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Writing Life Stories: A Phenomenological Study of Memory and Meaning for People with Early Stage Alzheimer's Disease

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**Writing life stories: A phenomenological study of memory and meaning
for people with early stage Alzheimer's disease**

Jennifer E. Dimond

Master's Thesis

Presented to the Faculty of the School of Social Work at
University of Southern Maine

In partial fulfillment of the requirements for the degree of
Master of Social Work

University of Southern Maine

April 13, 2016

Dedication

To the brave, resilient people who live with Alzheimer's disease
but refuse to be defined by it—and to those who love them.

Acknowledgements

Four years ago, I had the crazy idea to quit my day job and leave behind a successful two-decades long career in advertising, with no real plan for my future aside from traveling and trying to find a sense of purpose and balance in my life. Over lunch one day with my dad, I heard myself say aloud for the first time, “Maybe I’ll go to graduate school and become a social worker,” and I’ve never looked back.

Thank you to everyone at the Alzheimer’s Association, Maine Chapter, for offering me a field placement that opened my eyes to the world of Alzheimer’s in a whole new way and set me on a path I had not envisioned, but now consider a calling. I am especially grateful to Bill Kirkpatrick, LICSW, former program director at the Maine Chapter, for helping me develop the idea for this study, and for his willingness to serve on my thesis committee even after leaving Maine; to Peter Baker, LMSW-cc, the best first-year field supervisor I could have asked for; and to Mark Pechenik, who eagerly invited me to get involved with his Early Stage Social Engagement Program and the Volunteer Scribes and has been instrumental in providing resources and connections at many stages throughout this study; your enthusiasm for working with people with early stage Alzheimer’s is infectious.

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**Writing life stories: A phenomenological study of memory and meaning
for people with early stage Alzheimer's disease**

Jennifer E. Dimond

University of Southern Maine

April 2016

Committee Chair: Dr. Paula Gerstenblatt

Abstract

There are an estimated five million Americans living with Alzheimer's disease; experts believe that by mid-century, that number will more than triple. The disease is the sixth leading cause of death in the U.S., and the only one among the top ten with no known cure, treatment or means of prevention. An emerging body of research suggests that providing people with Alzheimer's opportunities to tell their life stories can help them negotiate their personal identities and may have positive impacts on their sense of self. A hermeneutic phenomenological approach is used to understand the lived experience of people with early stage Alzheimer's disease in telling their life stories. The study included interviews with eight individuals who participated in a life story-telling program. Three key themes emerged to describe participants' experience, including sense of self, relationship with family, and sense of purpose and meaning. The study supports the value of narrative approaches in contributing to positive self-image for people with AD. Implications for social work research and practice are discussed.

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CHAPTER ONE: Introduction

Problem Statement

In America today, an estimated five million people live with Alzheimer's disease; experts believe that by mid-century, that number will more than triple (Alzheimer's Association, 2015). It is a costly disease that takes an often devastating financial toll on families and society; the average family spends \$5,000 a year caring for a loved one with Alzheimer's, not including the 18.1 billion hours of unpaid care provided annually (Alzheimer's Association, 2016). Nationally, Alzheimer's and related dementias will cost \$236 billion in 2016 alone, a number expected to exceed \$1 trillion by 2050 (Alzheimer's Association, 2015). It is the disease that more than one-third of adults over age 65 say they fear most—even as the fear of cancer and stroke is on the decline (Alzheimer's Association, 2014).

While the cognitive and functional challenges caused by Alzheimer's disease are significant, and the economic and other demands for families and society are considerable, the emotional and psychic toll on those living with the disease is often overlooked. Until recently, most research has focused on the needs of and effects on caregivers, who undoubtedly bear a great burden as a loved one's disease progresses. The impact on people with Alzheimer's, however, goes beyond memory loss; this disease significantly affects an individual's entire identity. Researchers are only beginning to explore the ways in which people with Alzheimer's seek to preserve and express identity and meaning in their lives, and to identify interventions and supports that can help them maintain a sense of self in ways that positively impact their quality of life.

An emerging body of research suggests that providing people with Alzheimer's opportunities to tell their life stories can help them negotiate their personal identities and may have positive impacts on their sense of self. Studies are also beginning to identify social engagement, along with healthy diet, exercise and cognitive stimulation, as factors that can help maintain brain health across the life span and potentially even slow the onset of cognitive impairments, including dementia (Marioni et al, 2015).

Research Question

This study uses a hermeneutic phenomenological approach to answer the research question: what meaning do people with Alzheimer's disease derive from the experience of telling their life stories as participants in the Volunteer Scribes program?

Key Concepts and Definitions

Alzheimer's Disease and Related Dementias. Alzheimer's disease is the most common form of dementia, a group of brain diseases classified in the DSM-5 as neurocognitive disorders (American Psychiatric Association, 2013; Alzheimer's Association, 2015). Alzheimer's is estimated to account for 60 to 80 percent of all cases of dementia (National Institute of Aging, 2015; Alzheimer's Association 2015). Other types of dementia include vascular dementia, dementia with Lewy bodies, and frontotemporal dementia, among others (National Institute on Aging, 2016). It is not uncommon for an individual to have mixed dementia—a combination of Alzheimer's and other types of dementia (Alzheimer's Association, 2015a). Consequently, throughout this paper, the terms "Alzheimer's disease" or "ADRD" are, unless otherwise specified, intended to encompass Alzheimer's and related dementias.

Hallmark symptoms of the disease include: memory impairment, challenges with language, problem solving and cognition (National Institute on Aging, 2016; American Psychiatric Association, 2013). Neurons in the brain are irreparably damaged, impacting cognitive and executive functioning skills. The disease is fatal; it is the sixth leading cause of death in the United States, and the only one among the top ten without a known cure, treatment or means of prevention (Alzheimer's Association, 2015), though there are treatments that are sometimes effective in temporarily slowing certain symptoms of the disease (National Institute on Aging, 2016).

Causes and Risk Factors. Causes of Alzheimer's are still unknown, though researchers have identified two proteins, beta-amyloid and tau, that develop in areas of the brain responsible for memory, language and cognition, affecting and eventually destroying these cells. Beta amyloid forms deposits—called “plaques”—between nerve cells, while tau creates “tangles” inside the cells (National Institute on Aging, 2008).

Scientists have identified several risk factors for developing the disease including age, family history and genetics (National Institute on Aging, 2016). Age is the primary risk factor for Alzheimer's. The risk doubles every five years after age 65; by age 85, an individual has a one in two chance of developing Alzheimer's disease (National Institute on Aging, 2015). Family history is also believed to increase risk; an individual is more likely to develop the disease if one or more immediate family members has Alzheimer's. (National Institute on Aging, 2008; Alzheimer's Association, 2016c), though scientists are not certain whether this is due primarily to genetics, environment, or both. Scientists have identified genes that may play a role in determining risk; those with the APOE-e4 gene, for example, have a higher risk of developing the disease over their lifetime and

may also see symptoms manifest at an earlier age than those without the gene (Alzheimer's Association, 2016c). Though rare, genes have also been discovered that guarantee, if inherited, that an individual will develop Alzheimer's (National Institute on Aging, 2008; Alzheimer's Association, 2016c).

Stages of Alzheimer's Disease. Alzheimer's is a progressive disease that typically includes three stages, referred to as either mild, moderate and severe or early-stage, middle-stage and late-stage AD though neurocognitive changes associated with the disease can begin long before the disease is detectable (Alzheimer's Association, 2015).

Early-stage, or mild Alzheimer's, is characterized by increased memory loss and other challenges with cognition including:

- getting lost, even when traveling familiar routes, and wandering
- difficulties in handling personal finances
- repeating questions
- difficulty with normal daily tasks/routine
- misplacing or losing things and placing them in unusual locations (e.g. putting keys in the refrigerator)
- changes in behavior and personality

It is during this stage that doctors often detect Alzheimer's, though people living with the disease are still often able to live independently, drive and carry on normal activities after diagnosis (National Institute of Aging, 2016; American Psychiatric Association, 2013).

In the middle stages of the disease, the areas of the brain responsible for language, problem solving, sensory processing and conscious thought are damaged. This can result in such symptoms as:

- increasing confusion and memory loss
- difficulty recognizing family and friends
- loss of ability to learn new information
- challenges with tasks that require multiple steps, such as dressing
- difficulty adjusting to new or unfamiliar situations
- hallucinations, delusions, and paranoia
- impulsive behavior (National Institute of Aging, 2016).

People with late-stage, or severe, Alzheimer's disease lose the ability to communicate and become fully dependent on others for their care and safety. As the body begins to shut down, the person may become bed-ridden, with symptoms that can include:

- inability to communicate
- weight loss
- seizures
- skin infections
- inability to swallow
- agitated sounds, such as groaning or grunting
- sleeping most of the day
- incontinence of bowel and bladder (National Institute of Aging, 2016)

Evolution of the Volunteer Scribes Program

The Alzheimer's Association, Maine Chapter is the state's leading resource providing education, support and advocacy around Alzheimer's disease and related dementias. As part of the national Alzheimer's Association, the organization's mission is:

To eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health (Alzheimer's Association, 2016).

In the summer of 2012, the Maine Chapter launched the Early Stage Social Engagement Program with a grant from the national Alzheimer's Association. The main objective of this pilot initiative was to determine the interest in and feasibility of developing a robust series of activities for people with early stage Alzheimer's as part of the Maine Chapter's roster of programs and services (M. Pechenik, personal communication, March 14, 2016). By fall of that year, it was clear there was sufficient demand to develop a fulltime Early Stage Social Engagement Program.

The main objective of social engagement programs offered by the Maine chapter and other Alzheimer's Association chapters across the country is to encourage people in the early stages of dementia—referred to as participants—and their care partners, to be active, make connections with others and focus on their abilities rather than the limitations posed by their disease. As Mark Pechenik, Director of Community Engagement and Outreach for the Maine Chapter, notes, “[Participants] are determined not to surrender to their dementia diagnosis and, instead, enjoy life to the fullest while they are still able to do so.” (M. Pechenik, personal communication, March 14, 2016).

The program has grown substantially since its inception four years ago. Four to six activities are offered each month in venues around the state, drawing seven to 12 participants, on average, for each event. A diverse array of activities is planned to appeal to a variety of interests and has included guided nature walks, museum tours, live entertainment, bowling, snowshoeing, and more (M. Pechenik, personal communication, March 14, 2016).

Rationale for the Study

Anecdotally, the Volunteer Scribes program and the overarching Early Stage Social Engagement Program offered by the Alzheimer's Association Maine Chapter have been very successful and well received by people with Alzheimer's disease and their care partners. The chapter has, however, not had the resources to formally assess the program to determine its impact on participants. I designed this study, in consultation with the former program director of the Alzheimer's Association, Maine Chapter, as a means of evaluating the program's effectiveness in meeting the needs of people with early stage Alzheimer's.

Personal Context

My family is among the millions that have been impacted by Alzheimer's disease. In 2008, my stepfather died at age 88 after a roughly three-year battle with dementia that eventually left him unable to speak, walk, eat, or recognize my mother, his beloved wife of nearly 25 years. His time in the late stages of the disease was blessedly short, but I can remember when he was beginning to exhibit the telltale signs of early Alzheimer's, including forgetfulness and confusion that appeared to be more than normal signs of aging (National Institute of Aging, 2016; Alzheimer's Association, 2015). For quite a

long period of time he was still fairly active, including daily walks with his faithful canine companion, Scruffy, and maintained his sense of humor and other traits we all loved about him. Our community offered a few daytime programs geared mainly toward people whose disease had progressed to middle or late stage Alzheimer's; these programs were intended as much to provide respite for caregivers as to engage the people living with dementia. At the time, no local programs offered meaningful opportunities for people with Alzheimer's disease to connect with each other in fun, enriching, diverse activities that recognized them as unique individuals, rather than a homogenous group of people afflicted with dementia.

In 2014, I entered the Master of Social Work at the University of Southern Maine and selected a field placement at the Alzheimer's Association, Maine Chapter. My interest in geriatric social work had not yet fully emerged, but I already felt drawn toward working with the population served by the organization, especially given my personal experience with the disease. In addition to staffing the Helpline, which offers support and resources to people with dementia, their care partners, paid caregivers and community members, I was assigned to help the director of the Early Stage Social Engagement Program facilitate the Volunteer Scribes Program, a pilot project that had evolved from the Legacy Writers Program launched a year earlier.

It was apparent to me almost from the beginning that the impact of the Volunteer Scribes went deeper than simply giving participants a keepsake story to share with friends and family. The participants, regardless of the degree to which their dementia had developed, seemed to blossom in unexpected ways. I recall talking with the wife of one participant who watched from across the room, with tears in her eyes as her husband,

who had grown shy and reserved in the two years since he was diagnosed with Alzheimer's disease, talked and laughed animatedly with his scribe partner. "It's so wonderful to see that side of him again," she said. "That's the man I remember."

CHAPTER TWO: Literature Review

This chapter examines the recent literature in the following areas: (1) Brain Health and the Importance of Social Engagement; (2) Theories of Aging and Identity; (3) Storytelling Approaches for People with AD; (4) Dignity Therapy, and (5) Key Findings.

Brain Health and the Importance of Social Engagement

Studies suggest that individuals who stay mentally and socially engaged over the life span may maintain brain health and reduce their risk of Alzheimer's and other dementias. According to Haslam, Cruwys and Haslam, memory loss may be reduced by as much as 50 percent—over a period of at least 5 years—and general cognitive decline may be up to 39 percent lower for older people who have the largest number of social connections, compared to seniors who are the most isolated. As remarkable as this is, the quality of one's social connections outweighs the quantity. The reduction in cognitive and memory decline was as much as 91 percent for people who were the most deeply engaged with their networks (Haslam, Cruwys, & Haslam, 2014).

Another study observed a correlation between risk of dementia and participants' level of engagement in physical, social and cognitive activities, as well as in their self-perception of being understood by others; those who ranked high in engagement had significantly lower risks of dementia (Marioni et al, 2015). Conversely, losing a spouse or having a diminished ability to participate in activities of daily living (ADL) correlated to an increased risk of developing dementia (Marioni et al, 2015). While individual relationships with family and life partners have important, positive impacts on one's health, participation in social groups, according to Haslam, Cruwys and Haslam (2014),

helps develop one's identity and sense of belonging to something bigger than oneself, identified by the authors as the "we" versus "I" effect. One possible explanation why groups have such a positive impact on the preservation of cognitive abilities is the increased effort required to maintain relationships with a group than with individuals, which increases cognitive stimulation (Haslam, Cruwys, & Haslam, 2014).

Theories of Aging and Identity

Reviewing several cases from the 20-year Southampton Ageing Study, Coleman, Ivani-Chalian and Robinson (1999) examine two theories of identity development and processing in later life that have implications for people with early stage Alzheimer's disease and other dementias. Noting that self-esteem has long been seen as an important contributor to one's ability to accept and adjust to aging, the authors observe that aging itself is not the primary cause of declines in self-esteem, as previously believed; the study indicated that adults had a healthy sense of self well into their eighties. Instead, it was the onset of illness and fragility that compromise one's self-esteem (Coleman, Ivani-Chalian, & Robinson, 1999).

Identity process theory provides a postmodern connection to Erikson's theory of identity formation across the life span, focusing on the use of assimilation and accommodation to maintain a sense of self through the aging process (Coleman, Ivani-Chalian, & Robinson, 1999; Sneed & Whitbourne, 2003). Assimilation involves self-correction and compensation for deficits in order to preserve currently held beliefs about oneself. An individual who is working to preserve self-esteem through assimilation is likely to remove him- or herself from situations that provide evidence to contradict how they see themselves (Brandstädter & Greve, 1994, cited in Coleman, Ivani-Chalian, &

Robinson, 1999). A person with ADRD might, for example, stop participating in activities and social groups after losing the ability to follow conversations or instructions. Overdependence on assimilation can be isolating and make it challenging for the individual to develop new coping strategies to overcome the sense of loss associated with illness and advanced age (Sneed & Whitbourne, 2003; Diehl, Coyle, & Labouvie-Vief, 1996). Assimilation is not inherently negative; Baltes and Baltes (1990, cited in Coleman, Ivani-Chalian, & Robinson, 1999) view it as a key coping skill that helps preserve identity in old age.

Accommodation occurs when one's identity changes in response to external influences and experiences. Sneed and Whitbourne (2003) identify the perils of relying on accommodation as a means of preserving self-esteem, such as overreacting to small age- or disease-related changes in ability to the point of becoming prematurely helpless, or relying on the opinions and feedback of others for reassurance and validation. Brandstädter and Greve (1994, cited in Coleman, Ivani-Chalian, & Robinson, 1999) view accommodation in more positive terms, noting the shift from assimilation to accommodation often marks greater self-acceptance and ability to develop coping strategies. Coleman, Ivani-Chalian and Robinson (1999) also observe that maintaining control over the meaning of experiences takes on new importance as one loses control over external factors and events. Social role theorists observe that life satisfaction and self-esteem are linked to an individual's self-identification within social networks; viewing oneself as a good friend or someone worthy of spending time with boosts one's self-esteem (Siebert, Mutran & Reitzes, 1999).

Striking a balance between assimilation and accommodation is, not surprisingly, identified as the healthiest approach to identity processing across the life span and is linked to healthy self-esteem well into old age (Coleman, Ivani-Chalian, & Robinson, 1999; Sneed & Whitbourne, 2003).

Storytelling Approaches for People with AD

The current literature reveals a number of different approaches used in studies of people with Alzheimer's, as well as the meaning and purpose participants derived from these methods.

Narrative and Reminiscence Therapy

Table 1 Summary of recent studies of narrative approaches used with people with AD

Author	Description of Study	Key Findings
Russell & Timmons, 2009	Narrative research approach to capture and analyze stories of nursing home residents with dementia; n = 5	Participants' stories and methods of telling them revealed their individuality; listening to these stories helps facilitate person-centered care for people with ADRD.
Holm et al, 2005	Examination of structured storytelling in a group setting as therapy for people with moderate to severe ADRD; n = 6	Engaging people with ADRD in storytelling helped participants access memories, interact meaningfully with each other and with caregivers.
Chodony & Wang, 2013	Reminiscence program that used young people as scribes/listening partners for older people; n = 26.	Participants benefitted not only from the telling of their story, but from the interaction with younger people and the overall group process.
Stenhouse et al, 2013	Use of digital storytelling techniques incorporating images, audio voices and music; n = 7	Participants appeared to experience more confidence, better communication skills and a sense of purpose and social connectedness while participating in the workshop.
Wiersma, 2011	Examination of Photovoice as a methodology for use	The challenges of using Photovoice with people with

	with people with ADRD; n = 4	ADRD are numerous, but are outweighed by the potential rewards and opportunity to educate, inform and influence the public and policymakers.
Ramanathan, 2009	Study of journals and diaries of people with ADRD	Writing becomes a method of identity preservation and coping for people with ADRD and their caregivers
Karlsson, 2014	Exploration of how people with ADRD tell their life stories; n = 9	Stories demonstrated life satisfaction, connectedness and self-confidence; People living with ADRD can and do still have hope.
Ingersoll-Dayton et al, 2013	Couples worked together to produce audio recordings or a scrapbook chronicling memories of person with ADRD	Working together to document the life story improved relationship and helped the couple navigate AD

Hyden (2008) explored the distinctions in the different types of narrative methodologies used in studies of people with Alzheimer’s and other diseases, observing that in the “narrative as text” approach, the content of the story was more important to individuals with dementia than the way in which they shared the story. Usita, Hyman, Jr. and Herman (1998) observed different patterns participants used to tell their life stories in order to convey the information about themselves that they found most meaningful. Those who employed a chronological storytelling approach tend to share stories in an orderly fashion; others tended to be repetitive, sharing the same parts of the story over and over. Still others used salient points or descriptive details, while some focused on meaningful highlights linked to emotional memories in order to convey a sense of who they were as individuals (Usita, Hyman, Jr., & Herman, 1998). Kuosa, Elstad, and Normann (2014) observed that narrative therapy used to aid people with dementia in sharing their life stories provided meaningful activity and a sense of purpose that is so

often lacking in the care they receive. Russell and Timmons (2009) conducted a similar examination of the storytelling techniques used by a group of nursing home residents based on their individual cognitive abilities; this study, however, was designed primarily to identify effective ways to communicate with people with dementia, a common theme of the literature until the last several years.

To others, the act of storytelling—“narrative as performance”—was more important than the accuracy of the details shared (Hyden, 2008). A Swedish pilot study involving six subjects explored the potential benefits of a structured storytelling group as a potential therapy for persons with dementia. This was part of a larger study, called Drama-Ger, involving a variety of creative activities involving dance, music and rhythm as well as storytelling. (Holm, Lepp, & Ringsberg, 2005). The researchers in that study noted that the skills of the group leader, who did not have dementia, were instrumental in the positive outcomes observed (Holm, Lepp & Ringsberg, 2005).

Reminiscence therapy, an approach that focuses on helping individuals access or recall memories from the past, is another approach that has provided positive outcomes for people with Alzheimer’s. For example, Trueland (2013) observed these positive results through a program at the Age Exchange, a London nonprofit dedicated to care of the elderly. The author documents the experiences of people with Alzheimer’s, as well as professional caregivers and family members, who have benefitted from the creative programs at the Age Exchange, asserting that not only do people with Alzheimer’s enjoy enhanced quality of life as a result of participating in these programs, but the quality of their healthcare may also improve when professional caregivers gain insight and understanding through their own participation (Trueland, 2013). Other qualitative and

content analysis studies of reminiscence programs indicate that participants benefit from the satisfaction of having an outlet for their personal stories, from the social engagement of these programs, and the relationships built through intergenerational connections, since many of these programs involve younger people as scribes or listening partners (Chodony & Wang, 2013).

Additional studies examined a number of other techniques to record the stories of people with dementia, including digital storytelling using images, audio voices and music (Stenhouse, Tait, Hardy, & Sumner, 2013); Photovoice, a technique where participants are given a camera and asked to take photos that visually convey their experience (Wiersma, 2011); and journals and diaries to record participants' memories and self-image (Ramanathan, 2009). While each of these approaches poses its own functional or technological challenges when used with people with dementia, the benefits are numerous and include improved self-confidence, communication skills, and a sense of connectedness to social networks (Stenhouse et al, 2013; Wiersma, 2011; Ramanathan, 2009). One study of nine people with Alzheimer's revealed characteristics of resilience, personal growth, and even optimism that debunk many of the commonly held stereotypes about the diminished abilities of people living with the disease (Karlsson, 2014)

Dignity Therapy

Dignity therapy, an evidence-based intervention designed for use with people nearing end of life due to terminal illness, provides important insights that can inform the development of storytelling approaches for people with ADRD. An interview protocol is used and covers topics such life history; how they would like family and friends to

remember them; most important roles they have played in life; most significant life accomplishments/sources of pride; what they feel they have not yet said to their loved ones; hopes and dreams for their loved ones; life lessons; and words of wisdom or instructions for family (Chochinov et al, 2005). Transcripts of the interviews, which take place over several sessions, are edited into a narrative and shared with friends and family. At every stage of the process, the participant is engaged in fine-tuning the story to be sure it reflects their intentions, much like the Volunteer Scribes model on which the current study is based.

A pilot study by Chochinov and colleagues (2005) evaluated the effectiveness of dignity therapy in relieving stress and depression for patients in hospice care who were approaching end of life, and to determine whether the approach could help improve patients' quality of life at the end of life. Participants reported an increased sense of meaning, purpose, and hopefulness after engaging in the therapy; more than three-quarters of the participants reported feeling a greater sense of dignity as a result of taking part in the therapy (Chochinov et al, 2005). A randomized controlled study of a dignity therapy intervention in long-term care facilities generated similar results, including a reduction in dignity-related distress and depression, and increases in hopefulness and perceived quality of life (Hall et al, 2012).

Key Findings

Regardless of the specific method used, providing people with Alzheimer's opportunities to tell their life stories can help them negotiate their personal identities. Receiving a diagnosis of early stage Alzheimer's disease impacts an individual's sense of self; Beard (2004) observed three key themes that emerged once individuals received the

news they had Alzheimer's: diagnosis as a "defining moment" in one's life; whether or not to share the diagnosis with others; and attempts to manage one's life in the face of receiving the news that they most likely had Alzheimer's. Clark-McGhee and Castro (2015) identified the key themes of "Construction of self," e.g., "who am I?" and "Person in the world," e.g., "where do I fit into my family, community, society?" expressed in poems written by people who have received a diagnosis of Alzheimer's disease or other dementias. Chrifton and Kock (2007) noted that, in one case study of a person with dementia, the subject's participation in storytelling increased the positive effects not only on her sense of identity and self-esteem, but on the quality of care she received. Young's (2010) study of a group narrative therapy program had similar findings.

Even patients experiencing challenges with verbal communication were able to reclaim a sense of identity through the sharing of their personal narrative. Hydén and Örvulv (2009) observed that some individuals were able to develop ways of compensating for their cognitive deficiencies by tapping into other verbal and nonverbal abilities in order to tell stories that revealed what was most important to them.

Individuals with the disease are not alone in benefitting from these narrative methods. At least one study indicated that couples, working together in a guided program to create a scrapbook or audio recording of their life story can help couples retain their shared identity and help them better navigate Alzheimer's disease (Ingersoll-Dayton et al, 2013). In fact, a randomized control study demonstrated that the positive benefits of capturing life stories in tangible forms, such as storybooks, are similar whether the person

with dementia participated in creating the book or someone prepared it for them (Subramaniam, Woods, & Whitaker, 2014).

Personal narratives can also be beneficial in combatting the stigma associated with the disease. A survey of people in the early stages of the disease, conducted by a team that included a person with dementia and her spouse, revealed the diverse strengths and challenges of people living with Alzheimer's, portraying the subjects as individuals with unique stories to tell rather than focusing on their diagnosis (Beard, Knauss, & Moyer, 2009).

CHAPTER THREE: Methodology

Research Method

Historic and Philosophical Roots of Phenomenology. Phenomenology, the study of lived experience, emerged as a philosophy and a method of inquiry at the turn of the 20th century through the writings of Edmund Husserl (1859-1938), a German mathematician who saw meaning and fact as two discrete components of knowledge (Lavery, 2003; Moustakas, 1994). As a method of inquiry, phenomenology seeks to answer the essential question, “What is this experience like?” (Lavery, 2003). Four key philosophical principles characterize the phenomenological approach:

- 1) A “return to the traditional task of philosophy,” namely, seeking wisdom (Creswell, 2013).
- 2) *Epoche*—from the Greek term meaning abstain or avoid; Husserl coined this term to describe what he considered an essential element of phenomenological inquiry—the setting aside of one’s personal views and biases through a process known as phenomenological reduction or bracketing (Grbich, 2013; Lavery, 2003).
- 3) “Intentionality of consciousness” (Creswell, 2013). In Husserl’s view, an object’s reality depends on one’s awareness of it (Lavery, 2003).
- 4) The reality of an object is dependent on the meaning ascribed by the person experiencing it (Creswell, 2013; Moustakas, 1994).

The classic phenomenology developed by Husserl and his contemporaries is called descriptive or transcendental—it endeavors to remove the observer and the observer’s consciousness completely from the phenomenon being observed (Grbich, 2013). Hermeneutic, or interpretive, phenomenology—the method used in this study—emerged through the writings of Max Heidegger, a theologian trained by Husserl who believed that one’s cultural, historical and social background provides a lens through which one interprets the experience of living in the world (Lavery, 2003). Heidegger’s focus was on what he called Dasein—“the phenomenology of human being” (Crotty, 1998/2015). Gadamer, Ricouer, and van Manen all made important contributions to the hermeneutic branch of phenomenology (Grbich, 2013).

An important distinction of hermeneutic phenomenology compared to Husserl’s classical approach is the belief that one’s experience of the world is shaped by one’s social, cultural and historic context (Grbich, 2013). Heidegger believed that this “pre-understanding” was an essential component of “being in the world,” and did not seek to completely remove the observer from the phenomenon being observed (Lavery, 2003). The observer and the observed create meaning together through their own subjective interpretations of the world (Armour, Rivaux, & Bell, 2009). Insight from the researcher is essential to uncovering the essence of the experience (Kleiman, 2004).

Phenomenological Method. This study uses hermeneutic phenomenology to understand the lived experience of people with early stage Alzheimer’s disease who participated in a structured life storytelling program. Hermeneutic phenomenology is more fluid than Husserl’s descriptive approach in that the steps in the method are less rigidly applied (Grbich, 2013); Armour, Rivaux and Bell (2009) note van Manen’s (1990)

position that “the method of phenomenology and hermeneutics is that there is no method.” Phenomenological reduction—removing the observer from the equation—is not the goal; documentation of the researcher’s experiences, assumptions and opinions is not set aside or bracketed, but instead is used to continually evaluate the researcher’s interpretations of the phenomenon and its meaning and how they influence the interpretation of participants’ experience (Armour, 2002; Grbich, 2013). Achieving rigor and reliability in a hermeneutic study requires the researcher to be self-reflective and transparent about biases and preconceptions that influence his or her understanding of the phenomenon (Armour et al, 2009).

In constructing this study, I began by acknowledging my past role as a co-facilitator of the Volunteer Scribes program and my experience working with people with Alzheimer’s disease and their families. I documented my attitudes and understanding in a reflexive journal (Grbich, 2013); before and after each interview, I recorded my impressions, reactions and new insights gained in the moment. Throughout the process of data analysis I referred to these notes to determine how my own experience influenced my interpretation of the data (Armour et al, 2009; Kleiman, 2004).

Theoretical Framework

This study is grounded in social constructionism, also known as social constructivism or interpretivism (Creswell, 2013; Crotty, 1998/2015). Social constructionists make sense of the world around them by creating discrete, varied meanings of objects or phenomena influenced by culture, history and social interactions (Creswell, 2013). Research conducted within this framework values participants’

experiences as a way of developing understanding, which dovetails with the phenomenological approach (Creswell, 2013; Crotty, 1998/2015).

Viewing aging and Alzheimer's disease through a social constructionist lens provides a framework for understanding why Alzheimer's has surpassed cancer as the disease adults, especially those age 60 and older, fear most (Alzheimer's Association, 2014). When Alois Alzheimer first observed the disease in an elderly female patient in the early 1900s, he referred to the condition as "pre-senile dementia," affecting people younger than 60; "senile dementia," by contrast, was considered to be part of the normal of the aging process (Davis, 2004). Today, advocates work hard to distinguish Alzheimer's and related dementias from the natural effects of aging on the brain; nonetheless, many in the general public, and even in the medical community, still believe the hallmark cognitive and functional declines of dementia are an inevitable part of aging, which can lead to missed diagnosis (Wilkins et al, 2007) as well as missed opportunities for people with Alzheimer's or other dementias to participate in their own legal, financial and care planning while they are still considered legally competent to do so (Bourkel, Fering & Weber, 2012).

Cruikshank (2013) observes that the "medicalization of the old" has created a culture in which the elderly are disempowered and dependent; in her view, illness becomes a status symbol that makes older citizens relevant in American society. Persistent cultural stereotypes about aging that focus on deficits, dependence and feeble-mindedness can be harmful not only by contributing to poor quality of care for older adults, but by deterring healthy seniors from fully participating in education, recreation and social engagement opportunities (Bousfield and Hutchinson, 2010; Low, Molzahn &

Schopflocher, 2013)—all things researchers now point to as contributors to a healthy brain that may slow cognitive decline over the life span (Marioni et al, 2015).

The socially constructed view of Alzheimer’s and related dementias has primarily focused on the emotional, physical and financial toll the disease takes on caregivers, families and society; the voices of people living with the disease have, until recently, been largely absent from this narrative (Phinney & Moody, 2011). This may further contribute to the marginalization of people with Alzheimer’s disease, who are frequently overmedicated, ignored or institutionalized because of the perceived difficulty of caring for them (Cruikshank, 2013; Davis, 2004). Much attention is paid to the suffering of close family members as their relationship changes from spouse or child to caregiver; the adjustment individuals make to this transition is viewed as grief, even though the person with dementia is still alive (Black, Schwartz, Caruso & Hannum, 2008).

Symbolic interactionism—the language and metaphors we use to discuss Alzheimer’s and other dementias—conveys and controls society’s fear of the disease. Zelig (2013) notes that the term “dementia” was not associated with old age until the 1950s and ‘60s, emerging as a social construct in the following two decades. The stigma and fear around the disease is enabled by metaphors of natural disaster (“flood,” “tsunami”), religion (“demon”) and war (“time bomb”) that have seeped into the culture. As a result, people with Alzheimer’s and their families—even those who do not report personal experiences of stigmatization—often conceal their diagnosis from friends, neighbors and even their own children (Swenson, 2008; Werner & Heinik, 2008). Perceived or experienced discrimination against people with Alzheimer’s disease can prevent people from accessing services, resources and support; this is thought to occur, at

least in part, because of the common belief that people with Alzheimer's do not have the capacity to utilize resources such as support groups and social engagement programs effectively, regardless of the stage of their disease (Werner & Heinik, 2008). This may help explain why, until recently, support groups for ADRD caregivers were prolific, while groups for people living with the disease were scarce.

Selection and Recruitment of Participants

Ethical Considerations. The Institutional Review Board (IRB) of the University of Southern Maine reviewed this study for adherence to ethical guidelines related to research with human subjects. The primary concern was obtaining informed consent from participants, which can be challenging when working with people with neurocognitive disorders, though Dewing (2002) affirms that people with ADRD are capable of providing informed consent. Before being enrolled in the Volunteer Scribes program, participants are pre-screened by a social worker at the Alzheimer's Association to determine their capacity to participate. The IRB determined that this pre-screening process was adequate for assessing an individual's capacity to give informed consent. To further protect participants, spouses or other care partners were permitted to be present during the interview if desired. Verbal and nonverbal cues of participants were monitored continuously throughout the research process, and participants were permitted to have their spouse present if they wished.

Sampling. This study used purposive sampling to ensure all participants were part of the phenomenon being examined (Creswell, 2013; Grbich, 2013). To qualify for the study, subjects must have participated in the Alzheimer's Association, Maine Chapter's

Volunteer Scribes Program at one of three locations during the 2015 series and have Alzheimer's disease or a related dementia.

Recruitment. The staff coordinator of the Volunteer Scribes program sent a recruitment letter to all potential participants to inform them of the study and invite them to participate. The staff coordinator also spoke about the study at one of the sessions, where he discovered that Scribes Program participants were generally interested but wanted to learn more and meet me before committing to the study. The staff coordinator invited me to attend two sessions of the Volunteer Scribes program in person to explain the research project, answer questions and invite participants to enroll in the study. This presentation yielded eleven volunteers, who received either an email or telephone follow-up. Of those, eight responded to the request for an interview and eight interviews were completed, which aligns with Dukes' (1984, cited in Creswell, 2013) recommended sample size of three to 10 participants for phenomenological studies.

Four research participants chose to have their spouse present during the interviews; these spouses had also attended the Volunteer Scribes program for most, if not all, sessions. The average age of participants was 71 and the average time since their diagnosis with Alzheimer's disease was 1.3 years. One participant had not yet received a formal diagnosis of Alzheimer's disease from his primary care doctor; prior to participating in the Volunteer Scribes, he had been prescribed the two drugs most commonly used to treat symptoms of early stage Alzheimer's. This is not an uncommon occurrence; a recent survey of physicians and people with ADRD revealed that more than half of doctors do not share the diagnosis with their patient (Alzheimer's Association,

2015). This participant was deemed eligible for the study. Participants were evenly split among females (4) and males (4); all were white.

Data Collection

Interviews took place in a location of the subject's choosing and included participants' homes, a coffee shop and a community center. I used an audio recording device to capture each interview, and removed all names and other personally identifying details during the transcription process to maintain confidentiality; I assigned pseudonyms to each participant's data for reporting purposes. Interviews lasted between 20 and 45 minutes each; I wrote field notes immediately before and after each interview to bracket my assumptions and impressions throughout the process.

A semi-structured schedule guided each interview, with the central focus being on the individual's experience as a participant in the Volunteer Scribes Program. The central question of the interview was, "What was it like to share your story? What was the experience for you?" (Creswell, 2013; Moustakas, 1994). Questions used to gain further insight included:

- How did you get involved in the Volunteer Scribes project? How did you learn about it? What was it that made you want to participate?
- What was it like working with a student? Was it what you expected?
- Did anything about this process surprise you?
- Did participating in this project change how you viewed yourself/your disease?
- Did participating in this project change how your family/friends viewed you and your disease?

Data Analysis

Audio recordings of all interviews were transcribed verbatim, with all identifying information removed to preserve confidentiality. I followed the steps of phenomenological data analysis, as described by Moustakas (1994) and adapted by Creswell (2013):

1. Before beginning my data analysis, I documented my personal experience and assumptions related to the Volunteer Scribes program and people with early stage Alzheimer's disease.
2. I conducted several "naïve reads" of the transcripts in their entirety, without annotation, to gain an overall sense of the data.
3. Focusing on each transcript individually, I identified significant statements that describe the participant's experience of the phenomenon and removed data not related directly to the phenomenon.
4. I interpreted the significant statements into meaning units (as illustrated in Table 2) and grouped the meaning units into clusters of meaning (Table 3) and provisional themes. Peer readers and my thesis advisor reviewed my analysis to validate themes.
5. The provisional themes (Table 4, see Appendix A) were distilled into three essential themes that represent the lived experience of participants in the Volunteer Scribes program.

Using the three essential themes that emerged from this process, I developed a textural description, using verbatim quotes, to illustrate "what" participants in the phenomenon experienced and a structural description to provide context as to "how" they

experienced it (Creswell, 2013), which were combined into a composite description of the participants’ shared experience of the phenomenon—the “essence of the experience” (Creswell, 2013).

Table 2 Examples of significant statements and meaning units

Significant Statement	Meaning Unit
So, that story came out. Things like that that, that you know, I don’t dwell on but all of a sudden they just, they opened my past and everything started flowing, you know. They made me feel comfortable.	The scribes created an environment where I felt comfortable sharing things I hadn’t thought about in a long time.
(pointing to printed version of his story) Would I give this up for a thousand dollars? No!	The story we wrote together is priceless to me.
I don’t want to be hard to please. I don’t want to be stuffed with anger. And the Scribes Project has helped me stay who I am. I was Class Optimist of [my high school]—I don’t want to be a pessimist now.	Participating in this program allowed me to see that I’m still “me”—I’m not letting my disease take that from me.
I was probably a little skeptical in the beginning thinking, “Oh, what am I going to have to say, blah, blah, blah.” But once I got into it, I understood and I just felt better about it.	I wasn’t sure I had a story worth telling, but the scribes helped me see that I did have something to say.
Seeing their father as kind of engaging, it was good for them to still see him as a person that could be part of their lives. The oldest boy has made an effort to really stay connected with us, and I do think the Scribes Program sort of helped with that.	Inviting our sons to participate with us helped them to see their father differently and understand that he is more than his disease.
It made me stop and think about what things I could remember more easily because now there was a purpose instead of just being somewhere in my brain.	Telling my story to the scribes helped me recall memories I didn’t know I could still access.
I felt that I had done something important to help others and maybe help myself feel better about it by doing that.	Telling my story gave me a sense of purpose.

Table 3 Example of cluster and associated meaning units

Cluster	Associated meaning units
Purpose and meaning	<ul style="list-style-type: none"> • Age difference was not a barrier to forming meaningful bonds • The relationship between scribes and participants transcended the program sessions • The students were interested in what I had to say • Participants felt like teachers (again) • The scribes put participants at ease • Participants felt comfortable sharing their most personal truths

CHAPTER FOUR: Results

Three essential themes emerged from participants' responses: (1) sense of self; (2) relationships with family; and (3) sense of purpose and meaning.

Theme One: Sense of self

Taking part in the Volunteer Scribes program enabled participants to see themselves as more than just a person with Alzheimer's disease. Many noted that the program helped instill a sense of hopefulness, and supported their determination to retain the essential qualities that had defined their personal identities before diagnosis. Jackie, a woman who received a diagnosis of AD four years ago, reflected on her sunny outlook, for which she had been known since girlhood and was determined to maintain.

And that's what I wish, that I will just enjoy humor and keep on as long as I can. I want to laugh about myself. And laugh with other people. And this program, the Scribes Project, has given me my premise for every day and has underlined it. The thing I wake up with in the morning is, "I will do today the best I can do for as long as I can." I don't want to be stuffed with anger. And the Scribes Project has helped me stay who I am. I was Class Optimist at [my high school.] I don't want to be a pessimist now. (Jackie, diagnosed 4 years ago)

At the same time, participants strongly identified with others who have Alzheimer's disease, and being in the program with them helped diminish feelings of isolation and stigma. Lucille, who has lived with a diagnosis of AD for more than a year and whose sister died with AD, said,

I wanted to be around people that also have Alzheimer's... Some people think it's a mental illness but it's not; it's a disease of the brain...[participating in the Volunteer Scribes program] made me feel like I wasn't alone because when you're sick, when you have something wrong with you, you just feel—like, I was depressed and now I'm better but I was very depressed. Being around people that also have it [and who] are pretty normal (laughs) like me was a godsend. It was really nice to be around others, to know you're not the only one. (Lucille, diagnosed 1 year ago)

Mike, who was diagnosed about three years ago, affirmed that participating in the program affected how he viewed himself relative to his disease.

It made me recognize that, ok, I sort of knew anyhow but, don't think a lot [about having a diagnosis of AD] and not to worry about it, which I think a lot of people do, but it was people I could talk to about what was going on. (Mike, diagnosed 3 years ago)

Each week of the program, the student scribes interview their participant about a specific period of their life, beginning in early childhood and ending with the present. While some are aided by their spouses or other family members to recall the details, many participants were surprised and often delighted by the quality and depth of memories they were able to access on their own, even going back to their earliest days. When asked whether he was surprised by some of the memories the program brought up, George said,

Oh God, yes. Growing up and working on the farms right in this area. And you got a lot of things, too many to explain, and they pop out of my memory unexpected. (George, diagnosed six months ago)

In many cases, the nostalgia of certain memories brought moments of joy:

It brought back some wonderful memories because we talk about when we were children. They said, “What was your favorite food when you were very young?” I had forgotten all about this but I used to pick wild strawberries and put them on my cereal because we didn’t have much when I was young. So that was my favorite food. Putting strawberries that I picked myself on my cereal. So it’s just things like that. The nice memories coming back, what we hadn’t thought about for a long time. It was wonderful. (Lorraine, diagnosed 1 year ago).

For some participants, the fact that the memories lingered beyond the session with their scribe made the experience meaningful.

I just talked, and I had three gals from the school, and they’re very nice, and they brought a lot of stuff out in me that I never thought of before. I felt good, and I got a lot of things out of it, things I had forgotten about, things that I still remember after the meetings that are still with me (Sam, no formal diagnosis).

For others, the realization that they still had the ability to access memories they might otherwise have assumed were lost was a powerful part of the experience.

It made me stop and think about what things could I just remember more easily because now there was a purpose instead of it just being somewhere in my brain. (Mike, diagnosed 3 years ago)

Theme Two: Relationships with family

Many respondents reported that participating in the Volunteer Scribes program helped enhance their family members' understanding of the disease. Some noted the difficulty in discussing Alzheimer's with family members, especially when it comes to changes in their behavior or personality that may emerge as their disease progresses. Sharing the stories written with their scribes has helped facilitate understanding and create a safe space for sharing important information.

It's been a way for me to tell my husband things that I'm going through that he doesn't know. Because some people can't read others, and he's not used to me asking for help for things. Like taking [phone] messages wrong. This is a new phase for him, and he's been struggling with this. So this has been a way for me to realize my changes, and that I'm going through it and all of my family and friends are going through it, too. And If I don't show them or tell them, they're not going to understand why some things are off, why [I'm] in the bed crying.

(Jackie, diagnosed 4 years ago)

Participating in the scribes sessions together, which is encouraged by the program organizers, helps participants and their loved ones forge new or deeper connections. Family members sometimes saw the person with AD in a new light as they shared this time together.

My daughter-in-law, who came with me, she's not been to college but she's always wanting to learn new things and because I have this [disease], she wanted to know more about it and I really appreciated that fact. We got closer and it was a wonderful experience. I'm glad I did it....It was quite emotional at times for

me...but it was also fun. My daughter-in-law, I asked her if she could take me because I didn't want to drive alone. So she came with me and I got closer to [her] than I've ever been. And she wants to learn more about [Alzheimer's]. She's going to help take care of me whenever that's needed. (Lucille, diagnosed 1 year ago)

We did invite two of his sons, who live locally, to sit in—each sat in at a [session of the Scribes]...Seeing their father as kind of engaging, it was good for them to see him as still a person that could be part of their lives. The oldest boy has made an effort to really stay connected with us. And I do think the Scribes program sort of helped with that. (Susan, wife of George, diagnosed 6 months ago)

Many participants noted that they had, on their own, attempted to document their life stories to share with family and friends prior to joining the Scribes program. The task often proved to be more difficult than they anticipated, so while their primary purpose in enrolling in the program was not necessarily to produce a story book, the narrative that emerged after five weeks served as a legacy to pass on to loved ones.

This is great because the one thing I had attempted, but not been able to work on, was getting a message to my great grandchildren that I only see once a year...one of the things I put in [my story] for my great-grandchildren was, 'Don't quit.' (Jackie, diagnosed 4 years ago)

Oh yes, [my story] makes me proud—of course it does...Would I trade this [points to printed story] for a thousand dollars? No! (Tim, diagnosed 2 years ago)

I have one son, and he lives in Massachusetts with his family and my two grandkids...so I'd like to have something to leave them...I'm doing a photo album...As far as writing goes, I have lost it. (Lorraine, diagnosed 2 years ago)

Theme Three: Sense of purpose and meaning

The student scribes conveyed a sense of empathy, eagerness and attention that helped put participants at ease. For many participants, meeting up with their scribes became a highlight of their week. The wife of Tim, a respondent diagnosed with AD two years ago, noted that even though the afternoon, when the program took place, is a challenging time for her husband—a common effect of AD—he would perk up enthusiastically when she reminded him it was time to leave for Scribes group. Tim said of the scribes, “I’ll tell you right off the bat it was a real treat to have them with us. They were good—A-number one!”

Some respondents admitted they weren’t sure what to expect, and were skeptical whether college students would be interested in hearing stories from older people, much less people with Alzheimer’s. The bonds that formed between students and participants, however, were almost immediate. Joan, diagnosed a year ago, said, “I really enjoyed it...if I hadn’t done this I would have missed out on a lot, because I just really enjoyed the time that I had with the scribes.”

It was interesting, because there was such an age differential [between participants and scribes]. And I was talking about things that happened long before they were born—and they seemed to get a big laugh out of that. (George, diagnosed 6 months ago)

Participants soon discovered that the students were engaged and genuinely enthusiastic to learn about their lives. They listened intently, which was reflected in the quality of the stories they wrote.

It was very interesting about [my scribe]. She let me learn a little bit about her life, too. She was just so sweet. I remember that first day, she was so comfortable, I thought, with herself, which makes the difference....she was able to be the perfect scribe for me. I think at times her questioning was to slow me down a bit, but I don't know how she was able to just get even the flavor, my flavor of telling a story. [My scribe] was able to keep an ear on me and ask me questions. She got every joke, she got every sad feeling that I had, she knew what motivated me to go on. She was just perfect. (Jackie, diagnosed 4 years ago)

Lorraine added,

My God, [sharing my story with the students] was a lot of fun [chuckles]. And if I would give them a story, one that I could tell them [laughter], they would come up with a story. They got into it with me, would really interface very nicely. And they're funny. We had a good time, and I'm going to miss them. (Lorraine, diagnosed 2 years ago)

Several participants reported that their scribes have become like family, staying connected through email, phone calls and even holiday visits for cookies. Knowing that the students were not merely participating in order to complete a class assignment made the participants feel important and valued.

Teaching the students what people with Alzheimer's disease are like instilled pride in the participants, many of whom had spent their careers as educators. One

participant commented, “We were making [Alzheimer’s] real to [them].” Tim’s wife noted that watching her husband, a “lifelong educator,” interact with the students made him feel like he was back in the classroom. George noted he had taught at a military academy and felt like a teacher again when working with his scribes.

I think what surprised my daughters...and really surprised [my scribe] was that I remembered every teacher I’ve ever had. We had such a long book that we didn’t really get into my college teachers, but I know most of them. I suppose this is the premise—that we with Alzheimer’s remember more from when we were young and had a family and all the things that went with it. (Jackie, diagnosed 4 years ago)

Mike, who had been a college professor and researcher, agreed.

They got it. It wasn’t like they were just trying to babble to say that, yes, I talked to them...we were talking with them about stuff and they clearly were getting engaged in it. (Mike, diagnosed 3 years ago)

Many of the participants were excited to learn that they had a role in inspiring some of the students, most of whom are studying nursing or occupational therapy, to pursue careers working with older people, including those with Alzheimer’s disease. One respondent observed, “These nursing students now see that someone with this diagnosis has a full life...maybe they’ll be more apt to get to know who the person was or is before they just think of him as someone who was sick in the hospital.”

[Initially] I missed the whole point of you guys having Scribes trained to come and learn from us about Alzheimer’s disease. I had no idea...even with the Bates kids, I got to teach them things, things that they were wondering about and that

they would need to have. One wants to be a doctor. And she knows this—she’s from Michigan but she likes the Northeast and she knows we’re the most aged state and we’re probably going to have many, many Alzheimer’s patients that she’s going to see. (Jackie, diagnosed 4 years ago)

What many participants did not expect was the depth sharing that would occur with the students, who put them at ease, creating an atmosphere of trust that made participants feel safe sharing their most personal memories. One participant confided to the students that she had experienced abuse as a child; she was moved by the gentle yet authentic way in which her scribes incorporated this truth into the narrative, feeling like she had really been heard and her story honored. Another participant was able to open up and share the story of “coming out” to his family about his sexual orientation, among other things.

We talked about everything, almost everything—my kids, my lifestyle, um, family, we went into detail about family, what trips, where do I like to go, almost everything. It was great, it just [exhales loudly], it all came out. I talked about my beautiful wife, ex-wife, who I lost last year. She was my best friend. We got divorced um, 25...26 years ago. And with that I came out of the closet and I’ve been married to this fella...25 years now. (Sam, no official diagnosis)

This experience of authentic sharing has helped make participants feel more comfortable being open and honest with their families outside the scribes program, too.

So if I hadn’t had the experience of telling it like it is, it wouldn’t be so easy for me to share that with my family. My daughter now gets it. And she’ll call me several times a day. ‘Well, how are you feeling now, Mom?’ And really listen,

where before when I shared, she wouldn't have known because I can bluff some things. (Jackie, diagnosed 4 years ago)

Essence of Participants' Experience

The experience of telling their life stories to students helped people with AD participating in the Volunteer Scribes Program maintain and develop a positive sense of self, viewing themselves as unique individuals not defined by their disease. At the same time, being among others who understood the challenges of AD brought comfort and alleviated the isolation the disease can foster. Participants were able to reconnect with a wide array of memories from across their life span—some which brought joy, others marking defining moments in their lives. Participating in the program helped many individuals, including several who had spent their professional careers as teachers, feel that they were teaching a new generation about what people with Alzheimer's are really like and contributing to something greater than themselves.

Telling their stories provided an important platform for connecting with their families and loved ones and starting difficult conversations. Participants felt their families gained understanding of what it is like to live with Alzheimer's disease as a result of the dialogue created through the sharing of stories or by participating together in the weekly Scribes sessions.

Perhaps most importantly, the experience of the Volunteer Scribes sessions gave participants a sense of purpose and meaning, helping them feel valued and valuable. Many participants entered the program wondering if their stories were worth telling; many were initially skeptical about whether young college students would be bored by stories of times long gone by. Instead, they met students who were genuinely interested

and engaged, with some teams forming friendships that continued well beyond the end of the program. The scribes' empathy and enthusiasm emboldened participants to share very personal, and sometimes painful, memories that helped paint an authentic picture of each participant's life.

CHAPTER FIVE: Discussion

Relevance of the Study

Five million Americans are living with Alzheimer's, a number that is expected to reach 15 million by 2050 (Alzheimer's Association, 2015). The impacts of Alzheimer's disease on the brain and body are well understood and documented. While researchers rush to find a cure or treatment to prevent people from dying of Alzheimer's—among the top ten causes of death in the U.S.—too few have looked for ways to help people *live* with Alzheimer's, even though the average life span after diagnosis is eight to ten years, and can reach as much as 20 years (National Institute on Aging, 2008; Alzheimer's Association, 2015). Like all older adults, people with Alzheimer's wrestle with issues of identity, especially in the early stages of the disease when cognitive and executive functioning are still largely intact. Yet, amid well-founded concerns about caregivers' struggles to maintain balance in the face of significant financial, physical and emotional burdens, the voices of people with Alzheimer's are often lost or marginalized (Beard, 2004).

Through the lens of hermeneutic phenomenology, the current study examined the meaning people with early stage Alzheimer's derived from writing their life stories, assisted by student scribes. The study indicates that while the narrative crafted collaboratively by students and participants was a positive outcome of the program, the process of participating in the program and telling the story was perhaps even more valuable, indicating that narrative methods may present an effective approach to helping people with Alzheimer's negotiate and maintain their identity and sense of self.

Participants in the program were often surprised by how many memories they were able to access, from early childhood to more recent events; in some cases, they shared stories their spouses or other loved ones had not heard, while in others the care partners who attended the program helped fill in details or correct inaccuracies when the participants asked, allowing for rich stories to develop while maintaining the participant's ownership of the story. Some memories provided participants a brief and welcome escape to days gone by—such as a recollection of picking strawberries in one's backyard. For others, the experience of being “on stage” before an audience of young people helped them see themselves as the educators they had been during their working lives. Participants were able to see themselves in terms of their abilities, rather than the deficits created by the disease; Alzheimer's was, in those moments, reduced to an aspect of their lives rather than the defining characteristic. At the same time, being among other people with Alzheimer's was recognized as an important part of the experience; “knowing I'm not alone” was a powerful realization affirmed through participation in the program.

Family connections were also strengthened. Participants found that attending the scribes sessions gave their loved ones a different perspective on what it is like for them to live with the disease. Some found it easier to start important conversations about daily challenges or to ask for help from their families after participating in the program. They were able to acknowledge the behavior changes that had already developed or are likely to come in the future as the disease progresses.

The scribes program enabled participants to document their stories in a way that could be shared with families as a lasting legacy. Many had tried to do this on their own, but found the task too difficult for various reasons; for them, holding a book in their

hands that they had written in collaboration with their scribes, in which they were the lead character, was itself a priceless experience.

Many participants wondered, as they enrolled in the scribes program, whether the student volunteers would even be interested in the stories they had to tell. The students, mostly enrolled in nursing or occupational therapy programs at local colleges, created an environment of trust, respect and enthusiasm that made participants feel valued and important. The social interaction with the students was an experience that, for many, carried at least as much weight as the stories themselves. Participants felt they were really being heard—some marveled at the nuances of the crafted stories that reflected the scribes’ attention to the smallest details and gestures they had shared. This nurturing environment not only bred lasting friendships between many scribes and participants, it emboldened participants to share deeply, often going “off script” from the writing prompts provided by the program coordinator in order to tell the most important stories of their lives, without shame or fear. The power and catharsis of this experience was evident as several participants retold these stories to me during their interviews for the study; they were re-experiencing what it felt like to have their stories received openly and without judgment.

Limitations. There are challenges inherent in any study involving people with Alzheimer’s disease that impact the reliability of the results (Wiersma, 2001). The current study asked participants to recall their experiences of a moment in time—the scribes sessions—which was difficult for some to articulate. Some were unable to distinguish between *describing* the experience and *reliving* the experience, and retold their stories during the interview. Field journal notes and frequent reflection became essential tools to

help me discern which stories were parts of the lived experience and which should be excluded from the study findings.

Some participants were unable to respond coherently to certain interview questions and relied more heavily on their care partners/spouses, also present at the interviews, to provide clarification and validation. The care partners, as a whole, recognized that their role in the interviews was to observe and reassure the participants who were the focus of this study. The study makes no assumptions about whether this participant-centered focus between spouse and person with Alzheimer's emerged as a result of participation in the scribes program or was a preexisting characteristic of the couples' relationships.

Review by peers and my thesis advisor was used as a primary method of evaluating the study for rigor and trustworthiness, an approach limited by individuals' knowledge of the method and the subject under study. "Member checking"—sharing data analysis with study participants to solicit feedback as to whether the results reflected their intentions—is commonly used for validation in phenomenological studies (Armour, Rivaux, & Bell, 2009) but was not practical due to the nature of the study and of the limitations posed by participants' disease.

The sample was small and homogenous in terms of race/ethnicity, stage of Alzheimer's and geographic location. Maine is a large, rural state that is not uniformly served by the Alzheimer's Association due to limited resources. Participants in the study were concentrated in the southern part of the state, which is more populous and affluent than the northern, central and eastern counties.

Evaluation Against Recent Literature

The current study supports the findings of other recent research around use of narrative with people with Alzheimer's. Participants in the scribes program shared unique stories that revealed their individuality and helped care partners gain a better sense of the whole person, rather than focusing on their deficits (Russell & Timmons, 2009). The social aspect of participating in the program was, for many, as important as the narrative that emerged (Holm et al, 2005; Stenhouse et al, 2013). The implications of this benefit are important in light of studies on social engagement as a contributor to overall brain health (Haslam, Cruwys, & Haslam, 2014; Marioni et al, 2015). The group aspect of the scribes program appears to be an important contributor to participants' positive experience, and helps them maintain a healthy self-view that looks beyond their diagnosis (Haslam, Cruwys, & Haslma, 2014). Documenting the life story together brought many families closer and helped participants feel better understood by their partners in relation to life with Alzheimer's disease (Ingersoll-Dayton et al, 2013).

The current study also confirms the findings of Chodony and Wang's (2013) examination of a similar reminiscence program in which young people served as scribes and listening partners for older adults; while it is impossible to determine from the current study to what degree the age of the scribes impacted the lived experience for participants, findings suggest that the interaction with students was an important, enjoyable component of the program. Many participants reported that helping the students—and, in some cases, their families and friends—better understand Alzheimer's disease helped foster a sense of worth and importance (Bettens et al, 2014).

Implications for Social Work Research and Practice

The results of the current study suggest that the experience of telling personal stories in a supported environment is meaningful on many levels for people with Alzheimer's disease: as a means of positive identity development and preservation; as a social engagement opportunity to connect with others living with dementia; and as a way of connecting or reconnecting with family and loved ones and sharing important life memories. Opportunities for future research to further understand the value and therapeutic benefits are numerous. Examination of other elements of the scribes program, including phenomenological inquiry regarding the lived experience of the volunteer scribes or care partners, for example, could offer important insights that help shape future volunteer and participant recruitment. It may also be worth exploring the adaptability of such a program for people with more advanced dementia, to identify modifications that would make the Scribes program accessible to people with moderate to severe Alzheimer's (Holm et al, 2005). Comparing results with other Alzheimer's Association chapters on the effectiveness of their narrative therapy programs is also warranted.

Dignity therapy, developed initially for use in palliative care and hospice settings, is an evidence-based approach (Chochinov et al, 2005; Hall et al, 2012) whose guiding principles and methods align closely with the structure and purpose of the Volunteer Scribes Program. The Alzheimer's Association (2016) recently awarded a grant to support research on the use of dignity therapy with people with Alzheimer's, which could yield important findings that impact future interventions and program offerings.

The literature suggests a strong correlation between social connectedness and positive sense of self (Haslam, Cruwys, & Haslam, 2014; Karlsson, 2014; Marioni et al, 2015), which merits further investigation. On a practice level, social workers have an

opportunity and a responsibility to advocate for more programs and activities that enable people with Alzheimer's to build and maintain many social connections, not only with other people with dementia but with young people, professional caregivers and others. Programs that connect caregivers and community members with people with dementia can foster improved understanding, reduce stigma around the disease, and potentially improve the quality of healthcare people with Alzheimer's receive (Trueland, 2013).

It is worth noting that the Volunteer Scribes Program and other social engagement programs offered in Maine and around the country are not therapeutic interventions. While an evidence-based focus has its place in the practice of social work with all populations, it is important not to lose sight of the fact that people with Alzheimer's, especially in the early stage, need to be engaged, stimulated, and valued, not "fixed."

Conclusion

Psychosocial development in old age is marked by a conflict between integrity and despair as individuals work to achieve identity balance between the past and present—reconciling "who I've been" with "who I am now" (Erikson, Erikson, & Kivnick, 1986). Most elders accept, in varying degrees, the inevitability of physical decline (Erikson, Erikson, & Kivnick, 1986); in fact, Cruikshank (2013) observes that infirmity becomes a status symbol for many older adults.

In Erikson's (1986) life cycle view, this stage of life is characterized by Wisdom, which "maintains and learns to convey the integrity of experience, in spite of the decline of bodily and mental functions." Yet Erikson's (1986) study reveals a nearly universal fear of cognitive decline among participants:

Many voice terror of losing their mind, speaking so quickly as to suggest superstitious avoidance of the very words. Most assert, “I don’t want to linger. No rest home. No convalescent home. I don’t want to go on living one minute after I’m mentally incapable.” To all of these people, apparently, physiological disability can be compensated for or denied in the service of willful autonomy. But a disabled mind can neither deny nor compensate. In its most profound sense, then, mental disability seems to loom as a shameful helplessness that will permit no vestiges of autonomy, in the realm either of behavior or of internal feelings (Erikson, Erikson, & Kivnick, 1986, p. 200).

Current social constructions of dementia support this view, as evidenced by a study that revealed adults’ fear of developing Alzheimer’s was increasing as fear of cancer sharply declined; this was true not only of those 65 and older, but among people as young as 18 (Alzheimer’s Association, 2014). By contrast, I was struck by the degree to which participants in my study spoke with relative ease, and even humor, about living with Alzheimer’s. One participant joked about making a list of things she’d like to accomplish:

I was starting a bucket list. I don’t know many Alzheimer’s people that bother to have bucket lists because number one, we get into Alzheimer’s and we don’t know what the hell the bucket list means, and we never have a long one, that’s one thing. It’s very short because you don’t have memory about everything that you were thinking of (laughs). (Jackie, diagnosed 4 years ago)

Others proudly showed me the day planners, smart phone apps and other tools and tricks they use to compensate for the challenges of recalling appointments and other

details. I heard no hints of shame, stigma, anger or self-pity that one might, not unreasonably, expect. This is not to presume the participants had no fears or concerns about what life would look like as their disease progressed; however, there was a prevailing sense of hopefulness and positivity that permeated most interviews. While their mostly positive outlook cannot be attributed to participation in the scribes program, it is almost certainly supported by it.

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Appendix A

Table 4: Provisional and essential themes

Provisional Themes	Essential Themes
<ul style="list-style-type: none"> • I feel valued • I feel valuable • This program helped me see myself differently • My relationship with the Alzheimer’s Association is important • The program helped me open conversation with my family about my disease • I’m more than my diagnosis • I found my voice • I remembered more than I expected • I built a strong relationship with my scribes • My story is worth telling • I can leave a legacy for my family • This program helped my family understand me better • I had something to offer as well as something to learn 	<ul style="list-style-type: none"> • Sense of self • Relationship with family • Sense of purpose and meaning

Appendix B: Final Approval Form

The University of Southern Maine

School of Social Work

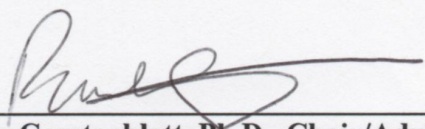
Master of Social Work Program

Date: 4/27/10

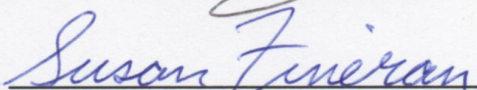
We hereby recommend that the thesis of Jennifer E. Dimond, entitled:

Writing life stories: A phenomenological study of memory and meaning for people with early stage Alzheimer's disease

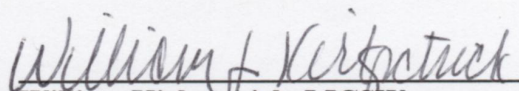
be accepted in partial fulfillment of the requirements for the Degree of Master of Social Work.



Paula Gerstenblatt, Ph.D., Chair/Advisor

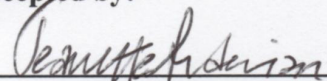


Susan Fineran, Ph.D., LICSW



William Kirkpatrick, LICSW

Accepted by:



Appendix C: IRB Approval



NOTICE OF IRB REVIEW AND APPROVAL

DATE: October 13, 2015
TO: Jennifer Dimond, Social Work
Paula Gerstenblatt, Social Work
FROM: Casey Webster, Human Protections Administrator, USM IRB
PROTOCOL TITLE: Meaning of telling life stories for people with early stage Alzheimer's
FUNDING SOURCE: NONE
PROTOCOL NUMBER: 15-09-611
APPROVAL PERIOD: Approval Date: October 13, 2015 Expiration Date: October 12, 2016

The project identified above has been reviewed by the University of Southern Maine's Institutional Review Board (IRB) for the Protection of Human Subjects in Research using an expedited review procedure per Title 45 CFR Part 46.110. This approval is based on the assumption that the materials, including changes/clarifications that you submitted to the IRB contain a complete and accurate description of all the ways in which human subjects are involved in your research.

This approval is given with the following terms:

1. You are approved to conduct this research only during the period of approval cited above;
2. You will conduct the research according to the plans and protocol submitted;
3. You will immediately inform the Office of Research Integrity and Outreach (ORIO) of any injuries or adverse research events involving subjects;
4. You will immediately request approval from the IRB of any proposed changes in your research, and you will not initiate any changes until they have been reviewed and approved by the IRB;
5. You will only use the informed consent document that has the IRB approval dates marked in the footer;
6. You will give each research subject a copy of the informed consent document;
7. As applicable, you will comply with the University of Maine Information Security Policy and Standards and/or the Muskie School of Public Service Securing Protected Information Policies and Procedures and any other applicable USM policies or procedures;
8. If your research is anticipated to continue beyond the IRB approval dates, you must request continuing review at least 60 days prior to the IRB approval expiration date; and
9. You will close the project upon completion (or discontinued).

The University appreciates your efforts to conduct research in compliance with the federal regulations that have been established to ensure the protection of human subjects in research.

Sincerely,

A handwritten signature in black ink that reads "Casey Webster".

Casey Webster

Appendix D: Recruitment letter

Dear (Name),

Jennifer Dimond, a Master's in Social Work student at the University of Southern Maine, is studying participants in the Alzheimer's Association, Maine Chapter's Volunteer Scribes program, in order to understand the meaning and experience of telling life stories for people with Alzheimer's disease.

As a participant in our Volunteer Scribes program, you may be eligible to participate in the study. Participants will be asked to meet with Jennifer for a one-on-one interview and answer questions based on their experience in the Volunteer Scribes program. The interview will last approximately 30 to 45 minutes. All participant names will be kept private.

If you are interested in participating in this study or have questions, please call Jennifer Dimond at (207) 756-0508 or contact her by email at jennifer.dimond@maine.edu. You may also contact Jennifer's faculty advisor, Dr. Paula Gerstenblatt, at 510-205-3395 or pgerstenblatt@usm.maine.edu. You will only be contacted about this study if you express interest.

Participating in this study is voluntary. It will not affect your participation in any programs or services of the Alzheimer's Association if you decide not to call about the study or participate.

Sincerely,

Mark Pechenik
Community Outreach Coordinator
Alzheimer's Association, Maine Chapter

Appendix E: Letter of Support



Maine Chapter

October 1, 2015

To Whom It May Concern:

I am delighted to submit this Letter of Support for Jennifer Dimond's research study of the Legacy Writers Groups: Volunteer Scribes Program, an initiative presented by the Alzheimer's Association, Maine Chapter.

For the past year, the Volunteer Scribes Program has enable college and high school students to interview and write the life stories of those living with early to mid-stage Alzheimer's disease or related dementias.

This program has proven highly beneficial for everyone involved. For students, most of whom are pursuing careers in health care or medical research, it provides them with unique insight into the every day lives of those facing the challenges of Alzheimer's disease.

For participants (those diagnosed with dementia), this program not only provides them with an opportunity to have their written legacy passed onto future generations, it allows them to advance the education of students who could, one day, be instrumental in bringing an end to Alzheimer's disease.

But, there have also been other, unforeseen benefits to the Volunteer Scribes program. Participants who have almost been non-verbal find themselves actively engaged with interviewers, while other participants indicate that the interview process has helped to "spark" once forgotten memories.

This is why we are very grateful to Jennifer Dimond in her efforts to conduct research on the Volunteer Scribes program. Through her work, we hope that concrete, definable results will reveal some of the anecdotal benefits of this program.

Having worked with Jennifer in the recent past, I can think of no one more capable and effective in conducting research on the Volunteer Scribes program. We at the Alzheimer's Association, Maine Chapter greatly appreciate and enthusiastically support Jennifer in her project focusing on the Volunteer Scribes program!

Sincerely,

A handwritten signature in black ink, appearing to read "Mark Pechenik".

Mark Pechenik

Director of Community Engagement and Outreach
Alzheimer's Association, Maine Chapter

Appendix F: Informed Consent

University of Southern Maine CONSENT FOR PARTICIPATION IN RESEARCH

Approved by USM IRB on October 13, 2015

Project Title: Writing life stories: Memory and meaning for people with early stage Alzheimer's disease

Principal Investigator(s):

Jennifer Dimond, MSW student, University of Southern Maine
Phone (207) 756-0508 E-mail jennifer.dimond@maine.edu

Faculty advisor: Dr. Paula Gerstenblatt, PhD, MSW, University of Southern Maine
Phone (510) 205-3395 E-mail pgerstenblatt@usm.maine.edu

Introduction:

- Please read this form. The purpose of this form is to provide you with information about this research study, and if you choose to participate, document your decision.
- The principal investigator will review this form with you and answer any questions or concerns you may have.
- Please ask any questions that you may have about this study, now, during or after the project is complete. You can take as much time as you need to decide whether or not you want to participate. It is entirely up to you.
- This is a research study.

Why is this study being done?

The purpose of this study is to better understand what the Volunteer Scribes life stories program means to people with early stage Alzheimer's disease.

Who will be in this study?

Participants who complete the Volunteer Scribes program, offered by the Alzheimer's Association of Maine and who have been diagnosed with Alzheimer's disease or another dementia are eligible to take part in this study. A total of 8 to 10 participants will be interviewed.

What will I be asked to do?

- You will be asked to speak with the principal investigator for an interview that will last about 30 to 45 minutes.
- The interview will take place in your home or another place you choose, such as a public library or school.
- The interview will be audio recorded; the audiotape will be available only to the researchers conducting the discussion, and will be destroyed after it is transcribed.

What are the possible risks of taking part in this study?

Taking part in this study could embarrass some participants or make them uncomfortable. You will not be forced to answer any questions you do not wish to answer.

What are the possible benefits of taking part in this study?

By taking part in this study, you may help the Alzheimer's Association improve the social engagement programs available to people with Alzheimer's disease. You may, if you wish, have your care partner (such as your spouse) present during the interview.

What will it cost me?

There is no cost to you to be part of this study.

How will my privacy be protected?

- Your name and other information that could identify you as a participant will not be shared with the Alzheimer's Association or any other individual or organization.
- Your interview will take place at your home, a private room at a public library, or other location that is comfortable to you to ensure your privacy.
- This research is being conducted for the student researcher's Master's thesis, which will be a public document. The results may also be submitted to other professional journals for publication.

How will my data be kept confidential?

- Research records will be kept in a locked file in the locked office of the Principal Investigator.
- Any information that identifies you will be destroyed after the study is complete.

- Data will be coded.
- Data will be encrypted using industry standards.
- Please note that regulatory agencies and the Institutional Review Board may review the research records.
- A copy of your signed consent form will be maintained by the principal investigator for at least 3 years after the project is complete before it is destroyed. The consent forms will be stored in a secure location that only members of the research team will have access to and will not be affiliated with any data obtained during the project.
- Audio recording of the interviews will be used only by the principal investigator and faculty advisor for the purposes of documenting participants' responses in their own words, and will be destroyed once the transcription is complete. Participants' real names will not be included in the transcripts.
- If, in the future, the researcher intends to use the data for other research purposes, you will be notified.

What are my rights as a research participant?

- It is your choice whether or not you take part in this research study. Your decision will have no impact on your current or future relations with the Alzheimer's Association, Maine Chapter, or any other entity.
- You may skip or refuse to answer any question for any reason.
- If you would like to see the findings of this research once it is complete, you may contact Jennifer Dimond, the researcher.
- Your spouse, caregiver or legally authorized representative may be in the room during the interview if you would like them to be. They are not required to be present.
- If you choose not to participate there is no penalty to you. You are free to quit this research study at any time, for any reason, without penalty.
- You will be informed of any significant findings developed during the course of the research that may affect your willingness to participate in the research.

What other options do I have?

You may choose not to participate.

Whom may I contact with questions?

The researcher conducting this study is Jennifer Dimond. For questions or more information concerning this research you may contact her at (207) 756-0508 or jennifer.dimond@maine.edu

If you choose to participate in this research study and believe you may have suffered a research related injury, please contact Dr. Paula Gerstenblatt at pgerstenblatt@usm.maine.edu or (510)-205-3395

If you have any questions or concerns about your rights as a research subject, you may call the USM Human Protections Administrator at (207) 228-8434 and/or email usmirb@usm.maine.edu.

Will I receive a copy of this consent form?

You will be given a copy of this consent form.

Participant’s Statement

I understand the above description of this research and the risks and benefits associated with my participation as a research subject. I agree to take part in the research and do so of my own free will.

Participant’s signature or
Legally authorized representative

Date

Printed name

Researcher’s Statement

The participant named above had sufficient time to consider the information, had an opportunity to ask questions, and voluntarily agreed to be in this study.

Researcher’s signature

Date

Printed name