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To the Graduate Council:

I am submitting herewith a dissertation written by Susan K. Blaine entitled "The Lived Experience of Losing Employment After Diagnosis with Dementia: A Phenomenological Analysis." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.

Sandra P. Thomas, Major Professor

We have read this dissertation and recommend its acceptance:

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Accepted for the Council:

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(Original signatures are on file with official student records.)

The Lived Experience of Losing Employment After Diagnosis with Dementia: A Phenomenological Analysis

A Dissertation Presented for the

Doctor of Philosophy

Degree

The University of Tennessee, Knoxville

Susan Kaye Blaine

December 2022

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Dedication

This dissertation is dedicated to my research participants. I am deeply humbled to have had the opportunity to learn about and share your experiences here in my dissertation research, and I am eternally grateful to each of you. Thank you. May your willingness to share help lay a foundation of knowledge upon which many future research studies may build.

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To my children, Courtney and Caleb, thank you for believing in me, and for encouraging me when the going got rough. Courtney, you cheered me on whenever I thought the journey was too long, and I am grateful to you. Caleb, I owe you so much for being my personal IT department, and for reminding me that I could do this. You never let me lose my vision and dream, and I thank you. I hope I have been an inspiration to you both as I have pursued my dream with your help and support.

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Abstract

The purpose of this study was describing the experiences of people with dementia (PWD) who lose their employment after diagnosis with dementia, but sooner than originally planned. A phenomenological approach based on tenets of Maurice Merleau-Ponty was used. Six telephone interviews were conducted, with participants sharing their experiences. Transcripts were transcribed verbatim, and subsequently analyzed via a hermeneutical analysis approach. Themes were identified within and between transcripts, considering the contextual grounds of Merleau-Ponty's phenomenology: body, others, time, and world, and the contextual ground of participants' experience: the stigma of dementia. An overarching, central theme of "still working" was identified across interview transcripts, as each participant shared accounts of continuing to "work" after leaving employment, albeit differently and at different activities. Six themes were identified within the central theme: (1) Doing no "harm," (2) The "struggle," (3) Strategically compensating, (4) Valuing "connection," (5) Still actively living, and (6) Still contributing. Findings support previous research that minor changes are usually noticed by the PWD themselves but are also sometimes noticed by others at work. These findings support the literature indicating PWD often choose to leave employment of their own volition to prevent making costly or damaging errors; however, some are given few alternatives and consequently are terminated from employment. Also supported is previous research indicating that meaningful interactions, or connections, and engagement in customary or even newly discovered activities and hobbies are integral for PWD as they transition out of employment. This study also confirms previous research demonstrating that leaving employment may be seen as a relief from stress and worry for PWD. Results from this study shed new light on previous indications that an unexpected transition from work often upends one’s life, frequently triggering feelings of loneliness and isolation. Key findings indicate that with access to solid support and the opportunity to engage in meaningful and enjoyable activities, one can continue to lead an active, socially connected life of value and societal contribution. A novel finding from this study is the hesitancy of PWD to reveal their diagnosis to their employers, largely due to societal stigma.

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Chapter I

Introduction

> Someday, I suppose I'll give up, and sit in the rocking chair. But I'll probably be rocking fast, because I don't know what I'll do without a job.
>
> —Pat Head Summitt, *Sum It Up*.

Imagine going to your primary care provider for an appointment and leaving that appointment with the life-altering news that you have a dementia diagnosis, meaning that your brain will, over time, begin to lose more and more cognitive function ranging from mild to advanced levels of severity. Think about the implications of such a diagnosis, and the questions you might have: Will you be able to continue taking care of yourself and your loved ones? For how long? Will you be able to continue doing the hobbies and activities you have always enjoyed? Will you still be able to drive an automobile to do shopping and keep appointments, and if so, for how long? Will you be able to continue working at your job? If so, for how long? Will your employer be understanding? How will this diagnosis affect your income? Will your family and friends be helpful and supportive? Will people treat you differently when they learn about your diagnosis?

Losing employment after diagnosis with dementia is a difficult issue faced by many people in the United States. An exact number of people with all types of dementia who leave employment after diagnosis is not found in the literature. This lack of data is compounded by the fact that dementia diagnosis is largely underdiagnosed (Alzheimer's Association, 2022a). However, a report from 2019 prepared by the Centre for Economics and Business Research (2019) in London for use by the Alzheimer's Society in England indicates that approximately

47,000 workers left England’s workforce in 2019 due to diagnosis with dementia. This figure is expected to rise to over 53,300 by year 2040, just for England alone. In a different study, Kandiah et al. (2016) found that 43.2% of those with young-onset dementia, and 2.4% of those with late-onset dementia, lost employment due to dementia diagnosis. (“Young-onset dementia” is defined in the section entitled “Early-Onset Dementia (EOD).”) In addition, among workers aged 25 and over, just over 37% of the essential workforce is aged 50 and older, a figure amounting to approximately 16.1 million workers; for those aged 60 and older, the figure is 14.7%, or about 6.4 million workers (Schramm & Figueiredo, 2020). Clearly, considering just these figures, many people may be affected by loss of employment after dementia diagnosis. Loss of employment after dementia diagnosis can be especially difficult when the diagnosis is made during years when people are still working and are still depending on their earned incomes for their families’ benefit. Those diagnosed with dementia often are expected to adapt and figure out the next steps for navigating their new diagnosis on their own after leaving their healthcare provider’s office.

Transition away from employment for people with dementia has not been thoroughly investigated, and no phenomenological research exploring the lived experience of employment loss was found in the literature. For context, this chapter will first present an overview of the known benefits of work in people’s lives, as well as some discussion of the meaning of work. Two theoretical models found in the literature regarding the meaning of work will be briefly described, with some discussion about how those models relate to, and differ from, phenomenology. This will be followed by a brief discussion of the modern economic, psychosocial, and practical implications of leaving work sooner than expected. Taken together, these perspectives lend a contextual background against which to consider the problem and purpose of the present study. Next, key terms will be defined, followed by philosophical underpinnings, assumptions, limitations, and delimitations of the study. The chapter concludes with some discussion about the significance of this topic to the discipline of nursing.

Benefits of Work

For people, in general, employment is recognized as the most significant source for acquiring sufficient income to meet one's daily needs (Jahoda, 1982; Nordenmark & Strandh, 1999; Waddell & Burton, 2006). In addition to income, employment provides a means for a person to attain a particular standard of living established by the society in which the person lives, as well as the expectation of being able to maintain that standard of living for the duration of employment (Friedmann & Havighurst, 1954). Employment also fulfills psychosocial needs that people have in societies where working for pay is considered the usual standard (Jahoda, 1982; Waddell & Burton, 2006). For example, it is known that employment contributes to establishment of our self-identities (Bauman, 2005; Friedmann & Havighurst, 1954; Jahoda, 1982), our roles attained within society, our socioeconomic status (Friedmann & Havighurst, 1954; Nordenmark & Strandh, 1999; Waddell & Burton, 2006), and quality of life (Kim et al., 2018).

Meaning of Work

Next, I will share a concise review of some of the extant literature about the meaning of work to people, in general. By no means does this represent an exhaustive review of the literature on the meaning of work. Rather, it is meant to shed some light on the topic and lend some understanding about the value and significance work often holds for people.

The meaning of work is highly varied, and beyond the scope of this study. However, here I will share some findings relevant to the reader. A review study by Rosso et al. (2010) has integrated and summarized much of the literature to the point of their publication. Not wishing to reinvent the wheel, I will first share an overview of these authors' summary, outlining the key points from this literature, followed by additional findings from other sources.

The body of research about the meaning of work, in general, crosses multiple disciplines including psychology, sociology, and organizational behavior, to name a few (Rosso et al., 2010). According to Rosso et al. (2010), much of the discussion about the meaning of work reveals that the terms meaning and meaningfulness often have been applied interchangeably, leading to uncertainty and confusion throughout the literature. Pratt and Ashforth (2003) propose that meaning refers to what work signifies to people, whereas meaningfulness refers to the amount of significance work holds for people.

The majority of researchers have investigated the meaning of work in terms of two primary areas: a) sources of the meaning of work; and b) mechanisms that result in work becoming meaningful (Rosso et al., 2010). First, Rosso et al. (2010) identified from the literature four sources of "work *meaning*": self, others, work context, and spiritual life. Categorically, the self is a contributing source of work meaning as one's values, motivations, and beliefs are thought to influence perception of the meaning of work. An influential source is the interactions with others, both inside and outside the work environment. Contextually, work influences the perception of work meaning through several environmental factors: the design of job tasks, the mission of the work organization, one's financial situation, one's experience in non-work domains, and the national culture. The last source category is spiritual life, representing one's level of spirituality and/or feeling sacredly called to their work (Rosso et al., 2010).

The second area of exploration in which many researchers have investigated the meaning of work is the mechanisms through which work is said to become meaningful (Rosso et al., 2010). Rosso et al. (2010) share seven such mechanisms: authenticity, self-efficacy, self-esteem, purpose, belongingness, transcendence, and culture and interpersonal sensemaking. These seven mechanisms each have to do with the degree of significance, or meaningfulness, of work to individuals.

Rosso et al. (2010) also share a proposed theoretical framework based on their review of the literature. The framework depicts two key dimensions that underlie the creation of meaningful work: the dimension of agency and communion, and the dimension of self and others. These dimensions intersect one another much like an x- and y- axis. In addition, the authors propose four major pathways to meaningful work: individuation (self-agency), contribution (other-agency), self-connection (self-communion), and unification (other-communion). Each of the four pathways occupies its own quadrant created by the crossing of the dimension lines (which resemble an x- and y- axis). Rosso et al. (2010) propose that at the intersections of the two dimensions is where meaningful work is most likely to be created and/or preserved. The authors share a model of their theoretical framework in Figure 1 of their article (Rosso et al., 2010, p. 114), and for ease of understanding, I also have included it **(**See **Figure 1,** Appendix A). (Note that all figures have been placed in Appendices near the end of this document.)

A second theory regarding predictors of meaning in work, drawn from research regarding meaning in life, is introduced and tested by Schnell et al. (2013). In this proposed theoretical model, having a sense of meaning in work (as opposed to the meaning of work) refers to one's experience, and it is subjectively measured in terms of the contexts of individual person, work tasks, and organizational levels. Within these contexts, meaning in work is related to one's perception of coherence, direction, significance, and belonging. In theoretical testing, a total of 197 employees of various Austrian companies participated. Hierarchical multiple regression analysis indicated the following factors contribute positively to predicting meaning in work, accounting for 46% of the variance: work-role fit, significance of work tasks, socio-moral climate, and organizational self-transcendent orientation (Schnell et al., 2013).

The two theoretical models described above both relate to phenomenology in the sense that the contextual grounds evident in phenomenology (more fully described in Chapter III), are also reflected in each of the theoretical models. Specifically, both theoretical models reference the individual (correlating with phenomenology's contextual ground of self), interaction with others (correlating with phenomenology's contextual ground of others), and the work environment, itself (correlating with phenomenology's contextual ground of world). The theoretical models differ from phenomenology in that both models are used for prediction, of sorts, which is not an element of phenomenology. In the first theoretical model, the prediction has to do with where, along two dimensions, the meaning of work is likely to be created and/or preserved. In the second model, the prediction deals with identification of factors that contribute to the prediction of meaning in work. In contrast, the goal of phenomenology is never prediction or asking *why* or *how*. Rather, the phenomenologist seeks simply to *describe* the phenomenon of interest.

Finally, work provides meaning to people through other recognized benefits, including: an organized schedule and way to pass the time; something to think about; a means and opportunity for achieving recognition from others; opportunities for socialization and formation of friendships and peer groups; the prospect of engaging in new experiences; an opportunity and means of self-expression; opportunities to be of service to others; a sense of satisfaction for having done a good job; and a basis for the development of self-respect (Friedmann & Havighurst, 1954). In addition, work provides opportunities to challenge oneself; a sense of being in charge; and a sense of meaningfulness (Schwartz, 2015). Finally, Clark (1967) states that work can provide meaning to people as they obtain a sense of self-pride for a job well-done, and a sense of having obtained social status.

Implications of Leaving Employment

Loss of employment (LOE) has some powerful implications for health and quality of life. A strong positive correlation exists between loss of employment and declining physical and mental health (Cohen, 1999; Fryers et al., 2003; Mathers & Schofield, 1998; Waddell & Burton, 2006). Factors that may influence the impact of LOE on one’s health are income, socioeconomic status (Cohen 1999; Nordenmark & Strandh, 1999; Waddell & Burton, 2006), age, education, reason for unemployment, and duration of time one experiences unemployment (Feather, 1990; Nordenmark & Strandh, 1999; Waddell & Burton, 2006).

Although it is important to recognize that a diagnosis of dementia does not necessarily indicate one must stop working, people with dementia (PWD) are often faced with LOE after receiving their diagnosis (Evans, 2019; Jacobs et al., 2018; Kandiah et al., 2016; Sakata & Okumura, 2017; Watkins et al., 2018). Frequently, this occurs much sooner than they had planned to stop working. For those who are still employed when they receive a dementia diagnosis, LOE may occur during a period of life when they expected to continue working and maintaining their independence (Harris, 2004; Ritchie et al., 2018; van Vliet et al., 2017). As cognitive difficulties begin occurring, PWD may begin experiencing trouble carrying out the responsibilities of their work roles. When this occurs, PWD often are faced with limited choices about continuing to work; some choose to leave employment of their own accord when they recognize they are experiencing cognitive changes (Ritchie et al., 2018). Other choices revealed by the literature include remaining in employment, but with altered job responsibilities (Ducharme et al., 2013); taking sick leave (Chaplin & Davidson, 2016; Johannessen et al., 2019; Ritchie et al., 2018); applying for disability (Johannessen et al., 2019); retiring (Johannessen et al., 2019, Öhman et al, 2001; Ritchie et al., 2018); or being terminated from employment (Chaplin & Davidson, 2016; Ducharme et al., 2013; Ritchie et al., 2018; Roach & Drummond, 2014).

For persons diagnosed with dementia, LOE often results in financial problems due to the unanticipated loss of income (Busted et al., 2020; Chaplin & Davidson, 2016; Harris, 2004; Johannessen & Möller, 2011; Ritchie et al., 2018; Roach & Drummond, 2014; Rose et al., 2010). The problems of dealing with a new diagnosis are often then compounded by the stressors of financial constraints and the loss of daily routines associated with going to work (Ritchie et al., 2018). In addition, PWD may experience narrowed social circles due to the loss of daily interaction with work colleagues (Harris, 2004; Johannessen & Möller, 2011), as well as other psychosocial effects (e.g., changes to self-identity and altered perceptions of societal roles) (Ritchie et al., 2018). In contrast, however, some PWD accept the increased free time provided by LOE to explore new hobbies and engage in activities at home with family (Chaplin & Davidson, 2016; Evans, 2019; Öhman et al., 2001; van Vliet et al., 2017; Wawrziczny et al., 2016).

Having shared information about the meaning of work, as well as the implications of leaving employment, I will next provide an overview of the purpose of the present study. In addition, I will define key terms used in the study, and I will share a brief discussion of philosophical underpinnings, assumptions, limitations, and delimitations. I will close this chapter with a discussion about the significance this topic holds with respect to nursing.

Study Purpose

Although much is known about the events that surround LOE for PWD after diagnosis, not much is known about how PWD experience these events. Given that PWD are recognized as a vulnerable population due to their cognitive deficits (and also frequently their advanced age) (Emanuel et al., 2003), it is imperative that healthcare professionals understand how best to support PWD as they transition out of employment after diagnosis with dementia. However, before measures can be taken to improve support, we must first allow these individuals' voices to be heard in the literature so that healthcare professionals understand the essence of the experience from a firsthand perspective. The purpose of this study is to describe the lived experience of PWD who lose their employment after receiving a diagnosis of dementia.

Key Terms

Dementia

The National Institute on Aging (NIA) (2017) defines dementia as “the loss of cognitive functioning—thinking, remembering, and reasoning—and behavioral abilities to such an extent that it interferes with a person's daily life and activities.” In addition, the loss of cognitive and behavioral abilities associated with dementia is not a normal function of aging. The term “dementia” does not refer to a specific illness or disease. Rather, dementia is a general, umbrella term for the range of symptoms that occur as the result of cognitive impairment. These symptoms may include: memory decline, poor judgment/reasoning, decreased attention/focus, language changes, and behavior changes (Mayo Foundation for Medical Education and Research, 2022a). Alzheimer’s disease is one of many possible causes of dementia (Alzheimer’s Association, 2022a).

Early-onset Dementia (EOD)

EOD (Alzheimer’s Association, 2020b), sometimes called young-onset dementia, is defined as dementia (the set of symptoms that occur with cognitive impairment) which is recognized and diagnosed in an individual before the age of 65 years (Mayo Foundation for Medical Education and Research, 2020). The set of symptoms that occur with EOD may be the result of Alzheimer’s disease, or they could be due to another disease that causes cognitive impairment.

Early-onset Alzheimer’s Disease (EOAD)

EOAD is defined as Alzheimer’s disease that is diagnosed in an individual before the age of 65 years (Alzheimer’s Association, 2022b). EOAD is sometimes mistakenly used interchangeably with EOD, however, they are not the same. While EOD refers to the set of symptoms of dementia that are diagnosed in an individual before age 65, EOAD refers to the actual disease known as Alzheimer's disease when it is diagnosed in an individual before the age of 65 years.

Loss of Employment

For this study, loss of employment refers to the act of leaving employment sooner than expected or planned, and after receiving a diagnosis of dementia. The loss of employment may occur as the result of the individual's own decision to leave employment after recognizing that he or she is having difficulties with continuing to carry out work duties, or it may occur due to the employer's decision to terminate employment or to encourage retirement sooner than the employee expected.

Philosophical Underpinnings

The term *phenomenology* may refer to both a philosophy and a research methodology. Phenomenological philosophy will be discussed in greater detail in Chapter III, along with discussion of the methods for this study. However, as a philosophy, phenomenology provides a lens through which this proposed research project may be viewed and understood. Fitting neatly within the social constructivist paradigm, or world view, phenomenology allows the researcher to make sense of the world by collecting and interpreting multiple constructions of meaning from participants who share their subjective accounts of experiences (Creswell & Poth, 2018). Layer by layer, the truth, or essence of the experience, is socially co-constructed by the researcher and each of the research participants as each individual account of the experience is recounted. In this way, ontologically (asking *what* we can know about reality) and epistemologically (asking *how* we can know about reality), social constructivism provides for multiple realities formed through our many lived experiences and interactions with those in the world around us (Gergen, 2015). Axiological beliefs (meaning the role of values) of social constructivism include the respecting of values of different individuals. Finally, methodologically, social constructivism calls for an inductive method that will allow ideas to be revealed through interviews and observation (Creswell & Poth, 2018). As a method, phenomenology allows for an inductive process of building from the individual accounts of the experience a composite understanding of that which is common amongst the accounts, to capture and reveal the essence of the participants' experience.

The phenomenological method involves viewing the research participants as the experts regarding the topic being studied. The participants have lived through the experience, and they have first-person knowledge to share with the researcher. In contrast, the researcher's stance in approaching the topic is fresh, humble, and *unknowing*, with a readiness to be shown that which stands out to the participant (Sohn et al., 2017; Thomas & Pollio, 2002).

Assumptions

The assumptions identified from my literature review are as follows:

- Some individuals are employed at the time that they receive a diagnosis of dementia.
- For some individuals, loss of employment occurs after they receive their dementia diagnosis, either by their own choice, or by the choice of their employer to terminate them from employment.

- Some individuals did not have plans to terminate their employment prior to receiving a dementia diagnosis; therefore, the loss of employment was unexpected or premature.
- The experience of loss of employment holds some meaning for the individuals who lose their employment after receiving a dementia diagnosis.

Limitations

It is not the intent for the findings from qualitative research, including phenomenology, to be generalized to a population of people. This is due to the fact that the study participants are purposefully selected because they exhibit the characteristics of or have direct experience with the topic of study (Sohn et al., 2017; Thomas & Pollio, 2002). Validation of findings from a phenomenological study is achieved through resonance and transferability. Resonance is achieved as follows: Once the findings have been developed into an overall thematic structure, this is presented by the researcher to a few of the participants to ascertain whether it resonates with their view and understanding of the phenomenon (Sohn et al., 2017). In addition, findings from qualitative studies are intended to contribute to a deeper understanding about the phenomenon, and they may be transferable to other settings or circumstances in which the findings resonate with others (Sohn et al., 2017). The rich, detailed descriptions included in the data and findings are valuable aids in establishing resonance and transferability.

Delimitations

Out of an abundance of caution and protection for participants, only those PWD who were able to pass the ESC screening (described in detail in Methods section) were included in this study. No tests were administered to ascertain cognitive status or to screen for depression because it was the general consensus of my dissertation committee that it was not likely for severely cognitively impaired or depressed individuals to volunteer to participate in the study; this appeared to be a correct assumption during recruitment.

Significance

Although several studies—primarily those about managing dementia or maintaining activities of daily living in PWD—have identified types of circumstances and activities that sometimes occur when PWD leave employment prematurely, no study has directly explored the *perceptions* of these experiences by PWD. In short, although we have some understanding of *what* tends to happen during such loss of employment, we do not yet know these individuals' *perceptions* of what happens. We lack an understanding of how PWD might describe their experience with prematurely losing employment, together with the meaning this experience holds for them.

Dementia has been recognized by the World Health Organization (WHO, 2020) as a priority of public health, and in May, 2017, the World Health Assembly stated their support of "the Global action plan on the public health response to dementia 2017-2025;" this plan calls for action in several areas related to dementia including "addressing dementia as a public health priority; increasing awareness of dementia and establishing dementia-friendly initiatives" (WHO, 2020). As of September 19, 2019, there were reported to be approximately 50 million people worldwide who have dementia, with close to 10 million new cases diagnosed every year (WHO, 2020). By 2030, the number of PWD throughout the world is expected to rise to 82 million, and on to 152 million by 2050 (WHO, 2020).

Chapter II

Literature Review

To be clear, the topic of interest in this study is the experience of people losing employment prematurely (either through their employer requiring they quit or retire, or through their own realization that they simply cannot continue to do their jobs) after receiving a dementia diagnosis. Both events occur frequently, according to the literature. It is important to investigate both to understand the experiences of PWD who lose employment before they intended to stop working.

Preparation of this literature review began with a systematic search of PsycINFO, PubMed, CINAHL, and Business Source Complete electronic databases to identify relevant peer-reviewed research articles. Google Scholar also was searched to capture additional articles not located by the database searches. Key terms used in the search included: (Alzheimer's OR dementia) AND ("working adults" OR "adult workers" OR "employment status" OR ((employment OR job OR worker OR working OR workplace OR occupation) AND (loss OR lose OR terminat* OR disrupt* OR unemployed OR retire* OR status))). To ensure all relevant articles were located, no time limits were imposed on the search. Inclusion criteria were: (a) peer-reviewed with available abstracts, (b) publication in English language, (c) primary research, (d) about any of the various pathologies with the label of dementia, and (e) the articles must (i) *be about* losing a job or forced/prematurely retiring after dementia diagnosis, or (ii) include job loss/premature or forced retirement as part of the findings within a theme or subtheme. Articles were excluded if they were solely about mild cognitive impairment (MCI) because MCI is not dementia, nor is it known to cause symptoms severe enough to affect one's daily activities (Alzheimer's Association, 2020a).

A broad search was intentionally conducted to ensure the capture of relevant articles including pertinent data in the findings that were not readily apparent from article titles. This resulted in an initial return of 3,936 potential articles. Examination of titles and abstracts reduced the number of articles retained for examination to 109. Using the ancestry method, additional relevant articles were located that met the inclusion criteria. Upon final review, 18 articles were identified that were relevant to the present study. Of these, fourteen articles were qualitative, and four were quantitative. Publication dates for the relevant articles range from 2001 to 2020.

Overall, the majority of literature expansion on this topic occurred during the last decade, with 16 of the articles being published between 2010 and 2020. A broad view of the literature reveals a trend illustrating how the literature is beginning to mature. First, the majority of studies published during the early years (2001-2013) of the relevant timeframe were directed mainly towards examination of general, lived experiences of those with dementia (Ducharme et al., 2013; Harris, 2004; Johannessen & Möller, 2011; Pesonen et al., 2013; Rose et al., 2010). Authors of these earlier studies sought to understand the nature of living with a diagnosis of dementia, as well as the nature of providing care. However, as time passed (2014-2020), the research questions evolved towards more specific issues including determining costs associated with dementia in the young (Kandiah et al., 2016), maintaining purposeful activity (Roach & Drummond, 2014), understanding experiences of those with dementia in employment situations (Chaplin & Davidson, 2016; Evans, 2019; Ritchie et al., 2018), evaluating likelihood of leaving jobs after dementia diagnosis (Sakata & Okumura, 2017), and recognizing predictive and associated factors of unemployment (Jacobs et al., 2018; Watkins et al., 2018). Thus, leaving employment after dementia diagnosis is a relatively young topic in terms of the literature because most studies about dementia and employment began appearing in publication within the last four to five years.

Discussion regarding the literature is organized into the following thematic categories: (a) Life Experiences of Persons with Dementia, and (b) Work Difficulties/Leaving Work. There are two subcategories for Life Experiences of Persons with Dementia: Living with Early-Onset Dementia, and Experiences Including Family and/or Caregivers (See **Figure 2,** Appendix B). This chapter concludes with a summary of the extant literature, including literature gaps.

Life Experiences of Persons with Dementia

All of the studies within the category of Life Experiences of Persons with Dementia are qualitative. In general, the purposes of most of the studies in this category are descriptive, and the chosen methodologies are appropriate and supportive of descriptive studies. Qualitative studies represent a relatively low level on evidence hierarchies for research (Polit & Beck, 2018), and this is in line with a field of inquiry that has not yet been well-developed.

Living with Early-Onset Dementia

This subcategory represents explorations of various facets of everyday life while living with a diagnosis of early-onset dementia (EOD). Participants in these studies happened to talk about leaving employment during their interviews about their experiences with dementia. Cognitive and/or functional difficulties are often first noticed by others in the workplace, and employers sometimes recommend the person with dementia take sick leave, see a physician, or simply retire (Johannessen et al., 2019).

The sudden, unexpected transition from employment to unemployment has been described as quite difficult. In a longitudinal, narrative, descriptive study conducted over four years by Johannessen et al. (2019), most participants spoke of their transition from work as “a serious life event, turning their existence ‘upside-down’” (p. 484). One participant in the Johannessen et al. (2019) study who had experienced job loss described the resulting effect on her emotions: “It is very difficult. Sometimes I cry a lot. Transitions are part of life. Now I am very afraid of the future. How will I be able to take care and manage my life?” (p. 484). Another participant spoke of his initial intense regret over losing his job, stating he felt “stamped, has lost his ‘badge,’ his main role in life, and he is feeling miserable” (p. 485).

Another important finding in this subcategory is that financial problems often occur as a result of premature LOE. Kandiah et al. (2016) provide context for this topic in their report that those with young-onset dementia experienced loss of employment at 43.2%, compared to 2.4% for those with later-onset dementia. These findings are not surprising given that more people in the younger group would be expected to still be working. However, the findings of this study should be interpreted with caution, as no mention of a power analysis was provided, so there is no way to know whether the sample size was sufficient. Still, the findings of Kandiah et al. (2016) serve as an important call to attention that LOE may lead to financial issues for many PWD; this topic may merit future investigation.

When financial problems associated with LOE do occur, this can lead to significant hardship for the family (Busted et al., 2020; Harris, 2004; Johannessen & Möller, 2011). For some, financial difficulties result in the person with dementia’s filing for disability in order to make ends meet until they reach an age of retirement (Harris, 2004; Johannessen et al., 2019).

This is especially significant for those with EOD because the loss of their work roles typically occurs before their expected retirement years, resulting in earlier than anticipated financial and functional dependence upon others (Harris, 2004). A participant in one study spoke of the financial difficulties related to LOE as being substantial: “Having to take a 40% reduction in income has had a severe impact” (Harris, 2004, p. 28). Yet another participant in the study by Harris (2004) shared:

> It’s such a challenge yet to work out finances. How are we gonna live out the rest of our lives until retirement? My retirement doesn’t kick in until I am 60, I think I am 55, my disability payment is not very big. (p. 28)

A participant in the study by Johannessen et al. (2019) who was still employed at the time of her interview, but who expected job loss soon, shared similar feelings: “After many years at work (…), it will be a terrible transition. I expected to work for many more years. It will be very difficult” (p. 484).

Feelings of loneliness and isolation from former social groups at work is another common problem associated with work loss for those with EOD (Harris, 2004; Johannessen & Möller, 2011; Johannessen et al., 2019). For example, one participant in the study by Harris (2004) stated: “I am a very social person. People counted on me, and I felt good about it. I love to be with people. It’s really hard because all my friends work. I don’t have anyone ‘to play with’” (p. 29). Similarly, another participant in the same study shared: “I no longer have any friends; they found it too depressing in someone so young” (p. 29). Feelings of being a complete social outsider have also been described:

> When you end up in a situation where you are not able to have a job, you lose your network and friends. You lose your feeling of social cohesion, become a sort of 'social outcast,' person on the outside of society and you sit there strong and fit in most ways—except for one thing, your memory loss…. (Johannessen & Möller, 2011, p. 417)

Still others apparently are able to cope with the changes and adapt to new social situations. For example, one participant in the longitudinal study by Johannessen et al. (2019) initially expressed great regret over his job loss, but by subsequent interviews, he had begun adapting to his new circumstances, especially since some of his friends also had retired: "Suddenly, I am a member of the club again. It is very usual. So, I am not completely alone any longer" (p. 485).

In contrast to feeling stressed and lonely, some have viewed the loss of work as a relief and a welcomed reduction of stress (Johannessen & Möller, 2011; Johannessen et al., 2019). For these individuals, there is a realization that they can remain active in hobbies and other activities at home and avoid the stress associated with trying to continue working (Johannessen & Möller, 2011). A participant from the Johannessen et al. (2019) study shared her thoughts about taking control of her own responses to her situation:

> In autumn, I got the diagnosis, and went just down. I cried and was very upset. Then I read an article in a newspaper about a girl who had had a very traumatic life. Then I thought, I have to decide that I must make myself happy. No other can.…What am I to complain?…I do not have to go to work; I can avoid the stress. I have decided to be glad since it is good for my health (…). (p. 484)

Within this subcategory, some of the research studies were limited by nonadherence to their stated study designs. For example, the study by Harris (2004) is purported to be a grounded theory study, although no theory is proposed. Similarly, Johannessen and Möller (2011) applied a “reformulated grounded theory” (p. 412) design promoted by Corbin & Strauss (2008). According to Corbin and Strauss (2008), the intent of this reformulated grounded theory is not to produce a theory, but rather to produce “theoretical constructs derived from qualitative analysis” (p. 2). Johannessen and Möller (2011) state that their study resulted in a model (p. 421); however, no model was found in the published article, so it is unclear whether the list of core categories and subcategories shared in the findings were expected to represent the model.

Some of the most notable strengths of literature in this category primarily center on researchers’ study design choices. For example, Harris (2004) used three different data collection strategies (i.e., focus groups, face-to-face interviews, and online interviews) to add strength to the study findings, and purposeful sampling included “typical and intensity-rich cases” (p. 22) to ensure variety of participant experiences. Johannessen and Möller (2011) adhered to open, axial, and selective coding strategies prescribed for grounded theory studies by Corbin & Strauss (2008). Another strength of the study by Johannessen and Möller (2011) is their longitudinal study design; this allowed researchers time to build trust with their participants across the four years of the study. Two notable strengths of the study by Busted et al. (2020) are: the interviewer was experienced in working with PWD, and the first author practiced “reflexive objectivity” (pp. 8-9) during interviews and analysis to remain aware of any presuppositions that could have influenced findings.

Experiences Including Family and/or Caregivers

This subcategory also is comprised of studies about the nature of living with a dementia diagnosis, but studies within this grouping include data collection from caregivers or other family members in addition to the person with dementia (Pesonen et al., 2013; Rose et al., 2010; van Vliet et al., 2017; Wawrziczny et al., 2016). One study in this subcategory involved only the experiences of spouse caregivers (and not the person with dementia), but because the spouse caregivers shared insights about the experiences of their spouses with dementia as they left employment, I made the decision to include this article (Ducharme et al., 2013).

Loss of autonomy and work role had a negative impact on feeling useful, but staying engaged and occupied with activities helped PWD cope and feel useful, as evidenced in the following quote:

> That I still can cook sometimes and do the laundry gives me satisfaction. My cooking, it isn't always flawless, but I manage. Then I think 'look, they say you have it (dementia), you wear the stigma, but you are still fine, you are doing it.' (van Vliet et al., 2017, p. 1893)

A second participant from the same study (van Vliet et al., 2017) shared similar thoughts:

> I didn't want to cook dinner at Christmas, but my children said let's do it together. I felt useful, because they still came to ask me things. I thought, yes I'm still here. (p. 1893)

Echoing findings from Subcategory One above, loss of work role was viewed as a common problem for PWD (Ducharme et al., 2013, Pesonen et al., 2013; Rose et al., 2010; Wawrziczny et al., 2016). Sometimes the individuals with dementia are the first to notice their own difficulties and confusion in the work environment (Pesonen et al., 2013). However, Ducharme et al. (2013) corroborated the results from Johannessen et al. (2019) that declining functional and/or cognitive abilities are often first noticed by work colleagues and supervisors, followed by supervisors' various recommendations that the person with dementia take leave, get rest, change job responsibilities, and seek medical attention. Work supervisors, however, are not always supportive of those with dementia; this is especially evident in the following participant's narrative:

> Even his employer said: Look, take a week off, see a doctor, something's not right. He was working at the time, it was his last job and, suddenly, it must have been the stress, he used to tell me that he was under a lot of stress at work and then…they demoted him a couple of times and, in the end, they let him go…he wasn't delivering the goods…. (Ducharme et al., 2013, p. 637)

All said, however, losing one's work role is not always seen solely as an unfortunate event, and this corroborates findings addressed previously from Johannessen and Möller (2011). Sometimes leaving employment is welcomed by people with dementia (van Vliet et al., 2017), because it allows for extra time to engage in everyday activities with their caregiving spouse (Wawrziczny et al., 2016) or other loved ones. Such an improved opportunity for closeness is beautifully illustrated by the following participant (caregiver of PWD) quote:

> We got closer. […] Here it's often just the two of us. I used to go out shopping by myself. He was off at his job. On Sundays, weekends, I was never there because I was working. Now there are always two of us, we go everywhere together. (p. 1091)

Potentially problematic issues identified in this category are as follows: Studies involving interviews with PWD and their family members or caregivers simultaneously in the same room may have allowed for skewed findings. This is because the individuals involved may have felt uncomfortable sharing certain information or details in front of others about whom they may have been speaking (Pesonen et al., 2013; Wawrziczny et al., 2016). However, it is worth noting that Pesonen et al. (2013) did conduct some individual interviews after their collective interviews. In addition, the exact method(s) of data collection by Rose et al. (2010) were unclear, but this issue may be due to publication page constraints. Finally, Pesonen et al. (2013) state their theory is a grounded theory study, but no theory is proposed; if the authors intended their study to be based on reformulated grounded theory, resulting in a list of constructs, there was no mention of this in the article.

Strengths of literature in this subcategory are varied. Rose et al. (2010) drew case studies from multiple geographical areas to increase the range of cases presented, and all study authors reviewed findings to increase reliability. Similarly, Ducharme et al. (2013) reported an interrater agreement for their data coding process of 98%. Pesonen et al. (2013) ensured that the same member of the research team conducted all interviews, increasing consistency of the interview process. In this same study, observational field notes added to data helped to increase strength of findings. With respect to Wawrziczny et al. (2016), the liability mentioned previously also could be viewed as a strength. While interviewing caregiver/partner with dementia dyads may have allowed for data skewing, this interview design also may have been a strength by allowing for observation of verbal exchanges and interactions between the two interviewees that may add to the data. Lastly, it is a strength of the van Vliet et al. (2017) study that their focus groups were heterogenous with respect to gender, age, education, dementia type and stage, and geographical location; these same authors also reached agreement about coding and themes via consensus groups.

Work Difficulties/Leaving Work

Six studies in this category were directly about leaving work after receiving a dementia diagnosis (Evans, 2019; Jacobs et al., 2018; Öhman et al., 2001; Roach & Drummond, 2014; Sakata & Okumura, 2017; Watkins et al., 2018). The remaining two studies included relevant data participants shared about leaving employment during their discussions about having dementia while being employed (Chaplin & Davidson, 2016; Ritchie et al., 2018). Five studies are qualitative (Chaplin & Davidson, 2016; Evans, 2019; Öhman et al., 2001; Ritchie et al., 2018; Roach & Drummond, 2014), and three are quantitative (Jacobs et al., 2018; Sakata & Okumura, 2017; Watkins et al., 2018).

Some study participants shared that their identities were linked closely to their work roles (Ritchie et al., 2018), and that LOE was harmful to their self-identities (Öhman et al., 2001). This is reflected in the following study participant's quote:

> I was babysitting for money when I was about 11; so I've been working since I was 11 but in paid work since I was 15. So it's a huge part of my life and you know that culture of work ethic and everything so that took a bit of getting used [to] not going to work. (Ritchie et al., 2018, p. 2162)

Another quote shared by a participant in the study by Öhman et al. (2001) reveals some of the strong emotions associated with the linkage of self-identity to work roles:

> Imagine having a superior physician who starts to forget everything at this unit. In time, his memory failures make him lethally dangerous in that position. But putting him in the

> hospital kitchen to wash the dishes—you don't put him there, do you? He will get retirement pension. And the same goes for me, doesn't it? (p. 39)

Corroborating findings from Ducharme et al. (2013) and Johannessen et al. (2019) in Category One, Evans (2019) and Ritchie et al., (2018) noted that minor changes in ability were first noticed by those at work. Findings indicate that very often employers who are aware of the issues experienced by their workers with dementia offer no support (Ritchie et al., 2018) or opportunities to shift work roles (Chaplin & Davidson, 2016; Roach & Drummond, 2014). Echoing findings by Ducharme et al. (2013), employees with dementia are often told by employers to take sick leave (Chaplin & Davidson, 2016) and subsequently are terminated from their work roles at the end of their leave (Ritchie et al., 2018). One participant in a single study within this category did mention remaining at work for a few weeks with job duties that were somewhat modified, but immediately after receiving his diagnosis, he was called to a meeting and terminated from work (Chaplin & Davidson, 2016).

Financial problems after job loss were mentioned again in this category (Chaplin & Davidson, 2016; Ritchie et al., 2018; Roach & Drummond, 2014), as was isolation and loss of social networks (Ritchie et al., 2018; Roach & Drummond, 2014). Feelings of resentment about the sudden termination of employment (Ritchie et al., 2018), as well as feelings of abandonment by the workplace and peers (Chaplin & Davidson, 2016) are reported in the literature. Feeling resentment and a sense of abandonment by those in the workplace are poignantly expressed in the following: "I'm desperately disappointed, humiliated and I've never been back to the place [former place of employment] since, not to visit at all because I just felt I was squeezed out really" (Ritchie et al., 2018, p. 2159). A second quote shared by a different participant reveals a sense of abandonment by the employer: “I did think they were trying to get rid of me, no one called me” (Chaplin & Davidson, 2016, p. 155). The sense of abandonment was compounded for a third study participant who felt those at his former place of employment completely forgot about him: “I had to keep phoning them…they just forgot me[;] I phoned them up at one stage and they didn’t know who I was” (Chaplin & Davidson, 2016, p. 155).

Conversely, some study participants in this category spoke of leaving work as being a relief from feeling embarrassed or threatened (Öhman et al., 2001; Ritchie et al., 2018), reaffirming the findings of Johannessen and Möller (2011). As one participant stated: “It’s a relief not to work, because I would only feel bothered and embarrassed at going there…I feel it as solely threatening and frightening” (Öhman et al., 2001, p. 39). Similar to the study in Category One by van Vliet et al. (2017), participants also shared about the importance of staying engaged in meaningful activities and hobbies after job loss (Chaplin & Davidson, 2016; Evans, 2019; Öhman et al., 2001; Ritchie et al., 2018); this is exemplified by the following quote:

> Well I’ve put my name down to do as much as I can because after being in work all my life just being stuck at home is not good enough for me, I need to do something, I’m not going to be sat down here and be moaning because my wife’s working shifts and my sons are all out working, I want to be doing something everyday [*sic*]. (Chaplin & Davidson, 2016, p. 156)

The three quantitative studies in this category share information from a different perspective. Two of these studies report conflicting results about predictive factors for unemployment in patients with Huntington’s disease, which is known to cause a type of dementia (Jacobs et al., 2018; Watkins et al., 2018). Jacobs et al. (2018) report that performing poorly on cognitive tests that are indicative of processing speed and cognitive flexibility are independent determinants of unemployment. These same authors found that apathy and executive functioning are also predictors of unemployment, but motor functioning is not a significant predictor of unemployment. With somewhat different results, Watkins et al. (2018) found that both cognitive and motor symptoms are significantly associated with the ability to maintain work and also with leaving work; both cognitive and motor symptoms were found to contribute similarly to decline of function at work. More studies will be needed to advance the science with regard to the findings from these two studies. Finally, Sakata and Okumura (2017) found that 14% of patients with early-onset dementia left their jobs within one year from their diagnosis, and this is twice the rate of those who do not have early-onset dementia.

The literature in this category does have some limitations. Evans (2019) provided no information about how cognitive status of participants was determined, and similarly, Chaplin and Davidson (2016) failed to share how they determined their participants were capable of providing informed consent. In addition, several studies involved participants drawn from a single location (Evans, 2019; Chaplin & Davidson, 2016; Jacobs et al., 2018; Öhman et al., 2001), which affects generalizability for the quantitative study (Jacobs et al., 2018); however, I think in some cases there also may be potential for cultural factors to influence findings in qualitative studies when a sample is drawn from a single location (Evans, 2019; Chaplin & Davidson, 2016; Öhman et al., 2001). As for strengths, several studies involved checking data and themes between researchers to establish intercoder agreement (Chaplin & Davidson, 2016; Öhman et al., 2001; Ritchie et al., 2018). Evans (2019) drew from two data sources, and this strengthens data collection and analysis via data triangulation (Creswell & Poth, 2018). Roach and Drummond (2014) began data analysis immediately after interviews, and this would reduce the opportunity for skewed data due to recall bias.

Summary

In summary, the extant literature indicates support is lacking for PWD as they transition out of employment after receiving their diagnosis. Cognitive and/or functional difficulties are often first noticed in the workplace, and options typically offered to PWD include voluntarily leaving employment, taking sick leave, applying for disability, or being terminated from work. Sometimes employers may offer to alter work roles and responsibilities to accommodate their workers' cognitive and/or functional changes, but this was rarely the case in this review. Only two studies provided evidence of employers suggesting or making accommodations to work roles for their employees with dementia diagnoses (Chaplin & Davidson, 2016; Ducharme et al., 2013). Financial difficulties associated with LOE are commonly reported in the literature. With respect to psychosocial needs, loneliness and feelings of isolation after LOE often are reported, although some PWD report managing these feelings by finding ways to stay busy with new hobbies and other meaningful activities. A few studies revealed that sometimes PWD welcome LOE and actually express relief at leaving the work role.

Literature Gaps

The review elucidated several gaps in the literature for this topic. One gap is the failure to apply theory (Smith, 2014) to guide quantitative studies, or to specify philosophical underpinnings for qualitative studies. Only two studies include any mention of a theory. Ritchie et al. (2018) mention a theory, but fail to share any information about the theory, its concepts, or how it guides the study; the authors simply relate findings back to the theory. Ducharme et al.

(2013) briefly describe a theory in their discussion section, but they provide no evidence of its application. It is important to note here that for the present phenomenological study, a guiding theoretical framework is not called for and, as an intentional part of the study design, will not be applied (Thomas & Pollio, 2002). Rather, it is a goal of the present study to elucidate a proposed global thematic structure after thorough analysis of the findings.

The second literature gap is lack of guidance by a philosophical lens in any of the studies in this review. The philosophical lens is crucial to establishing basic beliefs and assumptions that provide the worldview, or lens, through which the study is viewed (Smith & Liehr, 2014). The third gap is that, to date, no study has been focused on directly asking of those with dementia: “What was your experience of having to leave employment prematurely after you received your dementia diagnosis?” Before we can identify improved ways to be supportive regarding the issues raised by prematurely leaving employment after dementia diagnosis, we must first know of the experience and the meaning it holds for those to whom it happens.

The review of articles conducted for the present study revealed the experience of prematurely leaving employment for PWD has not been well studied. It is not yet known what meaning the experience of leaving employment earlier than planned holds for these individuals. For science to move forward in this topical area, it is essential to first lay a solid foundation of knowledge about the essence of this experience, derived first-hand from the voices of those who have lived the experience. This study is intended to help provide this foundation upon which future studies may build, and it will be designed with rigor to enable confidence in the results. In addition, the present study will offer a platform for sharing the voices of those who have experienced premature loss of employment after dementia diagnosis. Findings from this study may contribute baseline knowledge upon which future studies may build to help inform workplace guidelines and supportive policies for employees with dementia. These findings may also aid nurses in meeting the psychosocial needs of their patients with dementia, especially for patients who, as their disease advances, may exhibit signs of strong feelings associated with the routine and social aspects of their previous employment.

Chapter III

Methods

The aim of this study is to achieve a deeper, improved understanding of the experience of losing employment for PWD after dementia diagnosis. I applied the methods of existential phenomenology as described by Pollio, Henley, and Thompson (1997) and Thomas and Pollio (2002) to conduct data collection and analysis. Having described the philosophical worldview for this study in Chapter I, I will direct attention within this chapter towards a brief overview of the origin and history of existential phenomenology. I will then share information about some of the founders of phenomenology, namely Edmund Husserl, Martin Heidegger, and Maurice Merleau-Ponty. Next, I will provide a brief history explaining how the ideas of European philosophers came to be influential in current research, and how human science researchers have applied those ideas to develop research procedures in psychology, education, nursing, and other disciplines. Because this research project is based upon the tenets of Merleau-Ponty’s existential phenomenology, I will also share some of those key tenets. Next, I will share the premise for using phenomenology in this study, and more specifically, for applying Merleau-Ponty’s phenomenology in this study design. Finally, I will describe the research design for the current proposed research project.

Origin and History of Existential Phenomenology

Existential philosophy, or existentialism, may be traced back to Søren Kierkegaard (1813-1855), who was a Danish philosopher. Kierkegaard believed that our lives are shaped by our actions, and our actions are predicated on the choices we make. In direct contrast to philosopher G. W. F. Hegel, Kierkegaard further believed we have complete freedom to make the choices that will ultimately affect our life's path (Bakewell, 2016; Buckingham et al., 2011; Thomas, 2018). The tenets of existentialism gained popularity in the United States in the 1960s, especially with nurse writers such as Vaillot (1966) and Ferlic (1968). In addition, existentialism entered the literature of psychiatric nursing through writers such as Paterson and Zderad (1976) and Watson (1985).

Phenomenology originated with Edmund Husserl, who was a German philosopher. Key to Husserl's phenomenological philosophy was the "reduction," (p. 374) or bracketing, of one's previous knowledge, beliefs, and experiences about the phenomenon to capture the essence of the phenomenon in question (Thomas, 2018). Merleau-Ponty appreciated Husserl's approach towards identifying the essence of a phenomenon or experience, and he also was drawn to Martin Heidegger's tendency towards studying common, everyday types of activities and situations (Thomas, 2018). Although Merleau-Ponty eventually deviated from Heidegger's philosophy (Thomas, 2018), Merleau-Ponty continued his interest in understanding the nature of the everyday world with which we engage. Drawing from his mentors and contemporaries, Merleau-Ponty ultimately combined existentialism and phenomenology (Thomas, 2018). He drew the idea of seeking rich descriptions of phenomena from Husserl's phenomenological philosophy, and he blended this with existentialism drawn from Heidegger and other contemporary philosophers, including Sartre and Camus (Thomas, 2018). In the following sections, I elaborate on some of the ideas of the influential European phenomenological philosophers.

Edmund Husserl (1859-1938) and Martin Heidegger (1889-1976)

Edmund Husserl was a phenomenological philosopher who is often referred to as phenomenology's founder (Buckingham et al., 2011; Romdenh-Romluc, 2011). According to

Vagle (2018), the branch of phenomenology associated with Husserl is transcendental phenomenology. Key tenets of transcendental phenomenology include setting aside or bracketing all preconceived thoughts and notions (epoché) about the phenomenon to get to the very essence (Vagle, 2018).

Husserl, a mathematician-turned-philosopher, reasoned that through science we come to know things about the world of which we can be certain; however, science is empirical because it is based on our experience. Husserl further reasoned that since experience is fraught with assumptions and biases, then experience alone must not be science (Buckingham et al., 2011). According to Buckingham et al. (2011), this reasoning led Husserl to the notion of laying aside assumptions to approach the practice of his philosophy —phenomenology—from a completely fresh perspective.

Husserl believed phenomenology should evidence a "return[ing] to the things themselves" (Merleau-Ponty, 1945/1962, p. ix) which is understood to mean a study of the thing (or phenomenon) in a pre-reflective manner, just as it appears before any thought or reflection may be applied (Buckingham et al., 2011). Husserl's bracketing out of the "natural attitude," (Thomas & Pollio, 2002, p. 9) meant setting aside any assumptions that the world exists. What is meant by this is not doubting that the world exists, but rather momentarily and purposefully suspending belief to allow that which will appear to appear (Thomas & Pollio, 2002). However, Husserl believed that one should set aside [bracket] *all* prior assumptions, and this is one point upon which Husserl and Merleau-Ponty differ (Buckingham et al., 2011).

Martin Heidegger was a student of Husserl's, and he was inspired by Husserl to begin studying philosophy (Buckingham et al., 2011). The branch of phenomenology associated with

Heidegger is hermeneutic phenomenology (Vagle, 2018). Heidegger sought to understand what it means to be human by viewing the topic from an insider's perspective; this is to say he believed that since our existence occurs "in the midst of life," (p. 253), the only way to understand being human is to view it from inside life (Buckingham et al., 2011). Contrary to Husserl, Heidegger believed that because we experience phenomena in the world, the world should *not* be bracketed from investigations of phenomena (Buckingham et al., 2011). In fact, Heidegger viewed humans as Beings-in-the-world who never exist separately from the world, but are instead a part of the world; in this way, our beingness is closely tied to the world (Matthews, 2006). Matthews (2006) states that Heidegger referred to our human state of being as *Dasein*, which translates literally to "being there" (p. 12). Heidegger also studied what it means to live an authentic life, and he believed that the "meaning of our being" (p. 254) must surely be bound in some way with time (Buckingham et al., 2011).

Maurice Merleau-Ponty (1908-1961)

Merleau-Ponty was a French philosopher and teacher who was greatly influenced by Husserl (Romdenh-Romluc, 2011), but he differed from Husserl in that he believed our experiences of the world take place through the body and mind together, the body-subject (Buckingham et al., 2011). As mentioned previously, another important way Merleau-Ponty differed from Husserl was that Husserl believed *all* prior assumptions must be bracketed, or set aside, although his stance may have modified somewhat over time. Merleau-Ponty disagreed with Husserl's early stance, instead positing that assumptions can never be completely bracketed. Merleau-Ponty believed it important to bracket assumptions as much as possible (Merleau-Ponty, 1945/1962; Thomas, 2005; Thomas & Pollio, 2002).

Application of Existential Phenomenological Philosophy as a Research Method

The European philosophers were somewhat lofty thinkers, intent on understanding the nature of the lifeworld and the nature of being. The questions they asked tended towards the abstract, concerned with the nature of what can be known. In 1962, Duquesne University developed and offered a doctoral program in “existential-phenomenological psychology” (p. 374) that brought the ideas of the European philosophers into the practical realm and opened the door for the application of phenomenology to research studies involving human beings in psychology, education, nursing, and other disciplines (Thomas, 2018). The Duquesne scholars primarily drew their inspiration for applying phenomenology as a research method from Husserl (Giorgi, Fischer, & Von Eckartsberg, 1971; Giorgi, 2009). It bears noting that there was another group of scholars who drew their inspiration from Heidegger (e.g., Benner), and a group of Dutch scholars (e.g., van Manen). The Duquesne doctoral program gained popularity, resulting in Dr. Amedeo Giorgi’s development of a phenomenological research method at Duquesne, with techniques for interviewing study participants about their lived experiences (Duquesne University, 2020; Thomas, 2018).

According to Thomas (2018), because Merleau-Ponty’s earliest works were not translated from French to English until 1962 (after his death), Merleau-Ponty’s work was not evident in the wave of interest in existentialism that occurred in the nursing literature in the 1960s (Vaillot, 1966; Ferlic, 1968). However, the popularity of the Duquesne University existential phenomenology program did contribute to the utilization of phenomenology as a research method in nursing. Early published nursing studies establishing phenomenology as a useful method include the article “Phenomenology: A Method for Nursing Research” (Omery, 1983);

the book *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness* (Benner, 1984); and the book *Revisioning Phenomenology: Nursing and Health Science Research* (Munhall, 1994); Although these nursing scholars derived their inspiration from different phenomenological philosophers, together these studies demonstrate the usefulness and application of phenomenology to nursing. To date, phenomenology is still widely applied as a research method by nurses (Thomas & Pollio, 2002); educators (Sohn et al., 2017); psychologists (Pollio et al., 1997) and other human science researchers.

Key Tenets of Merleau-Ponty's Existential Phenomenology

Intentionality

With respect to Merleau-Ponty's philosophy, intentionality refers to a directedness toward the many objects and phenomena we encounter and experience in the world (Pollio et al., 1997; Sohn et al., 2017; Thomas, 2005; Thomas & Pollio, 2002). One way of understanding intentionality is: "What I am aware of reveals what is meaningful to me" (Thomas & Pollio, 2002, p. 14). Drawing from Husserl, Merleau-Ponty believed that through intentionality, there exists an essential component of human experience that is a necessary connectedness between humans and our world; through our connections and these relationships, a sort of co-creation takes place between the person and the world (Pollio et al., 1997; Thomas & Pollio, 2002). It is through this directedness and connection that the researcher and participant are able to co-create, or co-construct, in the moment, the telling of the participant's lived experience.

Perception

Perception refers to the way we experience the world and its objects and phenomena around us. According to Matthews (2006), Merleau-Ponty's phenomenology allows us to use language “to return, as Husserl had put it, ‘to the things themselves,’” (p. 149), looking at the world through fresh eyes. Perception enables us to view the world (or the phenomenon) the way our research participants view it (Sohn et al., 2017). The goal is to view the phenomenon through the eyes of our participants, which is achieved by application of figure and ground concepts as demonstrated in psychologist Edgar Rubin’s faces/vase drawing (See **Figure 3**, Appendix C) (Pollio et al., 1997; Rubin, 1921, as cited in Thomas & Pollio, 2002). The drawing is comprised of a white center area in the shape of a vase, with a darker area on either side of the vase that both resemble faces looking towards one another. When one gazes upon the white area representing the vase, that portion of the drawing becomes figural, or stands out, in the context of the rest of the drawing that provides the ground (background). However, if one gazes upon the dark areas representing the faces, the faces become figural (recognizable), in the context of the rest of the drawing, the white area, as background. Neither the faces nor the vase can be viewed without the other standing as a background; figure and ground are both essential components of that which is perceived. As we experience and perceive the world and its components around us, we take in the phenomenon as a whole, yet that which stands out as figural is always considered in context of the grounds—body, others, time, and world (Sohn et al., 2017; Thomas, 2005; Thomas & Pollio, 2002). This process is further described in Merleau-Ponty’s own words (1945/1962):

> [t]o see an object is …[to] become anchored in it, but this coming to rest of the gaze is merely a modality of its movement: I continue inside one object the exploration which earlier hovered over them all, and in one movement I close up the landscape and open the object. The two operations do not fortuitously coincide…It is necessary to put the

> surroundings in abeyance the better to see the object, and to lose in background what one gains in focal figure. (p. 78)

In a later work, Merleau-Ponty (1964/1968) again describes perception as necessarily involving both figure and ground concepts: "When I say that every visible: 1) involves a ground which is not visible in the sense the figure is…[o]ne has to understand that it is the visibility itself that involves a non-visibility" (pp. 246-247). Here, Merleau-Ponty shares that figure and ground are constantly working in concert. That which is figural is understood in terms of the context, and vice versa. Whether an aspect of a phenomenon is considered figural or ground is determined by where the gaze, or focus, lies.

Body

Rejecting Cartesian mind-body dualism, Merleau-Ponty promoted the idea of embodiment as the way, or means, through which we engage and interact with the world through the body (Thomas & Pollio, 2002; Vagle, 2018). Merleau-Ponty thought that the mind and body were *not* separate, but rather act together as the body-subject (Buckingham et al., 2011). Simply stated, Merleau-Ponty posited that our perceptions and thoughts are in the body, and the body and consciousness are in the world, all together as one system (Buckingham et al., 2011). In this way, Merleau-Ponty believed "the body 'lives the world'" (Vagle, 2018, p. 10). This is further described by Merleau-Ponty (1948/2004) himself: "[R]ather than a mind *and* a body, man is a mind *with* a body, a being who can only get to the truth of things because its body is, as it were, embedded in those things" (p. 43).

Others

Merleau-Ponty spoke of others in terms of an interconnectedness: “The phenomenological world is not pure being, but the sense which is revealed where the paths of my various experiences intersect, and also where my own and other people’s intersect and engage each other like gears” (1945/1962, p. xxii; Thomas, 2005). This description of engaging one another is reflective of the connections established between interviewer and interviewee in phenomenological interviews (Sohn et al., 2017).

Time

The contextual ground of time, or temporality, refers to the way all the activities taking place in the lifeworld are ordered in time (Romdenh-Romluc, 2011). To Merleau-Ponty, time is subjective; for some it is fleeting, and to others it seems to drag by (Sohn et al., 2017). Capturing the subjectivity and perhaps also an elusive nature, Merleau-Ponty (1945/1962) referred to time as “a succession of instances of now” (p. 479). In another example, Merleau-Ponty (1945/1962) spoke of time as being constantly in motion:

> There is a temporal style of the world, and time remains the same because the past is a former future and a recent present, the present an impending past and a recent future, the future a present and even a past to come….(p. 490)

Van Manen (2017b) echoes this fleeting nature of time in his statement:

> Even when remembering or anticipating an event, we always do so in this moment, the moment of the “now” (this second, minute, hour, day, year). But as soon as we try to (re)capture this “now,” it is already gone, absent. (p. 813).

Yet, no matter how fleeting instances of time may be, the goal of phenomenology is to "let a phenomenon (lived experience) show itself in the way that it gives itself while living through it" (van Manen, 2017b, p. 813).

World

According to Merleau-Ponty, "Man is in the world and only in the world does he know himself" (as cited in Buckingham et al., 2011, p. 275); this quote concisely illustrates how Merleau-Ponty believed the body and mind cannot be separated, especially since he also believed the body is how we live in, and come to know, the world. In Merleau-Ponty's (1945/1962) view, phenomenology is "a philosophy for which the world is always 'already there' before reflection begins" (p. vii). However, an issue Merleau-Ponty struggled with was that once one reflects on the world, it is no longer the same, pre-reflective world (Matthews, 2006).

Premise for Using Phenomenology

A phenomenological methodology is appropriate for this study because phenomenology is, at its essence, the act of "let[ting] something be seen (logos) that shows itself in itself (phenomenon)" (Heidegger, 1962, as cited in van Manen, 2020, p. 487). Phenomenology results in thick, rich descriptions of phenomena which are drawn from participants' own words, with the focus remaining on the phenomenon itself, as understood from participants' descriptions of the experience (van Manen, 2017a). In the case of this study, the descriptions of the phenomenon were elicited by conducting direct, in-depth, one-on-one interviews with individuals who have experienced the phenomenon of loss of employment after dementia diagnosis and wished to share their experiences. Conducting a phenomenological study allowed for the capture of the essence of the lived experience of this phenomenon, reflected directly in the words of the participants.

Variety of Available Phenomenological Methodologies

There are numerous phenomenological approaches reported in the literature, variously categorized as descriptive phenomenology, hermeneutic phenomenology, interpretive phenomenological analysis (IPA), lifeworld approaches, and dialogical approach, to name just a few (Finlay, 2012(a), 2012(b); Vagle, 2018). Vagle (2018) speaks of Giorgi's descriptive phenomenology as being a modified approach of Husserlian philosophy; those applying Giorgi's "brand" of phenomenology are said to be "searching for invariant meanings that belong to a structure" (p. 59) rather than seeking to capture the essence of a phenomenon. Another type of phenomenological approach is Max Van Manen's interpretive, or pedagogical, approach, which Vagle (2018) states involves a necessary interpretive component. The reflective lifeworld approach by Dahlberg, Dahlberg, and Nystrom (2008, as cited in Vagle, 2018) seems to bear some components of both Giorgi's descriptive phenomenology and Van Manen's interpretive approach, with a strong commitment to remaining "open" through the research process. The phenomenological approach used and taught by faculty at the University of Tennessee, Knoxville (UTK), primarily draws from the existentialist phenomenology of Maurice Merleau-Ponty, blending both descriptive and interpretive components (Sohn et al., 2017).

Premise for Merleau-Ponty's Phenomenology

For this study, Merleau-Ponty's existentialist phenomenology is an appropriate fit for several reasons. First, Merleau-Ponty was a strong believer in the importance of paying close attention to the everyday occurrences and activities that are a part of people's lives (Thomas, 2005). The topic of this study, the loss of one's employment after diagnosis with dementia, is an experience that happens to many people in American society alone (see statistics provided in introduction section of Chapter I), and it is a topic that is worthy of investigation by nurse scientists who interact with individuals experiencing dementia in a wide variety of clinical settings.

Next, according to Thomas and Pollio (2002), Merleau-Ponty places an emphasis on *holism*, "(viewing persons as irreducible wholes)" (p. 12), in that the mind and body are not separate. Rather, a person is seen as being comprised of mind and body, together as one. Further, the body is the means through which the person experiences and perceives the world. This is known as *embodiment*, which is another emphasis of Merleau-Ponty (Sohn et al., 2017; Thomas, 2005; Thomas & Pollio, 2002). Holism and embodiment are congruent with the core values of nursing (Thomas & Pollio, 2002), with a focus on providing care for the whole person rather than applying a reductionist view (Taylor, 1993). In the present study, the participants are experiencing the world through a body which is, at least in part, failing them. Because of their dementia, their brains are not able to function as well as in previous years, but they are still whole persons, and they are still subjectively engaging with and experiencing their world on their own terms, at their own pace, and in their own way.

Another reason that Merleau-Ponty's existential phenomenology is a strong fit for this study is the clear distinction made by Merleau-Ponty between the "body object" (the body referred to in medical care, for example) and the "body subject" (the body of reference when speaking about personal experiences) (Thomas, 2005). All too often in the world of healthcare, care is offered for the body object, with little thought given to providing care for the body subject. As I shared in Chapter I, the experience of losing employment sooner than anticipated often involves significant change, and even loss, for PWD. Premature job loss can have considerable impact on the body subject for PWD. By providing research participants with an opportunity to give voice to their experiences, care is offered for the body subject of participants.

Additionally, Merleau-Ponty valued relational connections with others, and the dialogue that often is a part of those connections (Thomas, 2005; 2018). The interview process for this present study is a process involving dialogue between the interviewer and the participant, and the establishment of a connection between the two. By applying the phenomenological values and methods of Merleau-Ponty, this study presents the opportunity for the interviewer to recognize and acknowledge in a meaningful way the experiences of the research participants through connection and dialogue.

Research Design

Phenomenology as a methodology is “a study of essences,” (Merleau-Ponty, 1945/1962, p. vii) and as such, the research design allows for the researcher to capture the essences, or qualities of the phenomenon that, according to Husserl “make ‘the thing itself’ the ‘thing itself’ and not something else” (Vagle, 2018, p. 12). According to Merleau-Ponty (1945/1962), phenomenology “tries to give a direct description of our experience as it is, without taking account of its psychological origin and the causal explanations which the scientist, the historian or the sociologist may be able to provide” (p. vii). Phenomenology involves capturing deep, rich descriptions of phenomena, rather than seeking explanations (Finlay, 2012a). Phenomenological investigators are interested in understanding the nature, or essence, of a phenomenon. We seek to know *what* it is, not how or why it came to be. The very nature of phenomenology’s inquiry and methods make phenomenology the best choice for answering the research question in this study, as my purpose is to know what the experience is of PWD who experience LOE after receiving a dementia diagnosis. In the remaining sections of this chapter, I will describe the research procedures used in my study, which are based upon the tenets of Merleau-Ponty's existential phenomenology.

Institutional Review Board

I obtained approval and permission from the Institutional Review Board (IRB) of UTK to conduct this research project for my dissertation work. The UTK IRB reviewed my research plan to ensure there were adequate and appropriate measures in place to protect those involved in my research and keep them from harm. Participants were provided with a copy of the voluntary consent for research participation form prior to their interview date so that they would have adequate time to read the form. The form was written at a 6th to 8th grade reading level that ensured it would be easy for participants to understand (Hadden et al., 2017; Tamariz et al., 2012). In addition, I inquired whether each participant had any questions about the study itself or about participation in the study prior to obtaining their consent.

The UTK IRB approved the use of telephone, videoconference, and face-to-face options for interviewing due to the need for extra precautions due to the Covid-19 pandemic. In addition, for telephone and videoconferenced interviews, the UTK IRB approved my obtaining voluntary, verbal informed consent from my participants. Because all of my study participants opted to interview by telephone, all consents were obtained verbally. Prior to my obtaining verbal informed consent, each participant successfully passed an evaluation (more fully described in the section entitled Special Protections and Strategies Related to Population) to determine their ability to understand the consent form.

Confidentiality

I maintained confidentiality of participants throughout the study by applying several measures. Audio-recordings of interviews were stored on the university's password-protected, secure computer storage drive. I redacted all potential identifiers (e.g., participant names, names of locations) from interview transcripts and demographic forms. In addition, each participant was assigned a first-name-only pseudonym, and these pseudonyms were used throughout the study. The master log of assigned pseudonyms was printed and filed in a locked cabinet in the office of my advisor, and this information was kept separate from any of the typed transcripts of interviews. Any demographic information shared in written study reports was shared in aggregate form only, with no identifying information provided for any individual person.

During the data analysis phase of this research, members of the University of Tennessee – Knoxville (UTK) Transdisciplinary Phenomenology Research Group (TPRG) assisted with data analysis discussions conducted via Zoom technology. Transmission of recorded files to the PI's advisor for use by the TPRG during its meetings occurred through Vault, the university's secure courier for file transfer. Use of Vault ensured that the file(s) could only be accessed by the person to whom the file was sent. Vault is password-protected, and both the sender and receiver must sign in with a password to access the Vault platform. All members of the TPRG who assisted in data analysis signed a confidentiality agreement, and no transcripts shared with members of the TPRG were retained after analysis concluded for that day's TPRG meeting.

Special Protections and Strategies Related to Population

First, and foremost, PWD are considered a vulnerable group due to their impaired cognition, (and in some cases due to their advanced age) (Emanuel et al., 2003). It was of paramount importance that adequate measures were taken at every step of this research project to protect the safety and well-being of study participants. I used a tool designed to measure participants' comprehension before obtaining informed consent for participation in this research project. This tool is called the Evaluation to Sign Consent form (ESC), and it has previously been used successfully by a faculty member in the UTK College of Nursing to ascertain comprehension of consent wording in her studies of patients with schizophrenia (Beebe & Smith, 2008, 2010). The ESC also has been used by at least one researcher in gerontology (Resnick et al., 2007).

During administration of the ESC, participants shared with me their real names, but I recorded their assigned pseudonyms on their ESC scoring sheets. The ESC tool consists of a total of five questions. The first question is an unscored, subjective question I asked the participant to determine alertness, and this question was followed by four additional questions for which the responses were scored. The questions were not yes/no questions; rather, they required answers using explanations of what was to be required of participants and what participants should have expected during the study (Resnick et al., 2007). The four scored questions revealed the participant's ability to a) name any risks associated with being in the study; b) name two things that will be expected of the participant as a result of being in the study; c) explain what the participant would do if he or she decides not to continue participating in the study; and d) explain what the participant would do if he or she experiences any discomfort as a result of participating in the study (Beebe & Smith, 2008, 2010). I patterned my administration of the ESC after that of Beebe and Smith (2008, 2010), meaning that if any ESC scored question was answered incorrectly, the PI would have prompted the participant by repeating the information once, and then asking the question a second time. If any scored question was then answered incorrectly the second time, the informed consent process would have been postponed by a minimum of 24 hours (thereby allowing for the chance that the participant could just be having an “off” or “bad” day); then a second trial of the ESC would have been conducted using the exact same procedures described previously. During the second ESC trial, if any prospective participant incorrectly answered any scored item, then informed consent would not have been obtained from that prospective participant, and that person would not have been included in the study (Beebe & Smith, 2008, 2010). However, this is a moot point, because each of my study participants scored perfectly on the ESC.

Prior to beginning the interviews, I checked with participants to ascertain what time of day each would prefer to be interviewed. This is important because some patients with dementia may experience an increase in fatigue or irritability in the afternoon or evening hours. This is known as “sundowning,” and by simply choosing a different time of day for the interview, sundowning can be avoided (Beuscher & Grando, 2009).

Effective communication skills were essential in this research project. During each interview, I made sure that I remained calm and reassuring, while taking care not to talk in a condescending manner to the participants. I also made sure to allow extra response time, and I monitored my participants for signs of anxiety or fatigue. In cases during which I sensed participants may have needed a break for some reason, I offered to pause or stop the interview;

however, none of my participants wanted to pause or stop interviewing (Beuscher & Grando, 2009). In the unlikely event that any participants may have become emotionally upset, uncomfortable, or distressed during the interview, I was prepared to interrupt the interview and paused to allow time for the participant to take a break. If necessary, the interview could also have been terminated at any time, allowing the participant to withdraw from the study at any point in time, with no repercussions whatsoever. However, as a trained and licensed RN with a master's degree in nursing, I am qualified and capable of offering support and comfort for emotional distress, and I was prepared to do so if the situation called for it. However, none of my participants became upset or distressed, and no one requested a break from the interview. It is important to note that many participants of previous phenomenological studies have found the phenomenological interview process to be cathartic, and even therapeutic, as it provides an opportunity to speak openly about one's experiences (Opsal et al., 2016; Rager, 2005; Thomas & Pollio, 2002); by sharing the experience through research, the participant may even gain a sense of having the potential to help others who may undergo a similar experience. Several of my participants commented that they hoped their participation in my research study might be helpful in some way to others with dementia.

Finally, it was important for me to remain flexible and understanding that every person is unique, and similarly, every PWD is unique. Furthermore, every PWD's experience of dementia is unique, and the signs and symptoms may vary from one day to the next (Beuscher & Grando, 2009). I reminded myself to be flexible with my interview techniques for each participant, as no two interviews would be expected to be alike.

Bracketing

Merleau-Ponty (1945/1962) refers to the importance of bracketing in his statement: "[I]n order to see the world…we must break with our familiar acceptance of it…" (p. xv). To that end, prior to beginning participant recruitment, I participated in a bracketing interview to help elucidate any of my own preconceived thoughts, ideas, and values about the phenomenon of leaving employment after diagnosis with dementia (Creswell & Poth, 2018; Sohn et al., 2017; Thomas & Pollio, 2002). Analysis of the bracketing interview helped by revealing themes of a) assumptions about work bringing identity to individuals; b) assumptions that participants *want* to keep working after diagnosis; c) assumptions about the typical trajectory and individuality of impairment progression; and d) the need for management of emotions related to personal experiences with persons who have had a dementia diagnosis. By acknowledging and maintaining an awareness of these themes regarding the research topic, I was better able to hold them, to the best of my ability, in abeyance as I conducted the study. However, it is important to note that bracketing is not an activity undertaken solely at the beginning of the study. Rather, purposeful bracketing occurred throughout the course of the study (Sohn et al., 2017; Thomas, 2005; Thomas & Pollio, 2002), and it was a sort of balancing act between holding in *awareness* my biases and presuppositions and holding in *abeyance* those biases and presuppositions in reduction (Finlay, 2008) to remain in the "phenomenological attitude" (Finlay, 2012b, p. 179), seeing with fresh eyes. To help maintain this awareness/abeyance balance throughout the study, I spent reflective time reviewing the notes from my bracketing interview prior to each participant interview.

Inclusion and Exclusion Criteria/Sampling Strategy

I used purposive sampling to identify and recruit participants who have experienced the phenomenon under study, and who were willing to share their stories of experiencing LOE with me (Sohn et al., 2017). Inclusion criteria for participation in the study are: a) living in the United States or its territories; b) speaking English; c) having received a dementia diagnosis; d) being employed at the time of dementia diagnosis; e) losing employment after dementia diagnosis, either voluntarily and by their own decision, or because their employer terminated them from employment; f) scoring with correct responses to all scored items on the Evaluation to Sign Consent (ESC) form (indicating full comprehension of the informed consent information; the ESC was previously described in the section entitled Special Protections and Strategies Related to Population); and g) (if the participant prefers to interview by videoconferencing (computer) technology), having Internet access and capability to use videoconferencing technology to interview, or having access to someone who is able and available to use videoconferencing technology on the prospective participant's behalf and assist with same; *or* (if the participant prefers to interview by telephone) having telephone access. Excluded from this study are: (a) those who did not speak English; (b) those residing outside of the United States or its territories; and (c) those whose dementia has progressed to such a degree that the potential participant did not score correct responses for all scored items on the Evaluation to Sign Consent (ESC) form.

Recruitment

Participant recruitment involved dissemination of my study recruitment flyer via local nursing schools, and amongst several local dementia support groups. Flyers were posted at area senior centers, public libraries, community centers, post offices, physicians' offices, and local businesses. In addition, my flyer was shared via several social media pages and through personal contacts. Information about my study was also spread by word of mouth (Schwandt, 2015). During recruitment, the decision was made not to screen for stage of cognitive impairment, because, given my methods of recruitment, it was not likely that anyone with moderate to severe dementia would pick up my study flyer or find it on social media and offer to participate in the study.

Typical sample sizes for phenomenological studies range from five to twenty participants, and the number needed is determined by data saturation (Sohn et al., 2017). Data saturation occurs when no new information is being shared, and the information that is being shared by participants sounds similar and repetitive of that shared by other participants. Once data saturation occurs, according to Sohn et al. (2017), one to two additional interviews are usually conducted to ensure that the data gleaned supports the findings already captured (Thomas & Pollio, 2002). However, according to Thomas and Pollio (2002), it also is not unusual for thematic consistencies to become apparent after three to five interviews.

After five interviews, themes were identified in the data. Following the proposed phenomenological methods, an additional (sixth) interview was conducted to provide corroboration of the themes developed to that date. The only new data identified in the sixth interview was the circumstances surrounding how that participant left employment; her employer terminated her employment before she had any chance to address the issue herself. Barring this difference, no new themes emerged, nor was there anything contradictory found in the analysis of the sixth interview. At this point, data collection ceased.

Data Collection

Pilot Interview. A pilot interview with one participant who met inclusion criteria was conducted prior to carrying out the research study. This pilot interview helped refine the interview process and aided in identifying any potential problems with the study itself or the materials that would be later shared with future participants (Marshall & Rossman, 2016; Sohn et al., 2017). In addition, the pilot interview served as an opportunity for me to address any barriers (e.g., building participants' trust; communicating effectively with participants; and helping participants become comfortable with speaking about their experiences).

Interviews. Prior to the interview, I checked with each participant to ensure that their selected location would be quiet, private, and as free as possible from disruptions. For the interview itself, I applied the training and education provided to me over the past eight years by mentor instructors in the TPRG about successful phenomenological interview techniques (Thomas, 2020). After consent was obtained, I began each interview session by collecting a small amount of demographic information for each participant (e.g., age, gender, nature of employment duties, length of employment, date of leaving employment).

I recorded each interview using two small, unobtrusive, hand-held, digital recording devices (Thomas & Pollio, 2002); two recorders were used to ensure the interview was recorded, in case of equipment failure of one of the recorders. The recording devices remained solely in my possession, kept in a locked cabinet in my home office until such time as the recorded interviews were transcribed and checked for correctness. At that point, the recordings were uploaded to the university's secure, password-protected, data storage platform and were deleted from the recording devices. The purpose of audio-recording was to allow for the interviews to be typed verbatim afterward. The typed transcripts of interviews provided the basis for data analysis (Sohn et al., 2017; Thomas & Pollio, 2002).

Phenomenological interviews typically do not follow interview guides or a structured set of questions. Rather, each interview began with a single, open-ended sentence (e.g., “Can you tell me about your experience of leaving employment after you received a diagnosis of dementia?”) This question structure allowed participants to share whatever came to mind and seemed figural to them. I primarily remained silent and allowed the participants to share as much as they wanted (Sohn et al., 2017; Thomas, 2020; Thomas & Pollio, 2002). As needed, I asked follow-up questions (e.g., “Can you please tell me more about that?” or “I heard you say [insert word or phrase]; can you tell me more about what that was like for you?” The interviews concluded whenever the participants finished sharing their experiences and indicated they had nothing else to add.

Field Notes. I maintained a journal of field notes throughout this study, writing field notes before and after each interview (Phillippi & Lauderdale, 2017; Thomas & Pollio, 2002). Field notes consisted of notations such as personal reflections about the interview space, notes about the activities in the surrounding environment that may have influenced the interview (e.g., loud noises outside the interview area), and any thoughts or ideas about the interview or the participant that I wanted to be sure to recall. Also recorded in field notes were thoughts about what worked well and what did not work in the interviews, and any improvements I might make for future interviews (Marshall & Rossman, 2016). Field notes also served as supplemental data for the data analysis phase of this research.

Debriefing/Reflective Journaling. After each interview, and throughout the study, I was careful to engage in debriefing as needed with trusted mentors and colleagues, and I sought appropriate support from these individuals as needed (Thomas & Pollio, 2002). I also engaged in reflective journaling to help process my own thoughts and feelings as I listened to multiple stories and interacted with participants who had lost their employment (Smith, 1999). In this way, I was better able to attend to my own emotional and psychological health as I conducted the study.

Data Analysis

Analysis of transcripts occurred with the aid of members of the TPRG, taking place simultaneously with continued interviewing. At present, the TPRG has 22 active members, including faculty from public health, psychology, education, and nursing, and students from social work, nursing, and education. The members of the TPRG represent a variety of ages, personal backgrounds, and levels of experience with phenomenology, but all are valued contributors of thought and discussion about the meanings found in the text under analysis. Guided by the tenets of Merleau-Ponty's phenomenology, data analysis followed specific procedures developed at the University of Tennessee, Knoxville by Dr. Howard Pollio (Pollio et al., 1997) and Dr. Sandra P. Thomas (Thomas & Pollio, 2002). Due to the ongoing Covid-19 pandemic, TPRG meetings have shifted towards a video teleconference platform, and my participant transcripts were shared with TPRG members through Vault, the university's secure file transfer service through which files are transferred via encrypted HTTP and stored in an encrypted data store. As previously stated in the section regarding confidentiality, all TPRG group members signed a confidentiality agreement covering all meetings for 2020-2022, and anyone new who joins a meeting (such as a student's committee member) signs a confidentiality agreement, as well.

It is the goal of phenomenologists to put on our ears to hear, and to hear well the described phenomenon, capturing the experience as through the eyes of the participants. During analysis, I first read each transcript through to get a sense of the whole. Then, each transcript was read multiple times, line-by-line, to determine the meaning intended by each section of data. Although transcript analysis was primarily my responsibility as principal investigator, members of the TPRG aided in transcript reading and analysis for four of the transcripts (Sohn et al., 2017; Thomas & Pollio, 2002).

Coding Meaning Units. During analysis, members of the TPRG and I especially focused on any words or phrases used by participants repeatedly or emphatically. Words or phrases that stood out as figural for participants were coded as meaning units (Saldaña, 2013; Sohn et al., 2017; Thomas & Pollio, 2002). Meaning units served as the foundation for theme development. The analysis focused on examination of parts of the text in context of the whole of the transcript, in addition to understanding the whole of the transcript in terms of its parts (Thomas & Pollio, 2002). This process of moving back and forth between the meaning units and the whole of the transcript allows the researcher to get at the meaning of the phenomenon as experienced by the participant; this is eloquently described by Merleau-Ponty (1964/1968):

> [T]o understand a phrase is nothing else than to fully welcome it in its sonorous being, or, as we put it so well, to *hear what it says* (*l'entendre*). The meaning is not on the phrase like the butter on the bread, like a second layer of "psychic reality" spread over the

> sound: it is the totality of what is said, the integral of all the differentiations of the verbal chain; it is given with the words for those who have ears to hear. (p. 155)

Comparative analysis continued, layer by layer, as the data from each transcript was added to the findings from the transcripts previously analyzed. This allowed for identification of commonly repeated words, phrases, metaphors, or focal points of discussion within each transcript and between transcripts.

Thematization. Thematization is the process of moving from the individual meaning units to identifying overarching themes that are present in all, or at least most, of the transcripts. The TPRG assisted with this phase of analysis, as well. Identification of themes requires that the word(s) or phrase must be found in every participant's transcript, or at the very least, not obviously contradicted by a transcript (Sohn et al., 2017). In this way, according to Thomas and Pollio (2002) themes are representative of "patterns of description" (p. 37) that are repetitively identified across transcripts as figural components of participants' experiences. Determining thematic content is not a matter of simply counting the numbers of times certain words, phrases, or metaphors occur within or across transcripts. Rather, it is more about understanding what the participants meant by those words in terms of situational context and in consideration of their interview transcript, as a whole (Thomas & Pollio, 2002). Themes that were identified across multiple transcripts are representative of "experiential patterns" (Thomas & Pollio, 2002), leading to the development of global themes which were depicted using participants' own words and phrases.

Thematic Structure. The thematic structure represents the essence of the phenomenon under study, and it depicts that which is common across the various accounts of the phenomenon. In developing the thematic structure, themes were collected and considered in relation to each other, while also taking into consideration the contextual grounds (Sohn et al., 2017; Thomas & Pollio, 2002). The TPRG assisted me with discerning the most aptly descriptive terms or phrases to use for each theme and the thematic structure, again taking care to ensure that each of the themes are supported in the transcripts. I developed a diagram (See **Figure 4**, Appendix D) to depict the themes and relationships between them within the thematic structure (Sohn et al., 2017; Thomas & Pollio, 2002). Data saturation was attained when no new information was evident and no further themes were identified in the transcripts.

Participant Validation. The primary investigator presented the findings within the thematic structure to two of the participants, together with a summary of the overall findings of the research project (Sohn et al., 2017; Thomas & Pollio, 2002). Both participants who were presented with the findings confirmed and validated that the findings were a correct representation of their experience of leaving employment after dementia diagnosis. This validation process may also be referred to as member checking. In this process, it was valuable for the researcher to collect participants’ comments about whether the thematic structure accurately captures the essence of the experience from their perspective. In this way, findings are co-constructed between the researcher and participants (Thomas & Pollio, 2002).

Written Report. The final task was to create the written report that conveying the essence of the phenomenon to the reader. The written report includes a section regarding implications for future research, practice, and policy (Sohn et al., 2017; Thomas & Pollio, 2002). In this way, this research project can help advance knowledge and practice, and it can help inform future policy initiatives. **Figure 5** in Appendix E reveals a diagram of the data analysis process for this study, applying existential phenomenological methods (Pollio et al., 1997).

Procedural Rigor

In qualitative research, researchers speak of achieving trustworthiness of findings as a means of measuring a study's rigor (Morse, 2015). Components of trustworthiness include credibility, transferability, confirmability, and dependability (Polit & Beck, 2004). According to Creswell and Poth (2018), there are several things researchers can do to achieve trustworthiness and enhance procedural rigor. These include spending a sufficient amount of time in the field; collecting multiple forms of data; validating the accuracy of study findings by conducting member checking, and peer auditing of the research. For my study, I have invested time in the field, listening to my participants' stories through interviews. I have collected multiple forms of data in that I have the recorded interviews, in addition to my own field notes containing information about my observations during each interview. I have conducted member checking to ensure my final report accurately represents what my participants meant to convey. Finally, my engaging the TPRG in data analysis helped ensure procedural rigor through peer auditing, especially since some of the members have many years of experience in conducting phenomenological research (Thomas & Pollio, 2002).

Credibility

Credibility refers to a state of confidence that your data and interpretations thereof represent truth with respect to the phenomenon under examination (Polit & Beck, 2004). Polit and Beck (2004) further share the importance of considering whether the study has been conducted in such a way that the findings will be believable to the reader, and that the believability actually has been conveyed to the reader. Following the recommendations of Polit and Beck (2004), there are a number of ways to I have increased the credibility of my study. For example, I ensured there was an investment of time and engagement with both my study participants and my collected data to enhance credibility. In addition, I applied data triangulation through the collection of a variety of data through interviews with multiple participants, as well as recorded observations in field notes, thereby adding to my study's credibility. Next, investigator triangulation occurred via my involvement with members of the TPRG (several of whom are seasoned, experienced phenomenological researchers) who assisted me with data analysis.

Transferability and Resonancy

Qualitative research is not meant to be generalizable to the population or to other groups; rather, the idea is for the findings to contribute to an improved understanding of the phenomenon or experience (Sohn et al., 2017). According to Sohn et al. (2017), at question is whether the research findings evidence critical characteristics of the phenomenon that then resonate with, and transfer to, others who find themselves in similar settings or situations. To this end, transferability has been addressed by my including rich, thick descriptions of my research findings (Polit & Beck, 2004). Resonancy is listed among Munhall's (2012) list of 10 Rs for evaluating phenomenological research, which are resonancy, reasonableness, representativeness, recognizability, raised consciousness, readability, relevance, revelations, rigor, and responsibility. She defines resonancy as "[t]he interpretation of the meaning of the experience is familiar, sounds correct, "resonates" of past experiences" (p. 524). Applying Munhall's definition of resonancy in this case, nurse readers would be reminded of past clinical experiences of individuals with dementia as they read my findings.

Dependability and confirmability

One way in which dependability and confirmability may be addressed is by providing detailed, written accounts of data collection and analysis steps that help the reader understand the researcher's progression from particulars (concrete) to more abstract concepts or terms (Creswell & Poth, 2018). In keeping with recommendations by Polit and Beck (2004), I kept a well-documented audit trail to ensure that my study findings are both dependable and confirmable. In addition, I addressed confirmability by engaging in ongoing bracketing of any biases and assumptions, in addition to maintaining a reflexive journal throughout my research project.

Chapter IV

Findings

Following the process delineated by Pollio et al. (1997) for conducting phenomenological research (See **Figure 5**, Appendix E), I aimed to achieve an improved understanding of the experience of leaving employment after receiving a diagnosis of dementia. After the bracketing and pilot interviews were conducted, I conducted telephone interviews with a total of six participants. Of these, five were initially interviewed, resulting in data saturation. At this point, I sought an additional interview as a means of confirming the preliminary findings and ensuring no new data was emerging (Sohn et al., 2017; Thomas & Pollio, 2002). With the assistance of the TPRG regarding four of the interview transcripts, I analyzed data from each transcript. This resulted in identification of six themes that were evident across the transcripts, in addition to a central, overarching theme. I developed a thematic structure (see **Figure 4**, Appendix D) that reflects the findings of this study. Feedback obtained post-analysis from two of the study participants revealed that these findings are an accurate reflection of their experiences with losing employment after dementia diagnosis.

In this chapter, I will first share basic demographics and brief descriptions of participants of this study. Next, I will describe the proposed contextual ground identified through participant narratives, and I will demonstrate how this is contextualized within Merleau-Ponty's grounds of body, others, time, and world. I will then share the central theme and each of the six themes identified during data analysis. Finally, I will conclude this chapter with a brief summary of findings.

Demographics

Not including the pilot interview, a total of six participants were interviewed for this study. Each participant acknowledged having direct experience with leaving employment after diagnosis of dementia. All participants were interviewed by telephone, with verbal voluntary, informed consents obtained in each case. The participants ranged in age from 61 to 71 years. Four participants identified as males, and two participants identified as females. Five of the participants worked in professions that required college education. All participants were previously employed in white collar professions, with four having worked in healthcare. Two participants were former physicians, with one having practiced as a neurologist, and another as a family physician; two participants had worked as registered nurses (one in pediatrics, and one as a surgical nurse). One participant reported having a former career as an attorney, and one participant had worked as a reliability coordinator, troubleshooting a multi-state power grid.

Length of time since leaving employment ranged from one year to nine years. All but one of the participants stated they did not reveal to their employer their dementia diagnosis, choosing to leave work of their own volition to prevent the potential occurrence of any negative or harmful event as a result of their memory issues. Five of the participants were from the same geographical area in which the study was conducted, and these five participants belonged to the same dementia support group. Although marital status was not included in the demographic questions, all participants voluntarily indicated during their interviews that they were currently married. However, one participant volunteered the information that he and his wife were having marital difficulties and were considering divorce at the time of the interview. All participants were assigned first-name only pseudonyms to protect their identities.

Participant Descriptions

Participant Bobby is a former neurologist who spent years diagnosing and treating people with dementia diagnoses. Armed with knowledge about diagnosing and treating dementia, Bobby learned as a result of some genetic ancestry testing that he possesses the e4 allele of the APOE gene, which is a genetic predisposition for dementia (Alzheimer's Association, 2022a). Thus, when Bobby began to notice symptoms of mild cognitive impairment in himself, he sought out cognitive testing from a friend in the profession. Bobby chose to retire approximately one year later, to prevent the possibility of making a mistake that could be harmful to someone as a result of his cognitive impairment. After retirement, Bobby shifted his efforts toward teaching, public speaking, traveling, volunteering, researching dementia treatment, and writing about dementia. Bobby continues many of these activities to date, always advocating for early recognition and treatment.

Participant Hope is a former pediatric registered nurse who worked for years in a pediatric hospital setting, although the last part of Hope's career was less clinical in nature, and more of case management and education. Hope began to notice that she was having difficulties with memory recall and tracking thoughts and information, and this prompted her to seek out diagnosis. Post-diagnosis, Hope felt she was unable to ethically continue to practice in the safest possible manner, and not at the quality level she expected of herself. Troubled by the stress and worry of potentially making a mistake that could cause harm to anyone, Hope chose to voluntarily retire before such a mistake could occur. Since retirement, Hope has remained busy by taking on multiple volunteer roles with her church and faith community, in addition to her membership in various groups for social justice and societal improvement. Hope also serves on the board of directors of her local dementia support group.

Participant Tony is a former attorney, having had a long, successful career in defending medical malpractice cases. Tony first became aware of his memory issues in the courtroom when he noticed he was unable to continue multi-tasking at the level to which he was formerly accustomed. Tony pursued diagnosis from medical professionals, ultimately coming to understand that his attempts to adapt at work were exhausting and overwhelming. Tony chose to retire from his law practice because he did not think he was able to adequately take care of his clients anymore; however, he did not tell his employer at that time about his dementia diagnosis. Since retirement, Tony has immersed himself in many activities, including singing in his church choir, taking voice and piano lessons, auditing college courses, singing in an opera, learning to bake, and staying involved with his dementia support group.

Participant Norman is a former reliability coordinator for a multi-state power grid, a position that required 200 hours of continuing education every three years to ensure safety. Norman first noticed his cognitive issues at work, when he was discussing a plan of action with a co-worker, but Norman found he was unable to retain information in order to log it. Norman’s co-worker pointed out that something seemed to be wrong, and Norman agreed. At this point, Norman took sick leave from work, choosing not to reveal his memory issues or his diagnosis to his employer, and hoping to address the memory issues before any serious errors could occur at his work due to his cognitive impairment. He sought diagnosis of his dementia, although the process required multiple appointments with several different specialists before he finally received his diagnosis. Since leaving employment, Norman has stayed busy with traveling, camping, involvement with his church, and serving on the board of directors of his dementia support group.

Participant Raymond is a former family physician who worked for 40 years in various roles in healthcare, starting as an orderly and working his way through medical school. Raymond first noticed he was having difficulty keeping up with his responsibilities at work, and he pursued a diagnosis to address the problem. When medical professionals believed his cognitive issues to be caused by his overworking, or worsened by his medications for hypertension, sleep apnea, and depression, Raymond had to advocate for himself and continue to pursue an adequate medical workup and diagnosis. Raymond chose to retire because he recognized his cognitive impairment made it impossible for him to continue safely practicing medicine; however, he chose not to reveal his diagnosis to his employer at the time. Since retiring, Raymond has immersed himself in volunteer work and statewide advocacy activities related to increasing dementia awareness and promoting early diagnosis. He serves on the board of directors of his dementia support group, and in his spare time, he has taken up cooking and photography.

Participant Grace worked as a registered surgical nurse in a medical specialty area for approximately 30 years. Grace began to notice she was experiencing difficulties related to memory loss, and she stated that when she left work to undergo a Covid test for herself, her employer told her to take some time off before returning. When Grace returned to work, her employer had her termination of employment papers ready for her to sign, signifying the end of her employment. Grace sought diagnosis and has not worked since leaving her position at the surgery center where she worked. Since leaving employment, Grace has busied herself with racing cars, autocrossing, and frequent traveling with her husband, as well as participating in a dementia support group. In her spare time, she enjoys cleaning and “purging” her house, decorating her home for holidays, visiting with friends, and caring for her pet dog.

Contextual Ground: “*Stigma of Dementia*”

For the participants of this study, the contextual ground is stigma (See **Figure 4**, Appendix D). Merriam-Webster online dictionary (2022) defines stigma as “a mark of shame or discredit: STAIN.” Participants spoke of experiencing stigma all across their world, including the workplace and at home. In addition, stigma was described by participants as being ever-present, but not continuously experienced. This is represented in **Figure 4**, Appendix D, by the purple shading which overlays the themes depicting the experience of leaving employment after dementia diagnosis. The purple shading representing stigma appears as waves, some of which are darker, indicating periods in which participants experienced stigma, and some of which are lighter, indicating times in which the participants were aware that stigma existed, but they were not actively experiencing it in that moment.

Stigma Experienced Through Body

As stated in Chapter III, Merleau-Ponty (1948/2004) believed the body to be the means through which we engage with and make sense of the world around us. Because the “body ‘lives the world’” (Vagle, 2018, p. 10), our meaning-making and perceptions of the world are experienced through the body. As previously stated, this is referred to by Merleau-Ponty as embodiment (Sohn et al., 2017; Thomas, 2005; Thomas & Pollio, 2002). In the case of this study, the participants’ bodies, namely their brains, are letting them down. They experience difficulties with information recall and retention, whether in the working world or in everyday activities, and they often are painfully aware of the stigmatic shame or sense of discredit directed towards them by others. This is evidenced by Norman, who stated:

> *Uh, but what happened is when you're labeled with that… or Alzheimer's… or MCI… you're automatically… the stigma from it, you're automatically put into a category in the public eye. And, uh, I experienced that… especially with co-workers.*

Another facet of experiencing stigma through the contextual ground of body is in a statement shared by Hope, wherein she references the stigma associated with the assumed narrative that a person with dementia is severely limited, physically at diagnosis:

> *We need to be doing more early on… and change the narrative that you're gonna be sittin' lookin' out a window, you know… droolin'.*

Stigma Experienced Through Others

Merleau-Ponty spoke of engagement with others as a sense of interconnectedness, where our experiences "intersect and engage each other like gears" (1945/1962, p. xxii). However, those experiences with others are not always positive. In this study, participants mentioned incidents in which they became aware of stigma during interactions with others. Tony shared his experience of encountering and dealing with stigma from others when he finally left employment:

> *I started to get some heat because my productivity had dropped down so low… and then I finally said, "ok, I'm just outta here." So, it was like I had planned to leave the firm … in December, I planned to leave the firm in September, and then it backed up to August, and then it backed up to July. Anyhow, it ended up backin' up… backin' up… until finally it was in May… that I left the firm… . I really didn't mention the cognitive impairment …. When you say "cognitive impairment," people freak. Uh… I've talked to them about it since then, but not at the time.*

Norman recalled experiencing stigma from witnessing interactions between distant family members and their loved one who passed away after dementia diagnosis:

> *I had another aunt, her sister, that died of ... uh, dementia. And these people just ... are in a closet. Their ... the family just sorta takes care of 'em, and that's it. They don't get any social ... any social action ... you know, they just ... they're shunned. I found that with a lot ... they're just totally shunned.*

Stigma Experienced Through Time

Time is especially relevant to the topic of dementia diagnosis because dementia, and especially Alzheimer's type dementia, progressively worsens over time, to the point that they become unable to communicate with others or respond, and eventually resulting in death (Alzheimer's Association, 2020c). However, this progression is usually slow, and it is different from one person to the next; the progression of the disease usually takes from three to eleven years, but it may take as long as 20 years (Mayo Foundation for Medical Education and Research, 2022b). Participants in this study experienced stigma related to time in terms of other people treating them as if they had already become incapable of carrying out certain activities when, in fact, they had not yet progressed to that point. Norman shared:

> *My goodness! They already think I'm gone! You know? Or not able to do anything ... or ... not able to comprehend ... don't know who they are.*

Stigma Experienced Through World

For participants in this study, the world around them can be, at times, supportive or stigmatizing, or some measure of both. Although participants described the support they received from their peers in their dementia support group, and also from their family members and friends, they also talked about experiencing stigma in their lifeworld. Because others are a component of the world around us, the lines of delineation may seem blurred between *others* and *world*, and the stigma encountered in the world often is experienced via the thoughts, deeds, and verbalizations of others. The perception of stigma experienced through the contextual ground of world may be overt, through statements overheard, or attitudes directly conveyed. However, at times, stigma may be perceived as covert, such as an expectation of their diagnosis not being well received by others. An example of covert stigma is seen in the way five of the participants chose not to immediately disclose their diagnoses of dementia to their employers, as they believed the outcome of such a conversation would not be favorable to them. Bobby portrays this response to stigma in the world in his statement:

> [O]f course there are all sorts of ancillary things, like, you know, once you have a diagnosis of Alzheimer's, you have trouble getting … long-term health insurance. You can't get long-term health insurance. Uh, you're stigmatized … for a number of reasons, uh, and … you know, that makes it hard for people to come out of the closet.

Bobby did later approach his chairperson and explain that he was going to need to retire and why, but the other four participants who had chosen not to immediately disclose their diagnosis did not reveal this information to their employers at all; some of these same participants acknowledged that they believed news of their diagnosis may have eventually "gotten back" to their employers later, well after they retired, but not because they themselves revealed it. Two participants, both physicians, went so far as to initially seek assistance with obtaining a diagnosis from physician colleagues with whom they were friends, in an attempt to collect the much-needed diagnosis information, but on a behind-the-scenes level that perhaps no one else need know about until such time as the participants may themselves have deemed it appropriate to reveal. In addition, one participant shared that part of the reason he did not reveal his diagnosis to his employer was financial, in nature:

> *I didn't tell 'em at work right away. … For financial reasons. [laughing] I wanted to work out a certain period of time. You know?* (Tony, attorney)

While not specifically stated, the implication of Tony's statement is that if his employer had known the diagnosis, he may not have been able to work for that extra period of time that he was hoping to remain employed. It is clear from these narratives that the majority of the participants in this study felt the need to, at least initially, conceal their dementia diagnosis due to stigma they experienced and/or expected to encounter from others in their world (society).

Central Theme: "*Still Working*"

An overarching, central theme of "still working" became apparent in the data and was present across the transcripts. The central theme is depicted in **Figure 4**, Appendix D, as a set of six interlocking cogs, or gears that fit together in a configuration that appears to "work." Each of the individual cogs represents an individual theme within the central theme. The individual themes will be described in upcoming sections. It is important to note that in the thematic structure figure, some of the teeth of the individual cogs appear to have been worn down and are rounded off. This is a representation that, although the cogs are not quite what they once used to be, they are still working – much the same as the participants in this study are not quite as cognitively well-functioning as they used to be, but they are still working.

Participants shared story after story about how they are continuing to stay busy after leaving employment, and are, in essence, "still working," albeit working differently and at different types of tasks and activities than before at their paid jobs. The new “work” is often viewed as therapeutic, as reflected in Bobby’s statement:

> *I mean, I’m still working. Uh, that’s the way I look at it. You know, ... I’m still ... I get the joy of working, but I have a little more free time for, you know, reading stuff that’s not work, but yeah, I write every day. I have a blog, that, you know, I’m probably putting an entry in ... about every week, on average, uh ... that ... are things to bring up ... to date, uh, issues from the [publication], or to talk about new discoveries. And you know, it’s got ... a pretty good following. I think there are about 69 people now, you know, signed up for the e-mails. Um, and I don’t know how many people are looking at it, otherwise. Some days I get zero, and sometimes I get a hundred people looking at it. ... So, I’m staying quite active as a ... pseudo-academic, I guess, in uh, specializing in Alzheimer’s information and ... discussion. Um, so that’s been very therapeutic for me to keep that... keep working, in a sense, in my field, although I’m not ... I’m no longer seeing patients.*

Five out of the six participants shared stories that indicated they had experienced their leaving employment as more of a transition, or shift, from paid employment to various types of volunteer work, advocacy activities, teaching roles, or spending quality time with family and others, rather than experiencing it as a loss. Raymond described this transition from employment to other activities:

> *[W]hen I retired, my cognitive therapist had me go do [community food group] work ... do something. I went to [community food group] every [day of the week] for five years ... and packed meals, just ‘cause I wanted to talk to people. I ... my whole life I spent talkin’ to people ... . And so that helps.*

Grace described the transition from paid employment as an opportunity to have fun, maintain a clean, neat house, and simultaneously help a charitable organization gain benefit from her new “work:”

> *Oh, I have fun. I mean, I stay … I can do any-- … I stay busy. 'Cause I like to keep my house neat, and I purge stuff like you would not believe. Take it to [organization], donate it, and stuff like that.*

This was echoed by Tony who indicated he kept busy taking care of his wife who had recently suffered a broken bone, and he also had been taking care of their house during his wife's convalescence.

On the contrary, some participants also expressed a tendency to become over-involved and to become so involved in their new "work" that they end up needing to scale back to avoid feeling overwhelmed. Hope described feeling overcommitted:

> *I started volunteering for a lot of things at our church, and our faith community … and you know, and then before … six months or a year was out, it's like, ok, now you're overcommitted doin' this, you know, and so you need to step back.*

The central theme of "still working" encompasses each of the individual themes in that the individual themes fit together, each describing a facet of how these participants made sense of and moved through their transition from paid employment to their new lives, post-employment.

Theme One: Doing No "*Harm*"

The first theme, "Doing No 'Harm,'" represents the first facet of participants' meaning-making of their experience of leaving employment. These participants expressed feeling a keen sense of responsibility to protect others from any potential harm that could have occurred if they had continued to work while their cognitive abilities further declined. Five participants chose to leave their employment before anything harmful could have happened. With several participants having been employed in health care, concern for patient safety was evident:

> *I know that nothing happened that caused any harm to anybody. It wasn't a dramatic type of event. It just was, um ... it was more of "oh, I forgot to document that," and I would have to go back and add to it. Uh, and it was ... "Oh, I've ..." you know, instead of calling a patient ... at a certain time, then maybe it was later. It ... was just ... and I began to be very anxious about what I might be forgetting. Um, and that ... has been a hard feeling, or was a really hard feeling ... . I just felt, ethically, that I couldn't safely practice, uh, nursing, my career, the way that I expected ... the level of quality that I expected. And that has been an adjustment."* (Hope, registered nurse)

> *Uh, so within a year, I retired just because, uh, I didn't want to be in the position of, uh, making a mistake because of ... cognitive problems while being a physician.* (Bobby, physician)

> *Executive function's gone. That's a myth, anyway, but it's really gone, now. Multitasking doesn't exist. That was a big, damaged area, to me, was executive function. So, you can't really practice medicine like that.* (Raymond, physician)

Similarly, Tony, who had been a medical malpractice defense attorney, verbally demonstrated his concern over leaving employment before a serious mistake could be made, and he voiced this in terms of taking adequate care of his clients:

> *I'm not just lazy ... and I'm not just ... and it's not ... age-related ... 'cause that's what ... my GP wants to say, and that's what most healthcare providers want to say ... [in a mocking voice:] "Oh, your problems are just age-related." Well ... bullshit! No, it's not age-related. It's actually a mild cognitive impairment. So ... [inhales deeply] because of that ... [exhales deeply], I quit working ... because I just ... didn't ... [heavily accents each word individually:] I. Did. Not. Feel. Like. I. Was. Able. To. Take. Care. Of. My. Clients. Adequately. Anymore.*

Tony went on to describe how he undertook preemptive damage control by leaving work before a potentially harmful or costly error could have occurred:

> *Well … I didn't … it never actually happened because I didn't let it happen. Ok? I recognized the problem before I was … before that could occur. Ok? ... Because of the difficulty I was having in the office environment, I knew … you know, I started thinkin', "Man, if I get into court with this thing, I'm gonna be…I'm gonna be havin' trouble with this."*

Participants took their responsibilities for the lives and safety of others, as well as prevention of costly damages, quite seriously. The magnitude of potential loss was made very clear by Norman:

> *No. No, I did not tell 'em … . I did not tell 'em the reason [for leaving employment]. I just said, "Something's wrong … and I don't know what it is" … . I didn't tell 'em that it … specific example where I'd forgotten. Because I knew the … the job I was in, I mean … I was responsible for lives … and decisions … and millions of dollars. And if I'd a did somethin' like that, I don't know what it would've done to me.*

Theme Two: The "*Struggle*"

Participants shared multiple accounts of how they have struggled in various ways. One such struggle involved difficulties participants experienced with locating a well-suited healthcare provider who was equipped with the appropriate diagnostic skillset and experience to diagnose their dementia. Although this did not rise to the level of a theme within the findings, three of the six participants mentioned encountering such difficulties, often resulting in a prolonged period of seemingly trial and error visits with various healthcare providers:

> *[I was] talking to my neurologist about the problems I was seeing at work, and he said "Well, I think you might have mild cognitive impairment." Well, I tell my psychologist, who's my therapist, about it. And he's like "Oh, you don't have mild cognitive impairment." And I say, "Well, my neurologist says I do." And, and …he says … "Let me do some testing." So he does some testing.* (Tony, attorney)

When I was finally diagnosed … and I knew something was wrong … I pursued this. Uh, and my diagnosis has changed back and forth … because of doctors. Uh, I knew something was wrong, and then when I was told … I think initially I was told I had, uh, vascular dementia … . And then, uh, the first diagnosis … I remember when I went back to the doctor, after they'd run all the scans and all this stuff or did what they were gon' do, and I said, "Well, what do I need to do? What do I need to do to take care of myself?" And his answer was, "Well, if ya … if ya get to where you're not feelin' good, or ya think somethin's not right, just come back to see me." And they wrote me off. And that was a neurologist. (Norman, reliability coordinator)

Norman continues his narrative about seeing yet another healthcare provider to try to obtain a diagnosis:

So, … anyway, in the long run, the same thing happened with this doctor that happened with the other neurologist. And this woman … she was not a neurologist. She was educated in … into … the Alzheimer's. And that was what she did. And uh … so the same thing went on with the other doctor. She ju-- … there's nothing else she could do for me, really, you know? She just gave me that diagnosis, and that was basically the end. I'd go in and see her nurse practitioner every so often. Ask about medications. (Norman, reliability coordinator)

[I]t's also really difficult to find an adequate … a physician who will adequately work you up. And I went from, uh … you know, we … it was really difficult … the whole … that whole few years in there was horrible. I had nightmares for two years about that … had nightmares about work … that … [stammers] … I go to cognitive therapy with therapists … I mean, everything to work through this. And it's really, really difficult. And I've sat in support groups, listening to talks … so many people telling the exact same story … how traumatizing it is … 'cause people don't … know how to work you up. The physician workforce doesn't recognize it … doesn't know what to do with it, if they do. So I had to get to the right doctor. And that … it takes a year or two to get all … it takes a couple of years to make the diagnosis. And it's real frustrating. And, as we have

> *progressed with this, and worked on it ... in group meetings ... and talking to people ... and advocating ... what we're trying to do is prom-- ... elevate this in the differential ... have people think of this earlier ... make the diagnosis earlier to support brain health.* (Raymond, physician)

Struggles encountered by participants also have involved effectively juggling responsibilities and keeping up with the pace and volume of work prior to making the decision to leave employment:

> *Uh, and I felt during that year with the uh, particularly with the administrative responsibilities, that I was handling it well, but it seemed to be a lot harder than it should have been. You know, keeping all the balls in the air.* (Bobby, physician)

> *I just lost confidence that I was remembering everything I should ... remember. Because it was showin' up in other areas of my life, so why wouldn't it show up there? You know. So ... it just created a lot of stress and sadness. You know, I think that I certainly have, at times, felt down and depressed about not being able to practice nursing. Um ... I retired from [hospital] when I was 62, which is certainly earlier than I had anticipated.* (Hope, registered nurse)

> *I remember finding notes in my desk ... "What's wrong with me?" I wrote notes to myself: "What's wrong with me?" ... I'd go in earlier in the morning to get dictation done ... and when I did that ... I'd stay later ... . I was going in earlier, before everybody else ... staying later, because I couldn't keep up ... trying desperately, trying to see ... to keep up with my ... all the data you're supposed to keep up with.* (Raymond, physician)

Other struggles participants have dealt with involved the ways their cognitive impairment has affected their attempts to stay engaged in activities after leaving employment:

> *I ... you know ... after doin' the chorus for the [music organization], ... I wanted to try out for the regular chorus. Well, the tryouts for the regular chorus, you've gotta memorize two arias. Well, I ... I had decided to do that in ... March. Ok? I have barely memorized one aria, and I keep losin' it! And the damn thing's only two minutes long.*

> *Now, admittedly, it's an Italian aria, but it's only a couple of minutes long. You see, and I can't do it. I ... I just can't. I just can't. That's the impairment. [long pause] ... Does that make sense? ... I struggle. I struggle an awful lot.* (Tony, attorney)

> *I read 100 books a year, but I don't remember them the next day. So… in fact, even when I'm reading one, I have to go back and re-read a few pages because I can't remember, you know, where I left off. Uh ... so, that's not, you know, a problem, 'cause I enjoy reading in the moment. Uh, but in terms of learning new things, I really can't do that very well anymore. Um, and ... so that's a problem.* (Bobby, physician)

> *I play the piano, and I've always, uh ... I can still play things I've ... known for a long time, but I really have a hard time learning a new piece. In fact, I really can't. Uh, I have to sight-read it every time I see it, you know, and it ... it doesn't carry over from the last time. Uh ... even that motor memory ... I can't, uh, activate ... anymore. Uh, so my short-term memory is ... getting pretty bad. And ... you know… I'm livin' with it.* (Bobby, physician)

As participants adjusted to their lives after leaving employment, they often became more aware of their own physical and mental limitations. They spoke of the need to make time for self-care, scale back activity levels, and plan their activities for the time of day when they might reasonably expect to have the most cognitive function. In contrast, there was an acknowledgement that trying to accomplish tasks later in the afternoon and evenings typically results in a struggle:

> *[E]very ... the evenings ... it's just ... you get a fog ... the fog rolls in. And if you talk to enough of our [support group] members, they'll tell you about the fog. The fog is horrible. When the fog starts rolling in, you just need to slow down. That's the point where you just need to stop what you're doin', don't try to ... "Oh, man, I haven't hung that thing yet, I need to take my drill out and go work on that." You'll screw it up. Just ... stop.* (Raymond, physician)

Theme Three: Strategically Compensating

As participants transitioned to life after leaving employment and encountered the struggles mentioned in Theme Two, they have developed methods of strategically compensating to help deal with some of their common struggles. Strategies for compensating may have been as simple as making reminder notes for themselves or planning ahead to lay out needed items so they won't be forgotten. These strategies are shared by some of the participants:

> *I had to screen … I don't remember how many it was … 300 applicants or something for our residency program, and decide, you know, which one of those we were going to interview, and … go through a selection process and … [takes a deep breath] … and, uh, so I had lots of committee meetings that I had to go to. And, uh, I had all these scraps of paper, you know, with things written on them.* (Bobby, physician)

> *Write it down. Write lots of notes. Keep notes around. But keep organized notes. You can write too many notes, and lose your notes. So, you've got to be structured in your note writing, be purposeful and think about what you're gonna do the next day the night before … try to execute that day … be ready to learn how to adapt to a sudden change, and that's really hard, with this.* (Raymond, physician)

> *[W]e have a basement garage, and so if there's something that I'm gonna do the next day that I need to take anything with me, I go immediately and put that in the car. The idea of "oh, I need to remember to take so-and-so" and the likelihood of me being able to remember that the next day? I've learned I can't rely on that anymore. So, it's like, "oh, I'm gonna, you know, uh … need to have so-and-so with me tomorrow." I'm gonna go put that right now in the car. Or I'll put it, you know … hang it … hang something over the door knob if I'm like, maybe having to make a return or something, I'll put that on the door knob that I have to go out, down to the car in. And so, I … I just have developed this "go take care of it now" mentality because I can't count on being able to remember it.* (Hope, registered nurse)

One participant shared another way of compensating for cognitive loss that involves making strategic choices about which activities to attempt to perform. If an activity involves mental or physical work that this participant knows is beyond his capabilities, he simply chooses to do a different activity, or to find an adapted version of the activity that works for him. Tony discussed how he has incorporated this compensatory strategy:

> *But, like I say, you know, I just compensate for the … uh … for the impairment. You know? I mean … [blows out a deep breath] … I do … I restrict myself to doing things that the impairment doesn't disturb … . You know, I think the singing is a good example … . I've given up on being in the opera chorus. I was able to fake it with the auxiliary chorus. But the choral society, they stand there, and they've got the music in front of them. See? So, I do music when I can read the music. If it requires memorizing the music, then I can't do it. You know?*

Other strategies participants developed for strategically compensating involved becoming self-aware enough to recognize their need, in the moment, for compensation and/or seeking support or assistance from others. Hope shared that she learned to recognize when she was feeling overwhelmed, and that she often takes steps to address her own needs in this regard:

> *So, I'm … I'm trying to … structure my life where things are simpler because I do … because I do better if I don't have as much … part is stimulation but part of it's just um … just having a … more of an ease in my day … day-to-day life. So, um … and sometimes I don't know that I'm gonna get overwhelmed until I'm in a situation, and … so … and so I do … you know … if I do get overwhelmed, I'll figure out a way to either go home or [laughs] … or excuse myself, you know, or … or whatever I need to do, I'm developing some strategies for how to handle that.*

Similarly, Norman spoke of incorporating self-care, recognizing when he needs help, and seeking out assistance when it is needed:

> *I said, "I take care of myself." I said, "I'll get the help I need." I said, "If I think I'm gettin' worse," I said, "I'm gon' go … do somethin' about it."*

For five of the participants, involvement with a strong support group has been a valuable resource for learning to strategically compensate for their cognitive impairments. From others within the support group, participants have found compassion, empathy, education, encouragement, and emotional support in times of need. Raymond illustrates how he learned to compensate by leaning upon the assistance of others in his support group:

> *We started those support groups. And to get people in and talk about it … and start … and they're able to now express what they went through 'cause we sit around talkin' about it. And find … you feel like you're on an island, and if you get with other people with it, you go, "oh, ok, you're dealing with this, too, and this is how you deal with it." So, everybody helps each other deal with it. Before, you're isolated with your family, and they're frustrated … it's just … I can't imagine that, otherwise.*

Theme Four: Valuing "*Connection*"

During interviews, participants placed a great value on connections with other people in their lives, both for socialization and mutual support. Several participants mentioned how much they value the connections they have with others in their support group, as evidenced by the following quotes:

> *I think connection became even more important, um, during that time. You know, and it can get really isolating, especially for people with … you know, with cognitive impairment. I mean, connection is huge. You know, exercise is huge, nutrition is huge, uh, but that connection and socialization is … is really important … that's one of the things that I found our … our [support group], you know, very helpful in, especially initially. I just wanted to pick the people's brains … you know, "what are you doin' to*

help you with your memory?" "What are you doin' to help you with word finding?" You know, that type of thing. (Hope, registered nurse)

It really is a wonderful, wonderful group. Um, I think, first of all, just not to feel alone was the big thing. And then, to also see that, you know, cognitive issues is like a big umbrella, and there are lots of reasons for those of us that are under the umbrella that might be different … . I have MS, somebody else might have vascular dementia, or somebody might have Lewy body, or Alzheimer's, or post-cortical atrophy, you know … there are lots of reasons for us to all be under that umbrella, but so many of the issues are the same, you know, in how it affects our daily lives. So, to be able to know that we're accepted, and that we're in a group of people that understand. They get it in a way that, as much as our family can love us, they don't have it. (Hope, registered nurse)

Yeah … you see, and it was my uh … psychiatrist who told me about [the support group], and I'm so glad she did. … So … I've got a regular Zoom [support group] meeting I do … uh, that I've ended up being the leader of. (Tony, attorney)

[T]his one group I got into, uh … they approached me, and it's people that's been diagnosed. And they were startin' up this [support group]. And they asked me if I'd like to, you know, participate, and I said "Sure." And it was a small group, at first … now there's, I think, three or four branches of it. Uhhh, and it's the best thing I ever did … because we are a group that's been diagnosed. We might have different diagnosis … but we understood everything that was goin' on with us. Or if we didn't understand, we could bring it out in this group and discuss it with these other people that was diagnosed … which was very helpful. It was like we're … it's our own little club. And if we wanna talk bad about ourselves, we can talk bad about ourselves … and laugh about it! And not … not the pity. Not the pity card. Uh, and … help others get through it. So, that was the best thing I've ever did, and I'm still in that, and I like to attend those other Zoom meetings with [other support group]. (Norman, attorney)

Uh … I reached out … I wanted to talk to other people with it. And so when I talked to [dementia support organization], "well, we have this [support group] that meets once a

> *month." ... I wanted to hear from the people with it. So that led to [name of person] and I starting our own little [support group name]. And we set up three independent, peer-driven support groups for people with early neurocognitive disorders. And it's now a thing. ... People need to talk to other people with it. And we all share the same experiences ... sometimes just laughin' your head off, saying "yeah, I do that! I forget that!"* (Raymond, physician)

Aside from support groups, participants found that they could establish meaningful connections through their volunteer work and other activities out in their communities. These meaningful connections often bring a sense of being appreciated by others. In addition, making connections with others in the community is viewed as an essential means of opening up oneself to new activities and opportunities. These are demonstrated in the following quotes from Bobby and Tony:

> *I would teach both medical students and residents. ... I speak to all the medical students at uh, the medical school here. There's uh ... a panel, which ... I'm almost always on it ... of, uh, three or four people ... either people with Alzheimer's or caregivers for people with Alzheimer's. And ... the students enjoy that, uh ... a lot. But I think they really connect with me because I can, I can talk their language, and kind of ... and get them engaged on, you know, the neuropathology, uh ... what's going on with Alzheimer's, and in my own brain. And that's been fun for me, and uh, I think it's been good for them.* (Bobby, physician)

> *I continued to be out in the community. You know? ... And it drew me out. It gradually drew me out. And goin' out and gettin' engaged. Ah ... you gotta be ... you gotta be ... yes, yes, yes, yes, yes, yes, yes, yes! Yeah! You gotta be out there! You know? You gotta ... you gotta put yourself out there. You know?* (Tony, attorney)

Finally, participants spoke of valuing and relying on meaningful connections with their families and others in their faith communities, and some also mentioned missing their close friends from their former places of employment. These valued connections are illustrated in the quotes below:

> *The … family thing, they were … my family, … they were, uh … they were very supportive. Uh, church family … they were supportive.* (Norman, reliability coordinator)

> *I miss a … I miss a lot of people in that … in the surgery center … a lot. Yeah. But I'm here, at my house … and I have a dog … and we … and my husband is … he's my pillar … so … he's awesome. So … I miss everybody. And so, I mean, I can see 'em every now and then, which is fine. So … that's good. I love my life … like I said, I've got a great husband! I've got a dog! I've got plenty of friends.* (Grace, registered nurse)

Theme Five: Still Actively Living

After leaving their employment, the participants have continued to lead active lives. They shared story after story of how they accepted opportunities to stay involved with various activities of interest and groups within their communities. There was a sense that, although they left behind the activities related to their former employment, the participants are taking great pleasure in the lives they are continuing to live. This is evidenced by the following quotes:

> *But, I … did that … uh, those trips up until, oh, about [year] or so. Uh, and I just, b- by that time, I was … my cognitive ability was getting too impaired … to teach. And then I switched over to being an advocate for uh, Alzheimer's disease, uh, for early … management and … for early recognition and management of Alzheimer's. So, all this is what I'm doing, and staying active, and keeping my mind going. Uh, and, and, uh, I'm not working at my old job, but I take a lot of pleasure in what I'm doing now.* (Bobby, physician)

> *And when I'm on the [institution] e-mail list, I get a letter from the … I get an e-mail from the guy who's gonna teach this course in the classics … and the course is gonna involve reading The Iliad, The Odyssey, The Aeneid, The Inferno, and Paradise Lost. I thought, "Well, that'll be fun." So I signed up, and I did that. So, then, I'm kinda busy!*

> *'Cause I'm going to church at least three times a week, I'm going to … music … I'm going to music lessons once a week … and I'm takin' this three-hour class … which is a lot of heavy reading. Ok? ... Having taken that class in the classics … motivated me to sign up for … to start auditing classes at the Orthodox School of Theology at [institution]. So last fall, on top of everything else, I was also auditing … no … last summer I audited the New Testament course, and then this past winter after I dropped chorus, I audited the Old Testament course. So!* (Tony, attorney)

> *We, uh … we autocross [racing cars] at [city]. Yes! We love [city]! My first … I guess my first, really, autocross was at [location]. Oh, yeah. Oh yeah. We have so much fun, though. We travel. We're gonna be going to [city, state] next week … and there's a lot of cars up there, too, so … um, he's gonna … of course he's gonna autocross his Mustang. And we've got a toy hauler. We got a car that … my car will fit into our camper.* (Grace, registered nurse)

Theme Six: Still Contributing

As the participants described their overall journey of "still working," only differently, they shared narratives about ways in which they are continuing to contribute to their community and are maintaining a sense of giving back to society. These individuals are still relevant, and still have knowledge, gifts, and abilities to offer. The following quotes illustrate the theme of "still contributing:"

> *Well, I think my whole life um, I loved bein' a nurse. I still identify … a lot … and I still have a lot of knowledge, you know, as a nurse … and experience.* (Hope, registered nurse)

> *I just evolved … my neurology teaching differently. Uh, so, as soon as I retired, I volunteered … locally … at a free clinic, … seeing indigent and … illegal immigrants, uh, doing general medicine. So … since [year], I think, I have been going to [geographic area], to [country], uh, for oh, two or three weeks every year to teach neurology. And I*

> *continued to do that for, uh, another three years after I retired, because there was nothing wrong with my ability to teach. I still had … an adequate … my neurological database was still intact. I could still retrieve the information and teach it. Uh, it's just that my short-term memory was getting worse and worse.* (Bobby, physician)
>
> *I speak to all the medical students at uh, the medical school here, through the Alzheimer's Association. They come in … they, they visit the Alzheimer's Association as part of, I think it's their second year. I don't even think it's elective. I think they all do it. Uh, and they get a little pitch from someone about the … what the Alzheimer's Association can do for doctors, um, and then, there's … a panel, which … I'm almost always on it … of, uh, three or four people … either people with Alzheimer's or caregivers for people with Alzheimer's.* (Bobby, physician)
>
> *And I came up with this thing when I talk to groups about PROS…Purpose, Routine, Organization, Structure. How critical! That's just a life thing. I mean, it's … we all have to have purpose. But to have a … routine and structure is … that's an everyday thing. It's almost like "Ok, I've got a cognitive disorder … so we have to work really hard to stay structured." And it works! You can stay in that and function a lot longer independently if you just follow those rules.* (Raymond, physician)
>
> *Well … and then what happened … was that the [name of music organization] … uh, Maestro … I forgot his name … [name of Maestro] … is gonna put on, … Mefistofele. And it's his last production … before he retires. And he's using … students from [institution] for an auxiliary chorus. So, I ended up in the opera! I've loved opera all my life. And I … the last … the first live production of metropolitan opera in years … after Covid started, and I was actually on stage in the chorus! Singing with 'em!* (Tony, attorney)

Summary

In summary, stigma serves as the contextual background against which the participants of this study move through the various facets of leaving employment with the idea of preventing any harm or damage to anyone due to their cognitive impairment. This stigma is always present in their lifeworld, but it is not continuously experienced by participants. As the participants have gone on with their lives and continued "working," only differently and at different types of activities, they have experienced various struggles associated with memory loss and cognitive impairment. These struggles have included difficulties with locating a healthcare provider who was equipped with the appropriate diagnostic skillset and experience to diagnose their dementia, and this issue often resulted in a prolonged delay of obtaining a correct diagnosis for their cognitive issues. Other struggles have involved keeping up with the responsibilities, pace, and volume of work at their former places of employment, as well as memory issues affecting their ability to engage in activities of interest after leaving employment. The participants in this study have learned and incorporated strategic methods of compensating for their cognitive impairment. These participants value the connections they have with others, and they actively seek to engage themselves in meaningful activities that will give them a sense of purpose and pleasure in life. In addition, the participants perceive themselves as able to continue contributing to their families, their communities, and society as a whole, despite the more pessimistic and stigmatizing view generally conveyed in the world.

Chapter V

Discussion

The aim of this study was to ascertain and describe the experience of leaving employment after diagnosis with dementia. I applied a phenomenological study design based on the tenets of Maurice Merleau-Ponty (See **Figure 5**, Appendix E), conducting six telephone interviews with participants who have experience with my topic of inquiry and met the inclusion criteria (described in Chapter III). During the interviews, I asked each participant to describe their experience of leaving employment after being diagnosed with dementia. The interviews were recorded and transcribed verbatim. I then analyzed each interview transcript, applying a hermeneutical method developed by Dr. Howard R. Pollio (Pollio et al., 1997), and utilized in nursing research studies by Dr. Sandra P. Thomas (Thomas & Pollio, 2002). Themes were identified by examining the whole of each interview in terms of its parts, and the parts of each interview in context of all of the interviews.

All of the participants had the option of having their interviews conducted by videoconference, telephone, or in person. All participants chose to be interviewed by telephone. Participants were told they could determine their own length of interview, and that the interview should take however long they wanted to take in order to share what they thought was important to share. The duration of interviews ranged from 47 minutes, 30 seconds, at the least, to one hour, 46 minutes, and 30 seconds, at the most. All six participants were eager to share their experiences and expressed their gratitude to me for conducting this research. In addition, all of the participants shared their experience of the potentially life-altering event of leaving employment sooner than originally anticipated, and this event carried with it the possibility of being viewed as a negative experience. However, all of the participants in this study described their experience in a positive light; they had taken the turn of life events and chosen to view their early retirement as an opportunity to become involved in and pursue other activities and/or to spend time with their family members.

Contextual Grounds

The experience of leaving work after diagnosis with dementia took place within the contextual ground of stigma, and this contextual ground was significant for the participants of this study. As illustrated in **Figure 4**, Appendix D, the stigma is always present for the participants, but it is not continuously experienced. Rather, at times the participants are able to go about their daily activities without much notice of the stigma, and it fades somewhat into the background as contextual and non-figural. At other times, the stigma is more noticeable and becomes the figural aspect, with the issues from the themes fading into the background. This shifting back and forth between what is contextual and what is figural is consistent with the previous discussion in Chapter III of Edgar Rubin’s faces/vase drawing (See **Figure 3**, Appendix C).

As previously stated, the participants in this study felt the need to hide their diagnosis of dementia, at least initially, due to societal stigma (or stigma experienced through the world). In particular, the participants did not feel comfortable with the option of approaching their employers and sharing their diagnosis. This may be due to fear of immediate job loss, fear of the subsequent financial hardship that may result from job loss, or fear of being labeled and/or treated differently (Rosin et al., 2020; Stites et al., 2018). It is true that these participants were willing to talk to me, as a researcher and interviewer, about their experiences, so one might counter that they seemed to overcome the societal stigma enough to engage in the interview. However, perhaps they were willing to acknowledge to me their stigmatized diagnosis of dementia and share in the interview process about their experience because they had been more successful surmounting their “struggles” than others with the disease. Five of the six participants are members of what was described as a very solid, structured, empathetic support group, so it is possible that their degree of support also played a role in their willingness to share via interviews.

Five of the participants were college educated people (two physicians, two registered nurses, and one attorney) who previously worked in roles that required them to regularly engage with others and offer assistance to other people. The sixth participant worked in a job which was highly technical and required 200 hours of continuing education every three years, just to ensure the safety of a power grid that affected the lives of many others. Thus, these participants presented as a collective of highly motivated people who were not strangers to overcoming problems and giving of themselves to help meet the needs of others.

The six participants included in this interview were the only participants who came forward and expressed interest in participating in this study during several months of vigorous attempts at recruitment, so it is clear that recruitment of participants was difficult during this study. However, all phenomenological studies can only report what willing interviewees consent to disclose to us. Until societal stigma is decreased, recruitment of people with dementia may always be somewhat difficult.

Themes

As depicted in **Figure 4**, Appendix D, the themes, taken together, tell the story of how these participants view themselves as “still working,” which is the central theme. These participants are not the same as they once were, and they are not working at their previous jobs. However, they perceive themselves as still being able to contribute to society in meaningful ways, and still being able to engage in activities that they enjoy doing. During interviews, there was a sense that these participants were getting on with life and being determined to continue doing all that they are able to do.

All but one of the participants in this study left employment of their own volition in order to avoid doing any harm or allowing any costly errors or damage to occur as a result of their cognitive impairment. The sixth participant believed that her employer recognized her memory issues and terminated her employment before an error potentially could occur; her termination from employment happened before she had an opportunity to make the choice to leave employment. All of these accounts are illustrated within Theme One, “Doing No ‘Harm.’” Despite the issues these participants were dealing with related to their own losses after receiving a dementia diagnosis, they generally put the needs and safety of others first; this is not surprising, given that four of the participants worked in healthcare professions, which are typically roles that are focused on caring for others. The fifth participant, a former medical malpractice defense attorney, also had spent years in a role that required him to think of the position and stance of others, and he had a long history of understanding how a single mistake, or mishap, could result in a costly and damaging error that is highly impactful upon others.

Within Theme Two, “The ‘Struggle,’” participants described multiple ways in which they have struggled, and often continue to do so. As mentioned in the Findings section, one particular issue that arose in several interviews, but did not rise to the level of a theme, is the struggle with finding an appropriate healthcare provider who was equipped and experienced to enable diagnosis of dementia. The “struggle” around obtaining an appropriate and timely diagnosis is likely an issue at this time in history for several reasons. First, dementia is a clinical diagnosis requiring certain knowledge and experience in order to recognize the signs and symptoms and make an accurate diagnosis. Next, there is not a singular screening test for dementia, because dementia refers to a group of symptoms that can occur as the result of several different hard-to-diagnose diseases. Despite the difficulties surrounding diagnosis of dementia, the participants in this study exhibited tenacity in that they were willing to pursue their diagnosis despite multiple visits with multiple providers to get the answers they sought. Perhaps this is a testament to their high-achieving roles in employment and their education/training levels. They all previously worked in positions which required them to “troubleshoot,” and to pursue the answers they needed to situations that arose.

Other struggles the participants have encountered include the difficulty with effectively juggling their responsibilities and managing their workload in their previous employment roles. These types of struggles have carried over into the participants’ ability to engage in various activities after leaving employment, as well. Some participants described writing many notes to themselves to try to stay organized, having to go in to work earlier and stay later, struggling to retain and recall what has just been read, struggling to learn a new piece of piano music, and struggling with engaging in activities if they occur during a time of day when the “fog rolls in.”

Here, again, the high achieving mentality and tenacity of these particular participants may play a role in their ability to address the struggles they encounter, and this brings the discussion to Theme Three.

The participants in this study are able to employ strategic compensation to address the struggles they have, and still do, encounter, as they sometimes struggle to keep up with their chosen activities. They variously described writing “copious notes” to themselves, trying to always be structured and purposeful in their planning for the next day, incorporating methods for ensuring they place any items they need to take with them in a strategic location to ensure they will see it the next morning. The compensation strategies also involve making adjustments as needed to their own activity levels or commitments to prevent becoming overwhelmed. These strategies are all evidence of the tenacious, high-achieving nature of this group of participants, as they troubleshoot their own issues with memory loss and strategically plan ahead for ways to circumvent problems. Perhaps these efforts are aided by the support these participants have from others in similar circumstances, which leads the discussion to Theme Four.

These participants place a high value on the “connections” they have established with others, and especially in their dementia support group. Within their support group, they are able to freely and openly share and discuss their problems with others who either are facing or have faced similar difficulties. They draw upon each other for socialization, support, and encouragement. They share with one another strategies and information about what works and what doesn’t work.

Other types of valued connections that these participants have made are with people they met and with whom they interact in their volunteer work and other chosen activities, as well as with their family members, faith communities, and close friends. Again, these connections provide positive feedback and interactions, and serve to shore up the participants by providing support and a sense of being valued as individuals. Through these interactions, the participants gain a sense of having contributed meaningfully to their own lives and the lives of others. Perhaps the ability to cope with difficulties and develop strategies would be much different for individuals who were not as engaged with such supportive groups of others.

It is important to mention, however, that these study findings should not be construed as painting a rosy picture of all being well for people with dementia. These participants certainly struggle, and they certainly face difficulties associated with cognitive impairment. There were hints mentioned in several of the interviews that, at times, participants experienced at least some tension and stress in their personal lives. One participant mentioned how his inability to focus on and capture the first few words of conversation was “annoying” to his wife. Another participant mentioned that his wife “never lets” him drive, unless she has difficulty backing a vehicle into a specific location, and then, and only then, does she need his help; this same participant mentioned that he and his wife had even begun fighting regularly, and they were discussing divorce at the time of the interview. However, it is significant that none of the participants in this study chose to dwell on the negative aspects. If tension and/or discord was mentioned in the interview, it was simply shared, and then the participants tended to move the discussion back towards positive topics. These participants are unique in that they primarily choose to focus on the positive aspects of living their lives, rather than the negative aspects and/or stressors and problems of living with dementia. This may also be, at least in part, attributable to the level of support these participants perceive that they have.

Participants chose to focus on the positive aspects of life, which informs Theme Five: “Still Actively Living.” These participants tended to describe leaving employment as an opportunity to work at other activities of their choosing, and they were excited about having the time and opportunity to travel, to learn to cook, to race cars, to audit college courses, to do volunteer teaching, and to sing in various choirs and operas, to name a few activities. Although several participants did mention feeling sadness about not being able to continue working as long as they had hoped, or about missing their friends from their former workplaces, they didn’t dwell in that mental space for long. This may be a function of the short-term memory issues often seen in PWD, but it also may be attributable to their sense of resilience and tenacity which they have drawn from the high level of support they feel from their dementia support group, families, faith communities, and friends. These participants have made the choice to stay involved and engaged with activities that bring them joy and pleasure in life.

Theme Six, “Still Contributing,” is significant for these participants because the life they have carved out for themselves is not just a life of pursuing activities to benefit themselves. They are finding ways to give back to their families and friends, their communities, and to society at large. They perceive themselves as still having a wealth of knowledge and experience to offer, and they seek ways to share that knowledge and experience with others. For some, that manifests as engaging in volunteer teaching opportunities, for others it involves advocating for earlier recognition and treatment of dementia. Other such activities include singing in an opera for community enjoyment, and developing and sharing mnemonic devices to assist others with dementia in improving independent function and organization. These participants are all using their personal strengths in terms of knowledge, experience, and skills to contribute towards others' well-being and enjoyment of life. The tendency of these participants to continue contributing to others fits neatly within Stage Seven of Erik Erikson's Stages of Psychosocial Development, which I will briefly discuss next.

Support for Erikson's Stages of Psychosocial Development

In the 1950s, psychologist and psychoanalyst Erik Erikson introduced his theory of Stages of Psychosocial Development. The premise of this theory is that humans advance through eight different stages of development throughout their lifespan. The various stages are influenced by social, psychological, and biological factors. The theory posits that, as humans grow and develop throughout their lives, they are faced with issues in each stage of development that require resolution, thus leading to critical junctures, or decision points. Within each developmental stage, there are "two opposing psychological tendencies" (Orenstein & Lewis, 2021, para. 1-2) which occur: one positive tendency, and one negative (Huffman, 2007). If the individual embraces the positive tendency, this is said to aid development of foundational beliefs regarding oneself and others and to contribute to further psychosocial development in later stages. On the contrary, if the individual embraces the negative tendency, then the opposite outcome occurs, and the individual is not aided in further stages of psychosocial development (Orenstein & Lewis, 2021).

The stage within Erikson's theory that is relevant to the present study is Stage Seven, which is the stage of adulthood, and the opposing psychological tendencies associated with this stage are generativity versus stagnation. Erikson theorizes that within Stage Seven, individuals wrestle with either manifesting generativity in their lives or falling short of generativity and experiencing a sense of stagnation (Erikson, 1950; Huffman, 2007). Generativity, as used here, connotes teaching or helping to guide the generation to come (Orenstein & Lewis, 2021), but it also refers to being productive and creative in one's life (Erikson, 1950).

In the present study, the participants clearly demonstrated a sense of being both productive and creative. Within this remarkable group of participants, there was no evidence of stagnation. In fact, in many instances conveyed by the participants during their interviews, they were actively involved in teaching activities to help guide others. One participant wrote a published book, conducted guest lectures, and maintained an online blog about dementia. Several participants held board positions within their dementia support groups, and they actively worked in their communities to alert others who were newly diagnosed with dementia to the availability of the group as an option for support. Another participant spoke of contributing to the arts by his involvement in community opera and other singing choirs. Several participants also shared accounts of how they have applied their knowledge and efforts to advocate for early diagnosis and treatment of dementia, thus working to help guide generations of others who may face similar diagnoses.

The participants in this study shared clear evidence of their determination and ability to remain creative, productive, and contributing members of their families, communities, and society. The lack of evidence of stagnation does not imply that these individuals experienced no hardship or difficulties in life. During interviews, the participants spoke of sometimes encountering difficult situations, but they chose to dwell on the positive aspects of life rather than the negative ones, and this enabled their perspective to be one of generativity rather than stagnation. Next, I will share how the findings of this study fit within the existing body of literature.

Findings Situated Within Existing Literature

Earlier research indicated that interaction with others, both inside and outside the work environment, is an influencing factor in perceived meaning of work (Rosso et al., 2010). The findings from this study align neatly with this previous research in that the participants in this study have established meaningful interactions, or valued "connections," with others in their families, faith communities, and support groups, and this has likely aided their perception of the meaning of their new found "work" in terms of the activities they have immersed themselves in, post-employment. It is not surprising that these participants view their new activities as simply their way of continuing to "work," only at different tasks and in different roles, especially since previous research indicates that work provides: a means of organizing one's schedule and a way to pass the time; opportunities for socialization and forming connections; opportunities to help others; a basis for gaining self-respect (Friedmann & Havighurst, 1954); and a sense of meaningfulness (Schwartz, 2015). The new "work" activities for these participants helps provide them with a sense of pride over having done well and accomplished something meaningful (Clark, 1967).

This is in contrast, however, to previous findings that unexpected transition from work may be viewed as "a serious life event, turning their existence 'upside-down'" (Johannessen et al., 2019, p. 484). The participants in this study demonstrated great resilience and flexibility at their LOE, choosing to view their transition from employment as an opportunity to engage in "other work," meaning activities they *want* and *choose* to do. This deliberate choice on the part of the participants in the present study corroborates earlier research findings indicating the importance of remaining engaged in meaningful activities and hobbies of interest after LOE

(Chaplin & Davidson, 2016; Evans, 2019; Öhman et al, 2001; Ritchie et al., 2018; van Vliet et al., 2017).

A finding that contrasts with the extant literature is the previous research indicating PWD who experience job loss often feel loneliness and isolation from their former social groups at work (Harris, 2004; Johannessen & Möller, 2011; Johannessen et al., 2019; Ritchie et al., 2018; Roach & Drummond, 2014). In the present study, the participants sought out opportunities to engage with and make connections with others after LOE. These connections and support also likely aided in preventing them from experiencing such a serious upheaval of their existence as was mentioned in previous research. Two studies in the literature indicated PWD sometimes experience LOE as a relief and a welcomed chance to reduce their load of stress (Johannessen & Möller, 2011; Johannessen et al., 2019), and the findings of the present study support this since at least four participants mentioned feeling relieved from worrying about the potential for making a costly or damaging mistake at work.

Earlier research indicates that minor changes in the abilities of PWD are often first noticed at work (Ducharme et al., 2013; Evans, 2019; Johannessen et al., 2019; Ritchie et al., 2018). The findings from the current study are somewhat consistent with this literature, as three of the participants in this study indicated others at work noticed their difficulties with memory, although those participants in the present study did not go so far as to confirm that the suspicions of those at work were correct. According to the literature, however, sometimes PWD are the first to notice their own memory issues at work (Pesonen et al., 2013); the findings of this study are congruent with this, as five of the six participants in the present study indicated they first noticed their own difficulties with memory at work.

Previous research also revealed that PWD are often faced with LOE after being diagnosed with dementia (Evans, 2019; Jacobs et al., 2018; Kandiah et al., 2016; Sakata & Okumura, 2017; Watkins et al., 2018), and that choices about continuing to work are often limited. The findings of the present study are consistent with Ritchie et al. (2018) who found that often PWD make the choice to leave employment of their own volition once they realize cognitive impairment is occurring, as this occurred with five participants in the present study.

However, other options revealed in the extant literature include remaining in employment with altered job responsibilities (Ducharme et al., 2013); taking sick leave (Chaplin & Davidson, 2016; Johannessen et al., 2019; Ritchie et al., 2018); applying for disability (Johannessen et al., 2019); retiring (Johannessen et al., 2019; Öhman et al, 2001; Ritchie et al., 2018); or being terminated from employment (Chaplin & Davidson, 2016; Ducharme et al., 2013; Ritchie et al., 2018; Roach & Drummond, 2014). Missing from the findings of the present study was any mention of participants being offered an option to remain in employment with altered job responsibilities, taking sick leave, or applying for disability. The findings did, however, support previous research (Chaplin & Davidson, 2016; Ducharme et al., 2013; Ritchie et al., 2018; Roach & Drummond, 2014) regarding some employees being terminated from employment once dementia is known or suspected, because this occurred with one participant in this study.

It is understandable that no options were offered for remaining in employment with alterations in job duties/responsibilities, taking sick leave, or applying for disability, because the participants in this study made the choice not to reveal their diagnosis to their employers. This study does, however, provide a new piece of the puzzle about PWD leaving employment, because the findings of this study reveal the hesitancy of PWD to even reveal their cognitive issues or diagnosis of dementia to anyone at their places of employment. This suggests that the stigma surrounding dementia diagnosis must first be addressed before the issue of encouraging employers to be more supportive or aiding in that effort could effectively be undertaken.

Previous research indicated that financial problems often result for PWD after LOE (Kandiah et al., 2016), and that this frequently results in significant financial hardship (Busted et al., 2020; Harris, 2004; Johannessen & Möller, 2011). However, in the current study, financial hardship was only mentioned by one participant, and that was only mentioned in passing, and not as a focal point of the interview.

Implications

Occupational health nurses may find the results of this study useful in terms of understanding the employee's perspective in situations and issues that contribute to termination from employment. Findings may be helpful as occupational health nurses make recommendations to employers about maintaining a safe, productive work environment that is inclusive of PWD for as long as possible after diagnosis. Home health, residential care, and acute care nurses may also be able to apply the findings from this study towards better understanding some behaviors and needs of patients in various stages of dementia who may be missing their former work role and the relationships with friends from work. In addition, nurses working in mental health may be aided by findings from this study as they provide counsel to PWD and their families; findings may also be helpful as mental health nurses engage with patients who require testing to differentiate between psychosis and dementia. Finally, the findings may be helpful to nurse practitioners (NPs) in primary care, especially in rural and underserved areas for which NPs often are primary caregivers, providing counseling and education to patients and their family members (American Association of Nurse Practitioners, 2022).

In addition to the above-mentioned clinical implications, there are also educational implications for this study. Nursing education programs may find these results helpful as their faculty teach their students about the significance of psychosocial aspects of nursing care for patients with dementia. More specifically, there is an opportunity for these findings to be incorporated within patient simulation scenarios of nursing education.

Limitations

This study had several limitations. First, there is the potential for recall bias by participants during interviews. This is especially significant given that the participants have a diagnosis of dementia; the cognitive changes associated with dementia often result in memory loss and difficulty with appropriate word recall. However, there did not appear to be any significant issues with recall or word finding. In the role of researcher, I maintained a relaxed, calm interview setting, and I provided verbal cues when necessary to keep the flow of conversation moving. I also made an effort to be present in the moment with the interviewees, patiently allowing them to find their words and express themselves in their own way and in their own time (Beuscher & Grando, 2009; Moore & Hollett, 2003).

Another potential limitation is researcher bias, which can occur when the researcher inevitably bears some measure of influence over the data collection and analysis. As a result, the findings may be biased (Morse, 2015). However, to the best of my ability, researcher bias was minimized by continuously bracketing my own thoughts, ideas, presuppositions, and biases with respect to the phenomenon as I progressed through the study. Prior to each interview, I reviewed the findings from my own bracketing interview, and I wrote in my field journal about any thoughts or presuppositions I was aware of. This allowed me to be more aware of those potential biases during the interview and make a concerted effort to avoid introducing them.

Other limitations are as follows: The participants were mostly males (four males and two females), and five of the six participants were highly educated; in addition, although the sixth participant did not have a college education, he had previously worked in a role in which he was required to routinely troubleshoot, and he was also required to maintain 200 hours of continuing education every three years to ensure safety. In addition, all of the participants worked in white collar jobs, with four in health care (two physicians, and two nurses), and one working as an attorney. This suggests that all of the participants of the present study were highly motivated and focused individuals, with experience in critical thinking, planning, and strategizing. These participants are not likely to be representative of PWD who are less educated or who have worked in blue collar jobs.

In addition, five of the participants participated in the same dementia support group. The level of support and socialization they provided to one another may not be the same for others who do not have ready access to such a supportive group. It is also possible that the participants in this study were perhaps more willing to talk to the researcher in this study because they had been more successful in surmounting their “struggles” than perhaps others would have been. The looming contextual ground of stigma was a factor in preventing these participants from revealing their diagnosis to their employers, and it is such a pervasive factor that stigma may possibly also have prevented other prospective participants from signing up to interview for the present study.

Strengths

A strength of this study is capturing the lived experience of a unique group of individuals with dementia who seemed motivated to remain generally focused on the positive, and on what they are still able to accomplish, rather than focusing on the stigma or the things they cannot do. The participants in this study were all eager to tell their stories, and I, as the researcher, found them inspiring and quite moving. Their narratives will allow both professionals and the general public to glimpse the courage and determination of some people with dementia, in contrast to the pessimism and despair prevalent in the current literature.

The use of the Transdisciplinary Phenomenology Research Group, or TPRG, during data analysis is also a strength of this study. Although I was ultimately responsible for the majority of data analysis and decisions regarding theme names, the members of the TPRG served as accountability partners throughout the data analysis phase. The TPRG assisted with my bracketing interview and helped me be cognizant of any biases and presuppositions I held regarding my topic. Members of this valuable group also aided the process of analyzing transcripts and recognizing what stood out to participants as figural in their experiences.

Another strength of this study is that the findings were validated through member checking. After completion of data analysis, I presented the study themes, together with a narrative describing the findings, to two of the participants. I asked the participants to read through the findings and let me know whether they thought I had accurately captured the essence of their experience of the phenomenon of leaving employment after diagnosis with dementia. Both participants indicated that my findings were correct and conveyed exactly what their experience had been.

Future Research

While it is not likely that this group of individuals is representative of those who may have a lesser reserve of personal motivation, tenacity, positive outlook, and support, this research project does provide a snapshot of insight into this group, at this point in time, with the resources available to these individuals. This information is beneficial and helpful as an addition to the extant body of research. Replication of this study with additional, more diverse, groups of individuals is highly recommended.

In addition, the findings from this study revealed the significance of stigma as a looming, ever-present contextual ground, that seemed to prevent the participants from revealing their diagnosis to their employers. Until stigma is better understood and addressed, PWD may never feel comfortable even revealing their diagnosis, and this certainly impedes the opportunities for any employers to work with and attempt to accommodate their employees who have a dementia diagnosis. There is an opportunity for further exploration of stigma experienced by PWD who are leaving employment.

There also is a research opportunity in exploring ways to better equip and train healthcare providers, including nurse practitioners, for improved recognition and diagnosis of dementia. Physician/healthcare provider hesitancy to diagnose, possibly fueled by a lack of information or a lack of familiarity with diagnosing dementia, may be a problem that could be addressed by future research. The two physicians who participated in this study both advocate for earlier recognition, diagnosis, and treatment of dementia. In fact, one of the physician participants mentioned he is working hard within his home state to promote the implementation of a statewide program and network for diagnosing and treating Alzheimer’s disease and related dementias that is similar to one already established in the state of Georgia (Bender et al., 2022). As stated previously in the section entitled “Themes” within this Chapter V, there are known confounding factors that can add to the complexity of diagnosing dementia, even for neurologists who are accustomed to making such diagnoses. Getting involved with implementation of this type of provider network and program to aid early diagnosis and treatment seems like it would be an excellent gateway for future research, especially since early, accurate diagnosis and treatment of dementia is a topic of critical importance.

Conclusion

In conclusion, the participants of this study showed a strong sense of resiliency and determination to continue “working,” but differently, and at different activities, after LOE. Because they were willing to be interviewed for this study, their experiences were audio-recorded, and their words preserved to be shared with others. Their voices were heard. A thematic structure was developed that represents the themes and shares the essence of their experiences of leaving employment after diagnosis with dementia. Despite the prevailing negative attitudes and stigma of society with respect to dementia, these participants have demonstrated they care about preventing harm to others, they can “still work,” albeit at different activities, despite their struggles. They value connections with others, and, in fact, these connections strengthen them, such that they are able to strategically compensate for their cognitive struggles and go on actively living, and still contributing in meaningful ways to themselves, their families, their communities, and society at large.

The findings of this study stand in sharp contrast to both the generally pessimistic view regarding this topic that is prevalent in the extant literature and the stigma of dementia often encountered in society. The participants of this study have demonstrated great motivation and tenacity to continue living their lives, pursuing activities that both bring them great pleasure and allow them to contribute meaningfully to society. Their willingness to share their stories ensures that their voices are heard as they contribute towards the effort to change the narrative regarding the experience of leaving work for people with dementia.

List of References

Alzheimer's Association. (2020a). *Mild cognitive impairment (MCI).* https://www.alz.org/alzheimers-dementia/what-is-dementia/related_conditions/mild-cognitive-impairment

Alzheimer's Association. (2020b). *Dementia vs. Alzheimer's disease: What is the difference?* https://www.alz.org/alzheimers-dementia/difference-between-dementia-and-alzheimer-s

Alzheimer's Association. (2020c). *What is Alzheimer's disease?* https://www.alz.org/alzheimers-dementia/what-is-alzheimers

Alzheimer's Association. (2022a). *2022 Alzheimer's disease facts and figures.* https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf

Alzheimer's Association. (2022b). *Younger / early-onset Alzheimer's.* https://www.alz.org/alzheimers-dementia/what-is-alzheimers/younger-early-onset

American Association of Nurse Practitioners. (2022). *Nurse practitioners in primary care.* https://www.aanp.org/advocacy/advocacy-resource/position-statements/nurse-practitioners-in-primary-care

Bakewell, S. (2016). *At the existentialist café: Freedom, being, and apricot cocktails.* Other Press.

Bauman, Z. (2005). *Work, consumerism and the new poor* (2nd ed.). Open University Press.

Beebe, L. H., & Smith, K. (2008). Examining informed consent in persons with schizophrenia. *Issues in Mental Health Nursing, 29*(4), 397-410. https://doi.org/10.1080/01612840801904472

Beebe, L. H., & Smith, K. (2010). Informed consent to research in persons with schizophrenia spectrum disorders. *Nursing Ethics, 17*(4), 425-434. https://doi.org/10.1177/0969733010364581

Bender, A. A., McIntosh, R. L., Sudduth, S., Harris, M., Tuckey, K., Morgan, J. C., Jungerman, J. M., Cox, A., Moore, M. A., Ingram, B., Pier, E., Johnson, II, T. M., Loring, D. W., Hepburn, K., Medders, L., Levey, A. I., Lah, J. J., and Hales, C. M. (2022). The Georgia memory net: Implementation of a statewide program to diagnose and treat Alzheimer's disease and related dementias. *Journal of the American Geriatrics Society, 70*(4), 1257-1267. https://doi.org/10.1111/jgs.17690

Benner, P. (1984). *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness.* London: Sage.

Beuscher, L., & Grando, V. T. (2009). Challenges in conducting qualitative research with individuals with dementia. *Research in Gerontological Nursing, 2*(1), 6-11. https://doi.org/10.3928/19404921-20090101-04

Buckingham, W., Burnham, D., Hill, C., King, P. J., Marenbon, J., & Weeks, M. (Eds.). (2011). *The philosophy book.* DK Publishing.

Busted, L., M., Nielsen, D. S., & Birkelund, R. (2020). "Sometimes it feels like thinking in syrup" – the experience of losing sense of self in those with young onset dementia. *International Journal of Qualitative Studies on Health and Well-being, 15*(1). https://doi.org/10.1080/17482631.2020.1734277

Centre for Economics and Business Research. (2019). *The economic cost of dementia to English businesses – 2019 update.* https://www.alzheimers.org.uk/sites/default/files/2019-

09/The%20economic%20cost%20of%20dementia%20to%20English%20businesses%20-%20edited.pdf

Chaplin, R., & Davidson, I. (2016). What are the experiences of people with dementia in employment? *Dementia, 15*(2), 147-161. https://doi.org/10.1177/1471301213519252

Clark, D. (1967). *Work & the human spirit.* Sheed and Ward.

Cohen, S. (1999). Social status and susceptibility to respiratory infections. *Annals of the New York Academy of Sciences, 896*(1), 246-253. https://doi.org/10.1111/j.1749-6632.1999.tb08119.x

Corbin, J. M., & Strauss, A. L. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Sage Publications.

Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry & research design: Choosing among five approaches* (4th ed.). Sage Publications.

Ducharme, F., Kergoat, M.-J., Antoine, P., Pasquier, F., & Coulombe, R. (2013). The unique experience of spouses in early-onset dementia. *American Journal of Alzheimer's Disease & Other Dementias, 28*(6), 634-641. https://doi.org/10.1177/1533317513494443

Duquesne University. (2020). *Founding members and early trailblazers of the department.* https://duq.edu/academics/schools/liberal-arts/academics/departments-and-centers/psychology/departmental-archives-project/early-trailblazers/amedeogiorgi

Emanuel, E. J., Crouch, R. A., Arras, J. D., Moreno, J. D., & Grady, C. (Eds.). (2003). *Ethical and regulatory aspects of clinical research: Readings and commentary.* The Johns Hopkins University Press.

Erikson, E. H. (1950). *Childhood and society.* W. W. Norton & Company.

Evans, D. (2019). An exploration of the impact of younger-onset dementia on employment. *Dementia, 18*(1), 262-281. https://doi.org/10.1177/1471301216668661

Feather, N. T. (1990). *The psychological impact of unemployment.* Springer-Verlag.

Ferlic, A. (1968, October). Existential approach in nursing. *Nursing Outlook,* 30-33.

Finlay, L. (2008). A dance between the reduction and reflexivity: Explicating the "phenomenological psychological attitude." *Journal of Phenomenological Psychology, 39.* https://doi.org/10.1163/156916208X311601

Finlay, L. (2012a). Debating phenomenological methods. In N. Friesen, C. Henriksson, & T. Saevi (Eds.), *Hermeneutic phenomenology in education: Method and practice.* Sense Publishers.

Finlay, L. (2012b). Unfolding the phenomenological research process: Iterative stages of "seeing afresh." *Journal of Humanistic Psychology, 53*(2), 172-201. https://doi.org/10.1177/0022167812453877

Friedmann, E. A., & Havighurst, R. J. (1954). *The meaning of work and retirement.* University of Chicago Press.

Fryers, T., Melzer, D., & Jenkins, R. (2003). Social inequalities and the common mental disorders. *Social Psychiatry and Psychiatric Epidemiology, 38*(5), 229-237. https://doi.org/10.1007/s00127-003-0627-2

Gergen, K. J. (2015). *An invitation to social construction* (3rd ed.). Sage Publications.

Giorgi, A., Fischer, W. F., & Von Eckartsberg, R. (Eds.). (1971). *Duquesne studies in phenomenological psychology*. Duquesne University Press.

Giorgi, A. (2009). *The descriptive phenomenological method in psychology: A modified Husserlian approach.* Duquesne University Press.

Hadden, K. B., Prince, L. Y., Moore, T. D., James, L. P., Holland, J. R., & Trudeau, C. R. (2017). Improving readability of informed consents for research at an academic medical institution. *Journal of Clinical and Translational Science, 1*(6), 361-365. https://doi.org/10.1017/cts.2017.312

Harris, P. B. (2004). The perspective of younger people with dementia: Still an overlooked population. *Social Work in Mental Health, 2*(4), 17-36. https://doi.org/10.1300/J200v02n04_02

Huffman, K. (2007). *Psychology in action* (8th ed.). John Wiley & Sons.

Jacobs, M., Hart, E. P., & Roos, R. A. C. (2018). Cognitive performance and apathy predict unemployment in Huntington's disease mutation carriers. *The Journal of Neuropsychiatry and Clinical Neurosciences, 30*(3), 188-193. https://doi.org/10.1176/appi.neuropsych.17070144

Jahoda, M. (1982). *Employment and unemployment: A social-psychological analysis.* Cambridge University Press.

Johannessen, A., & Möller, A. (2011). Experiences of persons with early-onset dementia in everyday life: A qualitative study. *Dementia, 12*(4), 410-424. https://doi.org/10.1177/1471301211430647

Johannessen, A., Engedal, K., Haugen, P. K., Dourado, M. C. N., & Thorsen, K. (2019). Coping with transitions in life: A four-year longitudinal narrative study of single younger people with dementia. *Journal of Multidisciplinary Healthcare*, *12,* 479-492. https://doi.org/10.2147/jmdh.s208424

Kandiah, N., Wang, V., Lin, X., Nyu, M. M., Lim, L., Ng, A., Hameed, S., & Wee, H. L. (2016). Cost related to dementia in the young and the impact of etiological subtype on cost. *Journal of Alzheimer's Disease, 49*(2), 277-285. https://doi.org/10.3233/JAD-150471

Kim, J., Noh, J.-W., Park, J., Huh, T., & Kwon, Y.D. (2018). Association between health-related quality of life and work status in older Korean adults. *Geriatrics & Gerontology International*, *18*(12), 1629-1633. https://doi.org/ 10.1111/ggi.13541

Marshall, C., & Rossman, G. B. (2016). *Designing qualitative research* (6th ed.). Sage Publications.

Mathers, C. D., & Schofield, D. J. (1998). The health consequences of unemployment: The evidence. *Medical Journal of Australia, 168*(4), 178-182. https://doi.org/10.5694/j.1326-5377.1998.tb126776.x

Matthews, E. (2006). *Merleau-Ponty: A guide for the perplexed.* Continuum International Publishing.

Mayo Foundation for Medical Education and Research. (2020, July 8). *Young-onset Alzheimer's: When symptoms begin before age 65*. https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/in-depth/alzheimers/art-20048356

Mayo Foundation for Medical Education and Research. (2022a, November 6). *Alzheimer's and dementia: What's the difference?* https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/expert-answers/alzheimers-and-dementia-whats-the-difference/faq-

20396861#:~:text=While%20dementia%20is%20a%20general,memory%2C%20thinking%20and%20reasoning%20skills.

Mayo Foundation for Medical Education and Research. (2022b, October 11). *Alzheimer's stages: How the disease progresses.* https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/in-depth/alzheimers-stages/art-20048448

Merleau-Ponty, M. (1945/1962). *Phenomenology of perception* (C. Smith, Trans.). Routledge. (Original work published 1945).

Merleau-Ponty, M. (1948/2004). *The world of perception* (O. Davis, Trans.). Routledge.

Merleau-Ponty, M. (1964/1968). *The visible and the invisible* (C. Lefort, Ed., A. Lingis, Trans.) Northwestern University Press.

Merriam-Webster, Incorporated. (2022). *Merriam-Webster.com dictionary.* Retrieved October 10, 2022 from https://www.merriam-webster.com/dictionary/stigma

Moore, T. F., & Hollett, J. (2003). Giving voice to persons living with dementia: The researcher's opportunities and challenges. *Nursing Science Quarterly, 16*(2), 163-167. https://doi.org/10.1177/0894318403251793251793

Morse, J. M. (2015). Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research, 25*(9), 1212-1222. https://doi.org/10.1177/1049732315588501

Munhall, P. L. (1994). *Revisioning phenomenology: Nursing and health science research.* New York: National League of Nursing Press.

Munhall, P. L. (2012). *Nursing research: A qualitative perspective* (5th ed.). Jones & Bartlett Learning.

National Institute on Aging. (2017, December). *What is dementia? Symptoms, types, and diagnosis.* https://www.nia.nih.gov/health/what-dementia-symptoms-types-and-diagnosis

Nordenmark, M., & Strandh, M. (1999). Towards a sociological understanding of mental well-being among the unemployed: The role of economic and psychosocial factors. *Sociology, 33*(3), 577-597. https://doi.org/ 10.1017/s003803859900036x

Öhman, A., Nygård, L., & Borell, L. (2001). The vocational situation in cases of memory deficits or younger-onset dementia. *Scandinavian Journal of Caring Sciences, 15*(1), 34-43. https://doi.org/10.1046/j.1471-6712.2001.1510034.x

Omery, A. (1983). Phenomenology: A method for nursing research. *Advances in Nursing Science, 5*(2), 49-62. https://doi.org/10.1097/00012272-198301000-00010

Opsal, T., Wolgemuth, J., Cross, J., Kaanta, T., Dickmann, E., Colomer, S., & Erdil-Moody, Z. (2016). "There are no known benefits…": Considering the risk/benefit ratio of qualitative research. *Qualitative Health Research, 26*(8), 1137-1150. https://doi.org/10.11771049732315580109

Orenstein, G. A., & Lewis, L. (2021, November 14). Eriksons [*sic*] stages of psychosocial development. In *StatPearls.* StatPearls Publishing. Retrieved November 6, 2022 from https://www.ncbi.nlm.nih.gov/books/NBK556096/

Paterson, J. G., & Zderad, L. T. (1976). *Humanistic nursing.* Wiley.

Pesonen, H.-M., Remes, A. M., & Isola, A. (2013). Diagnosis of dementia as a turning point among Finnish families: A qualitative study. *Nursing and Health Sciences, 15*(4), 489-496. https://doi.org/10.1111/nhs.12059

Phillippi, J., & Lauderdale, J. (2017). A guide to field notes for qualitative research: Context and conversation. *Qualitative Health Research, 28*(3), 381-388. https://doi.org/10.1177/1049732317697102

Polit, D. F., & Beck, C. T. (2004). *Nursing research: Principles and methods* (7th ed.). Lippincott Williams & Wilkins.

Polit, D. F., & Beck, C. T. (2018). *Essentials of nursing research: Appraising evidence for nursing practice* (9th ed.). Lippincott Williams & Wilkins.

Pollio, H. R., Henley, T., & Thompson, C. B. (1997). *The phenomenology of everyday life.* Cambridge University Press.

Pratt, M. G., & Ashforth, B. E. (2003). Fostering meaningfulness in working and at work. In K. S. Cameron, J. E. Dutton, & R. E. Quinn (Eds.), *Positive organizational scholarship* (pp. 309-327). Berrett-Koehler Publishers Inc.

Rager, K. B. (2005). Compassion stress and the qualitative researcher. *Qualitative Health Research, 15*(3), 423-430. https://doi.org/10.1177/1049732304272038

Resnick, B., Gruber-Baldini, A. L., Pretzer-Aboff, I., Galik, E., Buie, V. C., Russ, K., & Zimmerman, S. (2007). Reliability and validity of the evaluation to sign consent measure. *The Gerontologist, 47*(1), 69-77. https://doi.org/ 10.1093/geront/47.1.69

Ritchie, L., Tolson, D., & Danson, M. (2018). Dementia in the workplace case study research: Understanding the experiences of individuals, colleagues and managers. *Ageing & Society, 38*(10), 2146-2175. https://doi.org/10.1017/S0144686X17000563

Roach, P., & Drummond, N. (2014). “It’s nice to have something to do”: early-onset dementia and maintaining purposeful activity. *Journal of Psychiatric and Mental Health Nursing, 21*(10), 889-895. https://doi.org/10.1111/jpm.12154

Romdenh-Romluc, K. (2011). *Routledge philosophy guidebook to Merleau-Ponty and phenomenology of perception.* Routledge.

Rose, K., Yu, F., Palmer, J. L., Richeson, N. E., & Burgener, S. C. (2010). Care considerations for persons with early-onset dementia: A case studies analysis. *Alzheimer’s Care Today, 11*(3), 151-161. https://doi.org/10.1097/ACQ.0b013e3181ec0115

Rosin, E. R., Blasco, D., Pilozzi, A. R., Yang, L. H., & Huang, X. (2020). A narrative review of Alzheimer’s disease stigma. *Journal of Alzheimer’s Disease*, *78*(2), 515-528. https://doi.org/10.3233/jad-200932

Rosso, B. D., Dekas, K. H., & Wrzesniewski, A. (2010). On the meaning of work: A theoretical integration and review. *Research in Organizational Behavior, 30*, 91-127. https://doi.org/10.1016/j.riob.2010.09.001

Sakata, N., & Okumura, Y. (2017). Job loss after diagnosis of early-onset dementia: A matched cohort study. *Journal of Alzheimer’s Disease, 60*(4), 1231-1235. https://doi.org/10.3233/JAD-170478

Saldaña, J. (2013). *The coding manual for qualitative researchers* (2nd ed.). Sage Publications.

Schnell, T., Höge, T., & Pollet, E. (2013). Predicting meaning in work: Theory, data, implications. *The Journal of Positive Psychology, 8*(6), 543-554. https://doi.org/10.1080/17439760.2013.830763

Schramm, J., & Figueiredo, C. (2020). *AARP public policy institute fact sheet: The US essential workforce ages 50 and older.* https://www.aarp.org/content/dam/aarp/ppi/2020/10/essential-workforce.doi.10.26419-2Fppi.00111.001.pdf

Schwandt, T. A. (2015). *The Sage dictionary of qualitative inquiry* (4th ed.). Sage Publications.

Schwartz, B. (2015). *Why we work.* Simon & Schuster.

Smith, B. A. (1999). Ethical and methodologic benefits of using a reflexive journal in hermeneutic-phenomenologic research. *Image: Journal of Nursing Scholarship, 31*, (359-363).

Smith, M. C. (2014). Disciplinary perspectives linked to middle range theory. In M. J. Smith, & P. R. Liehr (Eds.), *Middle range theory for nursing* (3rd ed., pp. 3-14). Springer Publishing Company.

Smith, M. J., & Liehr, P. R. (2014). Understanding middle range theory by moving up and down the ladder of abstraction. In M. J. Smith, & P. R. Liehr (Eds.), *Middle range theory for nursing* (3rd ed., pp. 15-34). Springer Publishing Company.

Sohn, B. K., Thomas, S. P., Greenberg, K. H., & Pollio, H. R. (2017). Hearing the voices of students and teachers: A phenomenological approach to educational research. *Qualitative Research in Education, 6*(2), 121-148. https://doi.org/10.17583/qre.2017.2374

Stites, S. D., Rubright, J. D., & Karlawish, J. (2018). What features of stigma do the public most commonly attribute to Alzheimer's disease dementia? Results of a survey of the U.S. general public. *Alzheimer's & Dementia, 14*(7), 925-932. https://doi.org/10.1016/j.jalz.2018.01.006

Tamariz, L., Palacio, A., Robert, M., & Marcus, E. N. (2012). Improving the informed consent process for research subjects with low literacy: A systematic review. *Journal of General Internal Medicine, 28*(1), 121–126. https://doi.org/10.1007/s11606-012-2133-2

Taylor, B. (1993). Phenomenology: One way to understand nursing practice. *International Journal of Nursing Studies, 30*(2), 171-179. https://doi.org/10.1016/0020-7489(93)90066-4

Thomas, S. P. (2005). Through the lens of Merleau-Ponty: Advancing the phenomenological approach to nursing research. *Nursing Philosophy, 6*(1), 63-76. https://doi.org/10.1111/j.1466-769X.2004.00185.x

Thomas, S. P. (2018). Finding inspiration from the philosophy of Maurice Merleau-Ponty for the practice of psychiatric-mental health nursing. *Archives of Psychiatric Nursing, 32*(3), 373–378. https://doi.org/10.1016/j.apnu.2017.11.029

Thomas, S. P. (2020). Resolving tensions in phenomenological research interviewing. *Journal of Advanced Nursing.* https://doi.org/10.1111/jan.14597

Thomas, S. P., & Pollio, H. R. (2002). *Listening to patients: A phenomenological approach to nursing research and practice.* Springer Publishing.

Vagle, M. D. (2018). *Crafting phenomenological research* (2nd ed.). Routledge.

Vaillot, M. C. (1966). Existentialism: A philosophy of commitment. *The American Journal of Nursing, 66*(3), 500-505. https://doi.org/ 10.2307/3419729

van Manen, M. (2017a). But is it phenomenology? *Qualitative Health Research, 27*(6), 775-779. https://doi.org/10.1177/1049732317699570 van Manen, M. (2017b). Phenomenology in its original sense. *Qualitative Health Research, 27*(6), 810-825. https://doi.org/10.1177/1049732317699381

van Manen, M. A. (2020). Uniqueness and novelty in phenomenological inquiry. *Qualitative Inquiry, 26*(5), 486-490. https://doi.org/10.1177/1077800419829788

van Vliet, D., Persoon, A., Bakker, C., Koopmans, R. T. C. M., de Vugt, M. E., Bielderman, A., & Gerritsen, D. L. (2017). Feeling useful and engaged in daily life: Exploring the experiences of people with young-onset dementia. *International Psychogeriatrics, 29*(11), 1889-1898. https://doi.org/10.1017/S1041610217001314

Waddell, G., & Burton, A. K. (2006). *Is work good for your health and well-being?* The Stationery Office.

Watkins, K., Purks, J., Kumar, A., Sokas, R. K., Heller, H., & Anderson, K. E. (2018). Huntington's disease and employment: The relative contributions of cognitive and motor decline to the decision to leave work. *Journal of Huntington's Disease, 7*(4), 367-377. https://doi.org/10.3233/jhd-180296

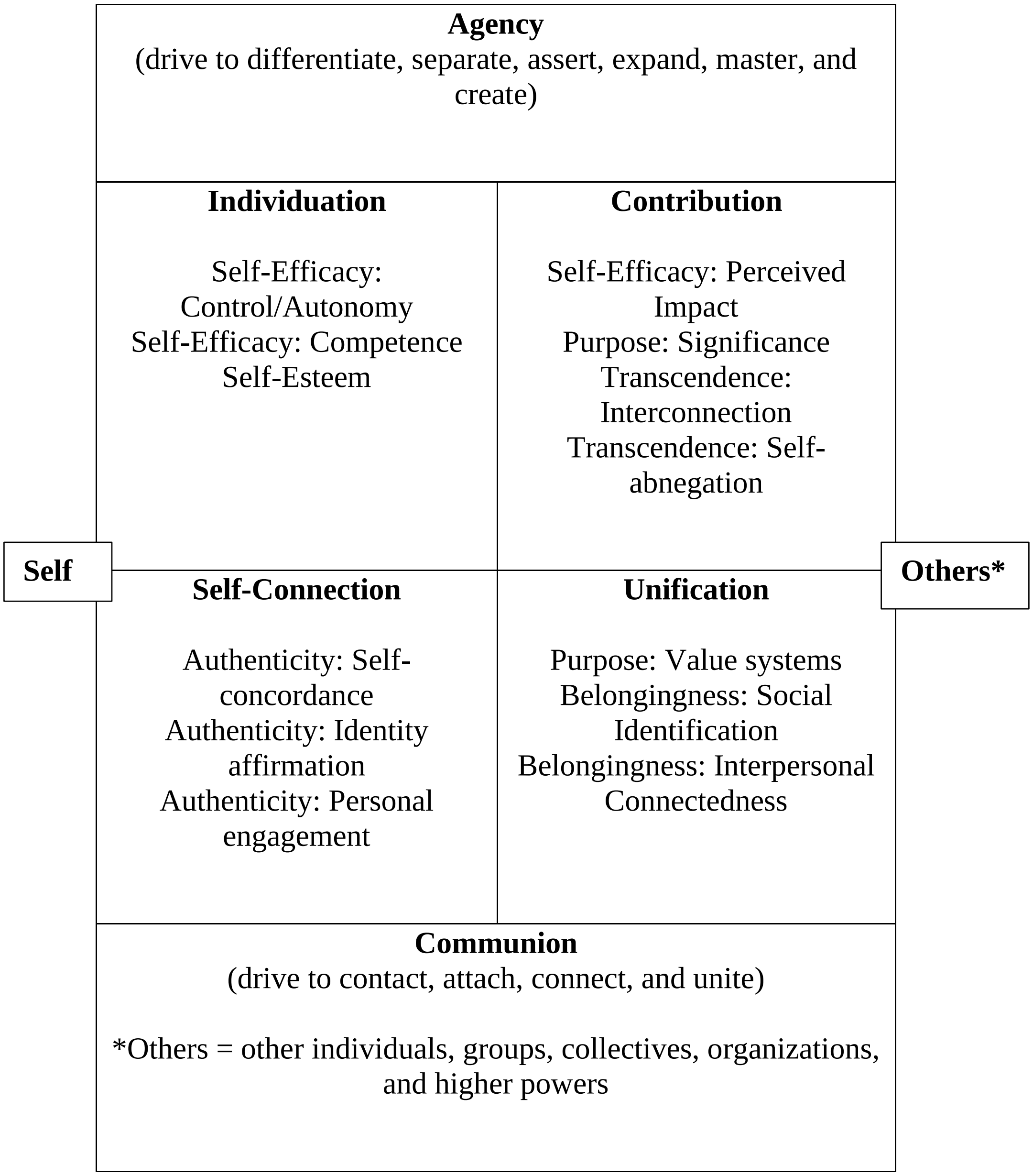
Watson, J. (1985). *Nursing: Human science and human care—A theory of nursing.* Appleton-Century-Crofts.

Wawrziczny, E., Antoine, P., Ducharme, F., Kergoat, M.-J., & Pasquier, F. (2016). Couples' experiences with early-onset dementia: An interpretative phenomenological analysis of dyadic dynamics. *Dementia, 15*(5), 1082-1099. https://doi.org/10.1177/1471301214554720

World Health Organization. (2020). *Dementia. https://www.who.int/news-room/fact-sheets/detail/dementia*

Appendices

Appendix A



Agency
(drive to differentiate, separate, assert, expand, master, and create)

Self	**Individuation** Self-Efficacy: Control/Autonomy Self-Efficacy: Competence Self-Esteem	**Contribution** Self-Efficacy: Perceived Impact Purpose: Significance Transcendence: Interconnection Transcendence: Self-abnegation	**Others***
	Self-Connection Authenticity: Self-concordance Authenticity: Identity affirmation Authenticity: Personal engagement	**Unification** Purpose: Value systems Belongingness: Social Identification Belongingness: Interpersonal Connectedness	

Communion
(drive to contact, attach, connect, and unite)

*Others = other individuals, groups, collectives, organizations, and higher powers

Figure 1. Four Major Pathways to Meaningful Work: A Theoretical Framework. Source: (Rosso et al., 2010)

Appendix B

Category / Subcategory Designation	**Title of Category / Subcategory**
Category (a):	Life Experiences of Persons with Dementia
Subcategory (1):	Living with Early-Onset Dementia
Subcategory (2):	Experiences Including Family and/or Caregivers
Category (b):	Work Difficulties / Leaving Work

Figure 2. Representation of Categories and Subcategories from Literature Review.

Appendix C

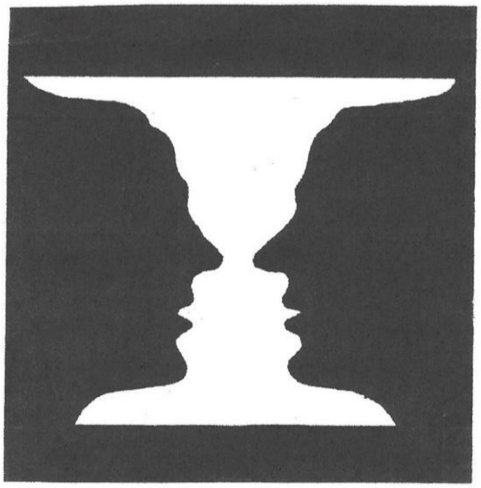


Figure 3. Rubin's Vase and Faces Drawing.

Source: Rubin, 1921, as cited in Thomas & Pollio, 2002; Copyright permission obtained from Springer Publishing Company.

Appendix D

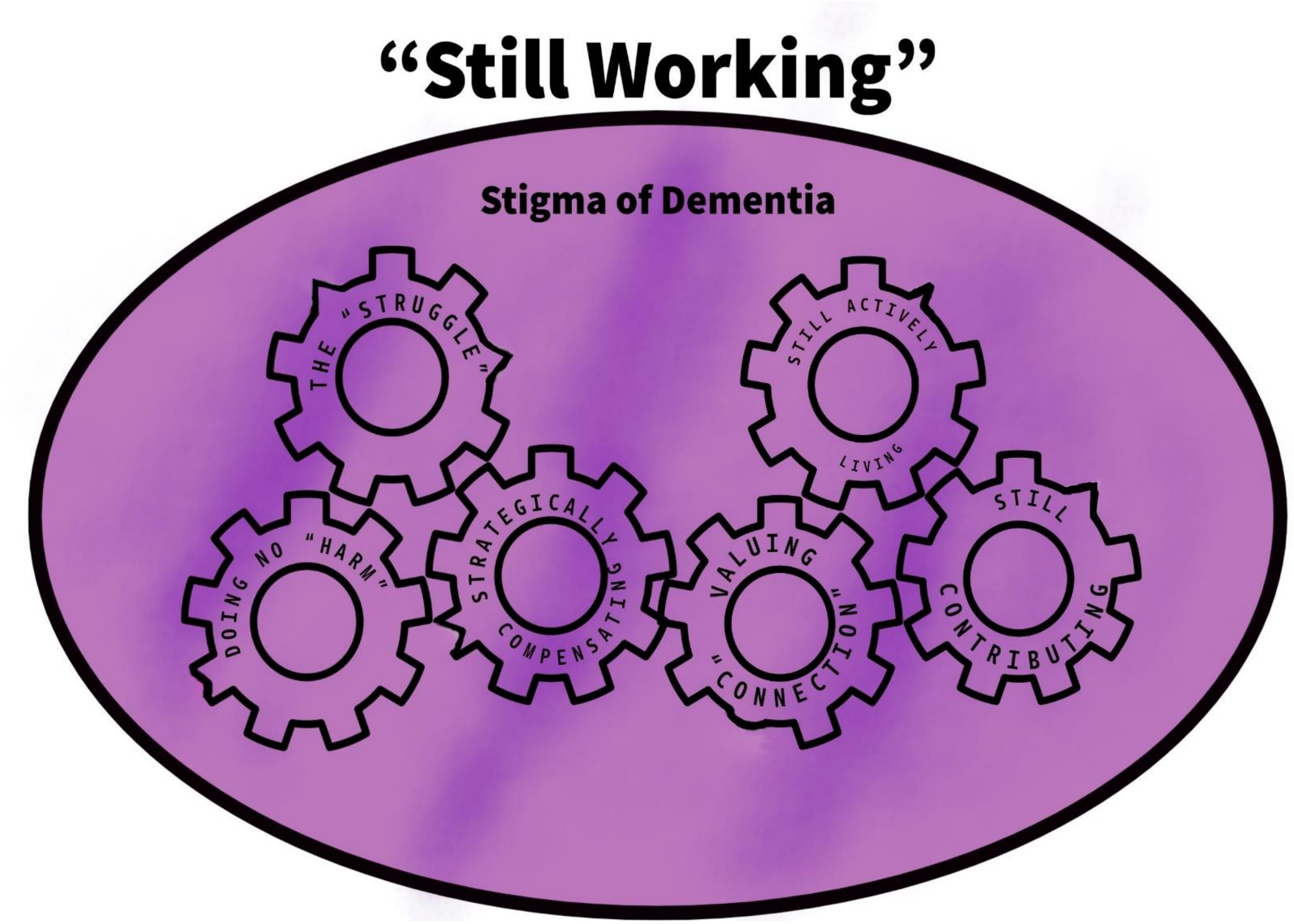


Figure 4. Thematic Structure Identified in the Present Study.

Appendix E

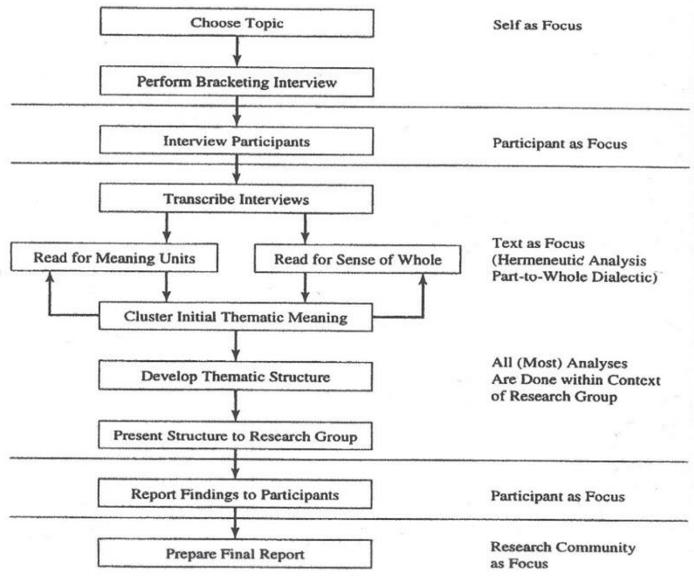


Figure 5. Process Used for Phenomenological Research.
Source: Pollio et al., 1997; Copyright permission obtained from Cambridge University Press.

Vita

Susan Kaye Blaine is a 2022 Ph.D. graduate from the University of Tennessee, Knoxville (UTK), and she also earned a simultaneous Graduate Certificate in Nursing Education from UTK in 2022. She earned an Associate of Science degree from Pellissippi State Community College in Knoxville, Tennessee in 2011; a Bachelor of Science in Nursing degree from Tennessee Wesleyan College (now Tennessee Wesleyan University), in Athens, Tennessee in 2013; and a Master of Science in Nursing Administration degree from UTK in 2014. She was a 2013 recipient of the Chancellor’s Honors Scholarship for her Ph.D. program at UTK, and she was selected as a recipient of the Extraordinary Professional Promise award in 2015. She was also a 2017-2018 recipient of the J. Wallace and Katie Dean Scholarship Fund. In addition, she was a 2021-2022 recipient of dissertation funding awarded by the Dean of the College of Nursing at UTK paid from the Sara Rosenbalm Croley Endowed Dean Chair. She was inducted into Phi Kappa Phi Honor Society in 2014, and she is a member of Sigma international nursing honor society (formerly Sigma Theta Tau). She is also a member of the American Nurses Association and the Tennessee Nurses Association. She currently resides in Knoxville, Tennessee with her spouse and has two grown children.