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PERCEPTIONS OF PERSONHOOD AND THE EARLY ONSET DEMENTIA EXPERIENCE
“I’M STILL HERE”

BY

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Approval of Thesis

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Perceptions of Personhood and the Early Onset Dementia Experience: “I’m Still Here”

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In memory of my mother
Claudette Latulippe Sakamoto
(1944-2012)

Abstract

Early onset dementia (EOD) is dementia before the age of 65. This research study examined the lived experience from the point of view of four adults under the age of 65 living with dementia, in particular examining how these individuals perceive their own personhood. One family member was also interviewed. Using Interpretative Phenomenological Analysis (IPA) as the research approach, this study revealed that the EOD experience can be incorporated into six themes: A Personal Journey, Navigating the System, The Stigma of Dementia, Connecting to the World, A Story Worth Telling and I'm Still Here. The participants' stories as presented via these six thematic threads reveal that people with EOD can have a strong sense of personhood. Findings from this study are discussed and situated within the current EOD body of knowledge, and new knowledge is presented. Implications for practice, as well as recommendations for future research are discussed.

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Chapter I: Introduction

A Picture to Paint

This is a story of a man surprised by his body and the sudden deterioration of his mind.¹

An Early Perspective

I sit at my desk as I work on this thesis project. Framed pictures of my family and mementos that I have collected over time are on the window ledge and bookshelves in the den where I have set up my desk. Well-loved paperbacks and old textbooks from my pre-graduate university days are stacked around me. I am in my milieu and I feel I know who I am: a person formed over time by my family, my upbringing and by my life experiences. I know that the person I will be in the future is still developing and I am comforted by the thought of the experiences to come that will help shape my future self. I am truly a being of past, present and future. Like an unfinished painting, I am the accumulation of layers of pigment on canvas built up over time, a picture still evolving.

But what would happen were I to have dementia? Would I know who I am as a person? What would happen to this sense of myself as an ever-developing person; would this cease? Similar to a painting stored in a forgotten corner its paint stiffening and cracking with neglect and its colours fading over time, I fear for who I would become as a person with dementia. Yet this is only my own conjecture and may not reflect the actual experience of having a disease like dementia.

Purpose of the Study

These initial thoughts and musings were the impetus for this research study. For some

¹ Thomas DeBaggio

time, I have wondered about sense of personhood when one has been diagnosed with a disease such as dementia. As an individual entering middle age, I have also speculated about what it would be like to have dementia at this time in my life. While a moderate body of research in terms of the subjective experience of late onset dementia (LOD) exists, the experience of younger adults with the disease has not been substantially explored. Thus, a study to explore the phenomenon of early onset dementia (EOD) from the point of view of younger adults was undertaken. This study sought to investigate how these adults' perceptions of their own personhood might be affected by a diagnosis of EOD. As a nurse, my goal was to shed light on an experience that is normally shrouded in confusion and deterioration, in the hopes that nurses and other health professionals will be able to understand and support younger adults in their dementia journey. This study is based on an assumption that in order to support and provide appropriate services for people with EOD, it is necessary to first understand how those with EOD perceive themselves, especially within their own context of younger people experiencing the disease.

Background

Dementia causes deterioration in cognitive ability with symptoms that include loss of memory, loss of reasoning and judgment, as well as changes in mood and behaviour (Alzheimer Society Canada, n.d.). It is an illness that eventually affects the ability to perform everyday activities (Alzheimer's Disease International, 2012). Dementia is a degenerative illness and the crux of its devastating effects is in the "gradual and unrelenting" (Sanders & Morano, 2008, p. 194) nature of its progression. Dementia is most often diagnosed later in life and it is often assumed that it is a disease that only affects older people. However, younger people can also be diagnosed with dementia, a condition that is known as early onset dementia (EOD).

Early Onset Dementia

EOD is dementia with onset before the age of 65 (Miyoshi, 2009). For the purpose of this thesis, the terms *younger adult* and *younger person* will refer to adults under the age of 65. It is estimated that between 2-10% of all dementia diagnoses are early onset (Alzheimer's Disease International, 2009). It is difficult to report exact prevalence rates of EOD as data are often based on referrals to services, which younger adults may not always take advantage of (Alzheimer Society UK, n.d.). In fact, EOD is often misdiagnosed and thus rates of diagnosis are likely under-represented in the literature. For instance, a 2012 WHO report indicates that prevalence may be closer to 6-9%, with all dementias serving as the denominator. While dementia at a younger age is a less common condition than older adult dementia, it is estimated that over seventy thousand Canadians are living with EOD (Alzheimer Society, 2009). Regardless of the prevalence, dementia at any age results in significant personal challenges as well as substantial economic costs to society (Alzheimer's Disease International, 2010; McCrone, 2008). There has been limited focus on the cost of care for those with EOD, but the existing findings do suggest that costs are equal to and possibly higher than costs for older adults (Werner, Stein-Shvachman & Korczyn, 2009).

Many different co-morbid conditions are associated with EOD, including Alzheimer's, Parkinson's and vascular disease (Werner et al., 2009). There is much research in terms of EOD epidemiology and symptomology and it is important to note that disease presentation tends to be different for younger adults compared to that of older individuals. People with EOD often experience higher levels of behavioural disturbances than those with LOD (Freyne, Kidd, Coen & Lawlor, 1999). They may become introverted, irritable and hostile, and can also exhibit paranoid delusions and hallucinations as the disease progresses (Kaiser & Panegyres, 2007). In

addition to memory problems, it is also common for younger adults with dementia to present with language and word-finding problems, as well as visual-spatial dysfunction (Toyota et al., 2007).

Family members and caregivers of those with EOD also experience substantial caregiver burden and stress (van Vliet, de Vugt, Bakker, Koopmans & Verhey, 2010). Caregivers of younger adults with EOD report greater levels of stress and burden compared to those who care for people with LOD (Ducharme, Kergoat, Antoine, Pasquier & Coulombe, 2013). For spouses of younger adults with dementia there can be a “double burden” of caregiver and work-related responsibilities (Bakker et al., 2013). It has also been found that younger adults with dementia are at a higher risk of institutionalization compared to older people (Rosness, Haugen & Engedal, 2008), due in part to the fact that caregiver stress can make it difficult to care for these individuals at home (van Vliet et al., 2010). While a diagnosis of dementia at any age implies serious consequences and care concerns, it seems that those with EOD face specific age-related problems and challenges (Bakker, 2013). To this end, EOD is increasingly becoming recognized as a condition that has significant medical and social consequences that warrant further research (Bakker et al., 2010).

Researcher Positioning

Interest in the EOD experience and personhood evolved from personal and professional experiences that I feel are important to articulate, as a part of further explaining the motivations for this study. My paternal grandmother was diagnosed with Alzheimer’s dementia when she was in her early seventies. As a young girl, I was puzzled as to why my normally efficient and intelligent grandmother kept repeating tasks and seemed to forget conversations that had just taken place. By the time she died, and her Alzheimer’s disease was long established, she no

longer seemed to be the person I had known. She was wheelchair bound and had to be cared for in all aspects of daily life. She no longer resembled the strong Japanese woman who had gone through internment during the Second World War. Nor was she the patient woman who had taught me how to fry an egg and how to fold origami cranes out of newspaper. My family and I had watched her slowly become subsumed by the brain-ravaging effects of her illness. Our one consolation was that my grandmother had lived a full life prior to the illness and we saw her disease, while very sad for her and the family, as something that did happen to some people as they aged.

I am a nurse and one of my very first nursing jobs was in a residential care facility. Many of the residents I helped care for had some form of dementia and seemed to live each day in a state of confusion. One day I came across a living will in the chart of one of the facility's residents, a woman who was particularly challenging to care for. She was mostly non-verbal and could be combative during care. What struck me the most when I read her living will was how clearly her sense of self came through in the words that she had written. Her words evoked a strong, passionate and articulate individual, and conjured an image of who she had once been as a person, an image that did not fit with the one that my youthful and inexperienced eyes saw before me. Without realizing it at the time, I started to wonder more about the personhood of people with dementia. What happens to sense of self as dementia progresses? What happens to the person? Nevertheless, I still felt that the patients I was caring for, including this remarkable person, were ailing in a context that I understood: They were older people with dementia.

For the last 15 years I have been a community health nurse and I have had the opportunity to care for many people with dementia. Three years ago I met a 50 year-old man with early onset dementia while I was working as a nurse case manager. He had been diagnosed

just a few years earlier and was quite far along in his disease trajectory when I had the opportunity to meet him. My main task as his case manager was to help waitlist him for a residential care facility, as his family could no longer meet his needs at home. He could no longer dress or bathe himself and could not be safely left alone at home. It was not uncommon for him to experience dementia-related hallucinations and to easily get upset. He had been the main breadwinner for the family but now his wife had to go to work each day in order to make ends meet. His appearance was quite youthful; in fact he seemed younger than his fifty years and did not at first give the impression of a person struggling with dementia. Yet, when I asked him to remove his jacket so that I could take his blood pressure, he could not figure out how to do this simple task.

I will never forget the look of confusion in his eyes when he tried to take his jacket off on his own. He sheepishly apologized and gently smiled at me, as I helped him with his coat. Here was a man who should have been in the prime of his life, yet he was now an individual much affected by his dementia. His family told me that they felt he was no longer the person he had once been. I wondered what it must have been like for him earlier on in his disease process, when the parts of him that made up the whole person began to slip away? Had he ever been aware of the loss of “himself”? What had the experience of having dementia been like for him as a person? These questions seemed especially relevant as I informed his family that a bed in a local care facility had become available. He shortly afterwards moved there, a facility where the majority of the residents were elderly. Since that time, I have thought of him and his family frequently and wondered how appropriately they were supported from the time of diagnosis and onwards: A younger person, not only living with a disease normally associated with older people, but also cared for in a system designed to provide dementia services for the elderly?

Research Approach

van Manen (1990) describes the concept of lived experience as “the breathing of meaning” (p.36). As a corollary to this idea, in order for a researcher to “breathe meaning” into a study that explores other people’s lived experience, and does justice to the breadth of meaning that this experience embodies for them, an appropriate research approach is required.

Interpretative Phenomenological Analysis (IPA) was chosen as the framework to meet the objective of this research study. IPA incorporates a two-stage interpretive process known as a double hermeneutic (Aisbett, 2006), which involves the researcher attempting to make sense of the participant’s experience, who is in turn trying to make sense of his or her world and experience (Pringle, Hendry & McLafferty, 2011). Similar to considering another person’s work of art, such as a painting, and trying to understand and interpret what a person “meant” when creating his or her piece, attempting to understand, as well as translating another person’s life experience into words, requires an interpretive stance. This framework from which to consider the EOD experience also seems fitting when considering the extent of “sense-making” that must occur when one has dementia.

This particular research approach also fits well with my own philosophy of nursing. I view nursing as an interpersonal and caring process that is an act of “moving between the universal and the uniquely particular with people as they live their health experiences, in order to collaboratively reveal possibilities in human healing” (Spenceley, 2004, p. 205). I have always felt that in order to best help and nurse others, I must try to relate to each individual as a person, as well as try to understand what each person is going through. I share in the human experience simply by being another human being, living and experiencing life. Yet despite one’s best efforts, there is the realization that another person’s subjective life experience, while at times

encompassing universal themes, is ultimately a unique phenomenon. We may all be human beings and share experiences and understanding, yet we are also individuals and thus, experience and understand life and health in our own manner. This view of nursing and of the world translates naturally to an interest in phenomenological enquiry, particularly from an interpretative standpoint.

Chapter Summary

This research study evolved from my experiences as a family member and as a nurse interacting with others with dementia. An interest in the subjective experience of younger adults with EOD, and particularly these individuals' perceptions of personhood as younger people with dementia, was at the root of this study. Understanding how younger adults with dementia perceive and experience personhood is important as this likely determines how they cope with the illness, how they relate to others, and could also ascertain what types of services and interventions could be most helpful for them: younger people with dementia. This study incorporated IPA as the research approach from which to examine personhood and the EOD experience. The following pages examine the existing literature on the subject of EOD and personhood to "prime the canvas" for the next parts of this study. It is my hope that as a nurse and novice researcher, as well as a person in my own right, that I have been able to paint a picture for the reader of what it does mean to be a younger person with early onset dementia.

Chapter II: Literature Review

Priming the Canvas

*I am forced into old age against my will and I am full of rage.*²

Overview

In order to lay the foundation for this work and especially as a way of situating and developing a research question, it is necessary to position this study within the existing knowledge and literature regarding dementia and the EOD context. The following pages will illustrate what EOD is in terms of the particular challenges younger people with dementia face. This chapter will also consider the different frameworks that exist for conceptualizing personhood and dementia, as well as discuss why it is important to involve those experiencing the illness directly in dementia-related research. As EOD is a less studied phenomenon than LOD, there is only a slim body of research that pertains to the younger adult experience of the disease. For that reason, the more extensive literature pertaining to the later adult dementia experience must be considered, especially as a way to contextualize the discussion of self, identity and personhood.

The EOD Context

EOD occurs within the period of middle life in terms of the cycle of adult development, a period believed to begin around the age of 40 and end at age 65 (Lachman, 2004). Erickson's (1980) psychosocial theory of development asserts that generativity is one of the main developmental tasks of middle adulthood. Generativity is concerned with productivity in terms of work, caring for family and maintaining social relationships (Hunt, 2011). In fact, middle-aged adults typically deal with multiple life roles, experience high levels of mastery and usually

² Thomas DeBaggio

are at the peak of their physical and social functioning (Lachman, 2004). Dementia diagnosed after the age of 65 occurs during a very different time of life compared to EOD. For instance, the period of life after age 65 is most often associated with retirement. In comparison, younger adults with dementia are often still employed at the time of diagnosis (Beattie, Daker-White, Gilliard & Means, 2002) and forced retirement at a younger age can cause financial stress and difficulties (Freyne et al., 1999). If the person with EOD is especially young, he or she may still have dependent children at home (Martin, 2009). It is also important to note that middle-aged adults may not only have children to care for, but may also have aging parents, situating them within what is known as the “sandwich generation” where tension exists between caring for both children and parents at the same time (Lachman, 2004). Thus, the impact on family dynamics for the person with EOD and for family members is significant.

Individuals diagnosed with EOD are also likely to be in better physical health than older people with dementia (Beattie et al., 2002). As a result, people with EOD do not fit the predominant image of an elderly person with dementia and they can experience a form of reverse ageism (Chaston, 2010). Unfortunately, services for younger people with dementia are commonly provided within the framework of older adult care (Roach, Keady, Bee & Hope, 2008). Most existing dementia services have been designed for older adults and do not meet the specific needs of people living with EOD (Flynn & Mulcahy, 2013; Martin, 2009). Overall, younger adults with dementia tend to experience high levels of unmet needs and concerns in several areas: lack of daytime activities, need for social company, changes in intimate relationships, and overall psychological distress (Bakker et al., 2013). It is also not uncommon for younger adults to struggle for quite some time before a diagnosis of dementia is confirmed (Martin, 2009). As EOD is not as common as LOD, it frequently is not recognized as such by

health professionals (Bakker et al., 2010). Much of the research examining the EOD experience has found that many people identify timely diagnosis as an issue of concern and a substantial hurdle early on in their disease journey (Bakker et al., 2010; Harris, 2004; Johannessen & Moller, 2013).

Other Challenges

Along with ageist challenges, those living with EOD simply feel that they are too young to have the disease (Clemerson, Walsh & Isaac, 2013). Many find it embarrassing to have dementia at a young age (Johannessen & Moller, 2013), while others discover that some of the people in their lives become uncomfortable around them once the diagnosis of dementia is known (Clemerson et al., 2013). It is not uncommon for people with dementia to experience stigma, which can create a sense of shame and inadequacy, as well as low self-esteem (Alzheimer's Disease International, 2012; Rose, Yu, Palmer, Richeson & Burgener, 2010). Often, people with dementia attempt to minimize or "cover up" their difficulties so as to avoid the social stigma that comes with a dementia diagnosis (Robinson, Clare & Evans, 2005). In terms of the younger adult context and stigma, dementia has been shown to cause a sense of isolation and exclusion, as well as feelings of guilt and helplessness (Beattie, Daker-White, Gilliard & Means, 2004; Roach et al., 2008). Maintaining existing friendships, as well as making new friends, can be challenging when suffering from dementia, especially at a young age (Johannessen & Moller, 2013).

Perceptions of the Dementia Experience

As evidenced by the discussion above, younger adults experience dementia in a specific age-related and social context, resulting in unique challenges that older adults with the illness may not face. Overall, the depiction of EOD in the literature is of a conflicting illness experience

at odds with more normative perceptions of dementia as a disease of the elderly. One way to consider the experience of having dementia is as follows: “In the end stages of dementia, patients are a shadow of their former selves – profoundly disoriented, incoherent, amnesic, and incontinent” (Kaiser & Panegyres, 2007, p. 398). This is quite a hopeless description of dementia’s deteriorating process. Research that delves into the subjective experience of people with LOD, has shown that those diagnosed perceive the concept of hope as an important factor in maintaining well being and quality of life (Wolverson, Clarke & Moniz-Cook, 2010). Yet despite such evidence, it seems that the greatest challenge presented by a degenerative disease such as dementia is the difficulty in trying “to hold on to certainty about self, the fundamental knowledge of who one is, arising from a growing uncertainty, a widening chasm in a hitherto reasonably robust sense of self-awareness and self-esteem” (Gillies & Johnston, 2004, p. 438).

In terms of the physical body, the person with dementia, even far along in the disease process, is still the same person they have always been. Yet how is the sense of self or of identity, as well as personhood, affected by the degenerative nature of dementia? The terms of “self”, “identity” and “personhood” are used frequently in the dementia literature and at times seem to encompass similar meaning. The following paragraphs will attempt to first distinguish between self and identity and discuss these concepts as they relate to dementia, in the hopes that this will clarify how these concepts are pertinent to the younger adult experience and the examination of personhood.

Selfhood and Identity

Social constructionism is a term used in psychology and is a stance utilized for understanding the world, in particular the social processes and interactions that people are engaged in (Burr, 2003). A social constructionist perspective is one way that the self can be

conceptualized, where the self is constructed through social interactions with others (Caddell & Clare, 2010; Sabat, 2002). From a social constructionist point of view, three different “selves” exist (Caddell & Clare, 2010). Self-1 is embodied and manifested through the use of personal pronouns such as “I” or “mine” (Hedman, Hansebo, Ternstedt, Hellstrom & Norberg, 2013). Self-2 comprises an individual’s beliefs and attributes, while Self-3 involves a person’s varied social personae (Hedman et al., 2013). Dementia can affect perceived selfhood, especially in terms of Self-2 and Self-3 characteristics (Sabat, 2002; Sabat, Johnson, Swarbrick & Keady, 2011). People with dementia have been able to describe how certain Self-2 attributes have been affected by the disease, as well as how construction of their Self-3 social persona could be influenced by how others perceive them (Hedman et al., 2013). A diagnosis of dementia and the onset of memory problems can affect how people with EOD view themselves and for some, dementia is definitely viewed as a threat to self (Clemerson et al., 2013). It is important to note that dementia is commonly socially constructed as an illness that “robs” people of their sense of self (MacRae, 2010). Nevertheless, LOD research has demonstrated that individuals with dementia do maintain sense of self by reappraising and reconstructing selfhood (Pearce, Clare & Pistrang, 2002). As Fazio (2013) states, “Self is the core of who we are as an individual, as a person, as a human – no disease can take that away” (p. 18).

Similarly to selfhood, construction of a person’s identity is a lifelong process and it is formed, maintained and altered over time and through interactions with others and life events (Beard, 2004). Identity can be conceptualized as a cumulative image of the self (MacRae, 2010). In general, loss of identity is thought to be a significant aspect of any chronic or enduring illness, and maintaining a sense of identity can be challenging when memory, thinking, judgment, and behaviour are all affected (Gillies & Johnston, 2004). In terms of the EOD context, identity in

middle adulthood is defined by work and by one's relationships with others (Clemerson et al., 2013). In fact, one study that examined the perspective of younger adults with dementia found that multiple aspects of their self-identity were affected, especially characteristics that defined them as a productive younger people (Harris, 2004). Similarly, a study by Harris and Keady (2009) examined perceptions of selfhood in people with younger onset dementia and several themes surrounding changes to identity were uncovered. These included changes to their identity as family members, as workers and as social beings (Harris & Keady, 2009). Although there exist other studies that examine the subjective experience of EOD, the Harris (2004) and Harris and Keady (2009) studies were the only ones found as part of this literature review that specifically examined identity and selfhood.

Research with older adults has shown that dementia does not necessarily represent a complete loss of identity and that people with dementia purposely engage in a process of identity preservation (Beard, 2004). It is not unusual for individuals to develop coping strategies to help them come to term with having dementia and in order to compensate for any losses associated with the illness (Williams et al., 2014). A literature review by Caddell and Clare (2010) of studies that have examined the impact of LOD dementia on self and identity reveals that these elements of the person are preserved to a certain extent, even into later stages of the disease. In some instances, this was based on the continued use of first person pronouns, while in other studies evidence of retained self was demonstrated in the way that some participants were able to talk about past attributes, as well as reflect on new attributes of self that developed as part of dealing with the illness (Caddell & Clare, 2010.)

It is clear that certain aspects of self and identity can be retained, although altered as part of experiencing dementia. These concepts, while constructed in a social context, also relate to

how individuals see themselves. Research suggests that relationships that are supportive and encouraging can help the person with dementia protect and preserve identity (Williams et al., 2014). However, what does it mean when another person considers an individual with dementia and thinks: “He is no longer the same person anymore?” How is the person with dementia’s sense of who she or he is affected by other peoples’ points of view?

Personhood and Dementia

Traditional views of personhood tend to focus on an individual’s cognitive attributes as a way of conceptualizing what personhood is. These would include qualities such as consciousness, rationality, memory and a capacity to communicate (Bartlett & O’Connor, 2007). From this traditional perspective, as dementia is characterized by progressive deterioration in these cognitive functions, one *could* view dementia as a disease that eventually negates personhood altogether (Bartlett & O’Connor, 2007; Dewing, 2008). Yet, personhood must consist of more than just cognitive function. For instance, as Reid, Ryan and Enderby (2001) state: “People with dementia are persons first with views, likes and requirements that co-exist with their illness” (p. 391). This idea of a co-existence of disease and of the person with an individual point of view and distinct characteristics implies that personhood, especially within the dementia context, can be more broadly considered.

Defining personhood is difficult and determining its essence is essentially an ontological act. As Malloy and Hadjistavropoulos (2004) state: “A person’s ontological position forms the manner in which one perceives the self and others” (p. 149). This point of view has interesting implications when it comes to considering how people in general perceive personhood. Is personhood determined by how we envision the self or identify ourselves, or is it determined by how others “see” us? Kitwood’s (1997) work on personhood and dementia is frequently

discussed in the literature. His definition of personhood is as follows: “It is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust” (p. 8). This involvement of others in terms of granting personhood is an important distinction. It calls to mind the efforts of various cultural and social minority groups in their endeavors to attain recognition of civil rights and liberties and acknowledgment of their personhood, and the fact that this involves seeking and establishing recognition and respect from others. It also demonstrates the power “others” have in recognizing and bestowing, or conversely eliminating, a status of personhood. This perspective seems particularly relevant in terms of the dementia experience, especially as individuals with dementia must increasingly depend on the care and regard of others as their condition deteriorates.

Kitwood (1997) argues that a diagnosis of dementia does not in itself occasion a loss of personhood. Rather, Kitwood and others have stressed that loss of personhood can occur as a result of the way that people with dementia are treated by those around them (Bartlett & O’Connor, 2007). While it cannot be denied that people with dementia will become different in many ways compared to who they were prior to the illness, it can be argued that if they are considered as lesser persons by others because of the effects of the disease, the quintessential nature of their personhood is no longer valued (Dewing, 2008). How often do health professionals and others in society look at a person with dementia and sum up their state of being as: “She is demented” or “He’s just a shell of who he was” and how do such limiting attitudes and perceptions affect personhood status? Kitwood (1997) coined the term “malignant social psychology” to denote the effect of depersonalizing and objectifying a person living with dementia, and the ill effect this can have on that person’s perceived state of personhood. In fact, society tends to view dementia as representing a complete loss of self and of identity, an

assumption that can situate the person with dementia within a category of difference and otherness compared to those who do not struggle with the disease (Naue & Kroll, 2008), essentially stripping them of their personhood.

While Kitwood's definition highlights that other people can powerfully influence sense of personhood, it seems that this perception is ultimately a subjective understanding. Were one to randomly ask several people about their subjective notion of personhood, it is likely that responses would be different. This highlights the unique aspect of being a human being: That we are all individuals in our own way. However, despite our individuality, we also share common life experiences such as illness, and the countless other experiences we share as living sentient creatures. This connecting thread of our humanness is how concepts of personhood can be collectively examined. Younger adults with dementia may be quite different people in their own right, but do share the experience of having a deteriorating illness that is most commonly associated with old age. This shared context provides the platform from which the EOD experience and personhood can be examined.

Thus, recognizing the subjective experience of the person with EOD is essential in order to understand and appreciate the individual's perspective and self-conceptualization of how they view themselves and what personhood means to them. O'Connor et al. (2007) also state that along with the subjective point of view, personhood is also constructed through interactions with the world, which could involve interactions with others, as well as with the physical environment within which the person with dementia is situated. Perception of personhood is further shaped and influenced by the socio-cultural context within which dementia is experienced (O'Connor et al., 2007). This is similar to Hughes' (2001) situated-embodied view of the person. According to this view, the person acts and interacts in a cultural and historical context in which he or she is

embodied (Hughes, 2001). The specific context and environment in which a younger person is embedded, and how this impacts how younger people living with dementia perceive their personhood, seem important to consider. It seems valid to also comment that any form of decline is part of being a person and does not in itself signify the ceasing of being one. One could state that:

Experience demonstrates that to be a person is to be liable not simply to change but also to gain and lose strength and ability, both mental and physical: a person is not only the sort of being that has memories and a sense of self, but also, like it or not, the sort of being that can lose memories and can lose the sense of self. (Lesser, 2006, p. 60)

Such losses do occur with dementia, but this does not mean that there is not worth in discussing personhood and recognizing the subjective experience of this phenomenon.

Why Examine the Subjective Dementia Experience?

In general, much of the existing research examining the dementia experience has investigated the phenomenon from the point of view of family members, caregivers and clinicians (Nygard, 2006; Phinney, Chaudhury & O'Connor, 2007; Reid et al., 2001). There has been less research that directly involves the people living with dementia, especially as it relates to the subjective experience of the illness (Mast, 2009). This is likely due to a belief that it is counter-intuitive to examine the experience from the point of view of someone who is suffering from cognitive and memory deficits (Aggarwal et al., 2003). Many likely question whether those with dementia have the cognitive capacity to contribute to a better understanding of the experience. However, studies have shown that people with dementia, especially earlier on in the disease process, can provide valuable insight into their experiences (Cowdell, 2008; de Boer et al., 2007; Nygard, 2006). It is important to note that research has also shown that the concerns

and perceptions of people with dementia differ from those of family and caregivers (Armari, Jarmolowicz & Panegyres, 2013; Reid et al., 2001). For instance, Aggarwal et al. (2003) revealed disparities in responses about aspects of care between those with dementia and their family members. This demonstrates that it is important to approach those with dementia directly to learn about their views and better understand their perspective. Furthermore, in order for service providers and policy makers to best support people with dementia, they should be able to draw on these individuals' views and experiences (Wilkinson, 2002). Younger people with dementia are an under-researched group and there is a paucity of evidence regarding their subjective needs (von Kutzleben, Schmid, Halek, Holle & Bartholomeyczik, 2012). While there is literature that examines personhood within the older adult dementia experience, there is a lack of research that considers this within the younger adult context (Tolhurst, Bhattacharyya & Kingston, 2014). In fact, the literature search for this paper did not result in a single study that specifically examined "personhood" from the EOD perspective.

One could argue that to involve the person with dementia directly in research is an affirmation of personhood. From a nursing point of view, it also affirms "the person", a foundation in many nursing theories and models (Dewing, 2008), as well as supports and validates care models such as person-centered care. Person-centered care involves "promoting a continuation of self and normality" (Edvardsson, Fetherstonhaugh & Nay, 2010, p. 2614). It is also an approach that "respects the inner life of persons with dementia, honors the individual's subjective experience of illness, recognizes the continuity of personhood in the face of cognitive decline..." (Williams et al., 2014, p. 499). This seems a worthwhile endeavor when considering that while dementia does impact identity and self, those very same aspects are reconstructed by the individual in order for "the person" to continue onwards. Furthermore, there is evidence that

the dementia experience can be improved by an approach to care that respects and supports personhood, and thus, enables further development of personhood throughout the disease process (O'Connor et al., 2007). While it seems vital to view people with dementia, although changed in many ways by the disease, as whole people who can still “experience the same feelings, thoughts and responses as we ourselves do” (Nowell, Thornton & Simpson, 2013, p. 395), it is also essential to seek their perspective on how they view themselves.

Synthesizing the Research Question

It is apparent that younger adults experience dementia within a distinct social context when compared to their older counterparts. Given that EOD occurs within a period of adult life characterized by specific age-related tasks and challenges, one cannot help but wonder how the experience of having dementia at a young age affects sense of personhood? The literature has shown that while personhood is a subjective experience, it is also a perception that is powerfully influenced by others. The literature also demonstrates that a person subjectively experiences dementia from his or her own socio-cultural and interactional context. As limited research has been conducted in terms of personhood and the EOD experience, it seemed worthwhile to pursue investigation into this particular realm of being. Thus the research question specific to this study was as follows: *“How do individuals with EOD perceive the impact of dementia on their sense of personhood?”* This question was based in the assumption that it is vital to understand how younger people with dementia see themselves and that answering this question would provide valuable information in terms of developing appropriate services and supports for this distinct population. It was also thought that care providers, as well as society as a whole, would also benefit from understanding the lived experience of this vulnerable group of people. Furthermore, it was hoped that telling their story and having their voices heard would be a powerful

experience for the participants themselves.

Chapter Summary

Dementia is a disease more often experienced by older adults but it does occur in younger people as well. This literature review has demonstrated that the psychological and psychosocial burden of a dementia diagnosis at a young age is substantial. Dementia is a devastating disease and its effects are compounded for younger adults by the ordeal of experiencing an illness normally associated with the elderly. The specific cognitive deterioration that is part of dementia's degenerative nature forces the person with the disease to over time reconstruct sense of self and identity, as part of maintaining overall well being. While identity and sense of self are challenged by the illness, the personhood of an individual with dementia can be negatively affected by how others perceive the person diagnosed. Personhood is also a subjective experience, which is affected by the socio-cultural context and environment in which the person interacts. As there exists limited knowledge of the EOD lived experience, especially as it pertains to perceptions of personhood, it is hoped that this study has shed light on this particular phenomenon.

Chapter III: Research Methodology

A Contour Emerges

*My crippled mind constantly sends me searching for meanings to inhabit my life.*³

Overview

As part of considering a research question and in preparing to undertake inquiry, it is essential to frame the process within a research paradigm, as this helps to give direction to a study. It is also important that the chosen research framework is appropriate to the research focus and question. This chapter will discuss the theoretical framework of Interpretative Phenomenological Analysis (IPA), as well as consider the value of using this particular research approach to examine the EOD experience. While theories and concepts form the foundation of a study, the actual research itself was carried out using certain methods. This chapter will also detail the sampling, data collection and analysis methods that were utilized in this study. A discussion of important ethical considerations is included.

Interpretative Phenomenological Analysis

IPA is a relatively recent qualitative method of research that was originally developed within the field of psychology. It was first discussed in Jonathan Smith's 1996 paper *Psychology and Health* and is an approach devoted to examining how individuals make sense of their life experiences (Smith, Flowers & Larkin, 2009). Smith et al. (2009) explain, "When people are engaged with 'an experience' of something major in their lives, they begin to reflect on the significance of what is happening and IPA research aims to engage with these reflections" (p. 3). IPA is a method of inquiry that is based in phenomenological, hermeneutic and idiographic traditions (Smith et al., 2009). The theory that informs these different perspectives provides the

³ Thomas DeBaggio

context from which to understand the totality of IPA, as a method for qualitative inquiry, and as a research approach that best suit the goals of this study. Thus, prior to discussing the actual procedures and methods that were used in this IPA study, it will be helpful to explore these separate paradigms further.

The Phenomenological Perspective

A phenomenological approach to research involves examining a person's lived experience of a particular phenomenon (Balls, 2009). As stated by van Manen (1990), "from a phenomenological point of view, to do research is always to question the way we experience the world, to want to know the world in which we live as human beings" (p. 5). While the common goal of all phenomenological research is to gain an understanding of lived experiences, there exist variations in research approaches that use phenomenology (Dowling & Cooney, 2012), and there is worth in examining how phenomenology has evolved in order to best understand its application with IPA.

This discussion begins with philosopher Edmund Husserl's view of phenomenology as he described it in the early 1900's (Pringle, Hendry & McLafferty, 2011; Richards & Morse, 2013). Husserl envisioned phenomenology as the exploration of the experience of life and of living, and what that experience is like "pre-reflectively" (Tuohy, Cooney, Dowling, Murphy & Sixsmith, 2013). Husserlian phenomenology involves examining an experience in the way that it occurs to the individual experiencing the phenomenon, focusing on the experience itself and describing its particular and essential features (Smith et al., 2009; Tuohy et al., 2013). Husserl was interested in the consciousness of the person experiencing the phenomenon (Smith et al., 2009). He also believed that in order to access the essence of the experience, the observer's preconceived notions of the world are to be put to one side (Dowling & Cooney, 2012). This involves a

philosophical practice of reduction that Husserl called “bracketing”, a process where the goal is the setting aside of preconceptions in order to approach the phenomenon in an unbiased way as possible (Converse, 2012). Methods of research inspired by Husserl’s philosophy are often called descriptive phenomenology, as phenomena are usually precisely described (Converse, 2012).

IPA utilizes a phenomenological approach in that the goal of an IPA study is to examine the lived experience of a particular phenomenon, from the point of view of the person experiencing it. However, an IPA analysis is not solely descriptive in the sense of the traditional phenomenological approach as described above. IPA is interpretative as its name suggests, and this leads naturally to a discussion of hermeneutics.

The Hermeneutic Perspective

Hermeneutic phenomenology is a philosophic approach aimed at attaining an understanding of the lived experience by means of an interpretative lens (Dowling & Cooney, 2012). Accordingly, hermeneutic research is concerned with interpreting the meaning of experience, rather than simply describing it (Lopez & Willis, 2004). Hermeneutics was first described in the 17th century as way of interpreting the meaning of biblical texts (Dowling, 2004; Smith et al., 2009). Schleiermacher, a philosopher in the 19th century, subsequently provided a human sciences context for hermeneutics (Ortiz, 2009). Schleiermacher was interested in grammatical and psychological interpretations of text and living speech (Ortiz, 2009; Smith et al., 2009) and this relates to the hermeneutic assumption that human beings experience the world through language (Dowling, 2004). Philosophers such as Martin Heidegger expanded the notion of interpretation further, especially as it relates to understanding the lived experience.

Heidegger was a student of Husserl’s and he believed in examining and trying to understand the lived experience interpretatively rather than descriptively (Pringle, Hendry &

McLafferty, 2011). Heidegger was interested in the “being” of a phenomenon, rather than just its essence and this is an important ontological shift away from Husserl’s experiential epistemology (Converse, 2012). In his seminal work *Being and Time* published in 1927, Heidegger discussed the concept of “Dasein” which literally means “there-being” (Smith et al., 2009). According to Heidegger, Dasein is “the uniquely situated quality of ‘human being’” (Smith et al., 2009, p.16), and this concept involves “being-in-the-world” (Tuohy et al., 2013). Being-in-the world refers to the manner in which human beings act within, are involved with and exist in the world (Dowling, 2007). This interconnectedness of being in the world underscores that in order to understand life experience, one needs to acknowledge that living is contextual and perspectival, and thus requires an interpretive act so as to understand its meaning. To elaborate: Rather than objectivity, the interpretivist paradigm is concerned with the intersubjective realm of experience (Shaw, 2010).

While Husserlian phenomenology calls for bracketing in order to avoid preconceptions, the hermeneutic view is that this is not always possible (Pringle, Hendry & McLafferty, 2011). The hermeneutic perspective does allow for the concept of fore-structure: Any pre-awareness or pre-understanding that may stem from prior experiences (Tuohy et al., 2013). As the fore-structure is always present, it can inadvertently influence interpretation. At the same time, one’s preconceptions or fore-structure are what allow for new ideas to emerge and what guide interpretation (Maggs-Rapport, 2000). Thus, assumptions and preconceptions must be acknowledged as part of the interpretive process, and this also relates to research where the researcher must recognize and identify preconceptions and engage in continuous self-reflection (Tuohy et al., 2013). Hermeneutic phenomenology has been considered and further developed by various others through the years from philosopher Hans-Georg Gadamer to social sciences

researcher Max van Manen (Earle, 2010). Regardless of permutations, the essence of hermeneutics found in IPA is that trying to comprehend others' lived experiences involves understanding how people "make sense of" their experiences. This is an act that requires interpretation on behalf of the observer. In fact, IPA identifies the analyst as having a central role in making sense of participants' subjective experiences (Pringle, Drummond, McLafferty & Hendry, 2011).

The Idiographic Perspective

Idiography is concerned with the particular, where "experience is uniquely embodied, situated and perspectival" (Smith et al., 2009, p. 29). The term "idiographic" stems from the Greek work "idios" which means "own" or "private" (Simply Psychology, 2007). It is an investigative approach that involves considering the personal and in-depth details of individuals in order to achieve a unique understanding of them and of their situation (Idiographic versus nomothetic approaches to psychology, n.d.). An idiographic focus allows insight into how "a given person, in a given context, makes sense of a given phenomenon" (Wagstaff & Williams, 2014, p. 9). IPA has an idiographic orientation in that it offers detailed analysis of particular aspects of lived experiences and allows for shared and unique experiences to be identified (Wagstaff & Williams, 2014). IPA's idiographic nature is most evident throughout the analysis process and thus, further discussion of this perspective is best left for the methods section of discussion found later in this body of work.

Why IPA?

IPA is a synthesis of phenomenological, hermeneutic and idiographic perspectives. IPA studies involve detailed examination of human lived experiences and this is what connects it to phenomenology (Smith et al., 2009). It is a hermeneutic style of inquiry in that it involves

interpreting the meaning of the human experience (Smith et al., 2009). Finally, it is idiographic in the way that it situates participants in particular contexts and explores their subjective experiences specifically (Smith et al., 2009). While the different traditions discussed above make up important aspects of IPA as a whole, it is also a research approach that promotes a perspective of its own. Much of the following discussion concerning IPA will be based on the Smith, Flowers and Larkin's (2009) method described in *Interpretative Phenomenological Analysis: Theory Method and Research*.

As the goal is not to test a pre-determined hypothesis, but rather to explore a phenomenon in an in-depth but flexible way, IPA is best suited to research questions that are broad and open-ended (Aisbett, 2006). In general, an IPA study enables the revelation of detailed perceptions and understandings of a particular group, rather than allowing for the making of claims about the nature of the world at large (Smith & Osborn, 2008). Thus, an IPA study typically asks how individuals are making sense of and perceiving a particular situation (Roberts, 2013).

Rather than the traditional view of bracketing or the hermeneutic concept of fore-structure, Smith et al. (2009) refer to an "enlivened" form of bracketing that is envisioned as a cyclical and evolving endeavor that occurs throughout a research study. This relates to the important need for reflexivity and self-awareness on behalf of the IPA researcher (Biggerstaff & Thompson, 2008). To be reflexive requires one to self-examine prejudice and bias and be aware of values, beliefs, interests and ambitions that might affect the research interest and focus (Clancy, 2013). The researcher needs to be self-aware and be prepared to bracket pre-conceptions and biases as much as possible. As part of being reflexive and self-aware, the researcher is then able to adjust bracketing as new awareness of fore-structures arises (Smith et al., 2009). It is important to note that this type of reflexive approach does not eliminate bias

altogether but brings it to the forefront, allowing interpretations to be more credible and realistic to the participants' accounts (Clancy, 2013).

While IPA has its origins in psychology, it has also been used as a research method in other fields, particularly in health studies where the meaning of lived experience in terms of health and illness can be insightfully explored. Research studies involving a diverse range of health professionals from nurses to physiotherapists, have either utilized or considered IPA as a means to uncover and better understand different aspects of the health and illness experience (Barrs, 2012; Cassidy, Reynolds, Naylor & De Souza, 2011; Fade, 2004). IPA has also been the research approach of choice for several dementia studies. For example, an IPA framework was used in a study that explored the shared experience of couples when one partner is diagnosed with dementia (Robinson et al., 2005). In two other studies, IPA was utilized to examine awareness of the changes and impairments that are part of having dementia (Clare, 2003; Clare, Roth & Pratt, 2005).

An important feature of IPA research is that it is well suited to examining the social and psychological aspect of a lived experience (Campbell & Scott, 2011). As with any health experience, living with dementia can only be truly understood by those who have been diagnosed with the disease and who are coping with the implications of the illness on a daily basis. IPA was ultimately chosen as the research framework for this study because the goal is to gain an in-depth understanding of what is like to be a younger adult suffering from an illness most often associated with old age, and how this affects sense of personhood. This understanding can only be achieved via a phenomenological lens. Furthermore, attempting to understand the experience of any illness requires not only the capacity to imagine what it must be like, but also requires an interpretative outlook in order to express the experience in words. In the case of this study's

focus, understanding of a particular aspect of the EOD experience was desired: The perception of personhood as a young person with dementia. This was the idiographic commitment in this particular study.

The concept of the double hermeneutic has already been mentioned, whereby the researcher is trying to make sense of the participant's experience, who is in turn trying to make sense of his or her experience (Smith et al., 2009). This is an important characteristic of the IPA approach to examining the lived experience, in the way that there is a double process of sense making and interpretation occurring. This concept of the double hermeneutic seems well suited to investigating the dementia process. For the person with dementia, it must be a challenging process to try to come to terms with the disease, especially as it threatens cognition and the person's sense of self. Not having dementia myself, I could not truly understand what this experience would be like. However, as the researcher, I attempted to try to understand the participants' experiences of living with EOD, as they were in turn trying to make sense of this experience themselves.

Research Design

Sampling

As IPA is idiographic in nature and is concerned with detailed accounts of individual experiences, Smith et al. (2009) recommend a small number of participants to focus on, usually between three to six people. A smaller sample size allows for a deep and rich analysis, which would be more challenging with a larger group of participants (Pringle, Drummond, McLafferty & Hendry, 2011). Selection of participants is also based on the assumption that they will be able to offer access to the particular experience the researcher is interested in examining (Wilde & Murray, 2009). Thus, ensuring a sample of participants who share common characteristics is

ideal (Roberts, 2013). It is vital that the sample consist of individuals for whom the research question will have meaning (Smith et al., 2009), as the goal is to be able to reach as deep an understanding of the phenomenon of interest as possible. The intent of the sampling strategy in this study was not to be able to form generalizations but to be able to establish a sample of participants that permitted exploration of the unique context of having dementia as a younger adult. This involved purposeful sampling and the following inclusion and exclusion criteria were utilized:

Inclusion Criteria

1. Individuals who are under the age of 65 with a diagnosis of EOD.
2. Individuals who speak and understand English.
3. Individuals who despite a diagnosis of dementia are able to carry on a conversation with others, even for short periods of time.
4. Individuals who have an awareness of their diagnosis, are in the earlier stages of the illness and are able to provide informed consent.
5. Individuals who have a primary caregiver or contact person. While this study does not seek a caregiver or spouse's perspective, it will be important that there be a person who knows the participant well, can assist with setting up interview times, ensure that the participant understands the purpose of the study and act as their advocate as needed.

Exclusion Criteria

1. Individuals with dementia who are over the age of 65.
2. Individuals whose dementia is so far progressed that they are unable to participate because they cannot provide informed consent and/or no longer have the language

and communication abilities to participate in a semi-structured interview.

3. Individuals who do not have a main caregiver or contact person.

As the researcher, my goal was to locate individuals with EOD who were not only willing, but also able to take part in the study. The intent was to be able to interview at least three participants. Ultimately, I was able to interview five participants, although only four of the participant accounts were used for analysis for reasons that will be explained shortly.

Participant Recruitment

Initially, as part of this study's proposal, the University of British Columbia (UBC) Alzheimer Disease and Related Disorders Program was approached as a potential site for recruitment. This program is the main tertiary care and referral center in the province for dementia assessment and management. It is also affiliated with Vancouver Coastal Health, a regional health authority for the Greater Vancouver area. In order to place recruitment posters (Appendix A) in the program's offices and waiting rooms, ethics approval from UBC and the Vancouver Coastal Health Research Institute had to be attained. Following ethics approval, an introduction letter (Appendix B) detailing the study's purpose and plan was provided to the program's manager. The goal was that individuals who might be interested in participating in the study would be able to contact the researcher directly, without having to involve any of the program staff. Thus, prospective participants would feel that participating would not have anything to do with their treatment or medical assessments.

First Link was also approached about recruitment for the study in the first wave of recruitment efforts. First Link is an intervention service for those affected by Alzheimer's disease and other dementias, offering support and education to individuals and families. It is associated with the Alzheimer Society of British Columbia and has several chapters in BC.

Contact was established with the Alzheimer's Society's manager for program development, coordination and evaluation. She was able to facilitate dissemination of the study's recruitment posters to several First Link programs within the Lower Mainland of BC. A URL named earlyonsetdementia.net was also created which featured study recruitment information. This URL was included on the Alzheimer's Society website under a section called "Participating in Research" where people who are interested in participating in research can be directed to study information links.

Despite these recruitment efforts, which were initiated in early 2015, there was no contact from interested individuals. It is possible that people with EOD who might have come across study information at either UBC or First Link, may have been too far along in their disease trajectory to consider participating in the study. They may also have been occupied with specialist appointments and/or already involved in support groups, and thus, not have the time or energy to consider participating in a research study. I started to feel that in order to connect with individuals with EOD who were still well enough to participate, I needed to consider posting recruitment material in community-based venues, as alternative locations where people with EOD might come into contact with study information and recruitment material. Thus, recruitment efforts were expanded and included dissemination of recruitment posters to local community centers, community newspapers, neighbourhood houses and libraries. I also advertised on the well-known website Craig's List, in its "Volunteers Needed" section, where study information for research studies is commonly posted. Shortly after the first posting on Craig's List in early March 2015, the first participant for this study came forward and volunteered.

This study has also benefitted from snowball sampling, as part of the overall recruitment

strategy. In late May 2015, I was fortunate to be able to attend the Canadian Gerontological Nurses' Association Biennial Conference in Charlottetown, PEI to present this research study. At the end of the presentation, I mentioned that recruitment had so far been quite challenging and that any suggestions and assistance would be welcome. From this addendum to my presentation, contact and follow up with three registered nurses attending the conference led to two prospective participants contacting me. Around the same time, I also reached out to a Facebook community support group based out of Australia called the "Young Onset Dementia Support Group". The facilitator of the support group agreed to post information about the study on the group's web page, and I was soon after contacted directly by two Australians who had been diagnosed with EOD and who were interested in participating. At this point in the study, I did notify the Athabasca University Research Ethics Board of this expansion in recruitment strategies and received approval for these changes.

By the end of the recruitment phase, five individuals had been interviewed, two in person, one via Skype and two over the telephone. All of the interviews were audio-recorded and transcribed verbatim by a professional transcriptionist; from these, only four of the participant accounts were appropriate for data analysis. In particular, one of the participants, a 61 year-old woman, had great difficulty answering questions and it quickly became obvious that her dementia was quite far progressed. It was also very challenging to interview her over the telephone. I ultimately ended up interviewing her daughter instead. Although the goal of this study was to interview people with dementia directly about their experiences, I did find that speaking with the participant's daughter was particularly illuminating and some of her account has been included in the findings section of this study.

Ethical Considerations

It could be argued that people with dementia, regardless of stage of disease, are a vulnerable population and thus could be put at risk in terms of participating in a research project. In the past, research among vulnerable people has been avoided due to the concern that it could be unethical and difficult to undertake (Alexander, 2010). Nevertheless, it is important to note that those who are considered vulnerable have a right to be heard (Wilson & Neville, 2009). It is also vital that research among vulnerable groups occur so that these populations are not excluded from any benefits that might be gained from research findings (Alexander, 2010). In fact, participation in research can provide a sense of catharsis and empowerment, as well as a sense of altruism whereby sharing one's story allows one to make a contribution to others (Alexander, 2010). Thus, researchers must overcome the challenges inherent in involving vulnerable people in research so that participants and others in similar circumstances can benefit from increased knowledge and improved interventions that may come from research (Alexander, 2010). While it is important that research involving vulnerable populations occur, it is imperative that this be ethically undertaken.

The challenge of consent. The 2010 Tri-Council policy statement for ethical conduct for research involving humans indicates that consent must be freely given, informed and ongoing. Furthermore, the decision to participate must be based on a full understanding of any possible risks of participating in the study, as well as potential benefits (Pesonen, Remes & Isola, 2011). The challenge inherent with wanting to involve people with dementia directly in research is that it is often presumed that they will not completely understand the implications of participating, and consequently, will not have the capacity to fully consent. It is important to note that incompetence or lack of capacity in one area does not necessarily indicate lack of incompetence

in another (National Council on Ethics in Human Research, 1996). As such, it should not be automatically presumed that some of the cognitive changes associated with dementia would render those living with the disease incapable of research participation and of being able to consent to do so. In fact, to assume that a person is incompetent to consent because of a diagnosis of dementia is excluding (DuBois et al., 2012; Heggstad, Nortvedt & Slettebo, 2013), and can reinforce stereotypes of incapacity (Slaughter, Cole, Jennings & Reimer, 2007). Thus, when it comes to involving people with dementia in research, capacity should be initially presumed (Sherratt, Soteriou & Evans, 2007).

In certain cases, when there is valid concern in terms of competence to consent, a third party such as a spouse or caregiver, can provide consent. While this may provide a solution to any concerns about acquiring informed consent, allowing a third party to determine capacity seems to undermine the person with dementia's essential personhood. As this study sought to understand personhood, it seemed important that consent to participate should come directly from the participants themselves. As Dewing (2002) states: "Informed consent via proxies is unsatisfactory in the moral context of person-centered values and relationships. Quite simply, another person has made decisions on behalf of the person with dementia" (p. 160).

Many people in the early stages of dementia still have capacity to consent when it comes to participating in research (Alzheimer Europe, 2009). This study did involve people with EOD who were still in the earlier stages of the illness and thus, retained the capacity to consent for themselves. This should not be viewed as a statement or a belief that those with dementia whose illness trajectory is more advanced cannot provide valuable information about and insight into their experiences. Nevertheless, people who are experiencing less severe symptoms were seen as more able to participate in the interview process that was a major part of this study. This study

did not use neuropsychological tests such as the Mini Mental State Examination (MMSE) to evaluate the capacity to consent, as such tests do not reveal whether or not participants are able to express their feelings or talk about their experiences (Heggestad et al., 2013).

Consent process. Once prospective participants contacted me indicating their interest to participate, an information letter (Appendix C) was sent to them. After the individual reviewed the letter and indicated that he or she was still interested in participating, further contact was made to set up a time for the interview. The study was discussed with each participant prior to beginning the interview and before seeking consent. The participant was encouraged to ask questions about the study. Following this discussion, I then reviewed the consent form (Appendix D) with the participant. Originally, I had planned to ask that the participant's main contact, a person that they know and trust, be present in order to witness the consent form, as a final check to ensure that consent was informed and freely given. However, all of the participants, except for one, were capable of providing consent on their own. This was evidenced by their ability to connect with me by email and telephone on their own behalf, by the questions they asked me regarding the study, and by their obvious understanding of what participating entailed. One participant was still gainfully employed, while several of the other participants were quite involved in dementia advocacy and community groups. It was quite apparent that it would have been an affront to their sense of personhood and autonomy if I had asked them to have their consent forms witnessed.

Data Collection

Data collection in an IPA study involves accessing detailed first-person accounts of life experiences (Smith et al., 2009). As a qualitative approach, IPA does not “seek to find one single answer or truth, but rather a coherent and legitimate account that is attentive to the words of the

participant” (Pringle, Drummond, McLafferty & Hendry, 2011, p.23). Rich data in the form of expressed ideas and concerns can only be accessible if participants are able to speak freely and reflectively and are able to tell their stories. This is best achieved with the use of one-on-one semi-structured interviews (Smith et al., 2009). I interviewed two participants in person, both in locations that best suited them in terms of convenience and accessibility. One participant did not feel comfortable being interviewed at home. I was able to secure a quiet and private room in a community center located close to his home for the interview. The other participant was from another province but was visiting Vancouver and made time during his visit for me to interview him. He asked that I meet him at his hotel in downtown Vancouver, and I was able to interview him in a quiet sitting area of the hotel. Two of the participants live in Australia, and I was only able to interview them by telephone conference call and Internet Skype. The final interview, which was mostly with the participant’s daughter, was also carried out via telephone conference call, as the participant and her daughter live in a rural town and at a significant distance from me. All of the interviews were audio-recorded using a digital recording device.

A semi-structured interview schedule was developed (Appendix E) that helped to facilitate a comfortable interaction yet still allowed for flexibility. The goal was for each participant’s “story” to unfold spontaneously without me as the researcher leading the process in any way. Smith et al. (2009) advise that the interviewer approach the research question in a “sideways” manner. This involved facilitating discussions that were relevant to the question but that allowed for it to be “answered” later via the analysis process. This also included the use of open-ended questions that did not make assumptions about experiences (Smith et al., 2009). The researcher’s observations and thoughts that emerge as part of the data collecting process can also provide additional data (Smith et al., 2009). This not only enriches and adds to overall data, but

can also impact the manner in which ensuing interviews take place, based on the knowledge and insight that the researcher acquires as part of interacting with participants. Thus, I endeavored to record thoughts, ideas and impressions in a reflexive journal throughout the research process.

Special considerations. As the participants all had dementia, I was aware that communication and memory deficits could affect the interview and data collecting process. Data collection and interviews should always be managed with sensitivity and care (Smith et al., 2009) and this is especially vital while interviewing people with dementia. A wide array of interview and observational skills were required to adapt each interview according to participants' communication abilities and severity of disease. This was particularly the case with the interviews that took place via telephone conference call, as I was not able to rely on any visual cues in order to assess how the participant was doing. As the interviewer I needed to draw upon my sixteen years of nursing experience, during which I have worked and interacted with many different people in a variety of settings and contexts, and honed interview and assessment skills along the way. Although I was interacting with participants as a researcher, I did not forget that I am foremost a nurse. In a way, each participant was similar to a nursing client whereby the relationship between the nurse and client is "focused on empathy, understanding, and an acknowledgment of both the individual and the situation" (McCabe & Homes, 2007, p. 19).

It was vital to build trust, warmth and empathy during encounters in order to reduce anxiety (Clarke & Keady, 2002), and I relied on my background as an experienced community nurse in order to do this. Throughout each interview, I kept foremost in my mind the idea that the person with dementia should be acknowledged as the expert, as well as respected as "the master of his/her thoughts" (Clarke & Keady, 2002, p. 35). Thus, the interview process was approached in a flexible manner and I was sure to take cues from participants regarding the flow and pace of

the interaction. Fortunately, four of the five participants were quite eager to tell their stories and answered my questions without difficulty. All of these interviews lasted over 60 minutes. In terms of the fifth participant, it became quickly obvious that she was having difficulty answering questions, other than with one-word answers and with substantial cueing from her daughter, who was also present during the interview. I realized within minutes of the conversation starting that she was not an appropriate candidate for this study and thanked her for agreeing to speak with me.

Arts-based Data

There are times when an account of an experience can be enriched in additional ways, such as through the use of art-based strategies for data collection. Arts-based research is increasingly recognized as a method with which understanding of the health and illness experience can be augmented (Boydell, Gladstone, Volpe, Allemang & Stasiulis, 2012). Arts-based research incorporates the use of any art form, which can be considered a representation of an experience, enhancing understanding while both engaging and empowering the participants (Boydell et al., 2012). Thus, participants were all invited to express themselves and their sense of personhood other than just through their words. They were given the option to include the use of photographs, drawings, poetry or music, or via whatever means they should choose, as part of the process of relaying their experiences as a person with dementia.

While the overall goal was to have participants “tell” their story in an interview setting, if they also chose to supplement their accounts in a more artistic fashion, this was encouraged. It was felt that since dementia can affect language abilities, remaining open to alternate forms of expression could provide additional data that could potentially be quite rich and meaningful, and add to the fullness of the analysis and discovery process. Three of the participants provided arts-

based data, two in the form of music and one with the use of poetry. These arts-based accounts will be further discussed and incorporated in the “Findings” section of this paper.

Data Management

Interviews were audio-recorded from which verbatim and semantic interview transcripts were produced. The professional transcriptionist hired for this project signed a confidentiality pledge prior to transcribing the interviews. The audio recordings and the transcripts were kept in a password secure computer file that only I was able to access. Each transcript and audio recording was identifiable by the participant’s initials only. Copies of the consent forms, which did include the participants’ full names, were locked in a separate and secure file cabinet designated for this research project only and kept in my home. Data from this project will be kept for the minimum five years as per university policy. The participants are aware that data may be used for possible future research and that it will be kept confidential and secure at all times.

Data Analysis

The aim of IPA analysis is to interpret meaning, and this interpretation can only be derived from the content of participants’ interviews. The first analytical step was to immerse myself in the data to ensure that the participant’s account was the focus of the analysis, and this involved the reading and re-reading of each interview transcript (Smith et al., 2009). This also included listening to the audiotapes, in some cases listening to them several times. The next step was to make initial notes with the goal of eventually producing detailed and comprehensive notes and comments that were descriptive, linguistic and conceptual in nature (Smith et al., 2009). As Smith et al. (2009) state, analysis “involves looking at the language that they use, thinking about the context of their concerns (lived world), and identifying more abstract concepts which can help you to make sense of the patterns of meaning in their account” (p. 83).

Eventually, the data set evolved into what Smith et al. (2009) refer to as exploratory notes or codes. Developing codes from the interview transcript involved an important analytic shift, a questioning and abstract form of thinking where analysis moved beyond the simply descriptive (Smith et al., 2009). From this point, I was working more with the initial notes rather than with the transcript itself. From the codes or notes that emerged, the development of themes became possible. Themes emerged as a result of discovering connections and patterns amongst the initial notes. Above all, themes represented ideas that were developed from the participant's original thoughts and words, but also were a result of my interpretations as the researcher (Smith et al., 2009). In the process of developing themes, I wrote all of the exploratory notes on pieces of paper. I then sorted through them, reading and re-reading them, until I was able to connect notes together into groupings, where the concepts and sentiments expressed in each of them seemed to correspond to one another. From the collected groups of notes, I was able to develop a theme that assimilated the meaning in all of the notes. These themes and corresponding notes were incorporated into a table (Appendix F).

As part of IPA's idiographic orientation, the entire analytic process focused on one interview transcript at a time (Rassool & Nel, 2012), as it was "important to treat the next case on its own terms, to do justice to its own individuality" (Smith et al., 2009, p. 100). I initially developed themes within each transcript prior to looking at themes across all of the transcripts. As part of focusing on one transcript at a time, I had to bracket as much as possible any ideas and themes that emerged from prior transcript analysis when working on the next one (Biggerstaff & Thompson, 2008). While challenging, this was a vital process that allowed for new themes to emerge with each account. The final step in analysis involved looking for patterns or overall themes that connected all of the interview transcripts and that could be developed into master or

super-ordinate themes (Smith et al., 2009). Here, the interpretative leap was most obvious, as I was searching for themes to emerge that told a collective story of the experience of living with EOD. Ultimately, six master themes surfaced that incorporated the various themes from each transcript (Appendix G). If participants chose to express themselves in an artistic fashion, the participant's artistic rendering or offering became the "transcript" from which further analysis took place.

Chapter Summary

This chapter has discussed the theoretical underpinnings of IPA. It has also demonstrated why this particular research approach has been useful and appropriate for examining personhood and the EOD experience. This chapter has also described the methods that were undertaken in order to carry out this IPA study, including how analysis of the data occurred. Four people with EOD and one family member were interviewed for this study. The outline on the metaphorical canvas is complete and the themes that emerged from analyzing the interview transcripts and arts-based data can now be presented. It is time to paint the experience and illustrate what it means to be a younger person living with EOD.

Chapter IV: Findings

Painting the Experience

*They see me differently. I see the outside world as they do, but I also see the inside, what I am thinking and feeling.*⁴

Overview

An analysis of participants' accounts of their experiences is of no use unless it can then be explained to others (Smith et al., 2009). As van Manen (1990) states, "research and writing are aspects of one process" (p.7). The written account of the lived experiences of participants is a crucial stage in the IPA process. Writing the story that will hopefully answer the research question, as well as shed light on the experience, is both a process of presenting the data and interpreting it. It is similar to trying to paint an experience, of trying to get the light and colouring just right, while at the same time painting from one's own point of view. The following pages include transcript extracts to assist in illustrating the experience, as well as detailed analytic interpretations of text (Smith et al., 2009). It also includes descriptions and analysis of the artistic data. In effect, the act of writing is considered the final and ultimate interpretative step, where all of the information that has been accrued throughout this research process is subsumed into an organic meaningful account.

Personal Reflections

Over the course of this thesis project, I sat for many hours at my desk, analyzing data, listening to the recordings and ultimately, writing text that articulates the experience of living with EOD. For clarity, I must say that I myself do not have EOD and in that sense, I cannot truly know what it would mean to have this illness, and how this might affect my sense of personhood.

⁴ Thomas DeBaggio

Yet, I have been very fortunate to be able to talk to people who do have EOD and who have entrusted to me their own personal accounts of being that person: a younger adult diagnosed with some form of dementia. Throughout the process of analyzing the data, a representation of the experience of being a younger person with dementia has emerged. My hand has been behind the figurative brush, but it is the participant's experiences and accounts, the pigments and paint if you will, that are the foundation for the "picture" of this experience that has emerged.

Participant Biographies

Prior to presenting the themes that make up the whole of their separate accounts, it seems essential to present a brief participant biography, to provide insight into the lives and people who have made all of this possible. It is also important to identify the participants by a name rather than just a participant number, even if it is an alias, in order to reflect the very personal nature of their stories of living with dementia. With the exception of one participant who wanted to have his actual name used, the participants' names have been changed in this account to protect their confidentiality.

Paul was the first participant to come forward. He is a 56-year old man living in a large western Canadian city. Originally born in Ontario, he was 52 years old at the time of being diagnosed with Alzheimer's disease. He believes that he began to experience dementia symptoms around the age of 49. Paul is divorced and currently single, he does not have any children and he is currently working as a security guard.

Barry is originally from the United Kingdom but currently resides in a western Canadian city. He is 62 years old and was diagnosed with a Frontal Temporal dementia at the age of 61. He is married and has one adult son. Barry has not been able to work for the last two years following symptom onset and eventual diagnosis.

Simon was born and lives in Australia. He is 46 years old, is married and has four children: two from a first marriage and two stepchildren from his current marriage. Simon was diagnosed with a Lewy Body dementia related to his Parkinson's disease when he was 41 years old. He has been unable to work for some time.

Mick is 59 years old and was diagnosed with a Frontal Temporal dementia when he was 57 years old. He is also from Australia. He is married with two adult children and one grandchild. He also has had to stop working due to his dementia. I asked Mick if he would like to have his real name used in acknowledgement of his original poetry, some of which he has also allowed to be used in the following pages. He asked that only his first name be used to identify him.

I also attempted to interview Joanne. She is 61 years old and was first diagnosed with dementia at the age of 59. Joanne and her family have never been given a clear idea of the type of dementia that has affected her. Joanne lives in an intermediate care facility in a small rural Western Canadian town. She is married, has 9 children and 15 grandchildren. I have not included Joanne's personal account below as part of the discussion of themes as I was not able to interview her in depth, as it became quickly apparent that her dementia was too far progressed for her to participate fully. Although I was not able to use Joanne's interview, I would like to acknowledge her effort in trying to speak with me. I cannot include her perspective in the following pages, but her own circumstances serve to remind us that while there are many people who can no longer share their own stories themselves, they still have a place in the tale to be told. With this in mind, I have included some of her daughter Beth's words, in a way part of Joanne's story, to supplement the following thematic discussion.

Presenting the Themes

As I collectively examined and analyzed Paul, Barry, Simon and Mick's accounts of their experiences of living with EOD, six overarching and super-ordinate themes became readily apparent. They are as follows: A Personal Journey, Navigating the System, the Stigma of Dementia, Staying Connected to the World, A Story Worth Telling and I'm Still Here. At times, I have included Joanne's daughter Beth's point of view, to highlight similarities and differences between the family and person with EOD's perspective.

A Personal Journey

When I think back on my life so far, I can only see it from my own lens, from my own personal perspective. This reflects part of the discussion in chapter one, that each person's life experience is truly a subjective and unique phenomenon. The theme of "A Personal Journey" embodies this idea and takes into account that although the participants shared similarities with one another in terms of being a younger person with EOD, each had his own story to tell about a personal journey of dealing and living with dementia at a young age. This interpretation of the EOD experience speaks to the reality that dementia is a diagnosis that encompasses many different brain conditions and reminds us that we cannot consider all types of dementia, including EOD, as the same. Nor can we assume that the person living with dementia is living the same experience as another person with dementia. As part of the interview process, I often asked the participants to tell me about themselves. Without asking them directly about the symptoms of their disease, telling me "about themselves" involved detailing their dementia symptoms, along with the effects dementia has had on their lives. Despite this similarity in approach in terms of telling me about themselves, all of their accounts were distinct in their own ways, reflecting each participant's point of view and experience, in effect their personal journey.

It seems important to validate the participants' personal journeys by revealing the ups and downs of this journey in their own words.

Distinct symptoms. What became apparent amongst all of the participants' stories is the plethora of symptoms that people with dementia can experience and how these symptoms affect them all differently. The participants all felt that many of their symptoms are distinct to their personal dementia experience, and they also believed that this "distinctiveness" is common among people with dementia. As Barry stated, "Everyone is so different" and "there's no one the same" and Mick explained, "there's 47.5 million people in the world with dementia and no people have the same symptoms". While all of the participants did report memory difficulties of some kind, each person also described symptoms and challenges that were distinct to his own experience and journey as a person living with EOD. For instance, Barry has experienced changes in the way he tastes food, as well as daily and "extreme nausea" that has confounded his medical specialists. He also has great difficulty with sleeping and often has "vivid" and "terrible" dreams. While sleep disturbances are a common symptom of dementia, several participants experienced these difficulties in their own ways. Simon can go several days without sleeping at all: "I have sleep disturbance and I can go 3, 4, 5, 6, 7 days without sleep. I just cannot sleep. My head doesn't sleep." While Mick simply can only get a few hours of sleep each night: "I probably have 3 maybe 4 hours a night and on a good night I'll have 5 hours." Mick can also experience what he termed "epileptic-like episodes".

Where I'd just blank out and the eyes would be very dilated and I wouldn't know what was going on for the whole episode. I can still function but wouldn't know exactly what was happening. I just couldn't remember and couldn't comprehend it. And they could last anywhere from 10 minutes up to 7 ½ hours.

Simon's symptoms are intermixed with those of his Parkinson's disease. He finds that when his Parkinson's is worse and he is in pain and experiencing more fatigue, his dementia symptoms are exacerbated.

With the Parkinson's I'll have muscles in my body that will switch on like that and it can be very painful and very tiring and it may be strong for hours or days or even weeks sometimes so being in pain can definitely affect things.

For Paul, living with dementia is a bewildering process of the familiar becoming less so over time. As he stated when describing the city he lives in:

It's not familiar anymore. And I've changed. I don't remember. I just don't remember. I'll be in the same area that I used to be, maybe even lived in but nothing is familiar to me anymore. It becomes less familiar.

Age-related experiences. While the varied symptoms and experiences that each participant described are distinctive to each person's own journey along the dementia continuum, it was also quite evident that each of these personal journeys is tinted by the fact that they are experiencing the illness from a younger person's perspective. As Simon explained, having dementia in his 40's has been extremely challenging, especially as most people his age are usually busy establishing their careers and personal lives.

But yeah, people in their 40's, they you know, people are buying houses, they've got good jobs, they've got good cars, they go on holidays and things like that so all that stopped. Everything completely stopped. I had the whole...it was like I felt like the rug pulled out from underneath me.

For Barry, who is in his early sixties, a diagnosis of EOD represents an end to his dreams of retirement. He has had to stop working early and register for a disability income. As he

explained, “It screws up all your plans. Just what you think of what your time is going to be like down the road as you’re working, going through life. You know it’s not going to be that way now.” What is significant about these accounts is that EOD is a distinct experience for each person that can differ depending on the actual age of the individual experiencing it. Barry has already raised his son and is focused on his sixties and what should have been his early retirement years. Simon still has young children at home and struggles financially, as it is very difficult to manage on his wife’s sole income. Despite facing challenges that older adults with dementia likely do not have to face, it is apparent that each person’s experience with EOD can be specific to quite definite phases in mid-life, for instance one’s 40’s or 60’s, as the two cases above illustrate.

A dichotomy of perspectives. Two very different points of view also became evident, in terms how the participants reflect on and evaluate their quality of life. For both Mick and Paul, it is very important for them to maintain a positive outlook and to celebrate new skills that they have learned since being diagnosed. While Mick is very open about how difficult the first year of his life was after diagnosis, he now feels that he is able to enjoy his life as much as possible and focuses on “living well” with dementia. Mick does find his symptoms challenging and is aware of the degenerative nature of his disease. Yet it is vital for him to remain as positive as possible, even in the face of his worsening symptoms.

There’s a lot of things that are frustrating and a lot of people look at them and say, you know, I’m getting bad and things are getting worse. Well I say, it’s part of it. Suck it up sunshine and keep going. I mean, you know, you’re not going to stop it. They are going to appear. Things are going to decline. Just build a bridge and get over it!

This perspective is also evident in his poem “Be Positive”:

I start my day just like you do except some days I start with mentia from early in the morning

Sometimes Sue tells me I have been snoring

Each day starts without a plan, because when an episode occurs you know not where or when

Some days we go to the local plaza, some days we stay home every now and then

Jigsaw puzzles are a big part of our life, make you use your brain they say

Personally I can't see any improvement but puzzles are here to stay

Stability is a big problem along with cognitive skills are getting harder each day

Frustration becomes a daily event at little things getting worse are here to stay

I often ask myself where did I go wrong what have I done wrong

Sometimes the feelings are so strong

A thousand questions only one answer, Dementia is here to stay

Blame and guilt do not help even though they will not go away

All of this can bring a tear to my eye giving in to a good old cry

I often say I am sorry to my wife for putting her through all of this does leave us dry

Enough of sad times now for good times

Be positive and say each day I will smile

Writing poetry is a new talent that Mick discovered after being diagnosed with dementia, and he has found that it helps him express what he is going through. For Paul, living with dementia has made him "a better person". He has discovered new aspects about himself, as well as new talents as he has learned to deal with his symptoms. Paul feels that he must continually challenge his mind, as a way of delaying worsening of symptoms. One of the challenges that he

set himself after his diagnosis was to learn a new language. He attempted to learn Dutch as his girlfriend at the time of diagnosis was from Holland. It turns out that he had a previously unknown talent for languages and this came as quite a revelation to him.

But I found that it was really easy. I had a knack for learning language and with dementia! Like that really shocked me! Like why my brain all of a sudden will let me learn another language like Dutch, which is what I was told was the most difficult language to learn.

While both Mick and Paul feel that they are living well with dementia, despite the challenges the disease presents them with, Simon and Barry feel quite differently. Barry is aware that not all people live well with dementia, and he seems to count himself in with those who struggle with the disease's effects on their lives, particularly in the way that much enjoyment in life is now gone. As he explains, "It's just...you know, there's no enjoyment in life anymore. You know, I used to enjoy food, cooking it, eating it, you know, cooking it for others. I don't enjoy that anymore." When Barry hears of other people with dementia who appear to be living well with the disease, he finds that he cannot relate.

I mean, I know I've got a problem and I try to get around it. I try to do the best I can but you know, I wish...I find it irritating to read stories about people that you know, with dementia, they'll ride bikes and climb mountains, and run. And I don't know how they do it. I don't know how they do it!

Simon feels similarly and while he understands the need for positive language when it comes to describing the dementia experience, he also feels that it is important that both side of the story be told.

There are people like me that don't live well with dementia. And when you see a lot of

the advocates and a lot of the news articles and a lot of things that are out there, they're all about people that are getting about and they're doing things and they're being positive, and they're able to travel. I can't do that. That's not my life and I can't relate to those advocates of dementia...living well with dementia. So for me it's really important to know that that sometimes people don't live well with dementia. And it's important that that side of the story gets told as well.

All of the accounts above relate to the personal nature of dementia and how the type of dementia, its symptoms and challenges, can differ dramatically from person to person, and within different phases of mid-life. A person's outlook can differ substantially as well, whether one feels he is living well or suffering with dementia. The disease's course and that person's overall experience of living with the illness is indeed a personal journey.

Navigating the System

When one is about to embark on a journey, maps and direction come to mind in terms of navigating and finding one's way. The idea of "navigating" evokes planning, clear paths and a sense of direction. However, rather than navigating a road as in a literal journey or trip, the personal journey of living with EOD seems to entail navigating a challenging medical and resource system, one that is particularly difficult for younger people with dementia to negotiate. Based on the participants' accounts, as well as on Joanne's family's story, the theme of navigating the system unfortunately reflects the obstacles they have faced and lack of direction and resources they have encountered, as part of living with EOD and trying to find help and assistance along the way.

The uneven road to diagnosis. A significant aspect of each participant's dementia journey began with the process of getting diagnosed with EOD. All of the participants had their

own story to tell in terms of the difficulties they encountered in dealing with physicians, and of how challenging it can be to get an actual diagnosis of dementia when one is a younger person. Barry explained how he ended up seeing several doctors in his search for a diagnosis, and he expressed how he felt that he was often not listened to when trying to explain his symptoms and concerns.

You see, I saw one guy you know, as the journey goes you're you know, when you're trying to figure out what's wrong with you. You see different specialists and doctors and they all have different opinions and the one thing I find is that doctors never listen to the patients. They just listen to their textbooks and what they're told to look for and what they're told to...they'd don't listen to your story, you know?

Several of the participants were initially told that they were likely suffering from a depression, or that their symptoms were related to causes other than dementia. As Mick described it, "They blame depression, they blame stress, they blame everything else." When their symptoms were finally being more thoroughly investigated, this often involved seeing multiple specialists. As Barry explained, he has seen "about six neurologists." Seeing multiple specialists and having to re-tell one's story over and over again seems an exhausting, demoralizing and depersonalizing experience. Barry described this process:

You know, and initially, my family doctor was...he was very good. He sends us to all sorts of you know, specialists but he was totally in denial. And I think he shouldn't have been. He was...he never listened to everything I told him about what my problems were. He would just oh okay, yeah, yeah. You know, go and see this guy and...they don't listen to what you're telling them. Well they don't have the time. You've got a ten minute meeting with them right? They just give you a pill and okay, we'll get you in to see a

specialist you know. You wait six months to see a specialist and then you see them and then they say, “Well, we can’t help you.”

For Paul, the process of dealing with doctors and specialist was so unhelpful that he simply stopped seeing his doctors. Similar to Barry, it was a de-humanizing process, and one that brought up feelings of anger and frustration. As he explained:

...I was already angry because every time I came there I didn’t learn anything and nobody was telling me anything or helping me or doing anything that benefitted me in any way at all. It’s just like I was just you know, a doll that they were just like testing or something but not offering any solutions or you know, nothing and I found it very, very frustrating and I just stopped going.

Getting a diagnosis of EOD can take a long time, and in Simon’s case it took “three and a half years.” As he was in his early 40’s at the time, he found that he had to “jump through hoops”, in order to not only get a diagnosis but to access resources normally easily available to people with dementia. As he stated, “According to the government here in Australia, I’m not supposed to have this disease until I’m after 65.” Joanne’s family also described similar frustrations in dealing with the diagnosis process. In fact, they felt left out of the diagnosis process, especially as they felt that they could provide vital collateral information. As her daughter Beth described, “it did take a long time for us to convince the doctor that she was not well.” Joanne’s family knew that there was something wrong but felt that the doctor was not taking their concerns seriously.

It was always...you know, she’s under stress and so it didn’t seem to matter how often we told the doctor that you know, things weren’t right. Like even my sister sitting right in there, the doctor right out told my sister that she had no right to speak for my mother.

When my sister was trying to say like this isn't right. Mom's doing these things that are totally abnormal and the doctor kept saying you don't know what's normal. You don't live with her 24/7 and you know, this is what happens when people age and like just kept kind of brushing off what we believed to be turning into a serious problem.

Based on the participants' stories, along with Joanne's family's perspective, an image of the road to diagnosis as a challenging and long process for all involved is evident. Unfortunately, they all found that there were few resources to support them in this process, and even after diagnosis the supports available to them did not fit their needs.

Resources: No sense of direction. The resources that are available to people with dementia are often not very helpful for a younger person, as some of the participants divulged. Barry attends a monthly support group with other people dealing with dementia. Unfortunately, he does not find the support group very useful, mostly because he finds that he cannot relate to the other members in the group. As he stated, "most of the time you know, you look at these people and they're all totally, totally different symptoms than you have. So you can't really relate." It also does not help that Barry finds the support meetings "boring as hell".

When Mick was first diagnosed, he struggled for about a year, trying to come to grips with his diagnosis and its implications. He did not find that there was much support available for him during that difficult time, and the resources that were in place were in his opinion "pretty damn useless anyway". As he further described that challenging first year: "That year it's absolute hell. You don't know where to go, you don't know what to do. They don't advise you." Joanne's family found that her age was a barrier to accessing resources. As Joanne's daughter explained, "Well, you can't get funding for this and you can't get funding for that. You're not the right age." Paul similarly echoed what he feels are a lack of resources, especially for younger

people. As he stated, “there’s very little for somebody my age you know, not that I’m super young but I’m 56.”

A common thread within the participants’ accounts is that they strongly feel that it would be helpful to have resources that reflect their experiences of being younger people with dementia. As Paul explained:

But I think the best thing that could have happened for me in a perfect world was when I was having these difficulties, was diagnosed with having dementia, that there was people that I could have gone to talk to, to see how they’re coping.

In the end, it has not so much been government or system-organized resources that have been helpful to Mick, rather it has been being able to access the support of other people with dementia through programs that have actually been organized by people with dementia. Mick is part of a weekly discussion group that he accesses via Dementia Alliance International, which he described as a self-funded organization run by people with dementia. For him, it is most helpful to talk to people who can relate to what he is going through: “And you’re sitting there talking to people that have the same...not the same symptoms but they’ve all got some form of dementia and to talk to like-minded people about their issues and they understand you, it’s so empowering.” Barry brought up Paul’s Club, a recreational group in Vancouver that he had recently read about in a Globe and Mail newspaper article. Paul’s Club attendees are viewed as members and not patients of the club, and the focus is not on discussing or focusing on the members’ dementia symptoms but rather on social and recreational activities. As Barry explained, “And that sounded very interesting, what they do. They kind of meet and they do...that sounds really good. I wish I had something like that. Yeah, I’d really get into that. I like that.”

Simon is very aware of the fact that he likely will require facility care as time goes on and as his dementia symptoms worsen. As Simon is still in his 40's, he knows that he will still be quite young, probably in his 50's, when that time comes, and that the facilities that would cater to his needs are in fact set up for adults who would be much older than him.

If I get to that point in the next 5 or 10 years, I'm only going to be 50, 55 years old and the only facilities that are available for me to go into are aged care homes so somebody my age who uses computers and the internet and you know, pay TV and all those sorts of things, I'm going to be going into a completely different environment where the people who I'm going to be with are in their 60's, 70's, 80's and 90's. So that's a big difference.

Paul is similarly aware of the age difference between himself and the people he often saw at the doctor's office:

A lot of Alzheimer's patients, the only ones that I ever saw, I didn't see anybody in my age bracket at UBC. They were all in their 70's and 80's and 90's. They were you know, well in their years. I think it's a totally different experience for them than it is for somebody who's my age who's going through it. But there is no resources really.

Navigating the system has been challenging and frustrating for all of the participants, not only in terms of diagnosis and treatment of their dementia, but in the way it has revealed to them the gaps in resources available for younger people with dementia. While some have eventually come into contact with helpful services, or have identified services that they feel would be useful to them, the sense that navigating a medical and resource system that does not recognize the needs and challenges of younger adults is a strong theme that colours the participants' and family's collective story of living with EOD. Along with the difficulties of navigating the system, each participant has also experienced stigma, a third overarching theme prevalent within

all of their accounts.

The Stigma of Dementia

Stigma is a powerful theme that weaves in and out of all of the participants' descriptions of living with dementia. All of the participants experienced various levels of lack of understanding, misperception, and poor treatment from other people, where their diagnosis of EOD became the "stigmata", the mark that distinguished them from others, making them feel different and affecting their self-worth. It is fitting to begin the discussion of this theme with another of Mick's poems which is appropriately entitled STIGMA.

As I lay awake at two am I wonder what today will bring
I will face all challenges head on if I have to even sing
I am told when I sing it rhymes in verse every time
Great amusement and delight to my grandson that it does rhyme
How long, how often will Mentia last
My greatest challenge is to reduce the amount of stigma and put it in the past
Stigma to me is the greatest education factor not which is the last
Make it your personal quest spread the word and educate all
I tell as many people about dementia and stand tall
Today will be just another day in the life of a person living with Dementia which will
stay
No you can not catch it like a cold
No need to avoid me like you have been told
If you know me well, I am still here, even though I may not remember your name
Yes its still me I am still the same

Mick's words that dementia cannot be caught "like a cold" and that there is "no need to avoid me" emphasizes the unfortunate power of stigma: the discomfort others can feel around the stigmatized which causes the sense of being avoided and treated like second-class citizens.

Lack of knowledge and understanding. At the root of stigma is often ignorance and lack of knowledge. Part of the problem in terms of ignorance and the EOD experience, identified by several of the participants, is that because they are younger than most people with dementia, they simply do not "look" like how a person with dementia is expected to look. This seems partly due to the fact that younger people with dementia can appear healthy and well at first glance. Barry often finds that people are surprised at how well he seems outwardly. As he related:

One of the frustrating things of people, well I find is that you meet people you know, the relatives and friends, and they'll say, "Oh you look fantastic!" And you feel like saying, "Well yeah, I probably do but I don't feel it."

While at first it seems a positive comment to tell a person with EOD that they "look fantastic", it can also create a feeling of dismissiveness and of not acknowledging the reality of living with EOD. Dementia is not always obvious to others as Mick's description of a recent encounter with a woman who had just found out that he has dementia reveals:

One of them said, "Oh, you don't look like someone with dementia. You're talking just like us and you're functioning just like us." And I said to her, "What does a person with dementia look like?" I asked her that. Oh she didn't know. I said to her, "Ok I don't have one arm and one leg off because it's in my brain. It's not in...it's not a disability that you can see."

Barry also iterated this same idea, that dementia is not always physically noticeable. He also talked about how the younger person with dementia does not fit the image of an elderly

person with dementia.

...that's what's so hard about this disease is that it's not noticeable on the outside. You know eventually, you know, probably, yeah. You know, and they always think you know, someone with Alzheimer's/dementia, it's an old guy sitting in a corner with a cane and they don't expect to see a younger man that can walk around, function, talk...

Mick believes that younger people have to deal with more stigma than older people with dementia. As he explained:

Because we're out a lot more. Like the most common thing is as I said before, you don't look like someone with dementia. You talk normal, you act normal, and as I've said to them, "You don't see what's going inside my brain. You don't see the way that I act at home. You don't see the difficulties I do have in everyday life."

The dementia label. Once a person's dementia diagnosis is out in the open and known to others, "a label of dementia" as Simon explained, is bestowed upon them. While those with dementia may still see themselves as normal people, having a dementia label has given them a sense that they are now different, an experience that is reinforced by the way they are treated by others. According to Simon, "when you have that dementia, people seem to treat you differently." As he stated, "It's sad that you can be talking to somebody and once you mentioned the D word, dementia, you can tell the conversation is going to end or change." Simon also recounted that at times it can seem that others are not even recognizing his presence, in the way that people will talk about him and not to him:

If we went to say a friend's house and they know that I have dementia, quite often they won't talk to me. They'll talk to my wife. So instead of saying, "How are you [Simon]?" They'll say to me wife. "How's [Simon] been doing?"

According to Mick, “people don’t know what to do. They don’t know how to talk to you.” Mick has experienced a woman at his local shopping center speaking very loudly to him, almost as if he were deaf. “She thinks I’m deaf and that’s how she handles me with dementia, you know? And she speaks very plainly as if I’m supposed to read her lips. I’m not deaf!”

While several of the participants are open about their diagnosis, it is a subject that Paul does not always bring up. While his family and friends are aware of his diagnosis of Alzheimer’s, Paul has developed coping mechanisms to “hide” his dementia from others. Of the four participants, Paul is the only one that is still working. He struggles a great deal with facial recognition and he has learned not to “let on” to people when he does not recognize them. He finds that eventually people will drop enough hints without realizing it in a conversation, and then he is often able to figure out how he actually knows people. As Paul stated, “that’s how you fool people I think, with dementia.” Paul is aware that he must hide his diagnosis from certain people in order to be able to keep working, highlighting the stigma that people with dementia must deal with regularly regarding their ability to cope and function. It is interesting that Simon has found that people can be more accepting if he uses the term “degenerative brain disease” rather than dementia. As he explained, “If I say I have a degenerative brain disease, people act more positively or respond better but if I say I have dementia, then that’s when I notice that things can drop off”.

The isolative nature of stigma. In fact, many of the participants have lost contact with friends and family members since being diagnosed with dementia. This loss of contact is attributed to people feeling uncomfortable and not knowing how to act around them, and this process of people distancing themselves or losing contact is extremely hurtful and difficult to reconcile. For Paul, it was an emotional experience to talk about how loved ones distanced

themselves over time after his diagnosis. As he explained, “I think that same year that my girlfriend left me my brother stopped calling me. My sister stopped calling me.” As Simon recounted his experiences with family and friends, “I was shocked. I was actually shocked. I honestly thought people would make more of an effort to ring and talk and I’ve actually found the opposite in fact...”

As illustrated in his poem earlier, stigma is an issue that Mick feels very passionately about and he works to break down the notion of stigma as a dementia advocate. According to Mick:

People have...it’s always been look, go and sit down in the corner. Sit there and stare into space and try not to dribble on the floor and they don’t think that we’ve got you know, our brains still function, that we’ve got feelings...basically we’re the same person inside. It’s just the functions, the normal functions don’t work and it’s so hard to break that stigma down. Stigma is the number one issue facing people with dementia worldwide. As Mick so powerfully explains, that pervasive perception that the person with dementia is no longer the same person and no longer has the same worth is terribly damaging and a constant challenge for those living with dementia.

Staying Connected to the World

While dealing with stigma can be hurtful and demeaning to a person with dementia, the changing life circumstances imposed by dementia, such as severed or affected social and family roles, can cause further isolation. The theme of Staying Connected to the World relates to the participants desire to find continued purpose and meaning in their lives, and of staying connected to the people and world around them.

Challenges to staying connected. While Paul is still able to work, most of the

participants have had to stop working. This has represented a great loss to all of them, not just in terms of loss of finances, but also in terms of their feelings of self-worth and of not feeling connected to the world around them. For Simon, the youngest of the participants, not working has been very difficult. As he explained, "...I've always had that work ethic where I have always worked hard so to go from that to not working has been awful!" It is not just the inability to be gainfully employed that is hard to deal with, but also the fact that there are many tasks he can no longer help out with.

...if a bill comes in and we're struggling to pay it or is something needs moving around the house or we have to go and help somebody do something, I can't do those things anymore. I just struggle and so that self-worth that I had has decreased a lot.

When Simon is having a "good day", he really notices that it feels good to be "doing tasks or being able to complete something or being able to step in and take charge of something."

However, he often recounted a feeling of being a "third wheel", a "third party" and "an outsider" when describing the world around him and his frequent inability to participate and be included.

For Barry, it is his struggle with motivation and pervasive exhaustion that isolate him from the world around him. It is extremely challenging for him to stay active and he described his daily life in a way that underscores his isolative and likely lonely days. "I'm stuck in a condo seven days a week doing the tai chi and trying to do my odd walk and that's about it. That's my life."

Finding meaningful activity. It appears that being able to take part in an activity, that allows the person to feel that they are productive and contributing in some way, is crucial to helping the person remain connected to the world and increase feelings of self-worth. As Paul described, "But I do know that feeling wise, quality of life wise, I feel better if I'm doing something and contributing to society, especially working." This could be anything from being

able to work as Paul does, to advocacy work and volunteering, or even participating in an enjoyable hobby. Simon enjoys stamp collecting and is the administrator for a large on-line stamp collection group. He really appreciates being able to participate in an activity that he can share with others and which makes him feel that he is making a contribution of some kind. “To me that’s become like my work and it gives me purpose and that’s something that’s really important to me is my stamp collecting and being involved in a Facebook community.” Mick feels similarly: “You’ve got to find something that you’re interested in and go out and do it. It’s got to be meaningful.” Mick credits meeting other dementia advocates and becoming involved in advocacy for helping him to pull out of the “dark place” his life was in the first year after being diagnosed. Mick is now involved in running his own on-line discussion group in Australia, work that he finds immensely empowering.

It is difficult for people with dementia to remain engaged with the world around them, especially when dealing with other people’s negative perceptions and attitudes about living with dementia. Mick finds these negative perceptions start right at diagnosis, especially when people are often told by their specialists to get their life affairs in order. As he explained:

Well the biggest thing out here too we’re fighting against is the day you’re diagnosed out here by the specialist and it’s the same worldwide, you’re told to get your life affairs in order and go home and prepare to die.

Thus, finding activities that give purpose and meaning seems crucial, as a meaningful way to stay engaged with the world and to combat the prevailing message that all is hopeless. It also seems important to remember that even once symptoms worsen, people with dementia are still connected to the world around them. Paul articulated this idea:

My facial recognition is bad but I also recognize that I’m not going to lose that

connection like they think I am. You know, I think with dementia when your brain gets to the point where it's damaged enough that you're not remembering you know, cognitively, your memory you know, much of anything, to the world, you still have a conscience going on in there. You still have a world that you're living in in your head. You may not be able to express it but it's there.

As Paul also succinctly explained, "Everyday is a bit of a challenge at times, but at the same time, you're still connected to the world."

A Story Worth Telling

As part of helping people with dementia stay connected to the world, it seems important to hear their stories in order to understand their personal dementia journey and the challenges they live with everyday. All of the participants felt that they had a story to share that was worth telling, and this was largely what led them to wanting to participate in this study in the first place. There was a strong sense within all of their accounts that not enough of the EOD experience is known about and understood, particularly from the person's subjective point of view.

The power of the personal account. Mick believes that if other people hear personal stories about what it is like to live with dementia, this will resonate with them and be more meaningful. "But unless they hear a personal story from somebody with dementia, they're not going to take a lot of notice." All of the participants expressed a desire for other people to ask them directly about their experiences living with dementia. Simon explained, "I would love people to ask information and ask questions because if they can understand where I'm coming from, they'll probably understand my situation a lot better and probably be a little more forgiving." Paul is aware that his family and friends have a lack of knowledge and understanding

when it comes to his dementia. “I think it’s like a lot of people who don’t understand dementia or understand you know, the symptoms of Alzheimer’s. It’s that they just look at the worst possible scenario and it scares them.”

Mick gives presentations about dementia as part of his advocacy work and he has realized that the general public has a lack of knowledge about what it means to live with dementia. He finds it dismaying at how little people know about dementia, especially as it is a disease that touches many families.

...it’s becoming very apparent that people, they know of the word dementia but they don’t know what it means. They don’t know how to treat people with dementia. It’s quite often been a very close member of their family and they don’t know anything about it. I mean to me, that’s got to be changed.

As he continued to explain, “...I’m finding that wherever I go and give presentations and talks, talks too, people are so hungry for information.”

Listen and try to understand. Along with hearing the person’s story, it also seems that this also involves asking the person how they are doing and avoiding the use of platitudes. For Barry, this reflects back to his annoyance and dismay when people tell him he is looking “good” or “great”. As part of trying to hear his story, he feels that “people should be saying like...you know, you’re having a hard time. Just ignore how he looks. Just say like you know sorry, how are you? Don’t say you look great because that doesn’t make it any better.” Trying to get people to really see the challenges that he deals with on a regular basis is very frustrating for him. As he stated, “You know it’s like what do you have to do to get it into them that there is a problem?” Having one’s story heard properly includes not only family and friends taking the time to listen and understand, but health care professionals as well. When Barry found a doctor whom he feels

finally took his symptoms seriously, it was very affirming to his sense of self and what he was going through.

And God! I mean, it was just so good. He listened to you. Yeah. He was the only doctor who even did. And I can't even remember what he...an internist...I can't remember if he was an internist or what it was. He might have been. I can't remember. But he was good you know, like all the others just sit you down. Oh yeah, yeah, and you just you know, they don't listen to you. Don't listen to your story, what's going on. Because you know yourself, they're all different. I was always different, right?

The theme that each person's story is worth telling harkens back to the theme of a Personal Journey, in that every experience with dementia, at any age, is distinct. As Simon simply but powerfully stated, "Their story is not my story" and this speaks to the uniqueness of the dementia journey. Mick explained that only the person going through dementia can really understand what it means, "see no one understands what we go through." The theme of a Story Worth Telling underscores an important reality, and this study's final thematic account, that the participants feel they are "still here" and that their experiences and realities need to be heard and understood.

I'm Still Here

This is an incredibly powerful theme that was collectively revealed when examining the participants' personal stories. Of all of the themes, this one was also most evidenced in the arts-based data that was shared by some of the participants. Mick's poem "Nothing for YOU to fear" speaks to his sense that he is still a person, not one to be feared or felt uncomfortable around because of his dementia, but a human being, deserving of respect and dignity:

Dignity and respect are what we expect

We have no obvious disability signs, that is correct

I don't dribble at all

I often come close to a fall

Treat me as you wish to be treated

There is no need to be conceited

I am still me

Can you not see

I am still here

There is nothing for you to fear

I'm still a person. Mick encourages people with dementia to speak up about living with the disease, "we need more people to stand up and say, 'Hey! I'm still me, I'm still here.' You know? 'I'm still a person.'" It seems it is a constant challenge to remind people of this idea, as the losses and changes that dementia force upon the person are difficult to look beyond, particularly for family members. Mick further elaborated:

And it's so hard to convince them that they are still the same person. Sure they've lost a lot of abilities, and yeah, as I've said, cognitive functions and memory and everything else and their brain's not all there like it was. There's part of it missing and whatever else but they can still think. They still feel the same. They basically still act the same....

While this subjective point of view is compelling, Beth provided a family perspective that is quite different. As Beth emotionally explained, "Mom's still here with us physically but she's not in other ways." This serves as a reminder of the losses family members and loved ones must reconcile with, as they deal with the changes that dementia incurs in their loved one over time. As Beth further recounts, "I sometimes feel like Mom's just been stolen from us right? I just feel

kind of...as her family and the ones who love her, I feel kind of like we've been robbed of something really precious to us." Beth also stated, "I would describe her as somewhat empty and I don't think she realizes it but it definitely affects us." I was not able to discern how Joanne sees herself as a person, now that her dementia is quite far progressed. Yet her family's point of view is significant and heartbreaking, revealing the extent of dementia's reach and its effects on the person's loved ones.

A person worth including. Mick strongly feels that if people with dementia are included in decision making and in basic conversation even, this could make a great difference for them. "They've got to include them. They must include them because that's when they get unhappy. That's when they start and act differently because decisions are being made without them and it shouldn't happen." While Beth and her family feel that Joanne is very different in many ways than prior to the advent of her dementia, they do notice that Joanne reacts positively to activities that she very much enjoyed in the past, such as family get togethers.

This past weekend we were all together at my sister's home for a birthday party and it was like Mom sat there and her eyes were light. She was smiling. She wasn't responsive in that...normally she would have been right up there making jokes with everybody and you know like if anybody was going to start a food fight, it would have been my Mom right? So she's not doing those things anymore but yet she's still enjoying that interaction that she sees happening and it's like calling to something deeper inside of her right?

This account speaks to the idea that a connection can still be made with the person, despite advanced disease, and that there is worth in still including the individual in the world around him or her.

Different but the same. The theme "I'm Still Here" speaks to the sense that the

participants on the most part feel like themselves and that their continued presence as fellow human beings in society needs to be recognized. This sense of still being here does include the perception that parts of themselves have been altered by dementia. Simon explained that because there are many tasks that he can no longer take part in, it does make him feel less of a person at times.

I can't drive anymore. Even just to get to the local shops, I can't do that. I've lost most of my independence. So from a feeling point of view, I feel less of a human being, less of a man. I struggle with that.

However, what is important for him is to be treated as he was before, as it seems this would help him feel a whole person. As Simon added, "I would tell the people just treat me like you treated me before. As simple as that."

Barry was able to relay his own sense that while he still feels that he is the same person in many ways, he does realize that parts of himself are different. As he explained, "I still feel like me. But different. It's like you know, I know I'm still me. I know I'm still there. But I know a lot of me isn't still there." Paul also was able to describe a sense that there are parts of himself that are now different, particularly in the way that he can no longer rely on his memory and on his brain. For him, recognizing that he could no longer trust his memory was a turning point for him in terms of accepting and managing his dementia.

I always trusted my own intellect, my own mind, my memories, trusted all of it but I recognized that I couldn't anymore and that was the start of really self-healing or you know, active-participation and making myself better, not giving up.

No longer trusting his memory and his "own mind" has not meant that Paul cannot trust himself. As he stated, "...I trust myself." He has a strong sense of who he is as a person with dementia,

that any difficulties and challenges he faces are due to the illness, and that who he is essentially has not changed. As he explained, “It’s how the brain works but it doesn’t change who you are.”

Paul contributed the song “I’m Still Here” as part of his arts-based data contribution. It is a song written by family members of a person with dementia. Paul finds it meaningful to him because he feels that it has an important message. According to Paul, “I love that it speaks from the person’s point of view who has dementia. It kind of expresses that point to the world...to the people listening that I’m still here you know?” An excerpt from the song has been included below:

Don’t get so frustrated

This is not what I had planned

I’m slowly losing control

And it’s out of my hands

But you came to my rescue

You hold me up

Stand by me...I’m still here (Steele & Rubino, 2009).

Simon iterated that the losses he has experienced and the challenges that he faces take away from his feeling of being a successful person. As he put it, “So...yes, I feel human. I feel like I’m still a person but also feel like a failure as well in a lot of areas.” While this feeling of failure is difficult to deal with, it seems that Simon also feels it is important that his status as a human being is recognized. As Simon explained the words of John Lennon’s song “Imagine” are meaningful to him and as he put it, “...they speak to me and they remind me that I’m still a human being you know? I can think yeah, imagining if we are all the same.” In the immortal words of John Lennon (1971):

You may say I'm a dreamer
But I'm not the only one
I hope someday you'll join us
And the world will live as one

While dementia incurs losses that only increase over time, it seems vital to remember that the person, though possibly changed in many ways, is still here. It is likely very difficult for family to reconcile this notion with the changed person they see in front of them. However, this final theme connecting all of the participants' accounts reminds us that we are all people, despite our differences and our personal challenges, and despite the losses and changes a condition like EOD imposes, we are all living in a world where ideally we all should be able to "live as one".

Chapter Summary

The super-ordinate themes that have emerged following data analysis amongst all four of the participants' accounts have now been presented. The findings have been supplemented by Joanne's daughter's point of view. The themes examined in this chapter, A Personal Journey, Navigating the System, The Stigma of Dementia, Staying Connected to the World, A Story Worth Telling and I'm Still Here represent the participants' collective account of living with EOD. Through the use of interview transcript excerpts, song lyrics and original poetry, a picture of living as a younger person with dementia has been interpreted: The "painting" is now revealed. The following chapter will consider how these findings answer the research question, what the implications of this study are to practice, and discuss the strengths and limitations of the study as a whole.

Chapter V: Discussion

Examining the Painting

They all try to understand, but losing your mind happens once a lifetime and their imaginations are lacking.⁵

Overview

Imagine you are standing in front of a painting and are trying to understand its particular meaning. In museums, there are often informative placards next to works of art, explaining their significance. The previous chapter has portrayed a collective account of the experience of living with EOD. This portrayal has meaning on a larger level and this chapter will endeavor to explain the “so what?” of this research study. In effect, this chapter is similar to the placards in the museum explaining the meaning and import of a display. In this case, this chapter will endeavor to describe how the study’s findings fit into the body of EOD knowledge, as well as add to it. The interpretative rendering of the experience of EOD that is this research study, the almost completed work, is coalescing into a representation that hopefully has significance and purpose. The following pages will explore the findings and discuss how they relate to the research question. Implications for practice, as well as the limitations and strengths of this study are also considered.

Reflecting on the Research Question

As the researcher and analyst, my task was to try to make sense of the participants’ experiences, as they were in turn trying to make sense of their experiences of living with EOD. The super-ordinate themes that tell the collective story reveal an illness and life experience that is being lived and understood by *people*. At first glance, this seems an obvious and perhaps trite

⁵ Thomas DeBaggio

observation. Yet, I feel this is important to state when considering the research question. To reiterate the research question, it was “*How do individuals with EOD perceive the impact of dementia on their sense of personhood?*”

When reflecting on the research question, it is evident throughout the combined narrative that a robust sense of personhood and of simply being people is present for the participants as a whole. Their story, as uncovered in the previous chapter, reveals that they are individual people living with EOD, each experiencing and dealing with the illness in his own personal way. This includes being a person who is either living well with or suffering from dementia. In fact, all six themes that emerged from the participants’ stories reveal that living with EOD is a very personal experience, wrought with changes and losses, frustration, isolation and many challenges that are specific to each person. It is also a personal life and illness experience filled with new realizations, acceptance and for some, triumphs along the way. The participants’ identities as men, fathers, husbands, friends, and undeniably people, are strongly portrayed. Of significance, they can also feel less of a person when others do not understand what they are going through, or when they feel that they cannot contribute and take part in the world around them.

Yet even this affected sense of self, of being different or changed from who they once were, adds to a fuller sense of personhood. This idea fits nicely with part of the discussion in Chapter Two, which considered that decline and change is in fact part of being a person, and does not in itself suggest becoming less of one (Lesser, 2006). Dementia is most often seen as a disease of ever growing losses that diminishes the person over time (Millett, 2011). For younger people, it can seem that the losses associated with dementia are magnified, as the disease takes hold in the prime of life. Thus, some may see the threat to personhood greater for younger people with dementia than for their older counterparts. Nevertheless, despite the great challenges the

participants face as younger people with dementia, their story in fact embodies personhood.

This sense of personhood is evident throughout each thematic thread, but none more so than in the theme I'm Still Here. Most importantly, the combined themes of A Personal Journey, Navigating the System, The Stigma of Dementia, Staying Connected to the World, A Story Worth Telling and I'm Still Here each relate in their own way to the greater human experience of being a person. This evokes the idea that as human beings, as people in our own right, we all have a personal journey to undertake, dealing with the challenges life throws our way. We all must navigate these challenges, which can be different depending on our life's circumstances. Some of us will experience more stigma than others, but we likely have all felt rejection and judgment at some point in our lives. As humans, we all have a desire to be connected to the world in some way, to be able to share our stories and experiences, and to have our presence in this world acknowledged.

To relate the combined thematic account to the human experience as a whole is not meant to diminish the specific EOD experience. Nor is it to detract from the very real challenges and experiences of being a person living with EOD. This is a disease that takes much away over time, in terms of one's ability to care for oneself, to communicate and to remember. Rather the participants' perceptions of their own personhood and how this connects to the human experience, serve to remind us of the human essence of each of the participants. They are all individuals and members of a greater community of people with EOD, and this must be recognized and remembered, especially as their disease progresses.

Implications for Practice

The following paragraphs will discuss the implications of this study's findings and consider them within the context of the literature. Based on the participants' stories and on the

super-ordinate themes that emerged from these narratives, several implications for practice have come to light. They include improving the diagnosis process, increasing and improving resources and supports, reducing stigma, honouring personhood and supporting caregivers and families.

Improving the Diagnosis Process

It is well documented in the literature that it can take a long time for younger people to be diagnosed with dementia, a process that is lengthier than for those seeking a diagnosis of LOD (Martin, 2009; van Vliet et al., 2013). Findings from this study confirm this reality, as well as the fact that dealing with the medical system is both a discouraging and challenging process. As EOD is much less common than later onset dementias, it is not surprising that a diagnosis of dementia is not the first condition to come to mind for a physician attending to a younger person with memory or cognitive issues. It cannot be easy for physicians to have to diagnose a younger person with dementia. In fact, diagnosing any kind of dementia is in general indisputably difficult for physicians (Iliffe et al., 2005). One can understand why a doctor would want to be absolutely sure that the diagnosis of dementia is correct. This would appear to be particularly true when diagnosing younger adults, especially as it is vital to rule out any other causes for the presenting symptoms, as the differential diagnosis of a condition such as EOD can vary widely (McMurtray, Clark, Christine & Mendez, 2006).

It also must be difficult to have to tell a person that they have dementia, a devastating reality for patients to have to accept. Some feel there is a lack of systemic dementia education and training for health care professionals (Nadeem, 2013), which could exacerbate this problem. International studies have also demonstrated that primary care teams can be reluctant to make the diagnosis of dementia (Milne, 2010; Mitchell, McCollum & Monaghan, 2013). In some cases, barriers to making the diagnosis were attributed to lack of knowledge, as well as a reluctance to

disclose the diagnosis in the first place (Mitchell et al., 2013). Regardless of the various reasons for why it takes so long to receive the diagnosis, the lasting impact of each participant's very difficult journey to diagnosis is hard to ignore. Their frustration, concerns and anger with the medical system are palpable amongst all of their very personal accounts. It is interesting that the participants often did not feel "listened to" when they began seeing their doctors, trying to describe symptoms that they knew were more than just a depression. From the family point of view, it is also significant that family felt shut out of the diagnosis process. They had an important point of view and perspective of how the person was coping and what they saw was "going wrong" or "not quite right".

There certainly are clear consequences to delay in diagnosis. Timely diagnosis is crucial so as to most effectively manage symptoms and to allow the person time to adjust and come to terms with the diagnosis (Mitchell et al., 2013; Westerby & Howard, 2011). Thus, it is important that public knowledge of EOD be augmented, and this would include increasing the EOD knowledge of health care professionals (van Vliet, 2013). As more people are aware that EOD is a condition that can affect younger people and that dementia is not just an illness of the elderly, the possibility of EOD might be more readily considered when younger adults begin to exhibit or complain of dementia-like symptoms. Health care professionals must also be made aware of how difficult it is for younger people to go through the diagnosis process. The impact of the lengthy and difficult diagnosis journey is best understood and acknowledged by hearing the first hand accounts of the people who have had to go through this difficult process. More research is needed to hear younger adults' subjective points of view, in order to both better inform the general public and health professionals of their experiences and difficulties, as well as to elicit their opinions of what could be done to improve the diagnosis process.

Increasing and Improving Resources and Supports

Findings from this study reinforce existing knowledge that resources and supports that are specific to younger adults are scarce and that most people with EOD must make do with services that have been set up for older adults (Roach et al, 2008). Moreover, this study also demonstrates that participants very much want to be able to continue contributing to society and engage in meaningful activity, and that finding supports and resources that would enable this would be helpful. Other research has demonstrated that younger people with dementia desire meaningful activity that gives them a sense of purpose (Roach & Drummond, 2014). It is significant that all of the participants spoke of the importance of finding something that is both meaningful to them and makes them feel that they are contributing to the world around them in some way. It is also interesting that how best to connect to the world varied substantially from person to person.

It is important to remember that the word “dementia” is a term that can be used to describe many different degenerative brain conditions. This was apparent in the fact that out of four participants, three different types of dementia were represented: Alzheimer’s, Lewy Body and Frontal Temporal dementia. As evidenced in the theme A Personal Journey, all of the participants experienced their own form of EOD quite differently. Thus, finding an activity to take part in seems to depend not only on disease presentation and abilities, but also on what interests the person most. For the participants, meaningful activities varied from still being able to work, to advocacy, volunteering and to taking part in a hobby. The various disease presentations combined with different personal interests, speaks to the need to be as person-focused as possible in resource and care planning for people with dementia (Mendes, 2015; Nazarko, 2015). Thus, a variety of services need to be offered for the wide variety of people who

live with EOD.

Support groups can be a helpful resource for those who need to talk to others experiencing similar circumstances, but from what this study has revealed, younger people want to be actively engaged in activities that give them a sense of having contributed to the world they live in. Support groups may not provide this sense of active contribution. Support groups also usually involve a professional facilitator, which can situate the person with dementia in a more passive role (Clare, Rowlands & Quin, 2008). This sense of passivity could lend to a feeling of not really contributing and actively taking part is something meaningful. It is significant that being involved in activities that were planned and arranged by other people with dementia was found to be empowering. Groups similar to what Mick has been involved with, likely create more of a feeling of overall contribution and meaning. As Clare et al. state (2008), groups that are not professionally facilitated “are likely to encourage an active search for meaning, emphasize empowerment through maximizing choice and control, and engage in advocacy and collective action aimed at changing social representations and attitudes” (p. 11). Activities that have a recreational focus have also been shown to be helpful or of interest, both in the literature (Kinney, Kart & Reddecliff, 2011) and in this study. Activities that emphasize shared social interactions and positive social identities, rather than focusing on the dementia symptoms or concerns, can foster a sense of wellbeing (Pipon-Young, Lee, Jones & Guss, 2011).

According to Beattie et al. (2002), specialized services for younger people with dementia are recommended. However, it is not clear what “specialized” signifies and more importantly, what this would mean for the people who would actually take advantage of these services. The Beattie et al. article (2002) did acknowledge that the discussion of younger adults’ needs is unfortunately most often considered from the professionals’ point of view, in terms of “others”

perceptions of what those needs are. Similar to the discussion above, the people who would take advantage of specialized services, those with EOD, need to be involved in the discussion into how these services would look. Supports for people with dementia in general must recognize their unique needs and preferences as people (Veselinova, 2014), and this certainly is the case in point for those with EOD.

Reducing Stigma

Reducing stigma is a concern that all people with dementia face, regardless of their age. In fact, it can in some ways define the entire experience of having dementia, whereby the label of “being demented” can become the most prominent feature of the person’s life (Milne, 2010). It is unfortunate that the common and damaging point of view that people with dementia are “no longer the same person” persists (Millet, 2011). Additionally, there is the perception that people with dementia have little or no quality of life, creating an environment where the person’s personal preferences and beliefs can be ignored (Garand, Lingler, Conner & Dew, 2009). The label of “being demented” is difficult to shed and for others to see beyond. Within the younger person’s context, this stigma is particularly pronounced, as younger people do not “fit” the image of an older person with dementia, causing a further sense of being different. Stigma only adds to feelings of disconnection and disengagement with the world, as evidenced by the isolation participants were made to feel when others treated them as second-rate citizens. As preserving hope is crucial to maintaining well being when living with dementia (Wolverson et al., 2010), it seems especially important that the prevalent and “hopeless” view that those with dementia have little quality of life be challenged.

The participants’ experiences with stigma confirm concepts such as Kitwood’s (1997) malignant social psychology. When the participants were not recognized as people in their own

right, but treated as individuals who could not hear or speak for themselves, this contributed to a further sense of isolation and was depersonalizing for them. The wider ramifications of stigma must also be considered, as it is felt that fear of stigma can affect a person's willingness to seek diagnosis in the first place, readiness to follow up with supports and possibly, inclination to participate in research (Garand et al., 2009; Swaffer, 2014). Stigma quite possibly could have been one of the factors that made recruitment difficult for this study. There are still few studies that involve people with dementia directly in research, which only serves to perpetuate stigma (Swaffer, 2014). It is important to involve people with dementia directly in research, not only to be able to gain access to and learn from their life stories and experiences, but to also affirm to them their value as people, worthy of being included in the body of dementia research.

Honouring Personhood

It is significant that all of the participants verbalized that they felt that they were “still here” and that they continued to have a sense of who they are as people. It is also interesting that they could acknowledge personal losses and changes to their sense of self, which accompanied this continued sense of understanding of who they are as people. Other research has demonstrated that people with dementia can experience a “state of flux”, in terms of a sense of both continuity and change in identity (Caddell & Clare, 2011). It has been stated that personal identity is “an immanent, continuous, and at the same time fluid concept” (Lawrence, 2007, p. 555). It makes sense that if a person with dementia can feel both changed and the same in terms of identity, then personhood could also be seen as an intrinsic and continuous concept or state of being. Thus, one could argue that personhood is constant and must be considered when planning for care and support. This speaks to the importance of providing person-centered care whenever possible, recognizing that each person with dementia is unique and that he or she will see the

world from a corresponding and distinctive point of view (Hurtley & Pitkin, 2013). As the dementia progresses, it is common for others to focus only on losses and changes, instead of on the person's continuing abilities and strengths (Ortigara & McLean, 2013). Regardless of stage of illness, it seems vital that personhood be honoured. This would involve looking beyond symptoms, the dementia label and whatever other preconceptions and prejudices that are normally associated with dementia, and connecting foremost to the person. To refer back to Simon's simple yet powerful words, "treat me as you treated me before." This is an important message for healthcare professionals, and for the general public as well. We cannot forget to treat those with dementia, regardless of age, as *people*. This has implications in terms of the manner in which we talk about and to individuals with dementia and the language that is used to do this, as well as how we treat them in our communities and in care.

Supporting Caregivers and Families

Much has been discussed in terms of other people's perceptions of those with dementia, especially what can be seen as potentially damaging point of views, such as the person as a "shell" of who he or she once was. Despite indications from this study that reveal that people with EOD feel very much "still here" as people, and not an empty shell, it is difficult to ignore the point of view of family members and loved ones. While the person may feel still himself or herself, despite acknowledged changes and challenges, the person's family and loved ones can have very different perceptions, especially as the disease progresses. From my discussion with Beth, it was apparent that she and her family are very supportive of Joanne. It was also obvious that they "miss" the Joanne that they knew prior to dementia entering her life. Their view of her as a changed person in many ways was not meant to be hurtful or demeaning, it was simply the reality that they felt they were facing. The grief that Joanne's family share in the face of her

progressive dementia was palpable in her daughter Beth's account. Although this study's intent was not to explore the caregiver or family point of view, an opportunity to begin to explore this very experience presented itself to me. Research has shown that the family's experience dealing with EOD is very difficult, especially for the children of the person diagnosed (Barca, Thorsen, Engedal, Haugen & Johannessen, 2014). It is not uncommon for family to feel that the person with dementia has been "lost" to them (Barca et al., 2014). In fact, after I interviewed Barry, his wife said to me "I'm losing my husband". This sense of loss is very real and needs to be acknowledged. Ongoing support is needed for families and caregivers to help them reconcile their feelings of losing the person whom they care for. At the same time, they also need to be supported to find ways to continue connecting with the person who is their loved one. Further research involving families and caregivers is required. It might be informative to conduct a study that examines personhood from a combined perspective of the person with EOD and his or her caregiver and family, as important differences in points of view could possibly be revealed.

Study Limitations and Strengths

All research studies have limitations and this study is no different. Unfortunately, this study did not include the perspective of any women living with EOD. It just happened that the only participants who came forward and who were eligible for the study were men. The fact that only men came forward does not reflect the possibility that EOD is more common in men. There is no evidence that incidence of dementia differs by gender (Alzheimer's Association, 2012). However, it would be interesting to know whether accounts of living with EOD, specifically with regard to perceptions of personhood, would differ in terms of a female perspective. It is also quite possible that those willing to participate in the study were people who were more open to talking about themselves and their experiences. Those who were not interested in participating

may represent a segment of the EOD population who may have completely different perceptions of what it means to be a young person with dementia. However, as this was a qualitative study, which did not seek to reach generalizations, one can only hope that being able to elicit rich and explicit descriptions of the experiences of those who did participate, has allowed for interpretation of the EOD experience to be as genuine as possible. While it was not the intent of this study to generalize findings, the hope is that the deeper understandings of living with EOD that have come to light in this study, will resonate with nurses and other health care providers, and may be transferable to their care settings.

Ensuring Rigour and Validity

In any study, the quality and credibility of the research are important consideration. As a qualitative researcher seeks to understand and explain rather than measure a phenomenon (Pyett, 2003), the challenge on the part of the analyst is to provide the most valid interpretation possible. How does a researcher know whether the interpretations are “right” and in fact, does a “right” interpretation exist? The researcher also needs to show that the process leading up to the final interpretation was conducted in a way that ensures valid results. Smith et al. (2009) discuss Yardley’s four principles for assessing the quality of qualitative research: Sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance (Yardley, 2000). This study has been considered with these four principles in mind.

Sensitivity to context refers to demonstrating an awareness of both the theoretical context of the study, as well as to the participants’ sociocultural setting and perspective (Yardley, 2000). An attempt has been made to clearly situate this study within IPA’s theoretical framework. In terms of demonstrating a sensitivity to the participants’ perspective, considerable amount of verbatim extracts in the findings section of this work were included. A chief strength in this

study lies in its first-hand and subjective accounts of the experience of living with EOD. As this was a personhood study, it was essential that the person living with dementia be the focus and that they should be able to tell their own stories. Other dementia research has found that sense of self can be expressed via the stories that individuals tell, in effect their narratives of self (Rodriquez, 2013). This study is based on not just narratives or stories of self, but is a narrative of personhood and what it means to be a person with EOD. For those participants who chose to contribute poetry or music to enhance their personal accounts, this seemed to add to the personal sense of narrative. Overall, the sociocultural and subjective perspective of the participants as younger people with dementia is evident and clearly articulated as part of the findings discussion.

Commitment and rigour refer to the thoroughness in data collection, analysis and reporting (Yardley, 2000). As part of ensuring that a study has rigour, it is vital that the study show that the “methodological grounding is appropriate to the research question” (Maggs-Rapport, 2001, p.380) and that each step in the research process has evolved around addressing the research question. Great care was taken to keep the research question in mind throughout each step of the research process and to maintain an IPA perspective at all times. This involved an ongoing commitment to the idiographic nature of an IPA study: Each transcript was examined individually and themes for one transcript were developed prior to moving on to the next account. Super-ordinate themes were not developed until after all of the transcripts had been examined on their own basis and worth. The goal was to be able to “honour the richness of the individual’s account” (Wilde & Murray, 2009, p. 237), and I feel that this has been successful. I was also able to send out an email to all of the participants with a description of each super-ordinate theme and I asked them to comment on the themes, inviting them to make suggestions,

especially if they felt that the themes were not meaningful to them. I received a response back from three of the four participants. Their responses included comments such as “you’ve hit the nail on the head”, “I agree with your findings”, “you’ve really listened to me” and the findings are “meaningful to me because they’re happening to me”. These responses are encouraging and seem to add to the validity of the interpretation. I also provided my thesis advisors with my lists of emerging and super-ordinate themes, and was able to discuss and review the thematic development with them. Overall, I have maintained an audit trail throughout the research process, which would allow for a person unfamiliar with the research to review my work and come to similar conclusions if they repeated the process that I carried out.

Transparency and coherence relate to the clarity of presentation, quality of the narrative and to the reflexivity of the researcher (Yardley, 2000). The need for reflexivity relates to how a researcher must “interpret, understand, and describe in a reflexive process” (Wilding & Whiteford, 2005, p. 99). It is important for qualitative researchers to acknowledge and reflect on their place in and their impact on the research process (Richards & Morse, 2013). It is also necessary for that process of reflection and reflexivity to be a visible and documented part of the research process (Davies & Dodd, 2002). As part of ensuring validity, thoughts and reflections have been documented in a reflexive journal throughout the research process. I was able to reflect back on these journal entries as I proceeded along, which helped me to not only stay focused but also ensured that any preconceptions and biases were actively considered and documented. Reflexive writing as part of the qualitative research process can also increase trustworthiness of a study, as well as add to the process of creativity and discovery (Jasper, 2005). I have included some of my reflexive thoughts below as part of my commitment to transparency and reflexivity.

Reflexive thoughts. While I was actively recruiting for this study, I came into contact with Paul's Club, a social and recreational group based in downtown Vancouver, first organized three years ago in order to provide activities for younger people with dementia. It is interesting that Barry brought up this recreational group in his interview not knowing that I was already in contact with its members. Although contacting the club did not lead to finding participants for the study, I was able to start volunteering there. This involved spending an afternoon about twice per month with the group, most often going on long walks around parts of the city. I became involved with the club for very personal reasons: I had been wanting to do some volunteer work for some time and here was an opportunity to help out with a cause that was of great interest to me. When I spent time with the club's members, I was not there because I was a researcher.

I mention this for although I was not there for my research, my time at Paul's Club has affected my perceptions as a researcher and of what it means to be a person living with dementia. All of the members at Paul's Club are treated with outmost respect and dignity and great effort is taken to not focus on their dementia. In keeping with this club directive, I very quickly became aware of the value of focusing on the person with dementia, on his or her abilities and not on the disease. Most of all, spending time with the people there has been fulfilling for me simply as one person spending some quality time with other people. In the spirit of the arts-based research approach that was utilized in this study, I ended up writing some reflexive poems about my experiences at Paul's Club.

I have included one of them here called "Strolling Around".

I first saw him

when I was waiting outside

He walked by and his walk

alone seemed aimless
Slouched, uncertain...
Later, on our stroll
he chatted about his past
describing life on a houseboat
and his adventures as a seaman
His smile was certain
his eyes expressive
as he described
and opened my mind to things
I knew nothing about

This poem speaks to my realization that without being aware of it, I had a somewhat negative perception of a person with EOD, a forestructure of my own that I had not been aware of. I remember the first time I went to visit Paul's Club, and my first thought was "Wow, some of these people look so young and well, they don't look to me like a person with dementia." For those whose illness was more physically noticeable, in regards to mobility concerns and other visible symptoms, I was also surprised at my negative preconceptions regarding their ability to interact with other people. Yet, as my poem reveals, I was able to realize, by spending time with the club's members, that there was very much a person present that I could get to know, enjoy and learn from. I present these personal revelations as part of my reflexive stance. I tried to bracket these ideas while I was analyzing the data but I am aware that my increasing experience being around people with EOD, have likely contributed to analysis results. However, I do not feel that this is in itself a limiting factor, as existing forestructures can enrich the analytic process

(Smith et al., 2009). Through my reflexivity as evidenced above, my voice and perspective as the researcher is clear (Darawsheh, 2014). In fact, my motivations for conducting this study and my interest in the EOD experience have been transparently presented from the start of this study.

The credibility of research is also measured by the *impact and importance* it reveals and whether it is able to ultimately yield interesting, important and useful information (Smith et al., 2009). As Yardley (2000) states: “The decisive criterion by which any piece of research must be judged is, arguably, its impact and utility” (p. 223). It is my sincere hope that this study has yielded important insight into the very personal and subjective experience of having dementia at a young age. In fact, it could be argued that many of the themes presented in this paper, are not only representative of the younger adults’ experience, but could also be related to the experience of having dementia at any age.

Chapter Summary

This chapter has examined the study’s findings and has situated them within the existing EOD body of knowledge. Implications for practice based on what the participants’ collective narrative account has revealed have also been discussed. Finally, the limitations and strengths of the study have been considered. The rendering that makes up the participants’ experiences as people with EOD is almost complete. It has been possible to learn from them what it means to be a person living with EOD, and what many of their needs and concerns are. As this discussion nears conclusion, I invite you to think about your own sense of personhood and consider what your own perceptions are of what it would mean to be a person living with EOD.

Chapter VI: Conclusion

Letting the Paint Dry

Doctors and advocates can help, but there is nothing like personal stories to humanize the silent, destructive power of this illness.⁶

A New Perspective

I have reflected on the initial thoughts that were first composed at the beginning of this thesis. If I were living with the illness, would I still know who I am: That sense of who I embody as the person that is me? I realize that I cannot truly answer this question myself, as although having entered middle life, I am not living with dementia. However, I feel that I am now closer to understanding what it would mean to be a person living with EOD. Through this study's examination of the participants' subjective EOD life and illness accounts, a realistic picture of the people living with this challenging disease has been generated. I hope that as the reader, you have been able to gaze upon the image portrayed and been able to see that the story is made up of very real people who are living their lives and embodying their personhood, dealing with their challenges, celebrating victories, and doing the best they can.

Revisiting the Purpose of this Study

The goal of this study has not been to create a great work of art, but a representation of what it means to be a younger person living with dementia, one that is hopefully as true as possible to the participants' words. I am sincerely hopeful that this representation, this interpreted embodiment of being a younger person with dementia, has touched and resonated with the reader in some way. The goal of this study was to try to understand how those with EOD perceive themselves as younger people experiencing the disease. As this study's alternate

⁶ Thomas DeBaggio

title of “I’m Still Here” suggests, this study has revealed that people with EOD have a strong sense of personhood, one that deserves recognition, understanding and respect.

Recommendations

Based on the discussion in the previous chapter, the following recommendations have been identified, that would help to recognize, understand and respect those living with EOD:

1. The diagnosis process for younger people with dementia needs to be improved.
2. Supports and resources that are meaningful to younger adults and that allow them to continue to feel that they are valuable to society are needed.
3. The stigma of having dementia must be reduced. The general public and all health professionals would benefit from information and education about living with EOD.
4. The personhood of the individual with dementia needs to be honoured.
5. Caregivers and families require ongoing support and involvement in the research process.

It is recommended that further research that directly involves the people diagnosed and living with EOD take place. Knowledge and understanding gained from the subjective accounts of the people living with EOD are extremely valuable and enlightening. It makes sense that the process of diagnosis, as well as the development of resources and supports, can only be improved if the experience and personal perspective of those living with the disease is better understood.

Individuals living with EOD need to be asked directly how they feel, what their wants and needs are, and what they think will be helpful to them. It is also important to continue to examine the language we use to discuss dementia, as well as society’s attitudes and perceptions of living with the illness, in order to reduce dementia-related stigma. Continued examination regarding what person-centered looks like from the person with dementia’s point of view is needed. As people

with dementia must depend more on caregivers and family members as their dementia progresses, these people must also be well supported throughout the dementia journey, as well as involved in ongoing research efforts.

The Researcher's Journey

Research generates knowledge but it is also a process that enables self-discovery. Working on this research study has inevitably made me reflect on my own state of personhood. The hermeneutical and phenomenological aspects of this study have not only shed light on the subjective experience of living with EOD, but have also revealed to me new ways of thinking as a nurse, a novice researcher, and as a person. More importantly, it has caused me to reflect on how I can better approach personhood from a nursing and caring perspective. When first embarking on this project, I had felt that I had a clear sense of being committed to a person-centered approach to care as a nurse. However, as I have come to know more about the life experience of being a person with EOD, I have also learned more of the importance of acknowledging and respecting personhood, of seeing beyond the diagnosis and the symptoms, and of remaining committed to the idea that each client that I encounter as a nurse, is foremost a person.

Epilogue

The four participants, Paul, Barry, Simon and Mick, have graciously allowed their collective accounts of living with EOD to be analyzed and presented. So too have Joanne and her family permitted their story to be shared. There has been great worth in hearing their collective account of living with EOD and of trying to understand their perspective of being younger people with dementia. While we all share in the human experience, we cannot understand one another fully without hearing others' experiences first hand. Thus, their willingness to share their

own accounts have allowed for greater understanding of the EOD experience to emerge. When I began this study, I wondered what would happen to me were I were to be diagnosed with dementia. I asked myself if I would continue to develop as a person? Reflecting on these questions, and on the insight gained from undertaking this study, I do not think that my personhood would resemble a faded and cracked painting, as alluded to in the first chapter of this work. Rather, I feel that the canvas of my life could still be added to: The colours might be different, the strokes of paint perhaps applied differently but the whole image would still be there, perhaps under more layers...but present and vibrant in its own way.

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Appendix A

Recruitment Poster



Seeking Volunteers for Early Onset Dementia Research

Are you a person **under the age of 65** with
Early Onset Dementia?

Are you willing to share your story?

Purpose: I am interested in understanding the experience of being a younger person with Early Onset Dementia. I would like to invite you to contribute your experiences by talking to me about how you view yourself as a person with dementia.

What is Involved: You will be asked to take part in an audiotaped interview in a location of your preference. You may share your experiences and your story in your own words. If you should choose so, you may also share photographs, drawings, music, or other forms of expression to help relate your experience of who you are as a younger person with dementia.

For more information, please contact:
Mariko Sakamoto, RN, BScN (604) 727-6099 or
eodementia@gmail.com

This study is being conducted as part of a Master's of Nursing thesis for Athabasca University. This study has been approved by the Athabasca University Research Ethics Board.

Appendix B**Introduction Letter****Perceptions of Personhood and the Early Onset Dementia Experience****Principle Researcher:**

Mariko Sakamoto, RN, BScN
Centre for Nursing and Health Studies
Athabasca University
eodementia@gmail.com
604-727-6099

Supervisors:

Faculty Members
Centre for Nursing and Health Studies
Athabasca University
Dr. Steven Johnson
sjohnson@athabascau.ca
1-877-848-6903
Dr. Sharon Moore
Sharon.moore@athabascau.ca
1-866-375-8570

To:

(will be addressed to program
staff and/or supervisors)

My name is Mariko Sakamoto and I am a registered nurse and a Master's student at Athabasca University. I am undertaking a research project as part of my degree qualification. The purpose of this study is to explore how people with early onset dementia view themselves as persons and how they experience their sense of self or personhood after diagnosis.

I would like to be able to recruit volunteer participants to take part in my study. I am seeking approval to be able to put up information posters in your waiting rooms and/or meeting rooms and invite people with early onset dementia to participate. Participation in my study is voluntary and will include involvement in an audiotaped interview. Recruitment will not involve any of your staff as gatekeepers or recruiters. Prospective participants will be able to contact me directly if they would like to take part in the research study.

Please see the enclosed copy of the information poster. I have also included the study information letter that will be sent to prospective participants. If you have any questions or concerns, please do not hesitate to contact me.

Sincerely,

Mariko Sakamoto, RN, BsN

Appendix C

Perceptions of Personhood and the Early Onset Dementia Experience Information Letter

Principle Researcher:

Mariko Sakamoto, RN, BScN
Centre for Nursing and Health Studies
Athabasca University
edementia@gmail.com
604-727-6099

Supervisors:

Faculty Members
Centre for Nursing and Health Studies
Athabasca University
Dr. Steven Johnson
sjohnson@athabascau.ca
1-877-848-6903
Dr. Sharon Moore
Sharon.moore@athabascau.ca
1-866-375-8570

Background

You are invited to take part in a research study. This study is part of a master's thesis from Athabasca University. Taking part in this study is completely voluntary and you may withdraw from the study at any time.

Purpose of the Study

The purpose of this study is to explore how people with early onset dementia view themselves as persons.

Purpose of this Letter

This consent letter is to inform you about what you will be asked to do in this study. It also will explain what the possible risks and benefits of participating are.

Who Will be Conducting the Study

My name is Mariko Sakamoto and I am a registered nurse and a master's student at Athabasca University, and will be conducting the study. Throughout the study, Steven Johnson and Sharon Moore, who are my research supervisors, will be advising me. They both are part of the faculty of Nursing and Health Studies at Athabasca University.

Study Design

In this study, I will interview you by asking you a few questions about your experiences with dementia. The interview will likely last from 45-90 minutes and will be audiotaped. As part of the interview process, you may choose to also express yourself and your experiences with the use of photographs, drawings, music or in whatever format you may wish to use. The audio recordings will be typed into text. Each text will be identified with a number and your name will not appear on the typewritten text. I will use the text to try to understand the experience of having early onset dementia and what that means to you as a person. Your interview will be read along with others to see if there are similarities and differences in experiences.

Who Can Participate

You may participate in this study if you are a person under the age of 65 who has been diagnosed with early onset dementia. It is important that you can speak and understand English, and this is primarily because I speak English and want to be able to learn about and understand your experiences. You must be able to consent to participate in this study.

Possible Risks

While there are no anticipated risks of participating in this study, sometime when people talk about certain subjects it is possible to feel sad or anxious. If this happens, please feel free to tell me. I have worked with many people who have experienced difficult times and I will watch for that. If talking about your experiences becomes difficult, we can take some time for you to gather your thoughts and return to the interview when you feel ready. I also know from experience that “telling your story” can help people feel better too. However, if at any time you feel that you would like to stop, we can do that and could carry on another time.

Confidentiality

Anything that you say during the interview will be kept strictly confidential. Only I will know your name. If you use artwork or photographs, or any other medium to help describe your experiences and thoughts, I will describe them in my text. I would also like to use copies of your art or photographs, unless you not want me to. The interview recordings and the written transcripts will be identified by number only and will not have any information attached to them that could identify you. They will only be accessible to me and to my thesis supervisors. The recording and one computer copy of your interview transcript will be kept in a secure location. I would like to be able to keep your data for possible future research use but again please be assured that this will be confidential information that cannot be used to identify you.

Your name and any other identifying information will not be used in any reports from the research. Short quotations from the interview transcripts may be used in the written thesis. Any quotations from your interview will not identify you in any way.

Possible Benefits

You may experience a sense of satisfaction in offering your unique point of view as part of this study. However, you will not likely have a direct benefit from this research. The results of this research may be useful for educating others and helping them understand what it means to have dementia. Information from this study could also be useful in helping to design services for people with early onset dementia.

Compensation

There will be no compensation for participating in this study. However, as a small token of thanks, I will be giving participants a ten dollar Tim Horton’s gift card.

Thank you very much for considering taking part in my research study.

If you decide you would like to take part in an interview, please contact me and we will then set up a time to meet at a time and place that most suits you. You can reach me at eodementia@gmail.com or 604-727-6099.

Sincerely,

Mariko Sakamoto, RN, BScN

Appendix D

Consent Form

Title of the Study: Perceptions of Personhood and the Early Onset Dementia Experience

Principle Researcher:

Mariko Sakamoto, RN, BScN
 Centre for Nursing and Health Studies
 Athabasca University
eodementia@gmail.com
 604-727-6099

Supervisors:

Faculty Members
 Centre for Nursing and Health Studies
 Athabasca University
 Dr. Steven Johnson
sjohnson@athabascau.ca
 1-877-848-6903
 Dr. Sharon Moore
Sharon.moore@athabascau.ca
 1-866-375-8570

	YES	NO
Do you understand that you have been asked to be in a research study?	_____	_____
Have you received and read the Information Letter?	_____	_____
Do you understand that you will be interviewed about your experience of having early onset dementia and how you view yourself as a person?	_____	_____
Do you understand the risks and benefits involved in taking part in this research study?	_____	_____
Do you understand that you are free to leave the study at any time?	_____	_____
Has confidentiality been explained to you?	_____	_____
This study was explained to me by: _____		
Name of Person		
I agree to take part in this study: _____		_____
Signature of Participant		Date

Printed Name		
_____		_____
Signature of Witness		Date

Printed Name		

This study has been reviewed by the Athabasca University Research Ethics Board. Should you have any comments or concerns regarding your treatment as a participant in this study, please contact the Office of Research Ethics at 1-800-788-9041, ext. 6718 or email to rebsec@athabascau.ca

Appendix E

Interview Questions

1. Can you tell me about yourself?
2. How would you describe yourself as a person?
3. How has dementia affected your life?
4. What is it like having dementia at your age?
5. In what ways has dementia affected how you see yourself as a person?
6. How do you think other people see you since your diagnosis of dementia?
7. What helps you feel most yourself as a person?
9. How do you see yourself in the future/as time goes on?
10. As time goes on, what do you think will help you feel most yourself?

Appendix F

Initial Themes

Table F1 – Participant 1

The Dementia Journey	The Emotional Ups and Downs	Recognition of Changes	Growth as Part of the Process	Losses Dealing with Dementia	Barriers Along the Way	The Person with Dementia
<ul style="list-style-type: none"> -Dealing with initial symptoms -Blaming others - Not realizing symptoms -Not recognizing dementia -Recognizing problems and symptoms -Taking ownership for his feelings -New awareness of limitations -Symptoms fluctuate -Dealing with challenges 	<ul style="list-style-type: none"> -Depression as a symptom -Initial anger -Frustration -Feeling abandoned -Blaming others -Inability to stay angry -Letting go of negative emotions -Feeling contented -Feeling connected to the world 	<ul style="list-style-type: none"> -Recognizing changes -Recognizing his memory is to blame -Recognizing his own mistakes -Recognizing that memory cannot be trusted -Recognizing limitations -Recognizing memory problems 	<ul style="list-style-type: none"> -Challenging himself and his brain -Self-discovery -Discovering new talents -Developing new talents -Developing new coping skills -Owning up to limitations -Acceptance 	<ul style="list-style-type: none"> -Friends distancing themselves -Loved ones “pulling away” -Lack of understanding from others -Losing trust of others -Facial recognition problems -Poor short term memory -“Foggy mornings” -Can no longer do certain jobs 	<ul style="list-style-type: none"> -Unhelpful medical system -“they don’t see me” -Few resources -Does not “fit category” -Feels left out 	<ul style="list-style-type: none"> -Wants to make a contribution to society -Needs to stay active -Is a better person since Dementia -Is not a shell of who he was -He knows himself / has a clear sense of self -Has is own logic and beliefs -Wants to help others -Trusts himself -He is proud of himself -Likes to stay busy -Feels connected to the world -Feels that the person’s consciousness continues -Is goal oriented -Feels connected to the world -Is contented -Is Accepting -I’m Still Here

Table F2 – Participant 2

His Own Symptoms	How he Copes/What Helps	A Personal Process	Experiences with Medical System	Experiences with Others	When he Looks in the Mirror	Losses
<ul style="list-style-type: none"> -Initially missed days of work -can no longer work -Retired early -Future plans derailed -Has difficulty figuring this out -Can no longer drive -Trouble with decision making -vision changes -Has daily and extreme nausea -Has poor sense of time -Medications didn't help -Poor sleep -Has terrible dreams -Change in taste -Change in appetite -Often awake at night -Exhaustion -Easily overstimulated -Easily stressed out -Struggles with motivation -Walking is exhausting -Poor short term memory -Memory is unreliable -Personality changes -Unusual symptoms -Has good and bad days -Bad days outnumber good 	<ul style="list-style-type: none"> -Puts on a brave face -Open about diagnosis -Not embarrassed -Would like to connect more with others -Has accepted his diagnosis -Tries to stay active -Would enjoy a recreational group -It is meaningful to be heard 	<ul style="list-style-type: none"> -Only I know how it feels -my own distinct experience -I am distinct -Dementia is different for each person -Has unusual symptoms 	<ul style="list-style-type: none"> -Diagnosis process was long and difficult -Not listened to -Frustrated with the medical process -Hard to deal with preconceptions -Was misdiagnosed -Saw multiple specialists -Diagnosis took a long time -Feels mistreated by the system -GP didn't listen -Specialists unhelpful -Medications didn't help -Frustration -Nobody asks me -Felt depersonalized -Does not fit dementia image 	<ul style="list-style-type: none"> -hard to deal with preconceptions -Feels frustration -Nobody asks me -Poor understanding -People don't see the dementia -Looks good to others -Others' attitudes irritating -Does not fit dementia image -Feels dismissed by others -Not everyone lives well with dementia -Challenges making others understand -Support group unhelpful and boring 	<ul style="list-style-type: none"> -Feels the same but different -Still here but also not the same -May look good but does not feel good -Does not fit dementia image -Dementia is not visible or obvious at first glance -I am distinct 	<ul style="list-style-type: none"> -Future is bleak -Losing enjoyment in life -Can no longer work -Cannot cook like he used to -Saddened by future outlook -Has lost enjoyment in life -Loss of hopes and dreams -Personality changes -Many parts of life unfulfilling now

Table F3 – Participant 3

Dementia’s Toll	Dementia and the Person	Challenges with the System	The Younger Person’s Experience	Coping Strategies	Needs and Concerns	His own Experiences /Symptoms
<ul style="list-style-type: none"> -Diagnosis took time -Missed a lot of work -Can no longer work now -Loss of independence -Loss of self-worth -Sense of letting family down -Rug has been pulled out from under him -Dependence on wife -Struggle for his family -Losses for his family -Dementia affects everyone -Feels abandoned -Family and friends contact less often -People pull away -Others get uncomfortable -People make less effort -No longer part of regular life 	<ul style="list-style-type: none"> -A person with a label -Is still a normal person -Feels less a human being -Has a thick skin but still difficult -Avoids use of term “Dementia” -Feels like a third wheel -Feels like a third party -We are all human beings -He is still a human being -I am the same as other people -Dementia varies from person to person -Each dementia sufferer has their own story -Not everyone lives well with dementia -He is a drummer -Living in the world as one 	<ul style="list-style-type: none"> -Diagnosis too time -EOD not recognized by the system -Jumping through hoops -Slow resource process -System not set up for EOD -Stigma 	<ul style="list-style-type: none"> -A life veered off course -Typical mid-life tasks denied to him -Personal costs of dementia- Aware of age gap -Reverse Ageism -Stigma 	<ul style="list-style-type: none"> -Keeps notes -Needs quiet time -Feeling productive helps -Avoids use of term “Dementia” -Would prefer people ask questions -Being open about his condition -Feels good to contribute and participate -Sense of purpose is vital -Music is therapeutic -Music quiets his mind -Drumming brings happiness and joy 	<ul style="list-style-type: none"> -Needs to still contribute -Wants to share his story -Don’t talk over me -Treat me the same -Needs quiet time -Does not want to be a burden -Needs to feel connected to the world -Needs to contribute -Needs to connect with others -facility placement = end of life -A sense of purpose is vital -People need to know realities of dementia 	<ul style="list-style-type: none"> -Pain and lack of sleep exacerbate symptoms -Sleep deprived -Easily overstimulated -Needs quiet time -Hard to switch brain off -Conscious of memory problems -Feels an outsider -People backing away -Cannot participate in life -Considerable losses -I suffer with dementia -Has good and bad days

Table F4 – Participant 4

A Dementia Expert	His Dementia Symptoms	His Own Journey	Finding Empowerment	Stigma	Dementia touches Everyone	Focus on the Person
<ul style="list-style-type: none"> -Talk to the experts -The person as the source -The person with dementia is the expert -Resources for people with dementia BY people with dementia -Ask me! -Understand me! -The power of the personal story -Include people with dementia 	<ul style="list-style-type: none"> -Gave up driving -Speech problems -Symptoms distinct to him -Epileptic-like attacks/episodes -Sleep difficulties -mobility issues -getting lost -being sneaky -comprehension and memory concerns -Vision challenges -Difficulties with words/spelling 	<ul style="list-style-type: none"> -Difficult journey to diagnosis -The Dark Place -Felt like giving up -Needed to find a purpose -Felt isolated after diagnosis -Found resources useless -Precautions needed and taken -Connected with others -Discovered inner poet -A desire to decrease stigma -Aware of degenerative aspect of illness -Does not dwell on it -Enjoys life -Finding a purpose -Building a bridge -Moving forward -Living positively with dementia 	<ul style="list-style-type: none"> -Discovered his inner poet -Finding a purpose -Connecting with others -Helping others -Advocacy is empowering -Dementia does not rule his life -Dementia as a disability -Exercises choice -Staying active -Choosing to live well with dementia -Dementia does not rule his life -Does not dwell on it -Enjoys life -Resources for people with dementia BY people with dementia -Build a bridge -Moving forward -Living positively with dementia 	<ul style="list-style-type: none"> -The damage of stigma -more stigma for younger people -People fear dementia -Not a visible illness -People don't understand it -Lack of knowledge by public -Treated differently -The distancing effect 	<ul style="list-style-type: none"> -The challenge for his family -everyone experiences it differently -Connecting with others makes a difference -Lack of knowledge by public -Why don't people understand? 	<ul style="list-style-type: none"> -Look beyond outward appearances -I am still here -The person is still THERE -Don't forget me -I'm not deaf -Having a purpose -It is the brain not the person -Ask me! -Ask questions -Treat me the same as you used to -I am still me -Needs to be needed -Needs to feel useful -Need to contribute continues -I am still an individual -I still feel

Appendix G

Super-Ordinate Themes

A Personal Journey	Navigating the System	The Stigma Of Dementia	Staying Connected to the World	A Story Worth Telling	I'm Still Here
<ul style="list-style-type: none"> -The Dementia Journey -The Emotional ups and Downs -Recognition of Changes -Growth as Part of the Process -His Own Symptoms -A Personal Process -Losses -Dementia's Toll -His Own Experiences/Symptoms -His Dementia Symptoms -His Own Journey 	<ul style="list-style-type: none"> -Barriers Along the Way -Experiences with the Medical System -Challenges with the System -The Younger Person's Experience 	<ul style="list-style-type: none"> -Losses Dealing with Dementia -Experiences with Others -Dementia's Toll -Dementia and the Person -The Younger Person's Experience -Stigma 	<ul style="list-style-type: none"> -The Person with Dementia -How He Copes/What Helps -Coping Strategies -Needs and Concerns -Finding Empowerment 	<ul style="list-style-type: none"> -The Person with Dementia -A Personal Process -Needs and Concerns -A Dementia Expert -Dementia Touches Everyone 	<ul style="list-style-type: none"> -The Person with Dementia -When he Looks in the Mirror -Dementia and the Person -Focus on the Person

Appendix H**Ethics Approval**

November 18, 2014

Mrs. Mariko Sakamoto
Faculty of Health Disciplines\Centre for Nursing & Health Studies
Athabasca University

File No: 21626

Expiry Date: November 17, 2015

Dear Mrs. Mariko Sakamoto,

The Faculty of Health Disciplines Departmental Ethics Review Committee, acting under authority of the Athabasca University Research Ethics Board to provide an expedited process of review for minimal risk student researcher projects, has reviewed your project, 'Perceptions of Personhood and the Early Onset Dementia Experience'. Yours was a well done application for an interesting study.

Your application has been **Approved on ethical grounds** and this memorandum constitutes a **Certification of Ethics Approval**. You may begin the proposed research.

AUREB approval, dated November 17, 2014, is valid for one year less a day.

As you progress with the research, all requests for changes or modifications, ethics approval renewals and serious adverse event reports must be reported to the Athabasca University Research Ethics Board via the Research Portal.

To continue your proposed research beyond November 17, 2015, you must submit an Ethics Renewal Request form before October 15, 2015.

When your research is concluded, you must submit a Project Completion (Final) Report to close out REB approval monitoring efforts.

At any time, you can login to the Research Portal to monitor the workflow status of your application.

If you encounter any issues when working in the Research Portal, please contact the system administrator at research_portal@athabascau.ca.

If you have any questions about the REB review & approval process, please contact the AUREB Office at [\(780\) 675-6718](tel:7806756718) or rebsec@athabascau.ca.

Sincerely,

Sherri Melrose
Chair, Faculty of Health Disciplines Departmental Ethics Review Committee

Ethics Approval Cont'd

June 15, 2015

Mrs. Mariko Sakamoto
Faculty of Health Disciplines\Centre for Nursing & Health Studies
Athabasca University

File No: 21626

Dear Mrs. Mariko Sakamoto,

The Athabasca University Research Ethics Board has reviewed the modifications to your research entitled 'Perceptions of Personhood and the Early Onset Dementia Experience' as outlined in the Modification Request form submitted June 15, 2015 and confirms that the amendments you have outlined are approved.

You may proceed with your project as amended.

At any time you can login to the Research Portal to monitor the workflow status of your application.

If you encounter any issues when working in the Research Portal, please contact the system administrator via research_portal@athabascau.ca.

If you have any questions about the REB review and approval process, please contact the AUREB Office at [\(780\) 675-6718](tel:7806756718) or rebsec@athabascau.ca.

Sincerely,
Gail Leicht
Research Ethics Officer
Office of Research Ethics