

**AUTOBIOGRAPHICAL ACCOUNTS OF EARLY-ONSET
ALZHEIMER'S DISEASE: OBITUARIES OF THE LIVING DEAD?**

Daina Stanley

A thesis submitted to the Faculty of Graduate and Postdoctoral Studies
in conformity with the requirements for the Master of Arts degree in Anthropology

Department of Anthropology and Sociology

Faculty of Social Science

University of Ottawa

Ottawa, Ontario, Canada

Copyright ©Daina Stanley, Ottawa, Canada, 2013

ABSTRACT

The thesis was designed to gain insight into how Alzheimer's disease influences selfhood from first-personal accounts of illness. The focus of the study was narrowed further by concentrating on the autobiographies of individuals diagnosed with Early-Onset Alzheimer's disease (EOAD). The purpose of this thesis was to analyze the autobiographies of individuals with EOAD with the aim of understanding their selfhood. In this thesis I argue that, Alzheimer's disease may influence a change in self, however, the self is not lost entirely. This thesis draws on the philosophical conception of narrated self as it allows for one perpetually constructed self, whereby a change in self does not necessarily mean the self is lost entirely. Through an interpretive analysis of six autobiographical accounts of Alzheimer's, this thesis demonstrates that Alzheimer's disease influences a loss of sense of self but that autobiography enables individuals with Alzheimer's to (re)construct self.

Keywords: Early-onset Alzheimer's disease, self, medical anthropology, biomedicine, illness narrative, autobiography, sense of self, narrated self

DEDICATION

For Nana, whose stories made me realize that everyone has a tale to tell.

ACKNOWLEDGEMENTS

Throughout the long journey that my thesis has been, an awareness of the many individuals who have helped me through was at the forefront of my mind. Many people helped in many ways, and this acknowledgement is my opportunity to express my sincere appreciation to at least a few of them. I had started to write this acknowledgement several months ago, but I felt that I was being somewhat eager by writing about the incredible individuals who have helped me throughout this process when my journey was not yet done and all its twists and turns had not yet been navigated. But here I am, back at this section and, as I write now, I finally feel like I did it. It was a bumpy road, to say the least, but here I am and here it is: 365 days of work in 129 pages. Forever indebted to the authors of autobiographies, who so graciously share their journeys, I feel it is only appropriate to share mine and to say thank you to those who have helped along the way.

Throughout my years at the University of Ottawa, there have been several professors who have made a lasting impression on me. Dr. Scott Simon is one such professor. I first met Dr. Simon in my fourth year of university when I returned to the University of Ottawa after spending a year studying at the University of Guelph. I became seriously ill during this period and Dr. Simon was both understanding and supportive in helping me to complete my course work successfully. When the following year brought an opportunity to work as a student research assistant to Dr. Simon, I applied, and was overjoyed when I was selected to spend four months on this very interesting assignment. Working closely with Dr. Simon I became inspired by his dedication and vision and decided that I would like to continue to pursue my

education. When I applied for a Master's degree, I followed Dr. Simon's advice and chose the thesis route as he encouraged me to one day pursue a PhD – a dream I hope to make a reality in the upcoming months. Throughout my Master's studies, Dr. Simon has continued to inspire me and has pushed me to think in new ways. His courses were always challenging and have helped me to develop and grow as a young academic. To Dr. Simon, thank you. Thank you for all of your guidance, help and support - you have had a great impact on me and I hope one day to inspire my students as you have inspired me.

As members of my Master's committee, Dr. Julie Laplante and Dr. Victor Da Rosa have been instrumental to this thesis. Both Dr. Laplante and Dr. Da Rosa have willingly shared their time and expertise and their guidance has been invaluable to me. I met Dr. Da Rosa for the first time at my thesis proposal defense. It was Dr. Da Rosa who encouraged me to explore new areas of literature, including cognitive anthropology, and to speak with medical professionals. Dr. Da Rosa also graciously took the time to meet with me when I was considering exploring a new direction and helped me to find the right path. I have learned a great deal from Dr. Da Rosa and am so thankful for having had the opportunity to work with such a dynamic and respected professor. To Dr. Da Rosa, thank you for your willingness to be a part of my journey and for all of your valuable insights and guidance throughout.

Dr. Julie Laplante has watched me grow and evolve over the past four years. The courses she taught with such passion introduced me to- and have given me an

understanding of several great theorists. It was in one of her classes that I suddenly “found” my voice in anthropology and for that I am so very grateful. I am also thankful to Julie for the support, advice and consideration she has give me over the years - for the always answered e-mails, the well-considered advice, and the many letters of support. To Julie, thank you so much for your ongoing support and for the many efforts you have made on my behalf.

I am also thankful to Julie for bringing Karim to our third year anthropology course as a teaching assistant (TA) several years ago. Karim proved to be the most involved TA I have ever had, meeting with me regularly throughout my undergraduate and graduate studies and making himself available whenever I needed advice. As I'm sure Karim would have agreed, I am someone who never chooses the easy route. Others have often been discouraged me from pursuing real interests and encouraged me, instead, to pursue easier or more superficial subjects. Karim, however, was different. He encouraged me to pursue something I was passionate about and to never settle for the simple and straightforward. To Karim, thank you for giving me the inspiration and courage to choose a complex topic I am passionate about rather than an uncomplicated, passionless path. You are missed.

I am forever thankful to my supervisor and mentor Dr. Karine Vanthuyne. Karine has pushed me to limits I did not even know I could reach. She has been a constant source of encouragement and support throughout this roller-coaster ride. There have been many highs and lows and Karine has helped me each step of the way. She has invested hours upon hours into me and this thesis and has gone above

and beyond the duties of a supervisor. She has not only encouraged and supported me, but she has inspired me and given me the courage to pursue a complicated topic and a non-traditional path in anthropological research. When my research application was rejected at the eleventh hour by a field site I had spent months building a relationship with, Karine was there to help me regroup and to find a new and exciting direction. I vividly remember walking into her office feeling completely demoralized from the rejection, only to walk out feeling rejuvenated and excited. I do not know anyone else quite like Karine. Even though she is endlessly busy, every time I walk into her office she has a smile on her face and always welcomes me with open arms. Without Karine, this thesis would not be what it is. I think back to my first draft – a less-than-stellar 70 pages – and shudder. To Karine, thank you so very, very much for guiding me in the right direction and for your patience, your insight, and your unvarying support.

To Carly Warnock, a fellow MA student, but more importantly a friend. It has been a pleasure to share this wonderful journey with you – we did it! To Natalie Ward, whom I had the absolute pleasure of working for as a TA, watching you teach and interact with your students was an incredible experience and I am so very grateful to have been part of it. A million heartfelt thank yous to both of you. Thank you for sharing your honest insights and advice with me, thank you for sharing some of the best (and funniest) moments with me, and for being there for some of the worst times, always ready with much-needed hugs, encouragement, and laughter.

To the other wonderful people in my life who have supported me through this journey, thank you. To Geoff's family, I am so grateful for everything over the past year: from kind words of encouragement, to delicious dinners, to opening your home to Geoff and me, to all of the help with "rotten" Rudy – it really made this year that much easier for us. To Lisa Lazarus and Ashley Shaw, thank you for the (many) vent sessions, the YouTube breaks (and ensuing laughs), awkward hugs, and for just understanding. In the 11 months that I worked with you both, I learned more than I could ever have imagined. You were more than just work colleagues, you were my friends and my mentors, and I can only hope to have as much passion and dedication for my career as you do.

To my incredible pals, thank you for bringing the fun to this year. Cheese fan, sparkles, fish bowls, and my raptors got me through. To Tina, especially, thank you for your constant support. Thank you for understanding when I had to miss out on a birthday or an important event, for listening endlessly to all of my long – and often pointless - rambling stories, for being there whenever I was in dire need of a break, and for bringing me back to "real life". In the final days of this thesis, Tina showed me, again, just how fortunate I am to have a friend like her, when at the last minute I had to cancel our plans for a short vacation that was meant to have been a celebration of the "end" of this chapter. With the amount of work I still had to do on my thesis, I couldn't spare the time away. Tina completely understood the value of the extra days for me and rather than expressing her disappointment, she was the supportive Tina who helped get me through this journey and who will undoubtedly be there for the next.

To my mum and dad, who encouraged my ambitions and never stopped feeding my ever-curious mind. From the time I was a little “sprite” I had question...upon question...upon question. From following the “cweaning wadies” all around the house asking, “Waaadies! What are you doing?” in my (incredibly) screechy little voice, to needing to know the answer to where the dead-bunny-beside-the-road’s mommy was, to asking “Mummy what’s that nanimal?” after every single cow we passed on the 24 hour drive to Florida.... Not only did I ask a lot of questions, but I also liked to answer a lot of questions – in grade 1, I got in trouble from the teacher for putting my hand up too much. To my parents, thank you for always answering my questions and for letting me answer questions. Thank you for being a constant source of support and encouragement and for helping me through this journey in so many ways: from financing my education to family dinners to retail therapy to vacations. To Kailen and Mike, my “seeeees” and little-big brother, who are two of my main supporters, thank you for believing in me, for encouraging me, and for supporting me. Whether you’re far away in Australia, or relatively nearby in Guelph, I know you’re always close to me and that I can count on you two for anything. I love you all very, very, very much.

To Geoff, my patient partner, thank you most of all. Shortly before I began the second year of my Master’s, Geoff, my partner of three years at the time, moved to Northern Ontario to take a position as a flight medic. We spent nearly a year living a four-hour drive and two plane rides apart. While Geoff was pursuing his dreams, I was pursuing mine and, despite the distance between us, every day Geoff continued – and continues – to inspire me. His drive and passion for his career are

rare and I admire him more and more for it each day. In the past four years we have watched each other dream big dreams and have helped each other to make these dreams a reality. I look forward to continuing our journey together as you begin your next dream and I begin mine. Every day I feel lucky to have you by my side. Your love, patience, and unwavering support have given me the drive to continue to follow my dreams. Thank you so much for giving me the motivation to never give up and the strength and support to pursue my dreams.

TABLE OF CONTENTS

Abstract ii

Dedication iii

Acknowledgements iv

Table of Contents xi

List of Tables xiv

Chapter 1: Introduction 1

 Why Alzheimer's? 2

 Living Out My Commitment 4

 The Chapters 5

Chapter 2: Theoretical Considerations 8

 What Is Self? 9

 The Autonomous Self 9

 The Experiential Self 10

 The Narrated Self 14

Ipse and Idem 16

The Story and The Plot 17

 What is Alzheimer's? 19

 Deconstructing the Biomedical Treatment of Alzheimer's 20

 Classification 20

 Types 21

 Stages 22

 Causes 22

 Pathology 23

 Clinical Symptoms 24

 Diagnosis 24

 Interventions 25

The Biomedical Construction of Alzheimer's and Self	25
Chapter 3: A Review of the Literature	29
The Literature	30
Anthropological Studies of Alzheimer's and Self	34
Filling the Gap and Breaking Tradition	40
Chapter 4: The Methodology	43
The Beginning	44
Initial Ideas	44
A New Direction	46
Autobiographical Text as Data	46
Autobiographical Accounts of Alzheimer's Disease	49
"Recruitment"	51
The Autobiographies	53
The Authors	56
Robert Davis	56
Larry Rose	57
Thomas Debaggio	58
Jeanne L. Lee	60
Charles Schneider	62
Richard Taylor	63
Data Analysis	65
Chapter 5: Analyzing the Data	67
Autobiographical Accounts of Alzheimer's	68
Sense of Self	69
Functioning	69
Language	69
Writing	70

Social Roles	70
Familial Roles	70
Memory and Recall	70
Responsibilities	71
Loss of Functioning	71
Others	75
Self (Re)Construction	80
Self-preservation	82
Self-expression	83
Self-reflection	83
Self-creation	84
Obituaries of the Living	84
Chapter 6: Conclusions	95
Concluding Thoughts	96
Implications of this Study	99
The Limitations of this Study	101
Where Will I Go From Here	102
References	105

LIST OF TABLES

Table 4.0	52
Table 4.1	54

CHAPTER 1: INTRODUCTION

One can never truly stand in another's shoes. However, when others without Alzheimer's disease try their best to stand in our shoes, to experience the world as people with Alzheimer's do, it helps both of us.

- Richard Taylor 2007: 80

WHY ALZHEIMER'S?

I met Lyn for the first time three summers ago. She was my partner's grandmother, and in our first year together, he would tell me stories of his much-admired "Grandma". From what I knew, she was a strong, vivacious French Canadian woman, with a lively sense of humor. My first meeting with Lyn was brief. We were attending a family wedding in Chelsea, Québec, and we were exploring the lush gardens nearby. Along our walk we stopped to read a plaque written in French. Lyn urged her beloved grandson to read the plaque to her in her native tongue. Unsure of his accent, he "graciously" passed this task on to me, informing Grandma that I too spoke French. Lyn was immediately overjoyed and delightedly encouraged me to read the plaque. In this moment, I felt instant affection for this 89-year-old woman. Something in me was drawn to her and although I did not see Lyn much over the next three years, I looked forward to the times that I did; Lyn was never far from my mind.

Shortly into the beginnings of my Master's research, Lyn passed away. She had been diagnosed with Alzheimer's disease a year before. It was not the disease that eventually killed her, but it played a part in her death, and, more importantly, in how she lived the last year of her life. In the last days of her battle, Lyn was increasingly disoriented, confused and scared. I watched those around her looking at her helplessly as she slipped away from this world into a world she herself did not seem to understand.

While my original interest in Alzheimer's was piqued several years ago after losing my Great Uncle Donald to the disease, Lyn's passing made me want to understand it even more. In speaking with my partner and his father of the pain and challenges associated with watching someone they loved so much be stolen away, I could see the effects of this disease on family members and loved ones. While the difficulty of watching a family member slip from this world was relayed to me throughout Lyn's year with Alzheimer's, I remember thinking of Lyn and wondering what she was going through: what was going on in her mind? Did she know what was happening? How did she feel about all of this? I did not have the answers to these questions and it became glaringly obvious that I was but an outsider of the disease. My curious thoughts, similar to the ones I had previously entertained when Uncle Donald was losing his battle with Alzheimer's, became a burning desire to know. I needed to know what Lyn may have been thinking, I needed to know what Uncle Donald may have been feeling; I needed answers. I could not get these answers, however, as the two people I knew who had lived with Alzheimer's had not been able to open up to me about their experiences with it. I knew nothing of their perspectives and the impact of the disease on them individually. Instead, all I had were outside perceptions and this, quite simply, was not enough for my ever-curious mind.

Having been avidly reading Alzheimer's literature for the past year, I knew there was no one, defined, "Alzheimer's experience"; I knew that the disease had more than likely affected Lyn and Uncle Donald differently. While I learned a great deal about Alzheimer's disease through my hours of endless reading, I also became

increasingly frustrated with the literature on Alzheimer's. In my reading of Alzheimer's narratives, I read of painful personal battles with Alzheimer's and rather cold biomedical discussions of the disease. Not long into my "journey", I began to feel as though there was a disjuncture with much of the literature, characterized by a sharp divide between *actual experience* and *medical conceptions* of Alzheimer's disease. At times, it seemed as though the Alzheimer's "patient" was nothing more than an object, "less" than a person because his or her cognitive functioning was no longer "perfect". I became frustrated by the objectification of individuals and began to think that the discipline of anthropology could be useful to the discussion of Alzheimer's disease.

Characterized by a holistic perspective, I thought: perhaps anthropology could "solve" this problem or at least offer an alternative understanding of Alzheimer's disease. Turning to anthropological literature, I realized that I was not the only one who felt this way. Others shared similar sentiments and had, in recent years, begun to explore the subjective experiences of individuals with Alzheimer's disease. After finding the works of Pia Kontos (2004, 2006) and Annette Leibing (2006), I was both encouraged and inspired, and while I was already committed to the study of Alzheimer disease, Lyn's passing cemented this commitment.

LIVING OUT MY COMMITMENT

This thesis is entitled "Autobiographical Accounts of Early-Onset Alzheimer's Disease: Obituaries of the Living Dead?" As this title suggests, it analyzes subjective experiences with Alzheimer's disease from the perspective of the ill person as

presented in their autobiography. The research focused on autobiographical accounts of illness as, while “statistics tell one story, another belongs to the person behind each figure” (Page and Keady 2010: 512). Moreover, viewing an individual in the context of their life story is crucial to finding meaning in the act of living with Alzheimer’s disease (Kitwood 1997). The focus of the study was narrowed further by concentrating on the autobiographies of individuals diagnosed with Early-Onset Alzheimer’s disease (EOAD), as these are the individuals with Alzheimer’s who have graciously allowed me, and others, to access their very personal experiences with illness through written autobiographies.

The thesis was designed to gain insight into how Alzheimer’s disease influences selfhood from first-personal accounts of the ill individual. In this thesis, I argue that the self of individuals with Alzheimer’s disease is not lost but *changed*. I argue that Alzheimer’s disease may change sense of self, but through narrative, some individuals with Alzheimer’s (re)construct self. In this thesis, I draw on the philosophical theory of narrated self to demonstrate that individuals with Alzheimer’s disease may lose sense of self, but, at the same time, they may also (re)construct self as revealed through an interpretive analysis of autobiographical accounts of Alzheimer’s.

THE CHAPTERS

To understand how Alzheimer’s disease influences self requires an understanding of the concept of self and the concept of Alzheimer’s disease. Thus, Chapter 2 is guided by the question: what is self? In an attempt to answer this

question, I present a discussion of the philosophical conceptions of self that continue to permeate present-day discourse. More specifically, I discuss three distinct approaches to self: the *autonomous self*, the *experiential self*, and the *narrated self*, as, to begin to address the issues associated with selfhood in Alzheimer's, we need to first understand what a "self" is. Following this I ask: what is Alzheimer's disease? This chapter is my attempt to deconstruct the biomedical approach to Alzheimer's disease. I approach this question from a medical anthropology framework, arguing that Alzheimer's disease is a biomedical construct. I conclude this chapter by examining how the biomedical treatment of Alzheimer's influences self.

In Chapter 3, I review anthropological studies of selfhood and Alzheimer's disease, in order to situate myself among this evolving body of literature. I first provide a brief overview of studies of Alzheimer's and the self in the social sciences. I then offer a more detailed review of anthropological studies of Alzheimer's and self. I suggest that existing anthropological studies on self and Alzheimer's draw attention to the complexity of how individuals with cognitive impairment experience selfhood. However, while these studies enhance a rather "thin" body literature, what is largely missing are hermeneutical approaches to self. Hermeneutics are distant from the Descartes' dualism and overcome the unity inherent in Kant's theory of self, and, as such, are useful to the study of self among narrators of Alzheimer's narratives. I identify a gap in the literature, highlighting that, to date, there are no anthropological studies that focus on autobiographical

accounts of Early-onset Alzheimer's disease and self. This study will attempt to fill this gap in the literature.

Chapter 4 details my methodological approach to the study of Alzheimer's and self. I begin this chapter by describing my initial ideas and the beginning stages of the project. I then detail a "defining moment" for me, when my field site refused me access. This led me to pursue a new direction: the use of written autobiographies as anthropological data. I discuss this new direction and how I "recruited" of six autobiographical accounts of Alzheimer's disease. I then describe the background of each author of the selected autobiographies respectively. Following this, I describe my interpretive approach to data analysis.

In Chapter 5, I examine the selfhood of individuals diagnosed with Alzheimer's disease. In this chapter, through an analysis of autobiographical accounts of Alzheimer's disease, I demonstrate the dynamic nature of selfhood. I argue that Alzheimer's disease may influence sense of self, however, through narrative individuals may (re)construct self. I highlight that individuals ill with Alzheimer's may use autobiographies as sites for self-construction. As such, these accounts call for the understanding of selfhood, not as static or objective, but as dynamic, thus the narrated self is particularly relevant to Alzheimer's disease.

Finally, Chapter 6 includes my conclusions, limitations of the thesis, and my future directions.

CHAPTER 2: THEORETICAL CONSIDERATIONS

I am just not like most of the Alzheimer's patients I read about...Another good book was 'The Diminished Mind'. It was written about a New England school teacher who was diagnosed with Alzheimer's in his early forties. Again, I just couldn't see myself in him.

-Larry Rose 1996: 2

WHAT IS SELF?

To begin to address the issues associated with self in Alzheimer's, we need to first understand what a "self" is. To do this, a discussion of the philosophical conceptions of self that continue to pervade contemporary discourse of self is necessary. While there are many different theories of self, there are three distinct conceptions of self found in philosophical discourse: the *autonomous self*, the *experiential self*, and the *narrated self*. In making these distinctions, I draw on the work of philosopher Dan Zahavi (2008) who, in *Subjectivity and Selfhood: Investigating the First-Person Perspective*, distinguishes between three differing perspectives on the self: "A Kantian Perspective: The Self as a Pure Identity-Pole", "A Phenomenological Perspective: The Self as an Experiential Dimension", and "A Hermeneutical Perspective: The Self as a Narrative Construction". I adapt these categories and have broadened the conception of self to include René Descartes, as it was Descartes, in the 17th century, who provided the first systematic account of the relationship between the mind and body. The purpose of this section is not to critically analyze each conception of self, but rather to briefly describe each theory, in order to understand its application to the study of Alzheimer's disease. In this section, I will discuss the concepts of the self in turn, beginning my discussion with Descartes.

The Autonomous Self

The autonomous self is the self as a distinct subject, where the self is located in the individual. Descartes began from the belief of consciousness of the self. He

proposed the separation of the *res cogitans* – the mind – from the *res extensa* – the body. Descartes believed that the essence of human beings consisted in thinking and depended on no material thing to exist. Thus, for Descartes, self was located in the mind as distinct from the body. Descartes, essentially, separated the objective from the subjective to create an absolute basis for knowledge and truth. He stressed the autonomy of the first person and believed that humans identify their existence through mental reflections of self.

Immanuel Kant drew on this perspective to develop the Kantian perspective of self. Kant (1781) addressed Cartesian dualism from a rationalist perspective. Like Descartes, Kant believed that each person was an autonomous being, though unlike Descartes, he did not see the rational mind as defining the whole self. Kant extended the notion that each person is an autonomous being and suggested that each autonomous person is capable of envisaging a course of action that *transcends* relationships. For Kant, the *transcendental self* was the inferred locus of identity in the midst of changing experiences and is not directly experienced. In essence, our changing experiences all have the same subject and are lived through by the same self, thus over time, the Kantian self remains constant (Burkitt 1991).

The Experiential Self

The experiential self is grounded in the first-personal givenness of experience. A fundamental difference between autonomous theories of self and experiential theories of self lies in *experience*, as, unlike autonomists, experientialists favour an account of self that links self and experience and

acknowledges the socially situated character of selfhood (Zahavi 2009). Thus, in contrast to the autonomous self, under this model, self and other and subjectivity and intersubjectivity are linked. While there are many different experiential theorists, I will focus on: Husserl, Heidegger, Sartre, and Merleau-Ponty. These experientialists, or *phenomenologists*, are particularly noteworthy as they have been strong defenders of the experiential dimension of selfhood (Zahavi 2009: 554).

Edmund Husserl is credited with founding phenomenology. For Husserl, phenomenology was an interpretive process where there was a search for meaning. Husserl thought of *being* as objectivity and argued that subjectivity of the immediate experience of phenomena was the source of knowing (Koch 1995; Zolnierrek 2011: 46). Husserl believed that intersubjective experience played a key role in the continuation of self as objective subjects, other experiencing subjects, and the objective temporal world. Husserlian phenomenology was *transcendental*, in much the same sense as Kant, though Husserl disagreed with Kant and suggested that individuals can never know things as they are in themselves. Husserl's self - the *transcendental ego* - was the bare rational self and was considered only in terms of its basic cognitive structures (Guignon 2006: 144). Husserl studied time-consciousness and was committed to the idea that human experience is radically temporal. For Husserl (2002), self-consciousness – an individual's consciousness of themselves – was a defining feature of the experiential self.

Martin Heidegger is known for his existential and phenomenological explorations of the question of *being*. Like Husserl, Heidegger believed description

without interpretation was impossible (Mackey 2005; Zolnierrek 2011). In *Being and Time*, Heidegger (1927) followed in Husserl's footsteps, in identifying a link between *being* and *time*. Heidegger's (1927) "starting point" is *Dasein* (self), defined as being-in-the-world, a being-in-the-world that is historical (Guignon 2006: 151). *Dasein* often lets self-interpretation be determined, controlled, and articulated by others (Heidegger 1986). Experiential life, for Heidegger, was world-related and *Dasein* is present when a person is world-engaged (Heidegger 1993). In other words, when an individual experiences something, their self is present. Though important differences exist between Husserl's and Heidegger's notions of self, both favoured an account that links self and experience and recognized the socially situated character of selfhood. Moreover, they proposed the idea that an understanding of what it means to be a self calls for an examination of experience and vice-versa (Zahavi 2009: 554). Sharing this thought is French existentialist, Jean-Paul Sartre.

According to Sartre (1976), self, or *ipse*, "is not *in* consciousness...but in the world; and like the world, it is the object of consciousness" (xii). Thus, though Sartre drew his conception of phenomenology from Husserl, he took a different direction in accepting Descartes' consciousness of self as thinking (but rejects consciousness as thinking substance). Sartre (1976) was critical of Husserl's *transcendental ego*, believing self was not in consciousness but was in the world and was an object of consciousness. He conceived objects of consciousness as constituents of consciousness. Sartre argued that the other is central to self-consciousness, highlighting that, "The other is the indispensable mediator between

myself and me" (200). For Sartre, self is realized through being-with-others. An experience, under Sartre's model of self, does not simply exist. It rather exists for itself. Essentially, it is given for itself and this pre-reflective self-givenness is the very mode of being of the experience.

Maurice Merleau-Ponty's (1945) phenomenological approach understands *ipse* – self – as an indeterminate process to engage or become oriented in the world; it is a whole of processes in which aspects of the world are thematized into different Gestalts and, next, portrayed as a person with one or many identities. He referred to Husserl's investigations of inner time-consciousness and wrote that the original temporal flow must count as the archetypical relationship of self to self and that it reveals an *ipseity*. Similar to Sartre, Merleau-Ponty suggested that consciousness is always affected by itself and that the word "consciousness" has no meaning independently of this fundamental self-givenness. In *Phénoménologie de la perception*, Merleau-Ponty (1945) spoke of the subject as realizing its selfhood in its *embodied* being-in-the-world. *Embodiment* essentially collapses the difference between mind and body, by focusing on lived experience – of being *in* the world (Merleau-Ponty 1964), instead of being *of* the world. Merleau-Ponty (1945), ultimately, argued that at the root of all experiences and reflections, there is a being who immediately knows itself through direct contact with its own existence.

The compelling idea set forth by all of these philosophers is that an understanding of what it means to be a self demands an examination of experience and vice versa (Zahavi 2009). They are all in agreement that if we wish to

understand a self, we should look at self-experience, as self-experience gives us a vivid sense that there is something like a self (Strawson 2000; see Zahavi 2009: 554). Moreover, these phenomenologists were concerned with *how* individuals experience phenomena and the meanings ascribed or hidden in these experiences.

The Narrated Self

The narrated self is a more recent conception of self. It is an interpretive construction that is dynamic and reflects an individual's history and ideologies – it is essentially a product of reflection. A narrative conception of self views the self as constituted by how we structure the story of our lives. The narrated self has its roots in experiential understandings of self, as, for narrative theorists, the self includes an interpretation of who we are and is structured in a story (Zahavi 2007).

In recent years, as part of the narrative turn in the social sciences, a growing number of scholars have come to suggest that identities are narratively constructed (Bruner 1986, 1989, 1990, 1991; MacIntyre 1981; Ricoeur 1979, 1984, 1986, 1988, 1992). The interpretive approach in narrative theory, or *hermeneutics*, reflects a sort of “synthesis” between the philosophy of history and literary theory. These theorists are not always in harmony (Smith and Sparkes 2008: 6), regarding what narrative is or how it should inform theory and method (Levy 2005: 10), however, they all emphasize both the temporal and social dimension of selfhood.

Jerome Bruner (1986, 1989, 1990, 1991, 1995 and 1996) highlights a “narrative mode of thought” and suggests that a narrative may be fictional or actual and involves a character who acts to achieve a goal in a particular setting by use of

certain means. Narrative, for him, is thus a way to order experience and to construct reality. Bruner (1991) argues that life narratives can reach only "verisimilitude". The point for him is how the text operates as an instrument of mind in constructing reality (McLean 2006: 170-171). For Bruner (1986), we have *experience* and *expression*: *experience* is how reality presents itself to our consciousness and *expression* is how the individual experience is framed and articulated through narration.

Like Bruner, Ricoeur (1979, 1984, 1986, 1988, 1992) and Alasdair MacIntyre (1981), emphasize a narrative construction of self that is both temporal and social. For MacIntyre, the notion of personal identity is associated with that of narrative identity, as the personal identity has no meaning if it does not include the idea of narrative intelligibility. The unity of an individual life is the unity of a narrative enacted through the course of that life (Phillips 2003: 315). MacIntyre's notion of self is similar to Ricoeur's, in that both argue that human existence as fundamentally temporal is experienced narratively. They both also argue that we live our narrativity tentatively and prereflectively (Phillips 2003: 314). For these philosophers, it is the challenge of each individual to mold their experiences into a meaningful and intelligible narrative structure.

While Ricoeur's work is more philosophical in orientation, once brought in to dialogue with the traditions of qualitative research, it suggests a useful approach to the narrative interpretation of lived experience that addresses some of the epistemological and ontological issues raised for qualitative research by cultural

studies and postmodernism (Ezzy 2000: 172). For Ricoeur, who follows an interpretive approach, narratives are both lived and told. He suggests that a corpus of our individual histories is brought together with fiction that, in articulating the various points of connection, transforms it into a coherent story (Becker 1997: 26).

Iipse and Idem

Under a Ricoeurian model of self, a tension exists between the two major acceptations of the concept of identity: on the one side, identity as sameness – *idem* – and, on the other, identity as selfhood - *ipse*. The more stable and permanent components of the self are related to *idem*, whereas *ipse* concerns the evolving, shifting, and dynamic aspects of the self. The narrative theory mediates this confrontation. Two models of permanence in time exist: “character” and “keeping one’s word” (Ricoeur 1992:118), which position the issues of *idem* and *ipse* in different manners. The permanence of character “expresses the almost complete mutual overlapping of the problematic of *idem* and of *ipse*”. In contrast, “faithfulness to oneself in keeping one’s word marks the extreme gap between the permanence of the self and that of the same” (Ricoeur 1992: 118). Between these two models, “an interval of sense” is formed “which remains to be filled in” (Ricoeur 1992: 124). *Narrative identity* intervenes “in the manner of a specific mediator between the pole of character, where *idem* and *ipse* tend to coincide, and the pole of self-maintenance, where selfhood frees itself from sameness” (Ricoeur 1992: 119; see Taïeb et al. 2008: 992). Ricoeur thus captures the middle ground between a sovereign self that is invulnerable and impermeable to the influence of others, and, on the other hand, a

deconstructed self that emphasizes the linguistic sources of the self and the influence of context “to the point where it engulfs, if not annihilates, the self” (Dunne 1995: 140). According to Ricoeur (1988), the narrated self, or *narrative identity*, is constituted through *emplotment* and is an interweaving of both history and fiction.¹ In the following section, I discuss this in greater detail.

The Story and The Plot

Narrative cannot be understood without an understanding of the concepts of *story* and *plot*. A narrative is a story that is composed of a plot. Plot is a construction by the narrator who selects and sequences particular actions, events and experiences, thereby imposing a meaning on these actions, events and experiences that comprise a story (Kramp 2004). The “plots of narrative identities are formed in a complex interaction between events, imagination, significant others, routines and habits, and the structure of the soliloquy that forms a person’s self-narrative” (Ezzy 1998: 251). This process, referred to as *emplotment*, has “a beginning, a middle, and an end” (Ricoeur 1984: 38), and reflects the intentionality of the narrator. Emplotment highlights the temporal configuration of narrative (Ricoeur 1981; 1984). Bruner suggests that, “Life consists of retellings”, thereby calling attention to the importance of time and process in narrative (Becker 1997: 27). Events and experiences that occur at different times are united by being incorporated into a single narrative. Ricoeur (1981) explains this, suggesting:

¹ Ricoeur (1984) expands the concept of mimesis, identifying three forms of mimesis. Taïeb and colleagues (2008) summarize Ricoeur’s concept of mimesis: *mimesis1* refers to the prefiguration; *mimesis2* constitutes the poetic configuration itself; and, finally, *mimesis3*, is the refiguration. Under

The narrative structure that I have chosen as the most relevant for an investigation of the temporal implication of narrativity is that of 'plot'. By plot I mean the intelligible whole that governs a succession of events in any story. This provisional definition immediately shows the plot's connecting function between an event or events and the story. A story is made out of events to the extent that plot makes events into a story. [167]

The plot, therefore, is a model of concordance, which is characterized by three features: completeness, wholeness, and an appropriate magnitude (Ricoeur 1984: 38). In other words, plot provides the underlying structure of a story and brings together heterogenous factors such as agents, goals, means, interactions, and unexpected results and renders that story's contents intelligible. A biography, for example, tends to reorder the significance of a life, reading that life backwards and using past events as explanations for the current state of affairs (Becker 1997: 27). The art of composing a narrative thus consists in making discordance appear concordant (Ricoeur 1984: 43; see Taïeb et al. 2008). It is an interpretive task (Bruner 1986). According to Ezzy (1998):

[The] plots of narrative identities are formed in a complex interaction events, imagination, significant others, routines and habits, and the structure of the soliloquy that forms a person's self-narrative. [251]

Narrative symbolically integrates the events of lived experience in the plot of the story a person tells about his or her life (Ezzy 1998).

Critics of narrative suggest that lived life does not have the narrative structure implied in notions of a narrative self or narrative identity (Phillips 2003). These anti-narrativists argue that self-narratives are fictive and bear little or no resemblance to actual lives. It has been argued that there is a disjuncture between narrative and lived experience, however, the value of narrative has grown as we

have come to understand how narratives assist individuals to make life experiences meaningful (Kramp 2004). Ricoeur provides a strong defense of narrative's connection to the lived world, as he argues for a narrative "preunderstanding" of the practical world. According to him, implicitly narrative terms such as "agent", "goal", "success", and "failure" are not the product of fictive imagination but are lifted from the practical world, thus plot has the capacity to model our experience (Becker 1997: 27). In addition, Ezzy (2000) suggests that "[i]t is erroneous to assume that life is lived and not told" (172). Both the events of lived experience and imaginative configuration are represented in narratives. From a narrative perspective, the important issue is not that narrators represent their lives accurately, rather, it is enough to note that they believe they are doing so (Ezzy 2000). Ricoeur's descriptions of "untold stories" bring home forcefully the realization that the experience has a prefigured quality that becomes visible upon framing it in words (Charon 2006: 73). As Anthony Paul Kerby (1991) reveals, "Experience naturally goes over into narration" thereby helping us to grasp the "elusive connections between being and telling" (Charon 2006: 74).

WHAT IS ALZHEIMER'S?

In the preceding pages, I presented and discussed the autonomous self, the experiential self, and the narrated self – the philosophical conceptions of self that pervade contemporary discourse – in order to provide the appropriate background for understanding how Alzheimer's disease influences self. However, in order to understand this, we must also ask: what is Alzheimer's disease? I approach this

question from a medical anthropology framework, arguing that Alzheimer's disease is a biomedical construct.

Medical anthropologists have been critical of the biomedical model and have identified the need to distinguish "disease" from "illness" (Garro & Mattingly 1994), as illness and disease have two fundamentally different meanings. "Disease" designates the biomedical construction of afflictions in Western medicine (Harvey 2008: 580), while "illness" is used critically by social scientists and anthropologists, and has come to specify an individual's personal experience with affliction. According to Kleinman (1987), to invoke the term "illness" means "to conjure up the innately human experience of symptoms and suffering." For Good (1994), disease is "paradigmatically biological" (2), and is reconfigured only as an alteration in biological structure or functioning (Kleinman 1988). Alzheimer's is a case in point. Thus, in order to gain insight into the self and Alzheimer's, we must deconstruct the biomedical treatment of the disease.

DECONSTRUCTING THE BIOMEDICAL TREATMENT OF ALZHEIMER'S

Classification

Alzheimer's disease is the most common form of dementia² and is a primary disorder of the brain that is, according to the current biomedical model, ultimately

² "Dementia" is a biomedical term used to refer to a large class of brain disorders characterized by a deterioration of cognition and memory (Alzheimer's Society of Canada 2013). Dementia is used to describe a decline in mental functioning that is severe enough to interfere with the daily life of individuals (Alzheimer's Association 2012), as brain disorders can impair one or more of the brain's three main functions: how we move, think, and feel (Alzheimer's Society of Canada 2012a). According to the current biomedical model, in the case of dementia, it is "cognition" - the thinking, knowing,

irreversible. In the latest version of *Diagnostic and Statistical Manual of Mental Disorders* (DSM), DSM-5 (2013), a manual that outlines the standard criteria for the classification of mental disorders, Alzheimer's falls into the category of "Neurocognitive Disorders" (NCD). This classification distinguishes Alzheimer's from psychiatric disorders (e.g. depression) as Alzheimer's has cognitive impairment as a defining feature, as opposed to a clinical symptom. In DSM-5, individual criteria sets are designated for "dementia of the Alzheimer's type", thus DSM-5 attempts to classify Alzheimer's based on what can be readily observed and measured.

Types

The current biomedical conception of Alzheimer's disease identifies two "types" of Alzheimer's: *Early-onset Alzheimer's disease* (EOAD), and *Late-onset Alzheimer's disease* (LOAD). Early-onset Alzheimer's disease is different from early-stage Alzheimer's disease as the latter term refers to mild cognitive decline. Alzheimer's disease is considered to be in its early-onset if an individual is under 65 years of age when symptoms first appear (Alzheimer's Association 2013b; Alzheimer Society Toronto n.d.). According to current biomedical data, most individuals diagnosed with EOAD are in their forties and fifties, though the rate and severity of decline vary by person. Two key differences exist between EOAD and

problem-solving and judgment function of our brain - that is primarily affected (Alzheimer's Society of Canada 2012a). As such, dementia can impair not only memory, but visual perception, communication and language, decision-making ability, reasoning and judgment, cause disorientation, and can alter personality.

LOAD: 1) EOAD appears to be linked with genetic defect; and 2) the age at which symptoms appear.

Stages

Current biomedicine identifies Alzheimer's disease as having three "stages". According to this model, *Early-stage Alzheimer's disease* refers to individuals who have mild cognitive decline.³ *Middle-stage Alzheimer's disease* applies to moderate cognitive decline.⁴ In *Late-stage Alzheimer's disease*, cognitive decline is considered "severe".⁵

Causes

While current biomedical researches are unsure of the causes of dementias, it is believed that they tend to arise out of many complex factors that include: genetic make-up (what you were born with)⁶, biological (physical) changes in the brain, psychological factors such as problems with coping or self-esteem, and external social and environmental factors (like isolation) (Alzheimer Society of Canada 2012b). Researchers believe that Alzheimer's disease is also caused by

³ Common symptoms in early stage Alzheimer's disease include forgetfulness, communication difficulties, and changes in mood and behaviour.

⁴ In the middle-stage, thinking and memory continue to deteriorate but many people will still be somewhat aware of their condition.

⁵ In the late-stages of Alzheimer's disease plaques and tangles have spread throughout the brain, and brain tissue has shrunk significantly. Individuals in the late stage have decreased mental ability, and eventually become unable to communicate verbally or care for themselves. The Alzheimer Society of Canada provides a more detailed description of each stage of Alzheimer's disease (Alzheimer Society of Canada 2011).

⁶ Alzheimer's has been attributed to the APOE gene. A significant proportion of Early-onset Alzheimer's disease is linked to three genes: the APP, PSEN 1 or PSEN 2 genes. Alzheimer's in general. The genetic path of inheritance is much stronger in Early-onset Alzheimer's. A genetic mutation in one of the three genes increases the likelihood of developing EOAD (Mayo Clinic 2011).

these various factors that overwhelm the body's ability to repair damaged brain cells (Alzheimer Society of Canada 2012: 1).

Pathology

According to current biomedical researchers, the pathology of Alzheimer's disease is complex. *Neurofibrillary tangles*, fiber tangles within nerve cells, and *neuritic plaques*, clusters of degenerating nerve endings in the brain, are two of the main features of Alzheimer's disease. Abnormal deposits of proteins form these plaques and tangles throughout the brain, causing once-healthy neurons to begin to work less efficiently. Over time, the neurons lose the ability to function and communicate with each other, and, eventually, they die (Islam et al. 2010: 149). Essentially, nerve cells become sick and slowly lose the facility to pass on messages to other nerve cells, dying altogether with time (Diamond 2011: 6). The damage then spreads to the *hippocampus*, the part of the brain that is critical in the formation of memories.⁷ As more neurons die, affected regions of the brain begin to shrink. By the final stage of Alzheimer's disease, brain tissue has significantly shrunk and the brain is considerably damaged (Islam et al. 2010: 149). Biological markers may appear before the onset of clinical symptoms (Blazer 2013: 585).

⁷ The outer layer of the brain, the cortex, may be divided into four sections, or "lobes": frontal lobe, parietal lobe, occipital lobe, and temporal lobe. The frontal lobe is associated with executive functions such as reasoning. The parietal lobe is associated with movement and orientation, while the occipital lobe is concerned with visual processing. The temporal lobe is associated with learning, perception and memory. It is here that the hippocampus is located.

Clinical Symptoms

Current biomedical knowledge suggests that the loss of connectivity among brain cells is responsible for the clinical symptoms of Alzheimer's disease. Some of the clinical symptoms experienced by individuals may include: confusion, disturbances and/or loss of memory, problems with attention and spatial orientation, changes in personality, language difficulties, unexplained mood swings, an inability to perform "everyday" tasks, and a loss of control over bodily functions (American Health Assistance Foundation - AHAF 2012). Symptoms may vary according to the type and/or stage of Alzheimer's disease and by individual. EOAD symptoms are similar to late-onset Alzheimer's disease (LOAD) symptoms (Alzheimer Association Toronto n.d.). Clinical symptoms occur much before the cells themselves die (Diamond 2011: 6).

Diagnosis

A definitive diagnosis of Alzheimer's disease can only be made after death through autopsy. As such, Alzheimer's is diagnosed only as "possible" or "probable". DSM-5 does not use the term "Alzheimer's disease" alone as a diagnosis. Instead, the diagnosis is defined as impairment in two or more cognitive domains that is accompanied by a loss of independence. A number of predetermined criteria lead to the diagnosis of Alzheimer's. According to DSM-5, diagnostic criteria require clear evidence of a decline in memory and learning.

The Alzheimer's Association and the National Institute on Aging (NIA) have diagnostic guidelines for Alzheimer's disease. The guidelines suggest the use of

biomarkers – benchmarks in the body, such as measures in blood, fluid or imaging, that can be reliably measured to indicate the presence or absence of a disease, or the likelihood of later developing it (Alzheimer's Association 2013), to diagnose Alzheimer's disease. The use of these biomarkers is still experimental and is not currently used in clinical settings. DSM-5 does not require biomarkers, or a biological basis, for diagnosis.

Interventions

To date, there is no cure for Alzheimer's. To address the loss of brain cells responsible for reduced cognitive functioning, current biomedical guidelines promote the use of cognitive enhancers – medications used to enhance concentration, memory, alertness, and moods – as standard treatment (Apeosa-Varano, Barker and Hinton 2011: 1470). Cholinesterase inhibitors are also used to treat Alzheimer's. They are used to help increase the levels of acetylcholine, a chemical in the brain that is important for memory and learning. With the deconstruction now complete, I now move to an examination of the self from the lens of biomedicine.

THE BIOMEDICAL CONSTRUCTION OF ALZHEIMER'S AND SELF

An analysis of the biomedical treatment of Alzheimer's disease reveals that Alzheimer's disease has its ontological grounding in the order of meaning and human understanding (Young 1976; Good 1994). In focusing on brain processes such as thinking, attention, perception, learning, memory, problem solving, decision-

making, reasoning and planning, biomedical reasoning regarding Alzheimer's treats the disease as an alteration in biological structure or function, thereby making it an object of medical practice. As such, Alzheimer's disease is deemed an "entity" that is modifiable through biomedical practices (Fox 1989; Chaufan et al. 2012). Thus, Alzheimer's disease is, to use the words of Good (1994) "paradigmatically biological" (2). As such, experiential and behavioural factors are treated as matters apart from the "real object of medical practice" (Good 1994: 70).

In addition, what emerges from a deconstruction of the biomedical treatment of Alzheimer's disease is the disease as "crystallized". This is achieved through "consistency-enforcing mechanisms" (Rosenberg 2007: 6), or *standardization*. Standardization, characterized by rigid pre-defined constraints, has had important implications for the medical reasoning of medical practitioners. DSM-5, for example, gives practitioners standardized guidelines to diagnose Alzheimer's. The diagnosis involves interpreting, or putting together pieces to formulate a creditable explanation of recorded signs and symptoms of disease and involves attention to some information and the neglect of other information and the organization of the information to fit the definition of an established disease. Thus, it leaves no room for narrative accounts of illness. Whitehouse et al. (2005) suggest that narratives "show variation, uniqueness, and local meaning all of which are lost when subsumed under a common biomedical label" (324). As Maretzki (1993) suggests, the culture of biomedicine presents to the outside the face of its universal, standardized, cosmopolitan nature, giving "at best lip service to the patient's individual experiences and perspectives" (135).

I suggest that neglecting illness narratives is a threat to self. As Charon (2006) argues:

Without the narrative acts of telling and being heard, the patient cannot convey to anyone else – or to self – what he or she is going through...More compellingly, only this kind of narrative listening will hear the connections among body, mind, and self. [66-67]

Compounding this threat is the biomedical treatment of the human body. What we see from the deconstruction of Alzheimer's is how biomedicine formulates the human body and Alzheimer's disease in a culturally distinctive fashion (Good 1994: 65). The consequence of this is that cognitive processes are treated as distinct from behavioural processes or action, drawing a divide between the body and the mind. We see the roots of Descartes' mind-body dualism in the biomedical treatment of Alzheimer's disease. Kontos (2006) suggests that "this is the legacy of Western philosophy's tendency to split the mind from the body, and position the former as superior to the latter" (196). Thus, as the mind diminishes, the self is also thought to begin to disappear and what is left is regarded increasingly as an "empty" body (Millett 2011: 513). This assumption has led biomedical practitioners to discount the narrative capacities of individuals with Alzheimer's (McLean 2006: 157).

As Phinney (2002) highlights, "illness narratives in dementia have been largely overlooked or discounted due to the assumption that the ability to narrate" is contingent on cognition (331). I argue that not only does this belief inhibit efforts to collect illness narratives (McLean 2006), but, in denying the narrative capacities of individuals with Alzheimer's, biomedicine is ultimately rejecting the narrated self. I argue that we cannot deny the narratives of the cognitively impaired as it is

through these very narratives that individuals are able to (re)construct self. In the following chapter, I situate my argument in the existing body of anthropological literature.

CHAPTER 3: A REVIEW OF THE LITERATURE

So, what have I learned from thinking, writing, rethinking, rewriting, and rewriting and again reading 60,000 of my own well-chosen words?

- Richard Taylor 2007: 219

THE LITERATURE

Recently, there has been a growth in academic work devoted to the study of Alzheimer's disease and selfhood. According to Martha Holstein (2000), author of *Aging, Culture and the Framing of Alzheimer's Disease*, the "complex and probably multiple etiologies, its threat to fundamental sources of human identity, and its effects on others in addition to the patient" (158), make chronic illness, such as Alzheimer's, a fascinating challenge for researchers (Orr 2010: 328). In "Struggling over Subjectivity: Debates about the 'Self' and Alzheimer's Disease", Elizabeth Herskovits (1995), suggests that conceptions of self have been applied and adapted to the study of illness, including Alzheimer's disease. In much of the Alzheimer's literature, individuals with dementia are said to experience a total loss of self as a consequence of the cognitive dysfunctions that lie at the core of the disease (Cohen and Eisdorfer 1986; Mills and Walker 1994; see Kontos 2006). Anthropologist Pia Kontos (2004) highlights that, "Much of the literature on Alzheimer's promotes the view that individuals with dementia experience a steady erosion of selfhood to the point at which no person remains" (105).

As sociologist Hazel MacRae (2010), author of "Managing Identity While Living With Alzheimer's Disease", reveals:

Identity is threatened when physical, psychological and social consequences of chronic illness begin to erode sense of self and challenge an individual's ability to continue to present the self she or he prefers to present to others.
[293]

For sociologists Andrea Fontana and Ronald W. Smith (1989), with advancing Alzheimer's what is "actually happening" is that the self is becoming increasingly "devoid of content" (36). They argue that:

The self has slowly unraveled and "unbecome" a self, but the caregivers take the role of the other and assume that there is a person behind the largely unwitting presentation of self of the victims, albeit in reality there is less and less, until where once there was a unique individual there is but emptiness. [Fontana and Smith 1989: 45]

Others echo similar sentiments, by describing Alzheimer's disease as a disease that "eradicates the essence of the person" (Dalziel 1994: 1407), or as a process of "drifting towards the threshold of unbeing" (Kitwood and Bredin 1992: 285; see Kontos 2006: 195). Ultimately, what we see in this literature is a *presumed* existential outcome: *a biosocial death* (Davis 2004; Herskovits 1995; Kontos 2006; Ronch 1996). A *biosocial death* is a specific form of social death that occurs in some medical conditions or with some medical technologies, in which a person's capability of participating in society diminishes to the point that the person is considered a "non-person", or as not having full *personhood* (Leibing 2006: 248)⁸. Whitehouse, a neurologist, and George (2008), a medical anthropologist, argue that we must overcome the view that "those inflicted with a 'disease' called Alzheimer's suffer a total and devastating loss of self resulting from a pathological event" (xiv). A central argument of Whitehouse and George (2008) is that there is no *total* loss of self or loss of personhood.

⁸ The term "personhood" was coined by Kitwood, who argued that viewing people with dementia in medical terms leads them to be seen as objects with no subjectivity, as a person's biology cannot be separated from the social body.

In increasing numbers, social scientists have offered theories that overcome this “death” and reclaim the “self” in Alzheimer’s (Herskovits 1995: 155).

Herskovits (1995) suggests that, in response to this loss of self, a number of studies have begun to offer diverse representations of the self in Alzheimer’s. Most build on a *social interactionist* foundation as there is a widely-held belief that the theory of *social constructionism* can provide new insights into the effects of Alzheimer’s disease on selfhood (Sabat and Harré 1992: 459).

Herskovits (1995) undertakes a review of the self and subjectivity in Alzheimer’s disease, in order to determine “what is ultimately at stake in representing the ‘self’ in Alzheimer’s” (147). She identifies various models of the Alzheimer’s self across different disciplines and, through this, she reveals that models of the self in Alzheimer’s imply several distinct notions of the nature of the self, including: the self as an internal personal identity (Sabat and Harré 1992); the self as an intersubjective public/social project (Sabat and Harré 1992; Bogdan and Taylor 1989); the self as an ontological construct (Robertson 1991); the self as an ongoing linguistic process and project (Gubrium and Wallace 1990); and the self as a dynamic interaction between intersubjectivity, subjectivity and the anatomic brain (Kitwood 1990; Kitwood and Bredin 1992) (see Herskovits 1995: 159). As Herskovits (1995) demonstrates, in her review of the literature, such scholars “disentangle the status or viability of self from cognitive ability, arguing for a relational kind of self that supersedes the autonomous self” (159; Bird-David and Israeli 2010: 56). Thus, despite early reports of people with dementia losing their

sense of self, more recent studies suggest that though identity may be compromised, it is not altogether lost (Caddell and Clare 2011).

Recently, scholars have begun to study selfhood at different stages of Alzheimer's. In her study of early-stage Alzheimer's, MacRae (2010) argues that people with Alzheimer's constructed narratives of self that both preserved and protected their identities from the threat of loss of self. Sociologist Renée Beard (2004), explored the subjective experiences of identity construction with Alzheimer's disease, demonstrating how individuals in the early-stages of the disease actively engage in preservation of self. These studies argue that individuals with early-stage dementia are able to implement strategies in order to preserve self. In such studies, accounts of how participants protect their sense of self focus on participants' awareness of their illness (Caddell and Clare 2011: 380). Caddell and Clare (2011) found that people with mid-stage Alzheimer's (or vascular dementia) experienced the tension of continuity and change of identity at the same time and use narrative strategies that range from self-maintenance to self-adjustment (Clare 2003). In their study, *Self in Advanced Alzheimer's Disease*, Tappen et al. (2007) found that:

Those in the late stages of the disease also seemed to indicate they retained a sense of themselves...they responded to their names and reacted emotionally to both frustrations and pleasurable experiences. It seemed to us that they had not lost their sense of self even though much of the literature and common wisdom on the subject indicated they had. [3]

Despite the different stages, what all of these scholars found was that there is a tension between the desire to maintain a coherent self against the knowledge that

the disease will get progressively worse, making self-maintenance increasingly difficult (Harman & Clare 2006).

ANTHROPOLOGICAL STUDIES OF ALZHEIMER'S AND SELF

Thomas Kitwood (1990), deemed a pioneer in dementia research, proposed a model of the “dementing process” that pivots on dialectical interplay between neurological and social-psychological factors. Based on the fact that “human beings are far more deeply affected by [the] social psychology that surrounds them than is commonly recognized” (Kitwood 1990: 181), aspects of “malignant social psychology” deprive the already cognitively impaired individual of his or her personhood (Herskovits 1995: 156). This model is built upon a foundation in which selfhood is felt to reside in the brain and in the social nexus, thus an cognitive dysfunction can be potentiated by the effects of malignant social psychology (Kitwood 1989; see Herskovits 1995).

In *Dementia Reconsidered: The Person Comes First*, Kitwood (1997) contests that dementia is death that leaves the body behind. For Kitwood, the loss of self may result from others projecting hopelessness and confusion onto people with dementia and failing to take the time to engage them and understand their needs (Whitehouse and George 2008: 25). Thus, cognitive dysfunction does not necessarily dismantle the person's subjective lived “self”. Rather, the “problem of dementia” arises from “a damaged, derailed and deficient intersubjectivity” (Kitwood and Bredin 1992). Under this model, the self is conceived as a dynamic interaction between intersubjectivity, subjectivity and the anatomic brain, with

subjectivity a process interweaving the social, the individual and the biological (Kitwood and Bredin 1992:269; see Herskovits 1995: 159).

Encouraged by Kitwood's "personhood", in recent years, anthropologists, specifically, have begun to study Alzheimer's disease and selfhood. Annette Leibing and Lawrence Cohen's (2006) *Thinking About Dementia: Culture, Loss, and the Anthropology of Senility* has made important contributions to an anthropological understanding of Alzheimer's. *Thinking About Dementia* (2006), is composed of 13 essays and approaches dementia from a variety of angles, exploring its historical, psychological, and philosophical implications. The book highlights that the aging process, while biologically influenced, is also culturally constructed and raises important questions about the diagnostic criteria used to define the elderly as demented. Through a number of case studies, the book also reveals how a diagnosis can affect how an individual is treated in clinical and familial settings. In addition, the collection of essays reveals a gap between biological understandings of aging and its cultural meanings. However, while the book advances our understanding of dementia and Alzheimer's, it is limited to dementia among the elderly and does not discuss Early-onset Alzheimer's disease, or dementia among younger individuals.

The anthropological works of Cohen (1995, 1998), Kontos (2004, 2006, 2011), McLean (2006), Chatterji (1998, 2006), and Basting (2006) are key to the study of self and Alzheimer's. Their individual works provide examples of phenomenological or hermeneutical inquiry and suggest new directions for anthropological work. Cohen (1995) discusses the *embodiment* - the self-in-the-

body - of individuals with dementia in India as part of social relations with their surroundings (Bird-David and Israeli 2010: 56). Cohen suggests that the discourse of Alzheimer's disease reconstitutes the ill individual as a non-person and, like Kitwood, he draws attention to the social process, rather than the biological process, that contributes to this loss of self.

In a 2004 study of a Canadian nursing home that provides long-term care for residents with senile dementia, Kontos studied the subjective experiences of individuals diagnosed with Alzheimer's disease. Kontos (2004) argues that selfhood resists the ravages of Alzheimer's disease as "it resides in corporeality" (203). Kontos demonstrates that individuals with Alzheimer's engage in meaningful social relations through bodily habits. Thus, for Kontos, coherence is a matter of bodily movement in space and time, and less so a matter of language (Cohen 2006: 16). She draws on experiential models of self, proposing the integration of Merleau-Ponty's radical philosophical reconceptualization of perception and Bourdieu's sociological exploration of the logic of practice – *habitus* – where the body has a corporeal awareness – a creative capacity to understand. In doing so, she "yields a theoretical framework that captures the immediacy of the body as well as its interrelationship with culture and history" (Kontos 2004: 106).⁹ Kontos (2004, 2005, 2006, 2011) proposes *embodied selfhood* to challenge the traditional idea that Alzheimer's disease is inherently linked with the loss of agency and offers a new perspective on the body. As such, Kontos ultimately challenges the "implicit

⁹ *Habitus* consists of dispositions, schemata, forms of know-how and competence, all of which function below the threshold of consciousness, as they are enacted at a pre-reflective level (Kontos 2006: 207).

assumption that personhood depends upon memory and cognition" (2004: 106). Kontos (2004, 2006) suggests that selfhood, in addition to having a primordial source, consists in the dispositions and generative schemes of habitus and thus, in the same way that dispositions are embodied and materialize in practice, selfhood is embodied and manifested in a socioculturally specific way of being in the world.

Roma Chatterji (1998) also uses a phenomenological approach in her ethnographic study of an elderly man with Alzheimer's disease, Mr. Rijder. Chatterji (1998), in her ethnography of persons with dementia in Holland, locates selfhood in their voices, which are heard by their attentive caregivers; in this way, the former become a part of corporal-based intersubjectivity (Bird-David and Israeli 2010: 56). Chatterji describes and analyzes Mr. Rijder's relations and interactions with his caregivers and family to study his intersubjective construction of self. Through this study, Chatterji, like Kontos, demonstrates that it is possible to access the subjectivity of an individual with Alzheimer's. In a later study of Mrs. Klasen, a "nondemented person in a ward for people suffering from dementia" (Chatterji 2006: 236), Chatterji (2006) suggests that, "Patients become who they are in the process of interactive reflexivity with others in the ward" (236). Through this, Chatterji contributes a relational perspective on self, by describing the influence of intersubjective processes, to anthropological literature.

Anthropological studies have also drawn attention to the narrated self. Athena McLean (2006) also adopts a phenomenological approach in her study of an old-age care facility in the United States with a primarily Jewish resident population, in an attempt to understand coherence in seemingly incoherent narratives. McLean

is informed by not just phenomenology but also narrative theories of self. She questions the idea that “capacity to produce a coherent and authentic life story” reveals a loss of selfhood and demonstrates, using the story of Mrs. Fine, a resident, that Mrs. Fine produces a coherent narrative. McLean argues that there is a “coherence within the person” and argues for a phenomenology attentive to the production of subjects through language and coherence work. McLean ultimately distinguishes storytelling from reminiscence (Cohen 2006: 14). She highlights the danger of privileging the narratives of people without dementia and suggests that to do so, is to rely too heavily on empirical ways of knowing and, in doing so, McLean (2006) argues for the importance of considering the narratives of people with dementia and their own construction of coherence.

Anne Davis Basting (2006) shares a similar sentiment, suggesting that coherence is intersubjectively achieved. Like McLean (2006), Basting separates storytelling from reminiscence. Basting “uses storytelling and theatre as experimental techniques in the fashioning of new milieus for coherence work” (Cohen 2006: 14). For her, creative storytelling supplies a social role with value and allows for the integration of past and present. It also acknowledges the strengths and potential of the lives of individuals with Alzheimer’s and other dementias and offers them an avenue for self-expression, free “from the demands of memory and rational language” (Basting 2006: 193).

Basting also conducted a 2003 study, in which she examined three books written by individuals with dementia. She focused on the narratives of Robert Davis (1989), Diana Friel McGowin (1993), and Cary Smith Henderson (1998). In this

work, she analyzed views of the self within narratives of Alzheimer's and raised important questions about the impact of a diminished memory on identity. She concluded that selfhood is more than memory as it is "forged on a continuum of memory and creativity that exists in a social context" (Basting 2003: 97; Ryan et al. 2009: 147).

These studies ultimately draw attention to the complexity of how individuals with reduced cognitive functioning, due Alzheimer's or dementia, experience selfhood. These anthropological studies of Alzheimer's embrace a phenomenological approach and are valuable as they enable outcomes to be defined from the person's perspective as what is meaningful - what matters to the person - is revealed. As Good (1994) highlights:

Any truly anthropological account of illness cannot afford to attend only to object disease and to cultural representation, with subjective experience bracketed as a kind of black box. [117-118]

What emerges from an examination of these studies is an understanding that the autonomous concept of self is not without its difficulties. Descartes' mind-body dualism is reductionist and has been criticized by many scholars. Under Descartes' theory of self, the individual with Alzheimer's, who has a reduced cognitive functioning, is reduced to a "non-human", a "shell". Kant's theory of self seems to presuppose a unity of the self (Lowe 2006). For individuals with Alzheimer's disease, this would presuppose a loss of self, as unity is often disrupted by disorientation and forgetting. Thus, in dismissing Descartes' cogito and Kant's transcendental self, the studies are able to embrace a much more complex understanding of the self and the body. In rejecting dualism, the body gains

propriety in the study of Alzheimer's disease. Through a review of the literature, we ultimately see that individuals with Alzheimer's disease are able to transcend their definition by bodies and are able to incorporate their experience of being embodied into their concept of self and their movement through the world and through life (Charon 2006). Importantly, what we see emerge from these studies, is that the self is not static, nor lost, instead it is dynamic and changed.

FILLING THE GAP AND BREAKING TRADITION

While these studies have enhanced a rather "thin" body of anthropological Alzheimer's literature, what is largely missing are hermeneutical approaches to self. What also becomes clear, especially from the studies of McLean (2006) and Basting (2006), is the importance of the narrated self in the study of Alzheimer's. Hermeneutics are distant from the Descartes' dualism and overcome the unity inherent in Kant's theory of self, and as such are useful to the study of self among narrators of Alzheimer's narratives.

In addition, what is largely missing from the literature are the narratives of individuals with Early-onset Alzheimer's disease (EOAD). Most studies focus on the experiences and selfhood among the elderly and link Alzheimer's to aging. However, Alzheimer's is not restricted to aging. Individuals under 65 may also experience Alzheimer's disease. EOAD presents unique challenges due to the age at which symptoms begin and diagnosis occurs. As such, we must examine EOAD separately. With no anthropological studies analyzing solely EOAD self-narratives, this study will attempt to fill this gap. To do this, I stray from the

anthropological tradition rooted in fieldwork, and use first-person narratives – written autobiographies – as anthropological data.

To date, few studies have analyzed these first-person written accounts exclusively. In her 2003 study, Basting undertook the task of analyzing written self-narratives in her study of autobiographical accounts of individuals with dementia. The 2009 study of Ryan, Bannister, and Anas also examined written autobiographical accounts of dementia. Ryan et al. (2009) built on Basting's study to examine the social context of individuals living with dementia. They analyzed thirteen memoirs of individuals with dementia published between 1993 to 2007. Ryan et al. (2009) suggest that writing renews an individual's status as a contributing social partner, provides new and positive roles, and introduces empowerment and control. They argue that self-narratives demonstrate that dementia can be a time of growth and that authors with dementia construct and project positive new identities, which are full expressions of personhood. In a 2010 study, Page and Keady conducted a meta-ethnographic analysis of autobiographical accounts of Alzheimer's disease, published between 1989 and 2007. In this study, they identified five themes: "awareness of change", "experiencing loss", "standing up and bearing witness", "sustaining continuity:", and "liberation and death". They suggest that the importance of reconstructing identity appeared a "pivotal process in living with the onset and progression of dementia together with maintaining key social relationships and networks" (Page and Keady 2010: 511). The studies all focused on dementia self-narratives. Thus, the originality of this study lies in its anthropological approach to the study of selfhood and Early-onset Alzheimer's self-

narratives. In the following chapter, I explain my methodological approach to EOAD and self.

CHAPTER 4: THE METHODOLOGY

The chronically ill become interpreters of good and bad omens. They are archivists researching a disorganized file of past experiences. They are diarists recording the minute ingredients of current difficulties and triumphs. They are cartographers mapping old and new territories. And they are critics of the artifacts of disease.

-Arthur Kleinman 1988: 49

THE BEGINNING

This study evolved from a project rooted in fieldwork to one now indebted to authors of autobiography. Beginning in February 2012, I conducted a literature review of preexisting data, gathered from an online database of peer-reviewed journals, newspapers, and scientific books. These secondary sources were used in order to gain an overview of the phenomenon, to assess the existing literature on the topic and to determine the social importance of Alzheimer's disease. Not long into my reading, I began to realize that there was a disjuncture in the literature between personal experiences and biomedical conceptions of Alzheimer's disease. This study emerged out of a frustration with the literature and a desire to know more.

Initial Ideas

In order to "know more", I proposed to explore the experiences of individuals living with Alzheimer's disease by conducting fieldwork with individuals living at a short-term care facility in Ottawa, Ontario. I initially hoped to conduct both semi-structured interviews and unobtrusive observation with three to five individuals living at the facility. With only a few potential field sites in Ottawa, and a little more research, it was not difficult to select a site. I reached out to my potential field site and was ecstatic when I was told that gaining access would be relatively simple, with the biggest challenge was to gain security clearance. I submitted an application to the University of Ottawa's Research Ethics Board (REB). Within only a few weeks I was making the necessary revisions to my application and it looked like everything

was nearly in place. However, when it became time to prepare for fieldwork, my project began to crumble. The last step to getting approval from the University of Ottawa's REB was a letter of support from my anticipated fieldsite. The request of the letter was a defining moment in my thesis.

Upon requesting a letter from my fieldsite acknowledging their approval of my project, major hurdles began to emerge. Security clearance became the least of my problems when my previous contact passed me off to another employee, who then passed me off to someone else, who then informed me that there was a tool developed by the organization that would evaluate my proposed research plan. While I understood that this would be important for the organization, I was rather shocked that after months of contact, I had not been informed of this. Unable to ignore my apprehension, I began to develop a "back-up" plan, though I did comply and provide the application I submitted to the University of Ottawa's REB. After several weeks, in which I continued to brainstorm over other sources for data collection I was informed that I was not approved by the organization.¹⁰ Unlike the University's ethics process, this organization did not "approve with revisions", it was simply a "not approved" and no opportunity for revisions or collaboration was given. I was upset because the end result did not match what I was told in my initial communications. I was not, however, discouraged.

¹⁰ During this time, I contacted several other organizations in Ottawa regarding the potential of conducting fieldwork. While one of the organizations promotes research and was encouraging of the possibility to conduct fieldwork with them, this required an application to their REB, which could take several months. Due to time constraints, this was not a feasible path for me to take. While waiting to hear back regarding approval from my original fieldsite, I was also exploring another opportunity, however, due to the death of a potential participant, I was unable to follow this direction.

A NEW DIRECTION

In my reading and “back-up” planning with my advisor, the idea of using autobiographical accounts of Alzheimer’s disease emerged. Though first-person accounts of Alzheimer’s are limited, I was aware of several that existed and familiar with a few of them. During a promising meeting with my supervisor, this idea really began to take hold and I began to feel that familiar feeling of excitement bubbling. It suddenly struck me that in my reading of Alzheimer’s disease, and more specifically of anthropological studies of Alzheimer’s disease, few acknowledged these first-person accounts and those who did, did not “take advantage” of what was lurking under the cover. The question suddenly hit me: why were these accounts being dismissed? How could this rich data be ignored? For me, it couldn’t. I simply could not neglect the rich insights tucked inside the pages of these books any longer.

AUTOBIOGRAPHICAL TEXT AS DATA

With a new direction in mind, I turned my attention to *autobiography*. Since the 1950s, autobiography has gained prominence in various disciplines (Karpiak 2003: 100). *Autobiography* refers to the telling and documenting of one’s own life. Autobiographical work is composed and then articulated through written texts (Lewis-Beck et al. 2004: 45).

Autobiography has increasingly been drawn upon as a resource and method for investigating social life. Autobiographical research is “part of a more general biographical turn within the social sciences, characterized by an emphasis on personal narratives and the life history method” (Lewis-Beck et al. 2004: 45).

Autobiographies may be considered “research events”, understood as the processes through which lives are remembered, reconstructed, and written. Although autobiography is a social science method, drawing on a range of empirical material or “documents of life” (Plummer 2001), including letters, diaries, and other documentary sources (Lewis-Beck et al. 2004: 45), the method traditionally involves the researcher’s own autobiography as a way of knowing and telling.¹¹ For the purpose of this study, I “broke” tradition, turning to the autobiographies of others, as I believe that these written stories are also a way of *knowing* and *telling*,

Many autobiographical sources are underused within social science research, despite their analytical potential. Autobiographical approaches to social science research can imply a clearer appreciation of the value of lived experience and personal knowledge as part of social science scholarship (Lewis-Beck et al. 2004: 45-46). Autobiographical texts have particular genres and narrative forms that can be systematically explored, as there are collective conventions of memory and specific “ways” of people telling (or re-telling) a life, marked by key events, places, people, and times (Lewis-Beck et al. 2004: 45). It is through the course of “writing our life” that we translate our life into a story, or a form of narrative (Karpiak 2003: 103). Autobiographies often detail life situations and events, associated feelings and may reflect exploration and reflection. Some may uncover experiences and emotions that were previously unspoken, inaccessible, incomprehensible, even “uncanny” (Karpiak 2003: 99). For Irene Karpiak (2003), author of “The

¹¹ *Autoethnography* is a researcher’s own autobiography. It is a reflexive piece of writing that explores the researcher’s own subjectivity.

Ethnographic, the Reflective, and the Uncanny: Three 'Tellings' of Autobiography", as profound learning experiences, autobiographies benefit both the writer and the reader (100).

A critique of my methods may be my use of autobiography as data. It has been suggested that researchers using autobiography risk losing rich data as life stories may have been edited to fit within the confines of publication (Cherot 2009: 122). However, as Natalie Cherot (2009), author of "Storytelling and Ethnographic Intersections: Vietnamese Adoptees and Rescue Narratives", suggests:

Using life stories previously written for public space and debate does not have the burden of eliminating all identifying markers...By using previously published life stories I could have more confidence in publishing the exact words...expressed, which will ensure that they felt comfortable with how their ideas are broadcasted. [122]

The autobiographies may also raise questions of authorship. In their 2009 study of dementia autobiographies, Ryan et al. found that the authors often revealed that they had help from others in completing the autobiography. They also found that the narrative is usually "cleansed" over the diseases (sentences, word and thought structure remains coherent for the most part) (Ryan et al. 2009: 147). Acknowledging this, Ryan et al. suggest that issues of authorship are less important when examining autobiography for the narrative of self than for form or literary style. Thus, because it embraces the editor, writing is an exceptional medium for individuals to express thoughts, feelings and emotions (Ryan et al. 2009).

It may also be suggested that the autobiographies may be partial, and the authors have their reasons for not telling everything there is to tell. This

selectiveness does not invalidate what they do tell, however. As Becker (1997) explains:

I assume my interviewees have edited their stories as I have edited mine, to lend their stories a greater coherence and a sense of wholeness, which in turn, lends one a greater sense of self-consistency. [28]

In the same vein, I assume the authors also have edited their stories, lending for a greater coherence. Thus, for anthropologists seeking insight into dementia and Alzheimer's disease, autobiography is particularly valuable as it provides insight into how individuals make sense of illness experience and how they articulate, or express, this experience. Drawing on Basting (2003), I have chosen to call the selected works "autobiographies" in order to emphasize their unique authorship (88).

Autobiographical Accounts of Alzheimer's Disease

Drawing on Page and Keady (2010), who analyzed first-authored accounts by people with dementia, this thesis focuses on Alzheimer's autobiographies "as they offer a highly specific insight into the lived experience" (513). While there are many books about Alzheimer's disease, these books are often written by a primary caregiver or spouse. There are only a handful of published texts in which the primary author is the person with the disease (Basting 2003: 88). While analyzing written first-person accounts of illness may not be traditional and has been critiqued by anthropologists such as Basting (2003) and Leibing (2006) as writing "*about*, and not *from within*, dementia, since a coherent text is thought to be the only way to address the readers" (253), I counter this and suggest that written accounts

help to overcome the challenges presented by oral narratives for individuals with Alzheimer's. As a disease that impairs verbal reasoning, memory and causes disorientation, answering questions, composing sentences and selecting words on-the-spot may be a challenge to individuals with cognitive impairment. Ryan et al. (2009), suggest that, "writing is a means of communication that provides many benefits to people with acquired disability: an increased level of control and empowerment, as well as more time and greater flexibility constructing thoughts" (145). The written autobiography, thus, is an especially powerful tool for the narrator of an illness narrative, as it gives the narrator the space to construct with few external pressures. For an individual ill with Alzheimer's, where language and questions can be challenging, the written narrative mediates this, as no questions are posed and the narrator can construct the narrative at his own speed. Unlike oral narratives, with written narratives the authors are able to access various tools and programs that help to resolve errors in word choice and spelling. Through writing, the narrators could also consult others. Thus, through writing and the composing of their own autobiography, the authors are able to take the time to develop their narrative to reflect their "true" feelings, thoughts and experiences, and express them in a way that is meaningful to them. As expressions of experience and meanings, the autobiographies of Alzheimer's are, therefore, a rich source of anthropological data.

In addition, there is also an ethical dimension to using written autobiographies. Using written autobiography as data is less obtrusive as I, as the researcher, cannot frame questions, thereby allowing the authors to tell their stories and themselves exactly as they would like. An important advantage of using *written*

narratives of Alzheimer's is that they are unsolicited and are driven by the concerns of the individual authors and not my concerns, as the researcher. Without myself present to prompt, the authors are free to narrate their experiences as they wanted and in their own words; thus, dementia autobiographies give voice to the condition and position individuals with dementia as the most appropriate advocates (Beard et al. 2009: 228). Therefore, autobiographies provide insight into the narrated lives of individuals with Alzheimer's who may be difficult to reach through standard interview methods and observation.

"Recruitment"

For this study, I chose to use only written autobiographical books as data, as, although "first-person accounts are available in diverse formats, from conference presentations to blogs...many were insufficient in length and depth" (Page and Keady 2010: 513). Based on this, I then identified 12 autobiographies (listed in Table 4.0), determined through the "selected list of personal narratives" from the Alzheimer's Associations in North America and as suggested readings on personal blogs¹² and webpages of individuals with Alzheimer's disease. To be included in the study the autobiography *must* have been written in the first-person by an individual diagnosed with Alzheimer's disease. Initially, 12 autobiographies were identified (Table 4.0). However, greater research into the background of each author revealed that the initial diagnosis of Alzheimer's was later changed to a diagnosis of

¹² A "blog" is defined as, a "Web site that contains an online personal journal with reflections, comments, and often hyperlinks provided by the writer; *also* : the contents of such a site" (Merriam-Webster Dictionary 2013).

Frontotemporal Dementia (FTD)¹³ for three of the authors: McGowin, Bryden (Boden) and Mobley. Thus, of the 12 identified autobiographies, only eight “qualified”.

For this study, I decided to analyze only one book per author, and more precisely, I chose to analyze the first book that had been written. Among the eight books, four had been written by the same two authors (Larry Rose and Thomas Debaggio each wrote two autobiographies). From the eight, I therefore selected six: Robert Davis (1989), Larry Rose (1996,), Thomas Debaggio (2002), Jeanne L. Lee (2003), Charles Schneider (2006) and Richard Taylor (2007) (shaded in table 4.0).

Author	Title	Year	Diagnosis	Age at Diagnosis	Gender	Country
Robert Davis	<i>My Journey Into Alzheimer's Disease: A Story of Hope</i>	1989	EOAD	58	Male	US
Diana Friel McGowin	<i>Living in the Labyrinth: A Personal Journal Through the Maze of Alzheimer's</i>	1993 (After word 2011) ¹⁴	EOAD; later FTD	45	Female	US
Larry Rose	<i>Show Me the Way To Go Home</i> <i>Larry's Way: Another Look at Alzheimer's from the Inside</i>	1996 2003	EOAD	54	Male	US

¹³ Frontotemporal dementia (FTD), also referred to as “frontal lobe dementia”, is often misdiagnosed as Alzheimer's as both diseases are characterized by a progressive loss of cognitive functioning. FTD leads to a decline in behaviour, language and movement, and less to the memory loss that is a hallmark of Alzheimer's. In addition, FTD often begins at an earlier age than Alzheimer's (The Association for Frontal Temporal Degeneration n.d.).

¹⁴ McGowin included an *Afterword* in 2011, telling that since the 1993 publication of “Living in the Labyrinth”, she has “been re-diagnoses and the subject diagnosis removed by newer medical wizards”.

AUTOBIOGRAPHICAL ACCOUNTS OF ALZHEIMER'S

Christine Bryden (Boden)	<i>Who Will I Be When I Die?</i> <i>Dancing with Dementia: My Story of Living Positively with Dementia</i>	1998 2005	EOAD; later changed to FTD	46	Female	Australia
Thomas Debaggio	<i>Losing My Mind: An Intimate Look at Life with Alzheimer's</i> <i>When It Gets Dark: An Enlightened Reflection on Life with Alzheimer's</i>	2002 2003	EOAD	57	Male	US
Tracy Mobley	<i>Young Hope: The Broken Road</i>	2007	EOAD; later changed to FTD	38	Female	US
Jeanne L. Lee	<i>Just Love Me: My Life Turned Upside Down by Alzheimer's</i>	2003	EOAD	53	Female	US
Charles Schneider	<i>Don't Bury Me...It Ain't Over Yet</i>	2006	EOAD	52	Male	US
Richard Taylor	<i>Alzheimer's From the Inside Out</i>	2007	EOAD	58	Male	US

Table 4.0 Autobiographies of Alzheimer's.

The Autobiographies

The autobiographies that I analyzed were: *My Journey Into Alzheimer's Disease* by Robert Davis (1989), *Show Me The Way To Go Home* by Larry Rose (1996), *Losing My Mind: An Intimate Look at Life with Alzheimer's* by Thomas Debaggio (2002), *Just Love Me: My Life Turned Upside Down by Alzheimer's* by Jeanne L. Lee (2003), *Don't Bury Me...It Ain't Over Yet* by Charles Schneider (2006), and *Alzheimer's from the Inside Out* by Richard Taylor (2007) (shaded in Table 4.0).

Author	Diagnosis	Age at Diagnosis	Age at Writing	Gender	Country	Occupation	Education
Robert Davis	EOAD; early-stage AD	58	58	Male	US	Christian minister	Graduate degree
Larry Rose	EOAD; early stage AD	54	54	Male	US	Engineer	University degree
Thomas Debaggio	EOAD; early-stage AD	57	57	Male	US	Journalist/horticulturist	Some university
Jeanne L. Lee	EOAD; early-stage AD	53	54	Female	US	Business owner/Manager	College
Charles Schneider	EOAD; early-stage AD	52	52	Male	US	Police/Fireman	Some high school
Richard Taylor	EOAD; early-stage AD	58	63	Male	US	Psychologist	PhD

Table 4.1. The Authors.

After identifying the autobiographies I would use as data, I then rigorously researched each author individually. I re-read the autobiographies to draw out background information about each author, I searched various websites (Google, personal Facebook pages, personal blogs, Alzheimer societies and associations, public obituaries), and read different articles and books that included information about each author. For some of the authors, detailed background information was readily available, while, for others, I spent hours and hours searching for details and checking and re-checking my information with other sources for accuracy.

A rather unforeseen outcome of the research process was that all of the authors were initially diagnosed with early-stage, Early-onset Alzheimer's and were living in the United States (see Table 4.0). It is important to reflect upon why it is

that individuals with early-stage, Early-onset Alzheimer's are responsible for all of the published autobiographies that are currently available. Page and Keady (2010) suggest that it is perhaps due to the age of diagnosis. According to them, the "onset of dementia in mid-life is a truly devastating and life-changing event and engenders a powerful range of emotions" (Page and Keady 2010: 521). Moreover, in his own autobiography of Alzheimer's, Schneider (2006) suggested that:

There is a lot of literature to guide caregivers, but still very little literature written by people with Alzheimer's disease. One reason why few victims of Alzheimer's disease ever write books is because they have often progressed too far in the disease by the time they are diagnosed, past the point of being able to perform a task that size. [89]

Nonetheless, to "truly" know the answer to this, you would have to ask individuals with Later-onset Alzheimer's disease themselves.

In addition the authors were middle-class individuals living in the United States (Table 4.1). As Page and Keady's 2010 study of dementia narratives reveal, nearly all first-person dementia narratives are authored almost exclusively by North American middle-class, well-educated individuals who have been involved in some form of public service (521). Perhaps this is because there is a market for this type of literature. EOAD has a "human interest and curiosity value as readers can identify more closely with the authors and project their own sense of self into the world of the author" (Page and Keady 2010: 521).

For this study, I therefore, examined only the Alzheimer experiences of middle-class American individuals who were expressed themselves through writing. This might mean that those who do not write might tell different stories. As Page

and Keady (2010) highlight, "The narratives do lack voices that reflect the diversity of the lived experience of dementia" (521). Therefore, I would caution to generalize the results of my study to all Alzheimer's experiences and all individuals with Alzheimer's disease.

THE AUTHORS

Robert Davis

Robert Davis' father died when he was five and his mother then moved him to his grandparents' 11 acre farm. As a child, Davis grew up in poverty. After high school, Davis worked at a feed mill, and later for Firestone in Akron, Ohio. He then attended Toccoa Falls Bible College, in Toccoa Falls, Georgia and later completed a degree in psychology at Taylor University in Upland, Indiana, where he was a nationally-noted football player. He went on to graduate from Union Theological Seminary in 1961 and was ordained in the Methodist Church. Davis married a woman named Betty, had two daughters, and worked as a minister for several churches, before his last ministerial role as minister of The Old Cutler Presbyterian Church in Miami. After being diagnosed with Alzheimer's disease, Davis retired as minister.

Robert Davis wrote *My Journey into Alzheimer's Disease* more than 20 years ago, only months after his diagnosis with early-onset, early-stage Alzheimer's disease. Davis' autobiography is one of the first written by someone diagnosed with Alzheimer's disease. Davis wrote his autobiography from the perspective of a "Christian with Alzheimer's" (16). As Davis (1989) writes:

I want to give the concerned families some insight as to the devastation felt by the Alzheimer patient. Perhaps understanding the "blackness" and "lost" feelings will help families to be more understanding of the reasonable actions they must deal with...The entire book is a story of a part of my recent spiritual journey. [17-18]

Davis (1989) also reveals his motivation behind his autobiography, telling:

Perhaps explaining my feelings and emotions will give a glimmer of understanding to those who must care for my fellow-sufferers who can no longer explain their tortured feelings. Perhaps I can still communicate so I can give new hope and assurance to those faithful Christians whose former emotional feelings and blessings are being washed away by the start of this disease, and who are in spiritual despair because they are unable to understand what is happening to them. [21-22]

Davis' autobiography begins with a "Foreward", which is followed by an "Introduction" by Davis' psychologist, Jack T. Tapp. Davis then introduces us to his autobiography in a "Preface" that he writes himself. The next 127 pages are "his", though Davis admits that:

[A]s I began to outline thoughts for this book, I was able to write them out. Although many words were missing and many sentences unclear, Betty...was able to decipher my intent and type it into the computer. Then together we read and discussed until I felt sure my feelings were recorded. Chapters 1, 8, 9, and 10 were completed this way...I rented a Dictaphone and wrenched Chapters 3, 4, and 5 this way. Chapter 7 became so disjointed that we had to take the paragraphs of my description of the physical aspects and let Betty re-write them. Chapter 6 and the Epilogue are Betty's alone. [1989: 18].

Davis passed away in 1993.

Larry Rose

Larry Rose spent most of his life working in the service industry for the "Oil Patch". He worked as a special projects engineer for a small electric wire line company in Lafayette, Louisiana. After retiring from this, he undertook various consulting jobs, lobbying in Baton Rouge for some large, independent oil companies in Louisiana. Rose was a father and a widower, who lost his wife to a drunk driver in

1985. He then shared his life with his “dear friend and long-time companion” Stella Guidry (Rose 1996: 2). Rose had a cabin in the Ozarks, near Clinton, Arkansas, where he liked to spend as much time as possible.

Rose was diagnosed with Early-onset, early-stage Alzheimer's disease at age 54. Rose wrote his autobiography in the early stages of the disease. In his first-person account titled *Show Me the Way To go Home*, he discussed his day-to-day experiences with Alzheimer's disease. He shared his thoughts, feeling and insights about the disease through short vignettes of daily “happenings” and interactions. Rose's 143 page book begins with a short introduction by his son Jeff Rose and ends with an “Afterword” by Stella. In his autobiography, Rose depicted, “real people, real events, in the very real world of an individual diagnosed with Alzheimer's disease” (Rose 2003: xi). For Rose, “the purpose of these writings [is] to let folks know how it feels to be on this side” (Rose 2003: 3). Rose also authored another autobiography, *Larry's Way: Another Look at Alzheimer's From the Inside* (2003), which is a reflection on his experiences with the progression of Alzheimer's disease. Similar to his first book, *Larry's Way* depicts Rose's “world”. Rose passed away in 2010.

Thomas Debaggio

Thomas Debaggio was born in Iowa but spent most of his life in Arlington, Virginia. He led a sheltered middle-class life. He left home at 18 years of age to attend the University of Arizona, but dropped out a few weeks later. He worked as a copyboy at *U.S. News and World Report*, living at home and earning little. He later

entered the American University in Washington, DC, with an interest in European literature, but dropped out again. He was married to Joyce for 47 years and had one child - a son, Francesco. He was an atheist, whose bible is J.D Salinger's *Catcher in the Rye* – a book that opened his eyes to the world and its ways (Debaggio 2002: 147). He gave up journalism to start a backyard farm with his wife and made a living this way for twenty-four years, growing and selling herb and vegetable plants from his greenhouse. He describes himself as a “new breed of urban farmer” (Debaggio 2002:3).

Debaggio was diagnosed with Alzheimer's disease at age 57; his book *Losing My Mind: An Intimate Look at Life with Alzheimer's* (2002) is his story of “hell to tell” (1). His 207 page autobiography, which began as a diary, is extremely detailed and discusses events of the past and the present, with short reflections, and information and statistics drawn from the large body of Alzheimer's literature. Debaggio (2002) describes his autobiography as “unconventional” and explains that its “multilayered style” is set up in three narrative lines to illustrate memory's faults and strengths (xi).

Debaggio (2002) “began the book to help expose my inner self in words from the deepest cavities of my being to help people understand the large picture of Alzheimer's disease, as well as the very personal one” (31). He writes that he has “found a way to use my frailties and illness to create a story that others will read and, perhaps, act on. I can open my heart and touch others to expand their lives and enrich their minds with human emotion” (121). Debaggio admits that his memory

“often does not distinguish between fiction and the facts that have been lovingly remembered” (124). The purpose of his autobiography is:

...to break through the sense of shame and silence Alzheimer's has engendered. I want people with the disease to come forward, unafraid of exposing their illness, and tell the world what it is like. Doctors and advocates can help, but there is nothing like personal stories to humanize the silent, destructive power of this illness. The more we talk about it and expose Alzheimer's, the greater the chance a cure will be found quickly (Debaggio 2002: 141).

Debaggio (2002) tells the reader that the book is “balanced between the wonder of childhood and the tottering age of memory” (xi), and is an attempt to preserve his dear memories. Debaggio continued to tell his story, writing *When It Gets Dark: An Enlightened Reflection on Life with Alzheimer's* in 2003. Debaggio passed away February 21, 2011 at the age of 69.

Jeanne L. Lee

Jeanne L. Lee was born in 1941 in Portland, Oregon, where she was also raised. She has been married several times, is the mother of nine children (4 by marriage) and a grandmother to 13 grandchildren. She attended beauty college and has owned hair and nail salons, a printing brokerage, a bar and restaurant; managed bars, and graphics and printing shops. She currently lives in Hawaii with her partner Vern.

Lee was diagnosed with Alzheimer's in 1995, five years after her first symptoms began. After years of suicide attempts, failed marriages, and mental institutions her diagnosis brought her relief. Lee “likes to say that she's living with Alzheimer's, not dying from it” (Feinberg and Yu 2005: 188). Lee wrote her 150-

page book *Just Love Me: My Life Turned Upside Down by Alzheimer's*, over seven years. Her book "is about the thoughts and emotions that go on in the mind of a person with Alzheimer's" (Lee 2003: xx). Lee's (2003) motivation for the book was twofold: her feelings of aloneness compelled her to write the book; she also wrote the book as a means of sharing what she has learned from others and "to help open things up for all of us, and if not for us, then those that will follow" (43).

The book begins with words from Valerie Brandon, a medical doctor, and David B. Dameron, a psychologist, two people she felt have been instrumental in her experience with Alzheimer's. It also includes several pages from her older sister, Caroline, and ends with information about different Alzheimer's resources, including an overview of the Dementia Advocacy and Support Network International (DASNI). Lee (2003) tells that:

Although I am now incapable of typing the words that appear in this book, I have personally reviewed every word that appears on these pages, to ensure that this book accurately portrays my own personal thoughts and feelings. It was a painstaking effort for someone in the throes of Alzheimer's, but I believe that effort was necessary to ensure that this book represents a credible journey through the emotional world of someone actually afflicted with the disease. [xxi]

She later acknowledges the assistance of an editor, who converted her "mumble jumble, night-typing, seven years of journals, and tape recordings" into a readable book (Lee 2003: 72). Jeanne's own mother had Alzheimer's for ten years and they went into comparison testing at the University of Indiana (Alzheimer Society Canada 2002: 35).

Since her diagnosis, Lee has started a group for people in the early stages of Alzheimer's (though the group is now disbanded) and has given lectures on the topic of Alzheimer's in order to spread awareness of "how very important early diagnosis" is (Alzheimer Society Canada 2002: 36). Lee also started a business called "Alzheimer's Awareness and Prevention", which is dedicated to research and education of what cannot be learned from books and integrates the knowledge of all those involved to include those who have Alzheimer's and other forms of dementia (Feinberg and Yu 2005: 190). Lee is also a member of the Dementia Advocacy and Support Network International, where she serves on the Board of Directors.

Charles Schneider

Charles Schneider is the author of *Don't Bury Me...It Ain't Over Yet* (2006). The book is 106 pages, with the first 97 written by Schneider himself, and the last nine by his wife and caregiver. Schneider, a husband to Barb, father to Charles IV and Melissa, and grandfather to five grandchildren, was diagnosed with Alzheimer's disease at age 52. Schneider dropped out of high school at 15-years-old, married at 16, was a foster parent by 19, and had his children at a young age. Schneider worked at a number of jobs: he was a business owner, a policeman and a firefighter. He was diagnosed five years before his retirement. Schneider was a spiritual man whose life was focused on his family.

A year after his diagnosis, Schneider began to write his autobiography. In his book, "you will read of good times, and heartbreaking times." He has "endeavoured to reduce the gloominess...found in much other literature about Alzheimer's disease,

without trivializing the extent it mercilessly plagues its victims” (Schneider 2006: ix). Schneider (2006) tells about the motivation behind his book, writing:

I do know that I want to use whatever time and capabilities I have left to help others as much as I can. Hopefully in some small way I can encourage caregivers, AD victims, and all of those seeking a cure for Alzheimer's. [35]

He later writes:

I am writing this book partially to help prepare my family. I also hope this book will bring more understanding and comfort to those traveling the same road as me. Hopefully it will provide caregivers and everyone who knows someone affected by Alzheimer's, a better insight into what their loved ones are experiencing. Some times it is easier to write down how you feel than to tell it to the people that you should. [Schneider 2006: 89]

In his book, Schneider talks about his past, his present and discusses the future. To write the book, he used “several forms of information gathering”: he tapped into his wife's memory, referred to business records, copies of police reports, family pictures, old home movies, and other resources. He also used his long-term memory (Schneider 2006: 38). While some events are discussed in great detail, others are not. Schneider (2006) suggests that this is so due to an “urgency I feel to complete this book” (41).

Richard Taylor

Richard Taylor lived in Houston, Texas and later moved to Cypress, Texas. He was married to his wife Linda for more than 20 years, with whom he shared two children. Taylor was a high school teacher and debate coach and later he became a psychology professor, retiring only after his diagnosis with Alzheimer's.

Taylor was told in 2001, at the age of 58, “You have dementia, probably of the Alzheimer's type”. Five years later, Taylor wrote *Alzheimer's from the Inside Out*.

The book is a collection of more than 80 short essays, daily letters to himself, that discuss the complex experiences of an individual diagnosed with Alzheimer's.

Taylor's autobiography resembles an academic text, which begins with a review by a number of individuals and includes a table of contents. It includes a brief note from his wife Linda and several photographs of Davis, over time. It is divided into four parts: 1) "What Is it Like to Have Alzheimer's Disease?"; 2) "From the Inside Out"; 3) "From the Outside In"; and 4) "Dear Doctor..." Each section includes a diverse array of essays and facts, statistics and information drawn from a number of sources. His autobiography ends with an appendix that includes: "What You Can Do" and a resource list. For Taylor (2007), "My writings don't offer answers, just my own observations from my own increasingly unsure perspective" (17). He further explains:

This is my attempt to leave a record of what is going on between my ears. I am writing about the disease as it is expressed by and is having an impact on my mind, my perceptions, and my world – as I perceive the process. I make no claims to speak to 'the Alzheimer's experience.' Although I have spoken to hundreds of Alzheimer's, no one sees the disease, himself or herself, or caregivers, exactly as I do. There is no one Alzheimer's experience which, if understood, becomes the key to understanding individuals with the disease...I wrote to clarify for myself what was going on with and in me. [Taylor 2007:4]

While Taylor originally wrote the essays to better understand himself and what was going on inside of him, he later wrote to share his experiences with others and their caregivers. He used voice recognition software which allowed him to speak while the computer types, in addition to spell checkers and grammar checkers (Taylor 2007: xix).

Taylor is now regarded as a champion for individuals with early-onset Alzheimer's disease. Taylor served on the board of the Houston and Southeast Texas chapter of the Alzheimer's Association and started over 50 chatrooms worldwide for people with Alzheimer's disease and their loved ones. Taylor was also the editor of an e-newsletter for people with early-onset, early-stage Alzheimer's and their caregivers (Taylor 2007b: 1-2). He also shares his life on a number of DVDs: "Be With Me Today: A Challenge to the Alzheimer Outsider" (2009), "Live Outside the Stigma" (2011a), and "Living with Dementia: To Change Your Minds About People Whose Minds Have Changed" (2011b). Taylor also has a blog: <http://www.richardtaylorphd.com/blog> (Richard Taylor Ph.D. BLOG n.d.), where he continues to share the details of his life with Alzheimer's disease, and more recently, his battle with cancer.

DATA ANALYSIS

In this study, I adopted an inductive approach to data analysis. As I did not follow "traditional" anthropological methods in using written autobiographies as data, deciding on how to do it was somewhat of a challenge. Though I had experience analyzing data gathered from interviews and observation, I had no experience in analyzing written narrative texts. I must admit that this was a rather intimidating task.

After researching different qualitative methods, I decided to conduct an interpretive analysis of my data. As interpretation is often associated with hermeneutics it is particularly useful to the analysis of autobiographies. According

to Bernard (2000), in hermeneutics, or interpretive analysis, the researcher “continually interpret(s) the words of those texts to understand their meaning and directives” (439). Interpretive analysis is useful for understanding narrative construction as it emphasizes the authors’ perceptions, feelings, and experiences. It gives voice to their stories and allows them to discuss their experiences freely and to construct their narratives as they choose.

I first conducted an individual-level analysis, first analyzing each autobiography individually. I read Davis’ autobiography first, followed by Rose’s, Debaggio’s, Schneider’s, Taylor’s, and lastly Lee’s (as I obtained this autobiography last). I analyzed the texts explicitly for words relevant to selfhood. I jotted margin notes in the books and wrote more detailed notes in a separate notebook. I then grouped my notes in each autobiography. Following this, I conducted a group-level analysis of the autobiographies, where all the themes were drawn together and grouped with similar themes from other autobiographies. I report the findings of my inductive inquiry in the following chapter. I selected detailed quotes to illustrate the dynamic nature of self. More precisely, I use these quotes to illuminate how Early-onset Alzheimer’s disease influences sense of self and how individuals with EOAD narratively (re)construct self.

CHAPTER 5: ANALYZING THE DATA

All I want, all I need, all I ask for is that others, especially my caregivers, be more like me. Not to act like me, but to understand me as I understand myself.

- Richard Taylor 2007: 21

AUTOBIOGRAPHICAL ACCOUNTS OF ALZHEIMER'S

This chapter is guided by the question: how does Early-onset Alzheimer's disease (EOAD) impact self? In this chapter, I examine the ways that EOAD influences sense of self and how individuals with EOAD (re)construct self. I suggest that sense of self may be adversely affected by loss of functioning and interactions with others. I argue that, despite reduced cognitive functioning, the self is not lost altogether, as through narrative, individuals may (re)construct themselves. Thus, while there may be a change in self, I argue that change does not necessarily mean an entire loss, as seen through the narrative (re)construction of self in Alzheimer's autobiographies. I illustrate this with quotations from six autobiographies of Alzheimer's.

Only those around me really know I am not 'myself' but I am, in effect, acting the part of my old, pre-Alzheimer's self. [Taylor 2006: 21]

It's not my nature, and I despise myself for it, but I can't understand why people make such statements...A year ago, a statement like that would not have bothered me. [Rose 1996: 72]

I've accepted that I'll never be the way I once was, but I'm still a person. [Lee 2003: 36]

My current concerns about Alzheimer's and death focus not on the moment when my brain waves go flat and my heart ceases to beat, and I draw no more air into my lungs. The death I currently ponder does not have an on/off switch. It occurs in the months and perhaps years when I drift between consciousness of my current self and a consciousness of...I know not what. [Taylor 2006: 34]

The disease works slowly, destroying your mind, stealing life in a tedious, silent dance of death. [Debaggio 2002: 1]

SENSE OF SELF

The autobiographies are stories associated with sense of self. The authors all write about an anticipated or actual loss of who they feel they are (Keady and Page 2010).

I am a very private Presbyterian who enjoyed the fullness of the Christian experience in my study time and especially in that very wonderful time in the stillness of the night just before I went to sleep. It was then that I worshiped and enjoyed the Lord in our most precious moments. The sunlight of Christ had always filled and thrilled my soul in those drifting moments before sleep carried me away. Now I discovered the cruelest blow of all. This personal and tender relationship that I had with the Lord was no longer there. [Davis 1989: 47]

You have no dignity and no sense of self, and eventually you just sit around waiting for your body to forget how to keep itself alive. [Taylor 2006]

I believe that making memories is far more important than accumulating an excess amount of material things that never last forever. I intended, the precious times we had spent memory making, to last forever in all of our minds. All those family vacations, sitting together in front of the fireplace with the kids, their first steps, and so many others, are mostly gone now. Some unidentified evil has stolen them from me. [Schneider 2006: 28-29]

I worry I will become too conversant with this disease in me, and it will hijack my life without my permission. [Debaggio 2002: 12]

Everything that is important to me is slowly slipping away. [Rose 19966: 16]

Functioning

Sense of self is described by all of the authors in terms of a change in the author's functioning.

Language

Sense of self may be influenced by language.

Within eight weeks of starting Gingko I was able to get back some order in my life, and most importantly, I was able to read again, which made a tremendous difference to my whole outlook. It was like I was re-born. [Lee 2003: 58]

I became a recluse. I was so ashamed of the way I talked. I felt stupid because I couldn't seem to put even a simple sentence together. I felt as though I hadn't gone past the fourth grade. [Lee 2003: 20]

Social Roles

Sense of self is associated with a change in social roles.

Fortunately, because I was the assistant manager, and left in charge most of the time, I was able to delegate almost everything. But even that was hard for me, because I had always prided myself on being able to hire good people, make them happy where they were, and work closely with them. I had always preferred to be in the middle of things, because I liked to know what was being done and that it was one right. Now I was in a spot where, if I was in the middle of it, I was the one screwing things up. I had never been good at delegating before, but I soon learned. [Lee 2003: 15-16]

Familial Roles

Sense of self may be influenced by a change in the familial role.

During this illness our roles have changed. Suddenly she is not only the wife I have loved, but now she is also my caregiver. She has to guide me through daily living as I have become a care-receiver. [Davis 1989: 22]

Somehow it worked better for me when I said, 'Because I'm your father.' I am still their father, but I am not the person I was. And everyone knows it, but no one seems to know what to do about it. [Taylor 2007: 168]

Memory and Recall

Sense of self is also influenced by memory and the ability to recall memories.

For me now, any question of identity becomes profound and difficult. Without memory you lose the idea of who you are. I am struggling more than ever to find answers to questions of identity. I am flooded with early memories preserved in protected places of my brain where Alzheimer's does not reign supreme. These memories become the last remnants of my search for who I am. [Debaggio 2002: 42]

I will eventually overcome this beastly thief and retrieve my precious memories. I believe they are somehow recorded in my Soul. When I step into eternity I'll have them all again. [Schneider 2006: 29]

Everything that is important to me in my life is slowly slipping away. Friends' faces, places and names are becoming harder and harder to remember. [Rose 1996: 12]

Responsibilities

A change in responsibilities may also lead to a changed sense of self.

It is humiliating to give up our areas of responsibility. There is a distinct feeling of the loss of self and all that we have been. Yet all is not gone. I have chosen to give up those areas where I will be met with failure or my wife would be filled with aggravation at having to live with the consequences of my foolish decisions. It is better to release willingly those areas and concentrate on the areas where I still have some ability. [Davis 1989: 104-105]

Loss of Functioning

For all of the authors, sense of self is linked to how they function; a change in functioning often lead to a changed sense of self. For most of the authors, this change in functioning was often a real or perceived loss, which often led to a loss of sense of self: with a loss of words, there is a loss of self, with a loss of responsibility, there is a loss of self, with a loss of recall, there is a loss of self. Thus, a loss of sense of self was inextricably tied to a loss of functioning.

I learned that E.O.A.D. [Early Onset Alzheimer's Disease] usually strikes its victims in their 20's to early 60's and that it is considered the most aggressive form of A.D. The normal life expectancy is eight years after a diagnosis is made of A.D., but E.O.A.D. is usually considered to be more aggressive. There is a three stage and a seven stage scale used to describe the progression of A.D. I am using the three stage scale. The first stage generally lasts about 2 years, in which the victim can usually remain basically independent. During the second state – which lasts from two to four years – the victim's independence erodes along with their capabilities. Knowing this suggested to me that I had about two years of living relatively independently left. [Schneider 2006: 3]

It's depressing to think you might not be able to work again; that your days as a productive member of society might be over. [Lee 2003: 37]

Slowly the memory is impaired, and then you wander into a world without certainty and names. Yesterdays disappear, except those long ago. Eventually

there is a descent into silence and a dependence on caretakers. [Debaggio 2002: 5]

We only ask for your permission that we be allowed to help and be useful...We don't want to be excluded from these things, so please count us in! please don't consider us the breathing dead. [Schneider 2006: 65]

Actually, what I need is to feel that I am still taking care of something. [Taylor 2009: 179]

I want to participate in life to my utmost limit, the reduced capacity, however, leaves me barely able to take care of my most basic living needs, and there is nothing left over for being a productive member of society. [Davis 1989: 100-101]

In Alzheimer's disease there is a loss of the personality, a diminished sense of self-worth. A highly productive person has to wonder why he is still alive and what purpose the Lord has in keeping him on earth. As I struggle with the indignities that accompany daily living, I am losing my sense of humanity and self-worth. [Davis 1989: 103]

The authors often felt that this loss of functioning meant that they could not live independently, be useful or productive, which posed a threat to their selfhood and often lead to an actual loss of sense of self.

The value put in functioning may reflect the authors' cultural values as American middle-class individuals, where the cultural value of the self is deeply connected to one's usefulness to society (Basting 2003: 96). As middle-class Americans, the "resulting inability to carry off their role as respectable middle-class individuals" may lead to a loss of sense of self. As Ballenger (2006) highlights:

Loss of self-control, awareness, and personal responsibility are perhaps the most horrifying things imaginable to middle-class Americans...In his or her total loss of self-control, the sufferer...was the epitome of the failed individual...If the Alzheimer's disease victim was, before the disease struck, a solid, respected middle-class citizen...he or she became something quite different. [115]

As functioning, such as the ability to act or behave in the way one desires, was compromised by the cognitive dysfunction associated with Alzheimer's, the authors' senses of self-value, self-utility and self-purpose were undermined (Keady and Page 2010: 517). Thus, a loss of function, or an inability to have total control over every aspect of their life, often led to a loss of sense self for the authors. Kontos (2006) identifies this as a "product of Western assumption that status as a full human being is completely dependent on" functioning (195).

What emerges here is the importance of being an autonomous self for the authors. For most of the authors, if they cannot "be" an autonomous individual, they lose their sense of self as the ability to be their own, independent person is often tied to their ability to function. This is highlighted when the authors suggest that they are reverting to childhood. Mental losses are often perceived as a "second childishness" (Ballenger 2006: 106).

I regress, losing adult characteristics. [Debaggio 2002: 119]

I am becoming a child again against my own will. [Debaggio 2002: 150]

In "becoming a child again", the authors reveal that they were once autonomous beings, however, with the onset of Alzheimer's, this autonomy is threatened. Children are often seen as lacking autonomy, thus in positioning themselves as children, the authors reveal that with Alzheimer's they lose their sense of self as independent, useful, contributing individuals.

What also emerges from this is how the biomedical model resonates with the authors' cultural values. According to Clarke et al. (2003), "Western biomedicine has become a distinctive sociocultural world, webbed throughout mass culture"

(163). From the point-of-view of the authors, the autonomous self is important but it is compromised by the cognitive impairment characteristic of Alzheimer's. The diagnosis of Alzheimer's disease led most of the authors feel loss of sense of self. According to Whitehouse and George (2008), "A diagnosis of [Alzheimer's disease] can act in many ways as a death sentence of the mind, which imprisons many still-functional adults to a mental death row" (xvi).

Once I was diagnosed with Alzheimer's disease I was constantly reminded of my pending death sentence. It is attached to all of us with Alzheimer's disease and every time we can't think of a word, or we have difficulty doing things that used to be easy, we are reminded of our disease and all that accompanies it, including death. [Schneider 2003: 59]

I am, I repeat, someone who heard the words 'you have dementia, probably of the Alzheimer's type' directed at him, by a neurologist I admired and trusted. [Taylor 2007: 10]

I was afraid of Act Two because I heard I would be required to drift in and out, back and forth, from my old self to my new self...I wasn't looking forward to being someone with two identities. [Taylor 2007: 57]

Thus, the authors accept the biomedical construction of Alzheimer's, as a disease that will rob them of their social value. As a model rooted premised on Cartesian mind/body dualism, a loss of their mind is equivalent to a loss of self.

The loss of self, which I was experiencing, the helplessness to control this insidious thief who was little by little taking away my most valued possession, my mind, had made me especially wary of the rest of my possessions in an unreasonable way. [Davis 1989: 91]

Thus, for most of the authors, they see themselves as beginning to disappear and becoming nothing but a body, experiencing a social death.

Although my body may still be sputtering along, the day will come when I can no longer write a clear sentence and tell a coherent story. That day will be the actual time of death. The person in me who lives on until natural death occurs is only a shadow left by the deadly laugh of Alzheimer's. [Debaggio 2002: 117]

I lay there without memory, just a live carcass, no longer human. [Debaggio 2002: 120]

Others

[The doctor] talked more to Stella than to me (Rose 1996: 15).

If I Were an M. Instead of a Ph. D...I would be aware that each patient's cognitive functioning is unique and that Alzheimer's presents itself as a syndrome (a group of symptoms). I would be prepared to explain things to my patient as many times as it took for the patient to be able to explain it back to me in his or her own words. I would never have more than three major points to make in an appointment with a patient. And, I would preview and summarize those points with the patient. I would ask the patient to repeat the three points back to me in his or her own words. I would never ask caregivers to speak with me outside of the hearing of my patient. If it was necessary for me to speak with them in private, I would call them. I would always direct my remarks to the patient. I would never act as if the patient were not in the room. I would strive to help the patient feel as if this appointment was his or her appointment, not the appointment of the caregiver; as if the patient, lacking a sitter, was brought along...I would meet with a person with Alzheimer's in my office rather than in an examination room. I would sit in my chair or on the couch next to the patient rather than behind my desk, I would not wear a white coat when I met a person with Alzheimer's. I would always look the person in the eye when I was talking, and speak directly to him or her. [Taylor 2007: 223]

Alzheimer's disease is a biomedically-verified disease. As such, Alzheimer's disease is understood in biomedicine, a system of medicine guided by a belief in autonomous selves, as a clinically identifiable object that exists within the human body. Drawing on Engel (1977), Valiis and McHugh (1986) highlight that:

Medical practice continues to be guided by the biomedical model. According to this model, an individual's complaints and ailments are viewed as the result of disordered biology, and interventions are guided by biological principles and mechanistic thinking based on 'either/or' and single-cause explanations.

Biomedical practitioners are often influenced by standardized classifications which guide their interactions with individuals with Alzheimer's.

For example, Rose (1996) writes that when asking “How long have I got, Doc?” the answer was usually that the earlier the onset, the sooner you die. When Rose questioned where this information came from, the doctors would reply, “Statistics”. Similarly, in his autobiography, Debaggio provided the notes from his neuropsychological evaluation, where he was described as a “patient”, whose abilities were assessed using standardized tests, test scores, and where he was placed into a percentile. What happens here, suggests Ingunn Moser, seems to be that life, from a medical doctor’s perspective, “falls apart: the body...is split off from the mind...the patient with dementia is seen to live on biologically, while the conscious... is diseased and lost” (2011: 711). Medical training frequently enables practitioners to detach from their “patients”, separating “the person from the body” (Leibing 2006: 245). The medicalization of the authors, as individuals with Alzheimer’s, often resulted in the depersonalization of the author.

Rosenberg (2007) acknowledges that “the clinician...remains at the interface between our bureaucratic world of agreed-upon, if ever-changing, data, procedures, practices” and the individual (1). Practitioners thereby engage in their medical practice under certain constraints (Einstein and Shildrick 2009: 296), which contribute to an impersonal treatment of the individuals with Alzheimer’s.

When the answers I receive come from individuals who are neither scared nor out of control in the way(s) I am, it is understandable why I feel a disconnect.
[Taylor 2006: 32]

I don't know how much value a psychiatrist puts in the results of neurological testing, but as far as I'm concerned only somebody like a psychiatrist, who knows me from the inside out and knows my daily life, can make any informed diagnosis on something as subjective as Alzheimer's. [Lee 2003: 58]

A number of studies have suggested that doctor-patient interactions frequently reinforce hierarchical structures in society by drawing particular attention to the need for the patient to comply with a social superior or expert's judgment (Singer 2004: 14). This often led to a disconnect between the author and their practitioner and led the author to feel like "less" than a person.

A disconnect was similarly felt between the author and others in their lives including family, friends, acquaintances, and strangers.

My caregivers are looking through 'Coke bottle' glasses and a number of other filters. [Davis 1989: 56]

Whenever you have first-hand experience with something you are sensitized to it in your surroundings...What happens when you tell someone you have Alzheimer's disease? My experience has been that the announcement is initially met with silence. People then express their sorrow, mention something about an article...and then change the subject. The next time we meet, they apologize for not 'saying more,' and then with watery eyes they tell me their experience with the disease in a relative, a friend, or neighbor. [Taylor 2006: 51]

The best for me is to be with one other person, and I'm able to carry on a pretty decent one-on-one conversation. I think that's why a lot of people who don't see me all the time say, 'No way do you have Alzheimer's'. [Lee 2003: 33]

I don't walk too well, and with the pain of the injury, I had trouble getting around...As I walked back to our booth, I stumbled a time or two. I kept myself from falling by holding onto the backs of the stools at the counter. As I passed one of the booths, I heard someone say, 'There's that old drunk again'. [Rose 1996: 47]

Others who know I have Alzheimer's generally assume that they are correct and that my disease causes me to be incorrect. [Taylor 2007: 154]

Interactions with others often influenced how the authors felt about themselves. More precisely, the authors' sense of themselves may be changed by others' perceptions of them (Leibing 2008: 185). There was a loss of sense of self for most of the authors. This may be due to the stigmatization associated with

Alzheimer's disease. Whitehouse and George (2008) suggest the current biomedical model, as the "medical story" of Alzheimer's, may generate this stigmatization by others (xvi). As Kleinman (1988) highlights:

Stigma has come to refer more to the disgrace than to the actual bodily mark. The change in meaning is an instance of a more general process of psychologization of experience in the West, through which metaphors of distress and other human problems that were once bodily have become mental. [158-159]

The stigmatization of Alzheimer's may draw a divide between an individual with Alzheimer's and the non-ill.

As Whitehouse et al. (2010) highlight, "[the biomedical] labeling of an individual as having [Alzheimer's disease] or MCI [Mild Cognitive Impairment] may create an artificial separation between the self, the family, and the larger community" (321-322). Negative stereotypes lead others to become unsure in the presence of the ill. Ryan et al. (2007) suggest that stigma creates impoverished social interactions (147).

I have become keenly aware of a patterned response from some individuals as soon as they find out I have Alzheimer's disease. They switch their eye contact and attention to whomever I am with. It is as if knowledge of the disease immediately cloaks me in invisibility. [Taylor 2007: 152]

When you answer, "I have Alzheimer's disease," there is a strange look and uncomfortable silence. When Mayor Steve Clark and Commissioner Clare Oesterle....presented me with a certificate, this strange treatment was illustrated. Commission meetings aired live on a cable channel...my family and I watched the presentation on television...some of the commissioners, unaware that their microphones were open, were laughing and commenting, 'He sure talks fine for someone with Alzheimer's'. [Davis 1989: 101]

What emerges from the autobiographies is others often viewed the author as less than a person. As an individual with cognitive dysfunction, the authors were

perceived “as a source of shame, guilt and fear to be approached with apprehension, benevolence, condescension and/or curiosity” (Ryan et al. 2009: 147). The stigma may internalized by the author as a “spoiled identity” (Goffman 1963: 3; see Kleinman 1988: 159). As Leibing (2008) suggests, “People describing their own experiences of living with Alzheimer’s generally discuss personhood in the context of the stigmatization of nonfunctional people in general culture” (186).

Enough people have ignored me or changed their focus upon learning that I have Alzheimer’s that I am extremely conscious, and self-conscious, of how people look at me when they are talking to me (Taylor 2007: 153).

As Kitwood (1997) and others (Sabat & Harré 1992) have persuasively argued, interactions with others critically influence how dementia is experienced; these interactions have the potential to either enhance identity or, conversely, damage it. No matter how positively persons with Alzheimer’s define the situation themselves, the success of their efforts to manage identity will depend on the support and cooperation of others (MacRae 2010: 301). Therefore, the loss of sense of self may be attributed to how others treat the ill individual.

When my recollections are corrected based on the generalization that my disease guarantees I am wrong, I lose another ounce of self-confidence in my ability to know and remember what is going on around me (Taylor 2007: 154).

The ability of persons with Alzheimer's disease to position themselves as functioning members of society may be compromised by the malignant positioning of others (Sabat, Napolitano, & Fath, 2004; Ryan et al. 2009: 148). Thus, loss of sense of self is rooted in the fact that human beings are impacted by the malignant social psychology that surrounds them (Kitwood 1990: 181). For example, the spousal

relationship was often the most changed relationship for the authors, as the spouse often became the caregiver.

The leader of my caregiver team is my spouse, Linda. [Taylor 2007: 163]

The relationship was redefined not as husband/wife, but care-receiver/caregiver. In addition, the authors' declining abilities beget treatment by caregivers that involved the domination of daily routines, including household chores, or errands, leaving them with few opportunities for self-assertion (Ryan et al. 2009:148). Attempts by the authors to assert themselves positively were frequently misunderstood or rejected by caregivers. Spouses are particularly influential sources of identity validation (MacRae 2010: 301), however, for most of the authors, the change in the spousal relationship, changed the authors' sense of themselves; as care-receiver, the authors felt they were a burden.

Barb is a strong woman, but I don't want to burden her with caring for a mindless body for a husband. [Schneider 2006: 4]

Thus, malignant social psychology may deprive the author of his sense of self (Herskovits 1995: 156).

SELF (RE)CONSTRUCTION

I now have an appreciation and admiration for how she uses that strength to support me, to protect me, to nurture me in ways neither of us thought would ever be necessary (Taylor 2006: 164).

My relationship with my spouse, my family, and my friends has broadened and in some ways deepened. We spend more time really being together. We talk more, we hug more, we cry more, we laugh more and harder and longer together (Taylor 2007: 169).

Though self is changed by Alzheimer's disease, it is not lost altogether. In this section, I argue the self is (re)constructed through narrative and suggest that the autobiography, as a narrative strategy, is an avenue for self-preservation, self-expression, self-reflection and self-creation. The narrated self is important to understanding self amongst individuals with Alzheimer's, as the notion of a narrative self allows for one perpetually constructed self, whereby change is not necessarily loss of self.

We do have a choice, at least in the early stages, to how we react personally to A.D. I am presently reacting to it by endeavouring to stay as active as possible, to resist its progress to the best of my ability, and remain as positive as I can. [Schneider 2006: 50]

There have been many changes in my life since the onset of Alzheimer's, some for which I am not at all ungrateful. I have more compassion for people, birds, deer, and the like. I have fallen more and more in love with Stella (Rose 1996: 126).

I am learning to take strength and comfort wherever and whenever it comes to me...I choose to take things moment by moment, thankful for everything that I have, instead of raging wildly at the things that I have lost. [Davis 1989: 57]

I was never able to do much one on one with my kids, because I had so many, and because I was always so busy working; sometimes two jobs, to keep our heads above water. But now, when I look back, I realize that wasn't a good excuse. True, I didn't have a lot of spare time, but I think it was more a reflection on how I was raised. I know now that I could have made the time if I had only realized then what I know now. [Lee 2003: 69]

A new world greets me every morning now. I will never see myself or the world the same way. [Debaggio 2002: 26]

Although much attention has been focused on presumed loss of self, the capacity to construct new dimensions of self while living with Alzheimer's disease has often been overlooked (MacRae 2010: 300-301). However, as Page and Keady's 2010 study highlights, narrative accounts of everyday living with dementia can

present as a complex mix of new, revised and disconnected storylines that combine to create a person's sense of self and identity. Individuals may experience the tension of continuity and change of identity at the same time (Caddell and Clare 2011) and may use narrative strategies (Clare 2003), to (re)construct self.

Watching my spelling, especially when it goes out of control, is a way I keep tabs on Ol' Alzheimer's...", using it as a "fingerprint" of what is happening in his brain. [DeBaggio 2002: 125]

I am writing about the disease as it is expressed by and is having an impact on my mind, my perceptions, and my world – as I perceive the process...When I started to write these essays, it was not my intent to address them to caregivers. I wrote to clarify for myself what was going on with and in me. [Taylor 2007: 4]

The words in my brain are silent, and the flood of sentences begins only when my pen unleashes a flood of writing memory. [DeBaggio, 2002: 199]

In the other, slower world where I write on paper or directly on the computer, vocabulary is more fluid and I often surprise myself when the perfect word finds its way into the sentence without effort. This has puzzled me from the first sentence I wrote for this book. It is only now, eight months later, I begin to see more clearly how necessary it is to slow the pace to achieve a former normality. [DeBaggio 2002: 180]

At my own speed and in keeping with my individual body rhythms, I can still act with the skills and knowledge I have acquired over the years. This book is an example of this. It was dictated at all hours of the day and night, whenever I had a clear enough mind to string thoughts together. [Davis 1989: 86]

Self-preservation

Through autobiography, the author may preserve self.

When I die nothing will be left except someone else's memory of me. Only these words of mine will remain to shred my life into moments I now quickly forget. [DeBaggio, 2003:19]

I will resist this beast as long as I have the ability to do so. This is "my way," as long as possible, I will continue to do it "my way." I am exercising my right and

commitment to do things my way in writing this book. I could seek advice assistance from professionals to aid me in writing this book. But, if I did, they would probably ask me to change many things in it. Take the book cover for example. I use the word AINT, and the drawing is by my 12 yr (sic) old granddaughter, Jessica. It's probably not what a large publisher or editor would accept. But it's my way; it's me. It's from my heart, and I feel it's the most honest way of expressing myself. So I will do it my way. [Schneider 2006: 84-85]

Self-expression

Through autobiography, the author may express himself.

You are writing the poetry of Alzheimer's disease, only most of the time it does not rhyme. The definition of poetry is communication that evokes feeling, usually in reverse form. For some reason, labeling a piece of writing as poetry often turns off most potential readers. I label the writing as poetry because the writing creates an emotional climate in which the description of even the most mundane of tasks becomes the communication of feelings. [Taylor 2006: 187]

While I am still able to communicate, I want to share this incredible journey into Alzheimer's disease. [Davis 1989: 20]

Self-reflection

Through autobiography, the author may be self-reflexive.

This is an unfinished story of a man dying in slow motion. It is filled with graffiti, sorrow, frustration, and short bursts of anger. While the narrator suffers his internal spears, he tries to surround himself with memories in a wan attempt to make sense of his life and give meaning to its shallow substance before he expires. Although incomplete, the story is full of sadness and missed opportunities, a lonely tale of the human condition. Behind it is hope, the tortured luck of a last chance. [Debaggio 2002: 6]

I am working today, tapping at this keyboard with little time left, in an attempt to understand who I was and what is left. [Debaggio 2002: 204]

I wrote to clarify for myself what was going on with me and in me. [Taylor 2007: 4]

I am not sure that I know why. It could be because I have already been face to fact with death so many times...Perhaps this has pre-conditioned me for a

trauma like being diagnosed with Alzheimer's. Maybe it's just that my diagnosis came early and I have not deteriorated enough to experience the depression and fear that it so often brings, or maybe I am still in shock...Or could it be because of the experience in my early 30's?...Here is another possible explanation...Could it be that I have so many physical ailments...that I am somewhat wore down and closer to accepting death. Or maybe it's because I simply have put my trust in God. [Schneider 2003: 34-35]

Self-creation

Through autobiography, the author may create himself.

Words not only describe my world, they create my world. [Taylor 2007: 158]

Obituaries of the Living

Since I started writing, I am more confident and comfortable with who I believe I am. I am marginally less afraid of the future. I have, I think, a better understanding of why and how I am changing; unfortunately, most of my insights come after the fact. I am mourning who I was, and I am sometimes uncomfortable with who I am. The rest, I will just have to experience and hope I maintain some ability to understand myself from the inside out, as well as from the outside in, at least until I become engulfed by Alzheimer's rather than my current state in which Alzheimer's is becoming me. [Taylor 2009: 220]

The inspiration for this book appeared a few days after I was diagnosed with Alzheimer's. It was to be a word picture of the outside and inside, present and past, of a man's naked struggle with the unknown on his way to trembling silence and unexplainable torment without the torturer. It was a story of unleashed anger and beauty brought forth by an unseen illness, incurable and relatively long-term in duration. [Debaggio 2002: 7]

Writing about it may be a way to legitimize by almost continuous contemplation of the subject, and I hope it will allow me to leave my thoughts of the disease locked up in the computer while I conduct everyday affairs. [Debaggio 2002: 7]

The only time I feel alive now is when I am writing, under the spell of work and memories. [Debaggio 2002: 121]

Through the construction of autobiographies, the authors (re)constructed themselves, choosing to find opportunity in the “social space of indeterminacy and ambiguity” created by illness (Hunt 2000: 91). The autobiography is a way for the authors to preserve part of themselves; the autobiography becomes a sort of self-written obituary. For many individuals facing disruption and a chronic illness, the need to leave a “legacy” behind may be especially strong. Basting (2003) found that people with Alzheimer’s actively engaged in storytelling. This can serve to reaffirm the existing personality, which may have been lost in feelings of lowered self-worth. The autobiography is “permanent”, thus it not only enables the author to engage in storytelling but it also allows for this storytelling, or the author’s memory to live on after death (Ryan et al. 2009).

The writing of the autobiography is a way for the authors to preserve self. In writing about their memories, the authors attempt to “preserve” self.

Somebody would say something and it would bring back a memory, and I'd have to get it down. If I had to hunt for a piece of paper or a pen, I would lose it. My friend Sharon even bought me a beautiful silver book of paper that hung around my neck with a pen inside. [Lee 2003: 50]

I am writing in a panic, racing against an insidious disease that gobbles memory and ends up destroying life. [Debaggio 2002: 25]

Debaggio, for example, attributes his loss of self to a loss of memory; therefore in writing down his memories, the autobiography becomes a way for Debaggio to preserve his memories and thus his selfhood. The autobiographies suggest that it is frequently the very act of narration, of writing it down, that offers an opportunity to preserve self, thus we see that, with Alzheimer’s, the self is not lost entirely.

In addition, focusing on intact abilities, such as the ability to create an autobiography, may be a means to preserve a positive sense of self while living with Alzheimer's (MacRae 2010: 299). Ryan and colleagues (2009) found that:

Writing enables an individual with dementia to explore and express a renewed social identity that is built upon positive traits, roles and personal controls. This helps individuals to move beyond 'suffering' to truly 'surviving'. [145]

Creative storytelling supplies a social role, one with value, that allows for the integration of past and present, and that acknowledges the strengths and potential of the present lives of people with Alzheimer's disease. According to Sabat (2001), individuals with dementia are not given many opportunities to direct activities. Writing helps an individual with Alzheimer's negotiate new functions. The next step in the process of social identity development is the simultaneous projection of these functions, and their acceptance by others (Ryan et al. 2009: 151).

Individuals with illness or disability have a unique need to find expression in narrative; they may feel that their sense of self has been taken from them by the expectations of others and by their medical diagnosis (Frank 1995). The "essence of the individuals' personalities and the idiosyncrasies of their lives come through in the words they choose and the stories they write," making the autobiography an important medium for sharing their expressions (Ryan et al. 2009: 153). As Charon (2006) highlights, "The gesture of telling ourselves is a plea for affirmation while it puts into action an honest, sometimes brutal, but always creative, knowledge of one's self" (70).

Individuals with illness may feel a need to find expression through narrative as they may feel that their voice has been taken from them by the stigmatization of others and by their diagnosis (Frank 1995). Writing can be a means to reclaim their voice (Ryan et al. 2009: 150). The books are evidence themselves that the social identity of the authors with Alzheimer's is not only intact, but strong (Basting 2003: 97). The autobiography provides the authors an avenue for self-expression that frees them from the demands of memory and rational language (Basting 2006: 193). Writing can be done at any time and in any time frame. It hides one's illness, and enables thoughts to become fully expressed without interruption and the fear of immediate rejection (Ryan et al. 2009: 155). Most of the authors' autobiographies are "cleansed" of any evidence of the disease in the form of the writing itself. Thus, their symptoms are described and not enacted (Basting 2003: 92). As such, the autobiography enables authors to (re)engage in positive interaction with others, which facilitates (re)construction of self, previously threatened by others.

Through the construction of the autobiography, the authors demonstrate that they are self-reflexive. The reflection on complex thoughts and ideas with the help of the written word often created new insights for the authors. Narrative enables an individual to find new meaning and allows an individual to see themselves in a greater context (Ryan et al 2009). As Ryan et al. (2009) suggest:

Writing provides an opportunity to engage in meaning-making dialogue with others, an activity which facilitates the integration of diagnosis and altered abilities into a new sense of self. By deconstructing the self and building it back up through the process of writing, an individual is able to achieve new clarity. [150]

This self-reflexivity can lead to lessons learned or new ways to think of themselves. For example, in writing about their lives, the authors were able to place their diagnosis within a greater context (Birren & Hedlund 1987). When seen as another event in a person's life, the negative meaning of a diagnosis may be diminished and can be seen positively as an event that enabled an individual to impart wisdom to others and to experience life from a new perspective (Ryan et al. 2009: 150).

Moreover, Basting (2003; 2006) draws attention to the creative potential of individuals with dementia. The Alzheimer's autobiographies demonstrate ample use of metaphor by some of the authors (Ryan et al. 2009: 151).

Instead, right now, I feel as if I am sitting in my grandmother's living room, looking at the world through her lace curtains. From time to time, a gentle wind blows the curtains and changes the patterns through which I see the world. There are large knots in the curtains and I cannot see through them. There is a web of lace connecting the knots to each other, around which I can sometimes see. However, this entire filter keeps shifting unpredictably in the wind. [Taylor 2007: 16]

Complex ideas can be confronted through the use of metaphor. The use of metaphors helps to make meanings more clear (Ryan et al. 2009: 150). The metaphor is used to create the image for the reader; but in deconstructing the image into words, the writer benefits from greater clarity and understanding of their illness experiences.

Keady and Page (2010) highlight that when faced with the deconstruction of the self, people with dementia attempted to construct something new through their narration. In particular, the authors created new identities for themselves such as

“advocate’, ‘survivor’ or ‘a voice for others’. There are echoes here of the work of Ricoeur (1986: 132), who argued that the self only comes into being through the process of “telling of the life story” (Page and Keady 2010). Through writing, the authors regain agency and take on new roles: as writer, as advocate, as expert.

Then, I showed them to a few other people who shared by diagnosis of early-onset, early-stage Alzheimer's disease. I saw their eyes brighten and sometimes fill with tears as they read of some of their own experiences in my writings. It was then that I decided to share my writings with others. I wanted others to know they are not alone with an Alzheimer's changing mind. [Taylor 2007: 5]

I want to write the truest sentences I can in the hope my words give others the sense of struggle and joy I feel. [Debaggio 2002: 29]

I began the book to expose my inner self in words from the deepest cavities of my being to help people understand the large picture of Alzheimer's as well as the very personal one. I decided the book was more important. It has a potentially larger impact on public awareness. I felt more comfortable with words than with doctors and scientists. [Debaggio 2002: 31]

Some of the authors constructed a new dimension of self as “one who does for others” (MacRae 2010). In her study, MacRae (2010) found that a desire to help others was one reason individuals had agreed to participate in the study. Thus, some individuals (re)position themselves in new roles, with new responsibilities, such as advocacy. For the authors, it may be through the writing the autobiography and in these new roles, that the authors are able to (re)establish themselves as contributing members of society, thus (re)affirming their social value.

The author makes choices about what to include, exclude, how to arrange events, and what degree of emphasis to give different kinds of events. It is important to consider what details the authors do discuss and what they overlook as

these choices reveal a great deal about the author and can affect the self who tells the story. Why does Davis omit talking about his children? Why does Rose omit the past? The reader's impression of the author's self is created by the text. How do these stories create the self of the author? The authors each have a different "starting point" of their autobiography – for Davis it was the past, Rose began with a defining moment in the form of a symptom, while for Taylor it was the diagnosis of "dementia probably of the Alzheimer's type".

The past, for example, was a theme that was present in most of the autobiographies, though the level of its integration in the autobiography differed by author. For some of the authors, like Davis and Debaggio, the past was a key part of their individual autobiographies.

I grew into a skinny kid and became the butt of jokes, tortured by children in the neighborhood who focused on my hairy arms and legs, and thin body. Older boys wrapped their hands around my wrists and bellowed about how tiny they were. They made fun of the splotchy red birthmark on my left wrist....Those early days of childish torture set me on a path of introspection. [Debaggio 2002: 59]

This introspection turned Debaggio to radio and television, which changed his "imaginative life" (2002: 83).

Like Debaggio, Schneider writes about past experiences and events. He begins his autobiography with his father's illness and impending death and throughout writes about different important events in his life – or defining moments. For example, Schneider writes about his adoption experiences with Social Services. After deciding to adopt, Schneider and his wife took physical custody of a young girl. Shortly before the adoption procedure was finalized, Social

Services took legal custody of Schneider's beloved little girl due to a formality (it was against policy to allow pending adoptee parents to have custody of a child during the adoption process). As a result, the adoption was never completed (Schneider 2006: 19-20). From this experience, among others, Schneider believes that life crumbles easily, thus we see that Schneider uses the past to illustrate his beliefs and ideologies.

For Page and Keady (2010), the person with dementia's narrative identity is primarily located in the "here and now" with the past subject to re-editing and revision at any time in the process of its telling. As a result, narrative accounts of everyday living with dementia can present as a complex mix of new, revised and disconnected storylines that combine to create a person's sense of self and identity. The autobiographies helped the authors to not only organize their histories but to also interpret these and intertwine their histories with fictions.

The autobiographies are selective and recast the past in terms of present concerns and values. Most of the authors wrote about their pasts, though to varying degrees and at different times throughout their autobiography. While Schneider writes about his past in the early pages of his autobiography, Rose writes very little about this past throughout, while Debaggio's entire autobiography fluctuates between past and present. The authors write about the past for a number of reasons. The new experience with Alzheimer's often leads them to be reflective of the past in new ways and brings new meaning to their past experiences. Past experiences may also be used by the narrator to construct self, to show sameness or

to show their changing self, over time, or in response to the experience with Alzheimer's. Debaggio uses the past to illustrate the fragmentation in his mind, while Schneider uses it to illustrate who he was and who he is. Much can be learned from their writings of the past. In his descriptions of the past, Debaggio reveals characteristics in himself. Debaggio uses these examples, such as the example of his parents' histories, to construct himself. In the case of his parents' challenging background, Debaggio (2002) writes that their responses to the "explosive reality of their time" created a great optimism in him (2). The author can be seen as an extension of the writing process, the process of using text to define who he is and to reclaim himself.

For the authors, narrating their life introduced a sense of connectedness and temporal unity to their life, that may have been disrupted by the onset of Alzheimer's. From the autobiographies, we see the way that the authors construct self to make sense of their experiences and to preserve a sense of continuity (McLean 2006: 174).

If nothing else, those notes reflected just how chaotic my life and thinking during most of those times. [Lee 2003: 51]

Writing is an active response to illness that brings coherence to the disruption of illness. The autobiography enables the integration of multiple events into a coherent account (Ryan et al. 2009: 150). According to Kleinman (1988):

The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering. The plot lines, core metaphors, and rhetorical devices that structure the illness narrative are drawn from cultural and personal models for arranging

experiences in meaningful ways, and for effectively communicating those meanings. [49]

The authors present Alzheimer's as being highly disruptive and destabilizing. They write about these disruptions and overcome them through the construction of the autobiography itself:

'Where was the moment of clarity' you may still be asking yourself. It came after I wrote this! [Taylor 2007: 206]

Essentially, through writing the life story, the autobiographies brought coherence for the authors. Through coherence, individuals can (re)construct self, even if that self, or narrative, is fictitious (McLean 2006: 171). According to disruption or a new experience that does not fit into existing narrative (171). Coherence depends on a unity of feeling and forms from its own constant emotional truth (McLean 2006: 171). Writing the autobiography is an attempt by the authors to rework – to give coherence to - their everyday experiences with Alzheimer's.

Ultimately, what we see from emerge is the dynamic nature of self. The authors were able to construct a narrative that provided an anchor from which they could affirm their self despite real or perceived threats to it (McLean 2006: 172). Thus, the autobiographical accounts of the experience of Alzheimer's disease call for the understanding of selfhood, not as static or objective, but as dynamic and subjective. Through the autobiographies the interweaving and mutability within the cohesion of one's lifetime resonated, was not lost but changed, thereby exposing the dynamic identity of the authors. It is through the narrativization of illness experience that individuals give coherence to disruption and (re)construct the

changing self. The findings of this study show that it is possible to (re)construct self despite EOAD.

CHAPTER 6: CONCLUSIONS

I am still human...I have seen people afflicted with one kind of dementia or another. When I relate to them, I do not do so with the assumption that they are silly, old, helpless people. I see the person they once were....There is still a part of that vital person living inside that sometime helpless-looking body, a person who deserves to be treated with dignity....A person in whatever state of dementia deserves to be treated with all dignity and respect

- Robert Davis 1986 : 100.

CONCLUDING THOUGHTS

As I conclude this project, I reflect on this study that began out of a curiosity to know more. This curious desire evolved into a commitment that was ultimately cemented by the passing of a special woman whom I admired very much. I think back to Lyn and Great Uncle Donald and reflect on their illnesses with new insight. I also reflect on this study and feel that this may just be the beginning in what I hope will be a long career in Alzheimer's research. In this chapter, I reflect on what I have accomplished in this project and the implications of this work, for the field of medical anthropology and the study of Alzheimer's disease more broadly. I discuss some of the limitations of this project and tell of where I hope to go from here.

This thesis was designed to gain insight into how Early-onset Alzheimer's disease influences selfhood from first-person accounts illness. In this thesis, I argued that the self of individuals with Alzheimer's disease is not lost entirely, instead the self is changed. I also argued that Alzheimer's disease may change sense of self, but through narrative, some individuals with Alzheimer's (re)construct self. I drew upon the philosophical theory of narrated self to show that individuals with Alzheimer's disease may lose sense of self, but, at the same time, they may also (re)construct self as revealed through an interpretive analysis of autobiographical accounts of Alzheimer's.

To understand how Alzheimer's disease influences self, I first presented a discussion of the philosophical conceptions of self that continue to dominate present-day discourse. To be precise, I discussed three distinct approaches to self: the *autonomous self*, the *experiential self*, and the *narrated self*. I then deconstructed

the biomedical approach to Alzheimer's disease, to provide the appropriate background for beginning to examine the question of Alzheimer's disease and self. Following this, I then examined how the biomedical treatment of Alzheimer's influences self.

I then reviewed anthropological studies of selfhood and Alzheimer's disease, in order to situate myself within this growing body of literature. Existing anthropological studies on self and Alzheimer's draw attention to the complexity of how individuals with dementia experience selfhood. However, while these studies have enhanced a rather "thin" body literature, what is largely absent from the literature are hermeneutical approaches to self, which I suggested are useful to the study of self among authors of Alzheimer's autobiographies. Thus, in applying a hermeneutical approach to the study of Alzheimer's, I attempted to overcome the "serious limitations" to viewing selfhood as dependent on cognition (Medved and Brockmeier 2008: 470). In addition, the narrated self is important to understanding self among individuals with Alzheimer's, as it allows for one perpetually constructed self, whereby change is not necessarily loss of self. In addition, with no anthropological studies analyzing EOAD narratives, this study attempted to fill this gap through a non-traditional anthropological approach to the study of selfhood and Early-onset Alzheimer's self-narratives.

After reviewing anthropological Alzheimer's literature, I then discussed my methodological approach to the study of Alzheimer's and self. I began by describing my initial ideas for my Master's research and the beginning stages of the project. I

then detailed a “defining moment” for me, when my field site refused me access at the eleventh hour. This led me to pursue a new direction: the use of written autobiographies as anthropological data. I discussed this new direction and my “recruitment” strategy. I then presented a background of each author, followed by a description of my interpretive approach to data analysis.

Following this, I presented the findings of my study; more specifically, I highlighted how the autobiographies exemplify how Alzheimer's disease influences self. Through an interpretive analysis of autobiographical accounts of Alzheimer's disease, I attempted to demonstrate the dynamic nature of self. I showed how individuals with Alzheimer's lose sense of self due to a loss of functioning and interactions with others. However, as I have also demonstrated, despite a loss of sense of self, the authors (re)construct self through autobiography. This study has highlighted that individuals ill with Alzheimer's use narratives as sites for self-construction. In doing so, I have attempted to draw attention to the narrative capacity of individuals with Alzheimer's and the dynamic nature of self.

As Laing (1964) highlighted, “the mad things done and said by the schizophrenic will remain essentially a closed book if one does not understand their existential context” (Roberts 2000: 436). The same could be said of the individual with Alzheimer's – the “mad things done and said” by the individual with Alzheimer's will remain a “closed book” if we do not understand their self. If we “open” these books – quite literally in this case – we begin to understand that, with Alzheimer's, the self is not altogether lost.

IMPLICATIONS OF THIS STUDY

As Kontos (2004) highlights, much of the existing Alzheimer's literature suggests the view that individuals with reduced cognitive functioning become a non-person (105). Whitehouse and George (2008), argue that we must overcome this view and suggest that there is no *total* loss of self. As Kitwood (1997) revealed, cognitive dysfunction does not necessarily mean a total loss of self. Recent anthropological studies also demonstrate that the self is not lost entirely. Cohen (1995) suggests social process contribute to a loss of self. Kontos (2004; 2006) demonstrates that individuals with Alzheimer's engage in meaningful social relations through bodily habits, thereby challenging the belief in loss of self. Chatterji also demonstrates that it is possible to access the subjectivity of an individual with Alzheimer's, contributing a relational perspective on self, by describing the influence of intersubjective processes, to anthropological literature. Basting (2003; 2006) reveals that selfhood is more than memory as it is "forged on a continuum of memory and creativity that exists in a social context" (Ryan et al. 2009: 147). McLean (2006) argues for the importance of considering the narratives of people with dementia and their own construction of coherence. Ryan et al. (2009) argue that authors with dementia construct and project positive new identities, which are full expressions of personhood. Page and Keady (2010) highlight that the importance of reconstructing identity appeared is central to living with the onset and progression of dementia together with maintaining key social relationships and networks (Page and Keady 2010: 511). What emerges from the existing literature is an understanding of the self as not lost but changed. This

study, adds to this body of literature, further supporting the finding that what actually happens with Alzheimer's disease is not a loss of self, but a change in self. Autobiographies bring a new perspective to understanding how Alzheimer's and self. Thus, an important practical implication of this study is highlighting how the autobiography enables persons living with Alzheimer's disease to (re)construct self.

In this study, I have attempted to highlight the importance of Alzheimer's disease narratives. Autobiographies of Alzheimer's tell us about the personal experience of living with reduced cognitive functioning. As Ryan et al. (2009) highlight, "These personal narratives are told with a distinct confidence that challenges popularly held beliefs about lack of insight" (147). For Charon (2006):

The triad of narrativity, relation, and the body seems particularly salient to the clinician's task, the clinician who may indeed be responsive to the body and, perhaps, to the relations within a patient's life but may not yet be equipped to be dutiful toward the narrativity of both their patients' telling of and living of their lives. [77]

Through these autobiographies we see that people with Alzheimer's continue to perceive and feel and continue to create a life-world and that with this continuing engagement in the creation of their world, they cannot become the "living dead" (Millett 2011: 520). Autobiographies allow others, including practitioners, family, friends, even strangers, to gain an inside perspective into Alzheimer's. They do not need to have experienced Alzheimer's, they need only to see the world from the vantage point of the individual ill with Alzheimer's and to experience, vicariously, illness from that position (Charon 2006: 112). According to Rita Charon (2006), a pioneer of *narrative medicine*:

The powerful narratives of illness that have recently been published by patients reveal how illness comes to one's body, one's loved one, and one's self. These narratives...demonstrate how critical is the telling of pain and suffering, enabling patients to give voice to what they endure and to frame the illness so as to escape dominion by it. [Charon 2006: 65-66]

Thus, autobiographies can help others become more attuned to an individual's dynamic self (Charon 2006).

THE LIMITATIONS OF THIS STUDY

This project had a number of limitations. Time was perhaps the greatest limit. As a Masters student I had only a short time to complete my degree as there was the expectation that I would begin my Ph.D. in the fall. Time constraints largely shaped the direction of this project. If time constraints had not been so rigid, I would have liked to carry out my initial project as I am interested to know what would have emerged from fieldwork. I would have expanded my original study to include not only interviews and observation, but also incorporated written autobiographical accounts. I believe this could have provided me with a greater insight into Alzheimer's disease and self.

I often felt that my positioning as a young researcher was limiting. When contacting various organizations in the hopes of conducting fieldwork, I was frequently passed from person-to-person and it was not unusual for my inquiries to go unanswered or dismissed. Reflecting on this now, and after conversations with several mentors and professors, I feel that, as a Master's student, I did not yet have the credibility or authority to conduct research with individuals often deemed "vulnerable". This is a hurdle I am still working on overcoming for future research

projects. I have spent the last year building different connections and relationships with individuals and organizations and gaining research experience with vulnerable populations, in the hopes that this will help me to tackle this challenge for future projects.

In regards to my “participants”, I have never been able to completely accept that I will never meet several of the authors. I would very much have enjoyed meeting the individuals I now feel so connected to. After having read the autobiographies over and over and over again, carrying them around with me day after day, I feel a deep personal connection with each author. After spending many inseparable months together, they feel like (very) good friends. Upon realizing I misplaced Debaggio and Rose one time, I went into complete “panic mode”, feeling like I had lost a part of me. Frantic searching ensued and did not stop until I was reunited with my dear friends. I would very much like to meet the authors who are still alive and to thank them for sharing their stories with me. Unfortunately, as Alzheimer's is a degenerative disease, several of the authors have passed away since the time of writing. Upon completing this thesis, I plan on reaching out to those who are still alive.

WHERE WILL I GO FROM HERE?

I spent the last fifteen months completing a graduate degree in anthropology, while working in public health. I have come to appreciate both fields of inquiry and to see the potential value of an anthropology of public health. This is ultimately the direction that I would like to take for my career. I have a keen interest in

Alzheimer's disease and hope to conduct future studies on the illness, using the knowledge and insights gained in this Master's thesis as a foundation. I am especially interested in Alzheimer's disease among inmate populations and have proposed to follow this line of inquiry for my doctoral research.

In my doctoral study, I propose to explore Alzheimer's disease among inmates currently housed in prison. I am particularly interested in this phenomenon for a number of reasons. First, it has been largely understudied by academia. Secondly, inmates are more prone to Alzheimer's disease as the prison environment exacerbates risk factors (e.g. poor diet, substance use, violence, stress), which can lower resistance (Rothschild and Sharp 1941: 53). In a process known as "fast aging", inmates' psychological age is ten to eleven and a half years older than their actual age. Age-related changes and conditions specific to confinement likely influence the mental health of aging inmates (Caverly 2006: 264). Despite this, Alzheimer's among inmates remains an under-studied yet rapidly growing phenomenon. The purpose of my proposed study is to fill that gap through exploratory research. I am influenced by questions of how an inmate with Alzheimer's disease experiences identity; how inmates with Alzheimer's embody and construct selfhood; and, how does the prison environment affect inmate selfhood?

This future study is both relevant and timely, given that the number of inmates with Alzheimer's is on the rise. An aging population in combination with stricter laws and longer prison sentences means the number of inmates with the

disease is likely to rise significantly in upcoming years. Through this proposed study, I specifically hope to contribute to ongoing debates in criminology, medical anthropology, public health, and the social sciences and health sciences more broadly, by providing important insight into the complex and unique ways in which inmates diagnosed with Alzheimer's experience and construct the disruption of self. More broadly, I hope to contribute a more holistic perspective to illness and disease and to advocate for the importance of the anthropology of public health and socio-basic science in health research.

REFERENCES

Alzheimer's Association

- 2012 2012 Alzheimer's Disease Facts and Figures. Alzheimer's and Dementia 8(2).
2013a 2013 Alzheimer's Disease Facts and Figures.
http://www.alz.org/alzheimers_disease_facts_and_figures.asp, accessed June 2013.
2013b Younger/Early Onset Alzheimer's and Dementia.
http://www.alz.org/alzheimers_disease_early_onset.asp, accessed August 2013.

Alzheimer Society of Canada

- 2002 I Have Alzheimer's.
<http://www2f.biglobe.ne.jp/~boke/AScanadapwd.pdf>, accessed September 2013.
2010 Rising Tide: The Impact of Dementia on Canadian Society. Alzheimer Society.
2012a About the Brain <http://www.alzheimer.ca/en/About-dementia/About-the-brain>, accessed April 2013.
2012b Alzheimer's Disease and Other Dementias – In Pursuit of a Cure.
http://www.alzheimer.ca/~media/Files/national/AW2012-everything/AW12_Fact%20sheets_EN_FINAL.ashx, accessed June 2013.
2013 Dementia. <http://www.alzheimer.ca/en/About-dementia/Dementias>, accessed June 2013.

Alzheimer Society of Toronto.

- n.d. Early-Onset Alzheimer's Disease.
http://www.alzheimertoronto.org/ad_earlyOnset.htm, accessed August 2013.
2011 Statistics http://www.alzheimertoronto.org/ad_Statistics.htm, accessed June 2012.

American Health Assistance Foundation

- 2012 The Facts on Alzheimer's Disease.
<http://www.ahaf.org/alzheimers/about/>, accessed May 2012.

American Psychiatric Association

- 2013 Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5).
Arlington, VA: American Psychiatric Association.

Apesoa-Varano, E. C, J. C. Barker, and L. Hinton

- 2011 Curing and Caring: The Work of Primary Care Physicians With Dementia Patients. *Qualitative Health Research* 21(11): 1469-1483.

Ballenger, Jesse

- 2006 The Biomedical Deconstruction of Senility and the Persistent Stigmatization of Old Age in the United States. *In Thinking about Dementia: Culture, Loss, and the Anthropology of Senility*. Annette Leibing and Lawrence Cohen, eds. Pp. 106-122. New Brunswick: Rutgers University Press.

Basting, Anne Davis

2003 Looking Back From Loss: Views of the Self in Alzheimer's Disease. *Journal of Aging Studies* 17: 87-99.

2006 Creative Storytelling and Self-Expression Among People With Dementia. *In Thinking about Dementia: Culture, Loss, and the Anthropology of Senility*. Annette Leibing and Lawrence Cohen, eds. Pp.180-194. New Brunswick: Rutgers University Press.

Beard, Renée L.

2004 In Their Voices: Identity Preservation and Experiences of Alzheimer's Disease. *Journal of Aging Studies* 18: 415-428.

Beard, Renée L., Jenny Knauss, and Don Moyer

2009 Managing Disability and Enjoying Life: How We Reframe Dementia Through Personal Narratives. *Journal of Aging Studies* 23: 227-235.

Becker, Gaylene

1997 *Disrupted Lives: How People Create Meaning in a Chaotic World*. Berkeley, CA: University of California Press.

Bernard, H. Russell

2000 *Social Research Methods: Qualitative and Quantitative Approaches*. Thousand Oaks, CA: Sage.

Bird-David, Nurit and Tal Israeli

2010 A Moment Dead, a Moment Alive: How a Situational Personhood Emerges in the Vegetative State in an Israeli Hospital Unit. *American Anthropologist* 112(1): 54-65.

Birren, James E. and Bonnie Hedlund

1987 Contribution of Autobiography to Developmental Psychology. *In Contemporary Topics in Developmental Psychology*, N. Eisenberg, ed. Pp. 394-415. New York: John Wiley and Sons.

Blazer, Dan

2013 *Commentary of Neurocognitive Disorders in DSM-5*. *American Journal of Psychiatry* 170(6): 585-587.

Bogdan, Robert and Steven J. Taylor

1989 Relationships with Severely Disabled People: The Social Construction of Human-ness. *Social Problems* 36(2): 135-148.

Bruner, Jerome

1986 *Actual Minds, Possible worlds*. Cambridge: Harvard University Press.

1989 Life as Narrative. *Social Research* 54(1): 11-32.

1990 *Acts of Meaning*. Cambridge: Harvard University Press.

1991 The Narrative Construction of Reality. *Critical Inquiry* 18(1): 1-22.

1995 The Autobiographical Process. *Current Sociology* 43(2): 161-177.

2001 Self-making and World-making. *In Narrative and Identity: Studies in Autobiography, Self and Culture*. Brockmeier & D. Carbaugh, eds. Pp 25-37. Philadelphia: John Benjamins.

Bryden, Christine

1998 *Who Will I be When I Die*. East Melbourne, Australia: Harper Collins.

2005 *Dancing with Dementia: My Story of Living Positively With Dementia*. London: Jessica Kingsley Publishers.

- Burkitt, Ian
1991 *Social Selves Theories of Self and Society* First Edition. Sage Publications.
- Caddell, L. S. and L. Clare
2011 "I'm Still the same Person": The Impact of Early-stage Dementia on Identity. *Dementia* 10(3): 379-398.
- Caverly, S. J.
2006 Older Mentally Ill Inmates: A Descriptive Study. *Journal of Correctional Health Care* 12(4): 262-268.
- Charon Rita
2006 *Narrative Medicine: Honoring the Stories of Illness*. New York: Oxford University Press.
- Chatterji, Roma
1998 An Ethnography of Dementia: A Case Study of an Alzheimer's Disease Patient in the Netherlands. *Culture, Medicine, and Psychiatry* 22: 355-382.
2006 Normality and Difference: Institutional Classification and the Constitution of Subjectivity in a Dutch Nursing Home. *In Thinking About Dementia: Culture, Loss, and the Anthropology of Senility*. Annette Leibing and Lawrence Cohen, eds. Pp. 218-239. New Brunswick: Rutgers University Press.
- Chaufan, Claudia, Brooke Hollister, Jennifer Nazareno, and Patrick Fox
2012 Medical Ideology as a Double-edged Sword: The Politics of Cure and Care in the Making of Alzheimer's Disease. *Social Science and Medicine* 74: 788-795.
- Cherot, Natalie
2009 Storytelling and Ethnographic Intersections: Vietnamese Adoptees and Rescue Narratives. *Qualitative Inquiry* 15(1): 113-148.
- Clare, L.
2003 Managing Threats to Self: Awareness in Early-stage Alzheimer's Disease. *Social Science and Medicine* 57: 1017-1029.
- Clarke, Adele E., Janet K. Shim, Laura Mamo, Jennifer Ruth Fosket, and Jennifer R. Fishman
2003 Technoscientific Transformations of Health, Illness, and U.S. Biomedicine. *American Sociological Review* 68(2): 161-94. Cohen, Donna and Carl Eisdorfer
1986 *The Loss of Self: A Family Resource for the Care of Alzheimer's Disease and Related Disorders*. London: W. W. Norton.
- Cohen, Lawrence
1995 Toward an Anthropology of Senility: Anger, Weakness, and Alzheimer's in Banaras, India. *Medical Anthropology Quarterly* 9 (3): 314-334.
1998 *No Aging in India: Alzheimer's, the Bad Family, and other Modern Things*. Berkeley: University of California Press.
2006 Introduction. *In Thinking About Dementia: Culture, Loss, and the Anthropology of Senility*. Annette Leibing and Lawrence Cohen, eds. Pp. 1-

19. New Brunswick: Rutgers University Press.
- Dalziel, William
1994 Dementia: No Longer the Silent Epidemic. *Canadian Medical Association Journal* 151(10): 1407-1409.
- Davis, Daniel
2004 Dementia: Sociological and Philosophical Constructions. *Social Science and Medicine* 58: 369-378.
- Davis, Robert
1989 *My Journey into Alzheimer's Disease*. Wheaton, IL: Tyndale House.
- DeBaggio, Thomas
2002 *Losing my Mind: An Intimate Look at Life with Alzheimer's*. New York: The Free Press.
2003 *When It Gets Dark: An Enlightened Reflection on Life With Alzheimer's*. New York: Free Press.
- Descartes, Rene
1998 *Meditations on First Philosophy*. In *Modern Philosophy: An Anthology of Primary Sources*, Roger Ariew and Eric Watkins, eds. Indianapolis: Hackett Publishing Company.
- Diamond, Jack
2011 *A Report on Alzheimer's Disease and Current Research*. Alzheimer's Society of Canada.
- Dunne, Joseph
1995 Beyond Sovereignty and Deconstruction: The Storied Self. *Philosophy and Social Criticism* 21:137-157.
- Einstein, Gillian and Margrit Shildrick
2009 The Postconventional Body: Retheorising Women's Health. *Social Science and Medicine* 69: 293-300.
- Engel, G.
1977 The Need For a New Medical Model: A Challenge for Biomedicine. *Science* 196: 129-136.
- Ezzy, Douglas
1998 Theorizing Narrative Identity: Symbolic Interactionism and Hermeneutics. *The Sociological Quarterly* 39(2): 239-252.
2000 Fate and Agency in Job Loss Narratives. *Qualitative Sociology* 23(1): 121-134.
- Feinberg, T. E. and W. Yu
2005 *What To Do When The Doctor Says It's Early-Stage Alzheimer's*. Gloucester: Fair Winds Press.
- Fontana, A. and R. W. Smith
1989 Alzheimer's Disease Victims: The 'Unbecoming' of Self and The Normalization of Competence. *Sociological Perspectives* 32(1): 35-46.
- Fox, Patrick
1989 From Senility to Alzheimer's Disease: The Rise of the Alzheimer's Disease Movement. *The Milbank Quarterly* 67(1), 58-102.
- Frank, A.

- 1995 *The Wounded Storyteller*. Chicago, IL: University of Chicago Press.
- Garro, L. C. and Mattingly, C.
1994 Narrative Representations of Illness and Healing. *Social Science and Medicine* 38 (6).
- Goffman, Erving
1963 *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice Hall.
- Good, Byron
1994 *Medicine, Rationality, and Experience: An Anthropological Perspective*. Cambridge: Cambridge University Press.
- Gubrium, Jabrium F. and J.B. Wallace
1990 Who Theorises Age? *Ageing and Society* 10: 131-149.
- Guignon, C. B.
2006 History and Historicity. In *A Companion to Phenomenology and Existentialism*. H. L. Dreyfus and M. Wrathall (eds.), Oxford: Blackwell Publishing.
- Harman, Guy and Linda Clare, Linda
2006 Illness Representations and Lived Experience in Early-Stage Dementia. *Qualitative Health Research* 16(4): 484-502.
- Harter, Lynn M., Phyllis M. Japp and Christina S. Beck
2005 Vital Problematics of Narrative Theorizing About Health and Healing. *In Narratives, Health and Healing: Communication Theory, Research, and Practice* L. M. Harter, P. M. Japp, & C. S. Beck, eds. Pp. 7-27. Mahwah, New Jersey: Lawrence Erlbaum Associates.
- Harvey, T. S.
2008 Where There is no Patient: An Anthropological Treatment of a Biomedical Category. *Culture, Medicine and Psychiatry* 32: 577-606.
- Heidegger, Martin.
1962 *Being and Time*. Translated by John Macquarrie and Edward Robinson. Oxford: Blackwell Publishing House: 2008.
- Henderson, Cary Smith
1998 *Partial View: An Alzheimer's Journal*. Dallas, TX: Southern Methodist University Press.
- Herskovits, Elizabeth
1995 Struggling over Subjectivity: Debates About the Self and Alzheimer's Disease. *Medical Anthropology Quarterly* 9(2), 146-163.
- Holstein, Martha
2000 Aging, Culture and the Framing of Alzheimer Disease. *In Concepts of Alzheimer Disease: Biological, Clinical and Cultural Perspectives*, P. K. Whitehouse, K. Maurer and J. F. Ballenger, eds., pp.158-180. Baltimore: John Hopkins University Press.
- Hunt, Linda M.
2000 Strategic Suffering: Illness Narratives as Social Empowerment Among Mexican Cancer Patients. *In Narrative and the Cultural Construction of Illness and Healing*, C. Mattingly & L. C. Garro, eds. Pp. 88-107. Berkeley: University of California Press.

- Husserl, Edmund
2002 "Noesis and Noema". *In* The Phenomenology Reader, Dermot Moran and Timothy Mooney, eds. London: Routledge.
- Islam, M., S. Alam, R. Ferdousy, and E. Chowdhury
2010 Analysis of Morphological Brain Change of Alzheimer Disease (AD) Patients. *Applied Physics Research* 2(2): 148-155.
- Kant, Emmanuel
1781 The Critique of Pure Reason.
- Karpiak, I. E.
2003 The Ethnographic, the Reflective, and the Uncanny: Three "Tellings" of Autobiography, *Journal of Transformative Education* 1 (2): 99-116.
- Kerby, Anthony Paul
1991 Narrative and the Self. Bloomington, IN: Indiana University Press.
- Kitwood, Tom
1989 Brain, Mind and Dementia: With Particular Reference to Alzheimer's Disease. *Ageing and Society* 9(1): 1-15.
1990 The Dialectics of Dementia: With Particular Reference to Alzheimer's Disease. *Ageing and Society*, 10: 177-196.
1997 Dementia Reconsidered: The Person Comes First. Buckingham: Open University Press.
- Kitwood, Tom and K. Bredin, K
1992 Towards a Theory of Dementia Care: Personhood and Well-being. *Ageing and Society* 12: 269-287.
- Kleinman, Arthur
1987 Anthropology and Psychiatry. The Role of Culture in Cross-cultural Research on Illness. *The British Journal of Psychiatry* 151: 447-454.
1988 The Illness Narratives: Suffering, Healing, and the Human Condition. New York: Basic Books.
- Koch, T.
1995 Interpretive Approaches in Nursing Research: The Influence of Husserl and Heidegger. *Journal of Advanced Nursing* 21: 827-836.
- Kontos, P. C.
2004 Ethnographic Reflections on Selfhood, Embodiment and Alzheimer's Disease. *Ageing and Society* 24(6): 829-849.
2005 Embodied Selfhood in Alzheimer's Disease: Rethinking Person-centred Care. *Dementia* 4(4): 553-570.
2006 Embodied Selfhood: An Ethnographic Exploration of Alzheimer's Disease. *In* Thinking About Dementia: Culture, Loss and the Anthropology of Senility. A. Leibing and L. Cohen, eds. Pp.195-217. New Jersey: Rutgers University Press.
2011 Rethinking Sociability in Long-term Care: An Embodied Dimension of Selfhood. *Dementia* 11(3): 329-346.
- Kramp, M. K.
2004 Exploring Life and Experience Through Narrative Inquiry. *In* Foundations for Research: Methods of Inquiry in Education and the Social Sciences. K. deMarrais and S. D. Lapan, eds. Pp. 103-122. Mahwah, NJ:

Lawrence Erlbaum.

Lee, Jeanne. L.

2003 *Just Love Me: My Life Turned Upside Down by Alzheimer's*. Purdue University Press, West Lafayette, Indiana.

Leibing, Annette

2006 *Divided Gazes: Alzheimer's Disease. The Person Within and Death in Life. In Thinking About Dementia: Culture, Loss and the Anthropology of Senility*, A. Leibing and L. Cohen, eds. Pp. 249-268. New Jersey: Rutgers University Press.

2008 *Entangled Matters – Alzheimer's, Interiority, and the 'Unflattening' of the World. Culture, Medicine and Psychiatry* 31: 177-193.

Leibing A, Cohen L, eds.

2006 *Thinking About Dementia: Culture, Loss and the Anthropology of Senility*. Piscataway, NJ: Rutgers University Press.

Levy, J. M.

2005 *Narrative and Experience: Telling Stories of Illness. NEXUS* 18: 8-33.

Lewis-Beck, Michael S., Bryman, Alan, and Liao, Tim F.

2004 *Autobiography. The SAGE Encyclopedia of Social Science Research Methods* 1. SAGE: 45-46.

Lowe, E. Jonathan

2006 *Can the Self Disintegrate? Personal Identity, Psychopathology, and Disunities of Consciousness. In Dementia: Mind, Meaning, and the Person*. Julian C. Hughes, Stephen J. Louw and Steven R. Rabat, eds. Oxford: Oxford University Press.

Mayo Clinic

2011 *Early-onset Alzheimer's: When Symptoms Begin Before Age 65*. <http://www.mayoclinic.com/health/alzheimers/AZ00009>, accessed July 2013.

MacIntyre, Alasdair

1981 *After Virtue*. Notre Dame: IN: University of Notre Dame Press.

Mackey, S.

2005 *Phenomenological Nursing Research: Methodological Insights Derived from Heidegger's Interpretive Phenomenology. International Journal of Nursing Studies* 42: 179-186.

MacRae, Hazel

2010 *Managing identity while living with Alzheimer's Disease. Qualitative Health Research* 20(3), 293-305.

Maretzki, Thomas

1993 *Review Article: Studying the Culture and Effectiveness of Biomedicine. Culture, Medicine and Psychiatry* 17: 133-144.

Mattingly, Cheryl and Garro, L.C, eds.

2000 *Narrative and the Cultural Construction of Illness and Healing*. Berkeley and Los Angeles: University of California Press.

McGowin, Diana Friel

1993 *Living in the Labyrinth*. New York: Delacorte Press.

McLean, Athena

2006 Coherence without Facticity in Dementia: The Case of Mrs. Fine. *In* Thinking about Dementia: Culture, Loss, and the Anthropology of Senility. Annette Leibing and Lawrence Cohen, eds. Pp. 157–179. New Brunswick: Rutgers University Press.

Medved, M. I. and J. Brockmeier

2004 Making Sense of Traumatic Experiences: Telling a Life with Fragile X Syndrome. *Qualitative Health Research* 14(6): 741–59.

2008 Continuity Amid Chaos: Neurotrauma, Loss of Memory, and Sense of Self. *Qualitative Health Research* 18(4): 469-479.

Merleau-Ponty, Maurice

1945 *Phénoménologie de la perception*. Paris: Éditions Gallimard.

1964 *Phenomenology of Perception*. C. Smith, trans. London: Routledge and Keagan Paul.

Merriam-Webster

2013 Blog. <http://www.merriam-webster.com/dictionary/blog>, accessed September 2013.

Millett, Stephan

2011 Self and Embodiment: A Bio-phenomenological Approach to Dementia. *Dementia* 10(4): 509-522.

Mills, Marie and Janet Walker

1994 Memory, Mood and Dementia: A Case Study. *Journal of Aging Studies* 8(1): 17-27.

Mobley, Tracy

2007 *Young Hope: The Broken Road*. Denver, Colorado: Denver Outskirts.

Moser, Ingunn

2011 Dementia and the Limits to Life: Anthropological Sensibilities, STS Interferences, and Possibilities for Action in Care. *Science, Technology and Human Values* 36(5): 704-722.

Orr, David

2010 The Pursuit of Certainty in Diagnosing Dementia: Cognitive Testing, Childishness and Stress in Two British Memory Clinics. *Anthropology and Medicine* 17(3): 327-338.

Page, Sean and John Keady

2010 Sharing Stories: A Meta-ethnographic Analysis of 12 Autobiographies Written by People With Dementia Between 1989 and 2007. *Aging and Society* 30: 511-526.

Phillips, James

2003 Psychopathology and the Narrative Self. *Philosophy, Psychiatry, and Psychology* 10(4): 313-328.

Phinney, A.

2002 Fluctuating Awareness and the Breakdown of the Illness Narrative in Dementia. *Dementia* 1(3): 329–344.

Pitchford, Paul

2002 *Healing With Whole Foods: Asian Traditions and Modern Nutrition*. Berkley, California: North Atlantic Books.

Plummer, Ken

2001 *Documents of Life 2: An Invitation to a Critical Humanism*. London: SAGE.

Ricoeur, Paul

1979 *The Model of the Text: Meaningful Action Considered as a Text*. In *Interpretive Social Science, A Reader*. P. Rabinow and W. M. Sullivan, eds. Pp. 73-101. Berkeley: University of California Press.

1981. *Hermeneutics and the Human Sciences: Essays on Language, Action and Interpretation*. Cambridge, UK: Cambridge University Press.

1984 *Time and Narrative I*. Chicago: University of Chicago Press.

1986 *Life: A Story in Search of a Narrator*. In *Facts and Values*. Doeser, M. and J. Kray, eds. Pp. 34–68. Martinus Nijhoff, Dordrecht, The Netherlands.

1988 *Time and Narrative, Vol. III*. Kathleen B. and David, trans. Pellauer. Chicago: University of Chicago Press.

1992 *Oneself As Another*. Chicago: University of Chicago Press.

Robertson, Ann

1991 *The Politics of Alzheimer's Disease: A Case Study in Apocalyptic Demography*. In *Critical Perspectives on Aging: The Political and Moral Economy of Growing Old*. Meredith Minkler and C. L. Estes, eds. Pp. 135-150. Amityville, NY: Baywood Publishing Company.

Ronch, J. L.

1996 *Mourning and Grief in Late Life Alzheimer's Dementia: Revisiting the Vanishing Self*. *American Journal of Alzheimer's Disease* 2(4): 25-28.

Rose, Larry

1996 *Show Me The Way To Go Home*. Forest Knolls, California: Elder Books.

2003 *Larry's Way: Another Look at Alzheimer's from the Inside*. Lincoln, NE: iUniverse, Inc.

Rosenberg, C. E.

2007 *Our Present Complaint: American Medicine, Then and Now*. Baltimore, Maryland: The Johns Hopkins University Press.

Rothschild, D. and M. L. Sharp

1941 *The Origin of Senile Psychoses: Neuropathologic Factors and Factors of a More Personal Nature*. *Diseases of the Nervous System* 2(1): 49-54.

Ryan, E. B., K. A. Bannister, and A. P. Anas

2009 *The Dementia Narrative: Writing to Reclaim Social Identity*. *Journal of Aging Studies* 23: 145-157.

Sabat, Steven R. and L. R. Harré

1992 *The Construction and Deconstruction of Self in Alzheimer's Disease*. *Ageing and Society* 12: 443–461.

Sabat, Steven R., Lisa Napolitano and Heather Fath

2004 *Barriers to the Construction of a Valued Social Identity: A Case Study of Alzheimer's Disease*. *American Journal of Alzheimer's Disease & Other Dementias* 19: 177–185.

Sartre, J-P.

1976 *L'être et le néant*. Paris: Tel Gallimard.

Schneider, Charles

- 2006 *Don't Bury Me...It Ain't Over Yet*. Bloomington, Indiana: AuthorHouse.
Singer, Merrill
- 2004 The Social Origins and Expressions of Illness. *British Medical Bulletin* 69(1): 9-16.
- Smith, Brett and A. C. Sparkes
2008 Contrasting Perspectives on Narrating Selves and Identities: An Invitation to Dialogue. *Qualitative Research* 8(1): 5-35.
- Strawson, G.
2000 The Phenomenology and Ontology of the Self. *In Exploring the Self*, Dan Zahavi, ed. Pp. 39–54. Amsterdam: John Benjamins.
- Taïeb, O., A. Révah-Lévy, M. R. Moro, and T. Baubet,
2008 Is Ricoeur's Notion of Narrative Identity Useful in Understanding Recovery in Drug Addicts? *Qualitative Health Research* 18(7): 990-1000.
- Tappen, R., C. Williams, S. Fishman, and T. Touhy, T
1999 Persistence of Self in Advanced Alzheimer's Disease. *Image. Journal of Nursing Scholarship* 31(2): 121–125.
- Taylor, Richard.
2007 *Alzheimer's From the Inside Out*. London, Baltimore, Sydney: Health Professions Press.
2007b *Alzheimer's From the Inside Out*. Baltimore, Maryland: Health Professions Press.
n.d. Richard Taylor Ph.D. BLOG.
<http://www.richardtaylorphd.com/blog.html>, accessed June 2013.
2009 *Be With Me Today: A Challenge to the Alzheimer Outsider*. Atlanta, Georgia: Have a Good Life Media.
2011a *Live Outside the Stigma: Confronting the Myths and Stigmas of Alzheimer's Disease and other Related Dementia from the Inside Out*. 62 min. Cokato, Minnesota: Brilliant Image Productions, LLC.
2011b *Living With Dementia: To Change your Minds About People With Dementia*, 80 min. Cokato, Minnesota: Brilliant Image Productions, LLC.
- The Association for Frontotemporal Degeneration
n.d. Frontotemporal Degeneration.
<http://www.theaftd.org/frontotemporal-degeneration/ftd-overview>, accessed September 2013.
- Vallis, M. T. and S. McHugh
1987 *Illness Behaviour: Challenging the Medical Model*. *Humane Medicine* 3(1): 2-9.
- Whitehouse, Peter J., Gaines D. Atwood, Heather Lindstrom, and Janice E. Graham
2005 Anthropological Contributions to the Understanding of Age-related Cognitive Impairment. *Lancet Neural* (4): 320-326.
- Whitehouse, Peter J. and David George
2008 *The Myth of Alzheimer's: What You Aren't Being Told About Today's Most Dreaded Diagnosis*. New York: St. Martin's Press.
- Young, Allan
1976 Some Implications of Medical Beliefs and Practices for Social Anthropology. *American Anthropologist* 78(1): 5-24.

Zahavi, Dan

1999 *Self-awareness and Alterity: A Phenomenological Investigation*, Northwestern University Press: Evanston.

2005 *Subjectivity and Selfhood: Investigating the First-Person Perspective*, MIT Press, Cambridge, MA.

2007 *Self and Other: The Limits of Narrative Understanding*. *In* *Narrative and Understanding Persons*, Royal Institute of Philosophy Supplement 60. D.D. Hutto, eds. Pp. 179–201. Cambridge: Cambridge University Press.

2008 *Subjectivity and Selfhood*, Cambridge: The MIT Press.

2009 *Is the Self a Social Construct?* *Inquiry* 52(6): 551-573.

Zolnierek, C. D.

2011 *Exploring Lived Experiences of Persons with Severe Mental Illness: A Review of the Literature*. *Issues in Mental Health Nursing* 32: 46-72.