interactions or through focus groups. Rhetoricians may also extend my study by comparing gender differences in use of metaphors among early onset AD patients. A comparison between male and female metaphors use could reveal different ways in which patients use different metaphors. Beyond that, rhetoricians should also consider expanding the study to include how non-English speaking early onset AD patients use metaphors to make meaning of their experiences with AD as each language and culture has its own idiosyncrasies when it comes to what metaphors are used and how they are used (Kövecses, 2005).

Implications of Study for Rhetoric and Writing Studies

The field of Rhetoric and Writing Studies need to be more involved in such a way as to help show that the discourse created through social media outlets, especially those related to terminal illness like Alzheimer's disease (AD) are not just "backchannels," which serve mainly to entertain but also spaces in which patient education in an informed manner can occur. Social media like blogs encourage increased participation by users, provide stronger connections to others with similar experiences, and increase levels of interactivity among users. Rhetoric and writing studies can help identify the ways in which participants communicate in virtual support groups like blogs that promote positive self-healthcare practices and improved healthcare overall.

The practice of medicine has advanced dramatically in recent years, but the language, especially the use of metaphors that were used to discuss and talk about illness by medical practitioners, caregivers, and the public as a whole has not kept pace. The language that we use to talk about AD matters as it not only impacts how we perceived people with dementia, but these disabling words that we used can backfire by creating fear and stigma, as well as how they can impact the way people with dementia viewed themselves. As scholars and practitioners, we bring our ability to identify the nuanced way in which language is used and how that language impacts the most mundane of and the most extraordinary of circumstances. Paying attention to and analyzing these problematic metaphors could help provide healthcare professionals with a tool that can afford better empathy for people with dementia. Most importantly, we need a new model for seeing and understanding AD. In the first chapter of this dissertation, I proposed the term nyanyuk as an important framework to view AD. The term nyanyuk is a local cultural idiom used by the Land Dayak and Sea Dayak community of Sarawak, Malaysia to describe someone who is childlike and senile due to memory lost. What I believe is useful and powerful about the term nyanyuk is that it introduces us to a new possibility of thinking about AD. Unlike the term dementia which denotes a negative label, the term nyanyuk carries a more sympathetic tone. It focuses on the language of respect and empathy. Moreover, in the rhetoric and composition classroom, paying attention to the plights and metaphors used to talk about diseases can encourage and foster a lesson about empathy and social awareness about the disease. Additionally, introducing the study of metaphors and illness narratives in Rhetoric and Writing Studies' classroom can introduce students to rhetorical analysis strategies and "rhetorical imagination that is informed by rhetorical consciousness (Assad, 2016, p. 282). Although reading about the experience of others argues Assad (2016) "does not necessarily make us more

empathetic, but through class discussions and focus on rhetorical analysis, teachers of writing can help students understand not only emotions, viewpoints, and struggles of someone else but also the connections between those lived experiences–as narrated on the page-and the world into which the text has be brought to life" (p. 282).

Ultimately, if we want our students to develop an aptitude for rhetorical listening (Ratcliffe, 2006) that enable them to hear and acknowledge others' stories and experiences, as well as an aptitude for rhetorical empathy (Blankenship, 2019) that allow them to feel compassion for others; we need to invite some level of personal engagement with course material if our students are going to move from narrative empathy toward social empathy and rhetorical listening. In this dissertation my definition of empathy echoes that of Blankenship (2019). Empathy she opines is "an epistemology, a way of knowing and understanding, a complex combination of intention and emotion" (p. 7). Like Blankenship (2019), I also opposed the use of the metaphor 'pity' as it is associated with colonization and other cultural movements in which the self is disconnected from the struggles of others (p. 5). Beyond engaging and empowering students to develop rhetorical listening and rhetorical empathy, students should also be introduced to the cunning art of *metis.* Dolmage (2006) defined *metis* "as a way to think and also a way to think about thinking" (p. 63). The affordances offered by *metis* is that "it provides the means of doing something to the world, rather than doing something in the world" (p. 80). Encouraging students to filter their understanding of disability through the concept of *metis* as Dolmage (2020) points out "can provide a model for the ways we might repurpose tensions around bodily values, recognizing the stigmatization and effacement of bodily difference, yet also mobilizing new stories and new expressive possibilities (para 10). In conclusion, I reiterate

133

that the term nyanyuk is the new stories and new expressive possibilities that we need to emulate

in how we think and talk about AD as it focuses on the language of respect and empathy.

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APPENDICES

The Pragglejaz Method for Finding Metaphorically Used Words

1. Read the entire text–discourse to establish a general understanding of the meaning.

2. Determine the lexical units in the text–discourse

3. (a) For each lexical unit in the text, establish its meaning in context, that is, how it applies to an entity, relation, or attribute in the situation evoked by the text (contextual meaning). Take into account what comes before and after the lexical unit.

(b) For each lexical unit, determine if it has a more basic contemporary meaning in other contexts than the one in the given context. For our purposes, basic meanings tend to be —More concrete; what they evoke is easier to imagine, see, hear, feel, smell, and taste. —Related to bodily action. —More precise (as opposed to vague) —Historically older. Basic meanings are not necessarily the most frequent meanings of the lexical unit.

(c) If the lexical unit has a more basic current–contemporary meaning in other contexts than the given context, decide whether the contextual meaning contrasts with the basic meaning but can be understood in comparison with it.

 4. If yes, mark the lexical unit as metaphorical.

Source: Pragglejaz Group (2007)

Journey metaphors samples and how are used in the blog narratives

When I started out on this journey, I never thought I would have to look at myself and see the real me. At times I don't like the person looking back but that only reminds me that I have not learned my life lesson and need to try harder. I feel I am in training for the late stages of my disease. (Hunter, Pos. 54)

Ultimately, it has been the third greatest gift of my life and created a deeper purpose than I'd ever had before. But the road has been very rocky, definitely 'the' roller coaster ride of my life, and one that has highlighted so many breaches of the most basic of my human rights.

(Mabel, Pos. 345-346)

As I travel down this dementia journey, I have found love, laughter and inspiration from a Silly Old Bear named Winnie-The-Pooh. Hopefully I will also be able to bring joy into the lives of others. (Lindsay, Pos. 199)

Someone tweeted me asking if there is any dementia pathway at all in Shropshire, in response to another of my desperate pleas for action here. Well, we're working on it! But is it a pathway? What is our journey with dementia? Well, it goes from start to finish, so it can be mapped. Afterwards. But is a dementia journey linear? Probably not. Dementia is a terminal illness, so we know where we are going. But we all take different routes, some quick, many slow. (Rockie, Pos. 171-174)

Loss and Transformation metaphors samples and how they are used in the blog narratives.

Have you ever said to yourself, I hate my life? This is the year that you find out what you hate and change it. Changing might just be the way you think about it. I hate my disease but I cannot change the fact that I have Alzheimer's but I can change the grip it has on me. I can make sure that Alzheimer's doesn't control me. I'm getting the hang of turning pens and having a blast. (Hunter, Pos. 5)

Death Sentence metaphors samples and how they are used in the blog narratives

An AD diagnosis is quite literally a death sentence. (Stephen CG, Pos. 272)

I refuse to be put into the end stages of Dementia until I am ready. (Hunter, Pos. 5)

Disability metaphor samples and how they are used in the blog narratives

'Burden' came up quite a few times during the interview. That feeling of being a burden to our care partners. (Wilma, Pos. 167)

Demented or having a dementing illness – I am a person first, always. (Mabel, Pos. 545)

War metaphors samples and how they are used in the blog narratives

Many people give everything up after a diagnosis of dementia, and simply give up the will to fight on. (Kenneth, Pos. 272)

I know I am losing my battle and slipping away but I also realize my plateau is within my reach. When I fall into my valley of despair, it takes me longer to climb out and I don't climb as high as I used to. Don't feel sad for me because I am ok with this. (Hunter, Pos. 56)

Robbery metaphors samples and how they are used in the blog narratives

The early progression of dementia is extremely frightening. Knowing that you are slowly being robbed of memories and abilities and knowing the struggles you and your loved ones will deal with gnaws at your heart. (Lindsay, Pos. 124-125)

You're a thief, a thief of the worst kind. You rob innocent people, not of material things, but of their most precious memories. (Bobby, Pos. 172)

Monster metaphors samples and how they are used in the blog narratives

It's a horrible disease, and awareness of the losses as I progress are devastating. (MarryAnne, Pos. 375)

The disease is a monster (to me). (MarryAnne, Pos. 283)

Storm metaphors samples and how they are used in the blog narratives

My life is like the weather, I can have a violent storm one day and the next, a calm sunny day. (Hunter, Pos. 104)

We are mostly ok, except that we live with a dark cloud every single second of every day, and although the denial bubble is useful, it is not always easy to retreat into. (Mabel, Pos. 564)

Game metaphors samples and how they are used in the blog narratives

It's just a waiting game, with a bit of life thrown in just to remind you what the illness is doing to you! (Conway, Pos. 4)

Speaking out has also helped me make sense of this disease, to feel as if there is a positive reason, I have been dealt this deck of cards. (Mabel, Pos. 33)

CURRICULUM VITA

Evelyn Saru Jimmy grew up in Malaysia. She completed her bachelor's degree in Digital Media and Graphic Design from Andrews University in Berrien Springs, Michigan in spring 2001. Upon completion of her bachelor's degree, Evelyn spent a year working as a freelance Graphic Designer while working on her pre-nursing program at Tarrant County Community College in Arlington, Texas. Evelyn completed her MA in Interpersonal and Public Communication from Central Michigan University in Mount Pleasant, Michigan in the fall of 2009. Upon completion of her master's program, Evelyn then spent two years working as a lecturer at University Malaysia Sabah in Malaysia. In 2012, Evelyn and her family permanently migrated to the United States.

While in the United States, Evelyn held several different adjunct positions. She worked as an adjunct instructor at Brown Mackie College in Findlay, Ohio from 2012 to 2013. Evelyn also worked as an adjunct instructor with the University of Northwestern Ohio in Lima, Ohio from 2013 to 2015. In the fall of 2016, Evelyn was accepted to do her Ph.D. in Rhetoric and Professional Communication at New Mexico State University (NMSU) with a full graduate assistantship. While working on her Ph.D program at NMSU, Evelyn also served as a graduate teaching assistant with the Department of English from 2016 to 2019. In addition to being a graduate teaching assistant, Evelyn served as a Temporary Training Specialist in the summers of 2017 and 2018 at NMSU's Center for Learning & Professional Development. Upon passing her comprehensive Ph.D. exam in 2019, Evelyn moved with her dissertation chair, Dr. Rosenberg, to the University of Texas at El Paso. Since then she has been an assistant instructor with the Department of English while finishing her Ph.D in Rhetoric and Writing Studies.