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Perceptions of Employed People with Narcolepsy

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2016

Abstract

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by

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MBA, Our Lady of the Lake University, 2007

BBA, Sam Houston State University, 2004

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

Many companies have used perceptions of their employees to understand how sleep disorders affect their working environment. Sleep disorders have had an undesirable effect on employee performance and often result in employee modifications to accommodate their condition in the workplace. Though information is available concerning employees' experiences pertinent to working with sleep disorders, research focusing on how employees with narcolepsy perceive their work environment appears to be missing from the literature. The purpose of this study was to gain understanding of perceptions of employees with narcolepsy about their work environment and strategies that may influence others to promote positive health maintenance of narcolepsy in the workplace. The repair and restoration theory of sleep and the disability theory guided this study. Fifteen employees with narcolepsy participated in this descriptive phenomenological study by sharing experiences of their working contributions to become or remain employed. Giorgi's data analysis strategy revealed thematic employee reports of declines in work performance as a factor for being employed with narcolepsy. Study findings established that participants believed sleep attacks and inability to multitask were barriers in the workplace. Scheduling naps and changing work tasks offset barriers to help the participants remain successfully employed. The results of this study may benefit the health services industry as it relates to knowledge and understanding about productivity, schedules, and tools of the work environment for employees with narcolepsy. Positive social change implications include improved work environments and accommodations for employees with narcolepsy.

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Dedication

I dedicate this study to my parents, Enricky, and Vanessa Jones, for their continuous encouragement throughout my entire educational process. I also dedicate this study to my grandfather, Ronald C. Spooner, for his continuous feedback, encouragement, and support throughout this process. This research is also dedicated to the 15 participants who brought this study to life (you know who you are). Lastly, I dedicate this study to those individuals who suffer from sleep disorders, and would give anything for a full night's sleep.

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Chapter 1: Introduction to the Study

Introduction

Sleep disorders disrupt the ability of people to function in work environments. Specifically, narcolepsy is one sleep disorder that may affect daytime activities (Roth et al., 2013). Clinicians have recognized narcolepsy as a neurological disorder for over 100 years (Sagili & Kumar, 2014; Stanford Medicine, 2016). Narcolepsy affects about one in every 3000 Americans (National Institute of Health, 2016). Narcolepsy is the brain's inability to regulate normal sleep and wake cycles (National Institute of Health, 2016). People with narcolepsy experience excessive daytime and intermittent sleepiness that lead to uncontrollable episodes of falling asleep during the daytime (De la Herrán-Arita & García, 2014). Narcolepsy may impinge upon a person's ability to become and/or remain employed.

For many people, narcolepsy affects work performance, which in turn limits the ability to remain employed (Jennum, Ibsen, Petersen, Knudsen, & Kjellberg, 2012). Additionally, employees with undiagnosed narcolepsy may have equated their inability to perform optimally to personal failure, while observers in the workplace may have equated their low performance to laziness or a lack of interest (Eugene, 2013). Many employees go undiagnosed for long periods before gaining awareness or understanding of a possible narcolepsy diagnosis. The impact of work environments on sleep disorders requires further investigation.

Few extant studies focus on the perceptions of people with narcolepsy in regards to their work environments (Flygare, 2016). This study is a phenomenological inquiry

exploring how employees with narcolepsy perceived the risks to their employment. This study may offer positive social change by highlighting the issues and difficulties that people with sleep disorders may have in becoming or remaining employed.

Research has demonstrated that those who have narcolepsy have greater health care expenses associated directly with general practitioner services, hospital care, medication, and indirect expenses consistent with the risk of losing their employment (Jennum et al., 2012). Data from a study conducted by Roth et al. (2013) included information regarding how the participants with narcolepsy experienced brief nightly awakenings with difficulties returning to sleep, which ultimately resulted into poor sleep quality. Not experiencing a good night's sleep can affect a person's ability to function during the day.

The remaining sections of Chapter 1 include: (a) the background of the study, (b) problem statement, (c) purpose statement, (d) overarching research questions, (e) the theoretical framework, (f) limitations and delimitations, (g) assumptions, and (h) the definition of terms.

Background

Neurologists have been aware of narcolepsy since the early 19th century (Cook, 2013; Stanford Medicine, 2016; Todman, 2007). The term narcolepsy was coined by Jean Baptiste Edouard Gelineau in 1880, and Irene E. Loewenfeld was the first to use the term cataplexy, as it related to narcolepsy, in 1902 (Stanford Medicine, 2016). The treatment of narcolepsy with amphetamines was introduced to medical practice in 1935 by Prinzmetal and Bloomberg (Parkes & Fenton, 1973; Stanford Medicine, 2016). It was not

until 1960 when Gretchen W. Vogel noted that sleep-onset REM was found to be linked with narcolepsy (Singh, Drake, & Roth, 2006; Stanford Medicine, 2016). In 1970, the multiple sleep latency test was introduced to measure how fast people could fall asleep during the day, in quiet environments (American Academy of Sleep Medicine, 2014; Stanford Medicine, 2016). By this time, other physicians began to notice their patients began to project narcolepsy symptoms more commonly.

In 1983 narcolepsy was associated with human leukocyte antigens and viewed as an autoimmune disorder, which led to the belief that narcolepsy is caused by or highly associated with a hypocretin deficiency that was first found in mice and dogs in 1999 and linked with humans in 2000 (Stanford Medicine, 2016). These early findings revealed sleep as being a concern for further study. Sleep is very important to the human condition and narcolepsy has been medically proven to have as large of an impact on health as other disorders such as heart disease, diabetes, and HIV (Parsons, VanOra, Missildine, Purcell, & Gomez, 2014). This recent discovery indicated that the knowledge in this field is still developing, and that there is a need for further scientific investigations.

Sleep medicine services and research have become some of the fastest growing subspecialties within the health care industry (Cassel & Reuben, 2011). There is a growing interest among scholars in how sleep disorders affect workplace productivity (Yazdi, Sadeghniiat-Haghighi, Loukzadeh, Elmizadeh, & Abbasi, 2014). Nevertheless, there is a scarcity of literature that explicitly examines employees' perceptions of how their narcolepsy disorder affect their ability to maintain secure employment.

Successful employment can be a challenge for those with narcolepsy. Some workplace issues that employees with narcolepsy have faced possibly originated from the lack of understanding concerning the health and social impact of narcolepsy. Other issues may be due to a lack of comfort among physicians in diagnosing narcolepsy as medical issues (Narcolepsy Network, 2012).

Evidence from a study conducted by Ueki et al. (2013) revealed that untreated narcolepsy symptoms could lead to academic underachievement or job loss due to dozing off, or mistakes caused by inattentiveness due to sleepiness. People with narcolepsy are encouraged, by clinicians, to have scheduled naps for sleep time management as a part of a maintenance regimen (Poryazova et al., 2013). Since napping occurs during the day, this regular interruption can interfere with a person's daily working routine.

It may be equally important for employers to recognize symptoms of the disorder. This is important when an employee may not acknowledge that what he or she is experiencing is much more than a simple bout of confusion, light-headedness, or other prevalent features of the disorder and thereby remaining oblivious of the medical condition they are experiencing in the workplace. If properly informed, employers could become key resources for people with narcolepsy in the workplace and advocate for employees with the disorder.

Problem Statement

This study addresses the issue that employees with narcolepsy have not been able to offer perceptions of their working contributions in order to become or remain successfully employed. The employment status of narcolepsy employees included

rejected for employment promotion, reprimanded, terminated, and /or not being able to obtain employment due to the severity of the disorder. Few studies conducted have been pertinent as related to the workplace perceptions of employed people with narcolepsy. In the past, narcolepsy research was conducted as it related to health (Narcolepsy Network, 2012) and social function (Karjalainen, Nyrhila, Maatta, & Uusiautti, 2013), and research endeavors have made significant progress in understanding the underlying diagnosis and management of the disorder. Though other aspects of the disorder have been studied, the perceptions of people with narcolepsy regarding their work environments has been an under researched phenomenon.

Past research concentrated on the vitality of sleep health to restore the human body, foster mending, and achieve revival (Cassel & Reuben, 2011). Consequently, while reviewing extant literature I discovered a gap that in research directed toward understanding the perceptions of people with narcolepsy in the workplace (Culbertson & Bruck, 2005; Eugene, 2013). Sleep researchers have recommended conducting more research on other social issues people with narcolepsy are exposed to (Culbertson & Bruck, 2005).

Purpose of the Study

The purpose of this phenomenological qualitative study was to explore the perceptions people with narcolepsy on becoming or remaining employed. The objective of this study was to focus on perceptions of employees with narcolepsy to understand how their experiences as employees may influence others to promote positive health maintenance of narcolepsy. This study was unique because it allowed the participants

with narcolepsy to express their personal perceptions as they pertained to employment in an office, clerical, healthcare, or educational setting. Although there is no known cure for narcolepsy, this study may offer options for employees with narcolepsy to attain the best possible health, wellness, and daily modifications related to their work. Employees with narcolepsy could play a vital role in researchers attaining a better understanding of how to use intervention processes to help resolve these issues early.

Research Questions

The following three research questions steered this study:

RQ1: What are the perceptions of employees with narcolepsy toward their risks of secure employment in the work place?

RQ2: What are the perceived barriers to remain employed for people with narcolepsy?

RQ3: What are the perceived facilitators to remain employed for people with narcolepsy?

The research questions acted as a guide in analyzing the information gathered.

Theoretical Framework

Two theories guided this phenomenological qualitative research study. The repair and restoration of sleep theory by Oswald (1966) and the disability theory by Siebers (2008) were the primary theories applied to this study. The theory of repair and restoration addressed sleep as being crucial for revitalizing and recuperating the physiological processes that keep the body and mind healthy and congruously functioning (Sammons, 2012). The disability theory addressed how to redefine the

identity of individuals with disabilities (Goodley, Hughes, & Davis, 2012). The theories were used for the purpose of this study by describing some of the lived experiences of employees with narcolepsy. The participant responses were categorized in order to develop common themes from the interviews.

The above theories operated as a theoretical lens for this study, in order to determine what to explore concerning the lived experiences of the employees with narcolepsy as it related to their perceptions of their workforce environment. Additionally, the theoretical framework acted as a guideline to formulate the research, the phenomenological interview questions, and to examine the viewpoints and perceptions of employees with narcolepsy.

Nature of the Study

The method of research used for this qualitative study on the perceptions of employees with narcolepsy was Giorgi's (1985) method of phenomenological analysis phenomenology. The rationale for using the Giorgian method of phenomenological analysis was the clear-cut and realistic processes. A research study conducted by Robinson, Giorgi, and Ekman (2012) utilized the Giorgian analysis tool to convey the lived experiences of people who suffer from early stages of Alzheimer's disease, which provided me with the guidance needed when analyzing data for this study

There was a need to investigate the perceptions of employed people with narcolepsy with at least 3 years of work experience. This study used semi-structured, open-ended interview questions in order to understand the perceptions of employees with narcolepsy. The participants were 18 years and older, diagnosed with narcolepsy, and

currently employed for at least 3 years. The Giorgian approach guided my organization of the steps in the data analysis procedure and provided a strategy for assembling the textual and structural descriptions from the participants' responses. I selected a qualitative method for this study because this method focuses on (a) perceptions, (b) viewpoints, (c) beliefs, (d) meanings, (e) attributes, (f) values, and (g) symbols. These are all aspects of experience are difficult to quantify mathematically, as in quantitative research.

Qualitative methods have an essential role in a study of this extent, particularly in understanding user needs and behaviors (Blandford, 2014). Phenomenological analysis styles such as the Giorgi's process work well with studies in health care, patient experiences, and psychology (Malterud, 2013). Qualitative methodology, in the broadest sense, uses descriptive data from a subject's written or spoken words and in his/her observable behavior (Moustakas, 1994; Patton, 2002). I used semi-structured open-ended interview questions to gather the qualitative data, in-depth perspectives, experiences, and viewpoints of the participants, as supported by AbuSabha (2013). I analyzed data by means of the Giorgian method using NVivo qualitative data analysis software to organize the collection of interviews into themes and trends for synthesis and interpretation.

The study participants included 15 people, ages 18 and older, diagnosed with narcolepsy, and employed for at least 3 years. The 15 participants in this study were a significant sample size to represent the population because qualitative phenomenological studies use sample sizes of five to 25 participants, based on views of Cleary, Horsfall and Hayter (2014). According to data from Narcolepsy Network (2012), a diagnosis of narcolepsy generally happens between the ages of 10 and 30. The age range of diagnosis

is important for this study's population because the representation of each age group indicated different stages of narcolepsy; diagnosis came at a younger age for some participants, while other participants were diagnosed at an older age.

Definitions of Terms

The following terms were operationalized in this study.

American Disability Act: is a legal act that prohibits discrimination against a disabled person in employment, transportation, public accommodations, communications, and government activities (Thompson, 2015).

Cataplexy: is the failure to control muscles, triggered by strong emotions (De la Herrán-Arita & García, 2014).

Insomnia: is the inability to fall asleep; this disorder is common among many people (Locke, 2011).

Narcolepsy: is a neurological disorder of sleep regulation that affects the control of sleep and wakefulness (De la Herrán-Arita & García, 2014).

Sleep Apnea: is a disorder in which people who suffer from the condition have pauses in their breathing or exhibits shallow breaths when they sleep (Park, Kannan & Olson, 2011).

Sleep Disorders: are conditions preventing individuals from sleeping, and may result in excessive daytime somnolence (sleepiness or drowsiness), fatigue, and dysfunction (NSF, 2015).

Assumptions

This research study included key assumptions. I used strategies from Rubin and Rubin's (2012) responsive interview model for managing assumptions. By utilizing this tool, I properly managed assumptions, created better data, effectively managed the interview process, create power differentials, and developed a user-friendly semi-structured interview guide.

I assumed that the research participants in this study shared experiences and were honest about their lived experiences and about their perceptions of working with narcolepsy. I assumed that the local setting was diverse enough to provide a considerable population from which to draw a functional and significant sample, based on information obtained from Englander (2012). Finally, I assumed that the data collected revealed the experiences of the participants concerning the research problem and clarified what these experiences meant to the individuals.

Scope and Delimitations

The scope of this study was the exploration the viewpoints of people with narcolepsy regarding their employment and work environments. Since people with narcolepsy must adjust their lifestyle to accommodate their working environment employment (Ozaki et al., 2012), it is important to understand their perspectives concerning their working environment. Transferability of this descriptive phenomenological qualitative study is set to the degree that other researchers may be able to generalize more studies in order to investigate the perceptions of employees with narcolepsy. Dissemination of a one to two page results summary to health care

administrators, corporate offices, human resources directors, and sleep medicine journals acted as contributing research for social change.

I delimited or restricted my study by only involving employees with narcolepsy within the United States using purposeful and snowball sampling with an age restriction of 18 years or older, and without restrictions related to ethnicity. I did not include individuals without narcolepsy or those not employed for at least 3 years. The objective for the research were to interview 15 people by telephone who had been diagnosed with narcolepsy and have been employed for at least 3 years. The qualitative interviews should range between 5 and 25 participants, which is appropriate for a phenomenological investigation based on the ideas of Cleary, Horsfall and Hayter (2014). I enhanced the validity of my study by interviewing 15 participants.

Limitations

There were several predicted limitations for this study. Financial incentives, time, and face-to-face technological feasibility were barriers to accessing a representative population of people with narcolepsy. To resolve these limitations, I elected not to provide financial incentives to participants, the participants scheduled their own interview times, and the interviews were all conducted using the telephone. The interpretative nature of a small sample of participants was a limitation to this study. I could not generalize the results of this study to any other persons with narcolepsy because they were limited to the experiences described by these employees with narcolepsy.

The interpretations of the study's findings were another limitation, due to the nature of qualitative interviews. According to Sandelwoski and Leeman (2012), the

interpretations of the study's findings were another limitation due to the nature of qualitative interviews. The research setting parameters of the current study limited acquaintances and friends in order to limit biases, during the interviews.

Significance

The significance of this qualitative phenomenological study is that it may provide additional awareness concerning narcolepsy for employers, health care providers, and the sleep medicine industry. This study was significant to people with narcolepsy because it provided an opportunity for all study participants to express their personal perceptions of employment in an office, educational, healthcare, or clerical setting. The results of this study added insights into the perceptions of employees with narcolepsy and the adjustments they needed to make to their lifestyles in order to accommodate their working environment.

Narcolepsy research is still in its infancy stages within the field of neurology (Cook, 2013). Therefore, contributions to this field may increase narcolepsy awareness for several types of professionals, including employers, health care administrators, and practitioners in the sleep medicine industry. Insights gleaned from this study may assist the aforementioned professionals with understanding about how they may help affected individuals better manage narcolepsy in the workplace, based on key perspectives shared by this study's research participants.

Understanding the relationship between employment and narcolepsy is an important health services concern because many people with narcolepsy remain undiagnosed and, therefore, are not receiving the treatment and support they need to be

productive or safe in the workplace (Naiman, 2012). Because of this, employees who are unaware that they have narcolepsy may not fully understand why they have a difficult time adjusting to their jobs. People in health care administration should be concerned about the relationship that exists between sleep loss and medical errors (Alireza, Jafar, Fatemeh, Samad & Neda, 2014) and the costs directly or indirectly associated with sleep disorders as related to people with narcolepsy (Black et al., 2014; Swanson et al., 2011). The results of this study offered possible techniques employers can use, such as schedule modifications and preparedness, when developing programs geared toward employees with narcolepsy.

Dissemination of the study results is possible through narcolepsy foundations and/or sleep study peer reviewed journals. Dissemination of study findings to families, friends, educators, and co-workers may increase understanding of what is required to actively support an employee with narcolepsy. Dissemination of study findings may contribute to an increased understanding of the challenges employees with narcolepsy face in a work setting. The study may affect positive social change by providing the data shared by participants and offering an in-depth understanding of the lived experiences of employees with narcolepsy. The results of the study may also contribute to information for people who may or may not be aware that they suffer from a sleep disorder such as narcolepsy, and educate them and others about possible symptoms.

Summary

Narcolepsy is a disorder that causes excessive sleepiness and frequent daytime sleep attacks (Pegues & Schub, 2012) and requires those who have been diagnosed with

the disorder to make modifications in their daily lives (Mullins, Cortina, Drake, & Dalal, 2014). This study is significant because the findings may present potential maintenance options, such as preparedness for present and future employment, for people with narcolepsy. By learning and understanding the different perceptions and views of employees with narcolepsy, other sources and solutions could possibly offer information on creating a successful working environment for employees with narcolepsy.

This study described the workplace perceptions of the participants with narcolepsy. Data from the study's interviews provided a unique opportunity to access the essence of some people's lived experiences with narcolepsy, and their encounters with employment. Chapter 2 consists of an overview of past and the most current literature pertaining to narcolepsy, including the history of narcolepsy, accommodations, and sleep disorders as they relate to the workforce. The unique issues related to employees with narcolepsy are addressed within the scope of the literature review.

Chapter 2: Literature Review

Introduction

Sleep medicine services and research are quickly advancing in healthcare areas such as neurology, psychology, pulmonology, and otolaryngology (Cassel & Reuben, 2011). Narcolepsy is a sleeping disorder where advances have been made, but many unanswered questions remain (Burgess & Scammell, 2012). Roughly, 1 in 3,000 people are affected by some form of narcolepsy in the United States (National Institute of Health, 2016; Scammell, 2015). Due to the amount of people affected, management of the disorder may be the deciding factor in maintaining employment status.

The research problem for this study was that employees with narcolepsy have not been able to express their perceptions of their working influences in the workplace, in order to become or remain successfully employed. Chapter 2 contains a review of the current literature and issues related to the socio-cultural and health-related challenges of employees with narcolepsy. It also includes literature pertaining to employees with narcolepsy, as well as topics related to disability identity and employment in society. Chapter 2 also includes search strategies, followed by the underpinnings of a theoretical foundation, and a section explaining the relevance of this study.

Literature Search Strategy

The documents reviewed and analyzed for this study focused on narcolepsy, sleep disorders, and employee performance. I conducted a review of literature using electronic database resources such as Thoreau, Google Scholar, and the Walden University digital dissertation and education full text archives. I searched for literature by using a

combination of terms beginning with “narcolepsy AND employment OR perception OR sleep disorders AND treatments AND maintenance.” The literature review sources included 130 documents from books, dissertations, journals, and qualitative and quantitative peer-reviewed research documents; the literature review included 97 of those documents. The remaining 33 documents did not support the topic of the dissertation empirically and were not appropriate to include in the literature review. Of the 97 articles included in the review, 54 articles were qualitative in nature, 28 articles were quantitative in nature, and 15 articles were mixed methods. The publications’ years ranged from 2008 to 2015, with the exception of the articles used for the theoretical foundation, which were as old as 1966.

Theoretical Foundation

There have been numerous theories concerning narcolepsy. One theory was proposed by Dr. Jean-Baptiste-Edouard Gélineau in 1880, and stated that symptoms of narcolepsy increased with exposure to extreme emotional stimuli (Todman, 2007). In 1973, Dr. Knecht and Dr. Mitler developed another theory, based on their experimentation on dogs, that led to the belief that narcolepsy is inherited (Morley, 2013). Due to the historical data of narcolepsy, I chose two theories to help conduct this study. The two theories that guided this phenomenological study were Oswald’s (1966) theory of repair and restoration of sleep and Siebers (2008) disability theory. This study’s theoretical foundation offered the basic support for systematic exploration of the concepts related to this research problem and phenomenon, based on views of Boyd, Cole, Cho, Aslanyan and Bates (2013).

Theory of Repair and Restoration of Sleep

The theory of repair and restoration of sleep (RRTS) stated that sleep is crucial for revitalizing and restoring the physiological processes that keep the body and mind healthy and properly functioning (Sammons, 2012). This theory suggested that nonrapid eye movement (NREM) sleep was important for restoring physiological functions and rapid eye movement (REM) sleep was essential for restoring mental functions (Sammons, 2012). In 1988, sleep researcher J. A. Home stressed the importance of understanding why slow wave sleep (SWS) was vital for normal physical growth of the body and REM for cognitive mental revitalization (Siegel, 2011). Researchers suggested that a sleep cycle is a segment of NREM rest, followed by a period of fast REM rest (Lu & Goder, 2012). A normal sleeper has a typical sleep cycle of approximately 100 to 110 minutes, beginning with NREM sleep and transitioning to REM sleep after 80 to 100 minutes (Sammons, 2012). People with narcolepsy frequently entered REM sleep within a few minutes of falling asleep and skipped NREM sleep (Sammons, 2012), which led to improper physiological and mental restoration of the brain. Due to the lack of physiological and mental restoration of the brain, daily activities, such as performing their occupations, became difficult tasks for employees with narcolepsy (Vance, Heaton, Eaves, & Fazeli, 2011).

This study addressed many ways narcolepsy affected the daily lives and employment of people with narcolepsy. As one of the theoretical approaches chosen for this study, the RRTS provided guidance regarding various perceptions employees with narcolepsy had concerning their employment, supported by views of Ingravallo et al.

(2012). Subsequent research and application of the RRTS offered suggestions on ways patients cope with and manage their working environment (Barnes, 2012). The RRTS is applicable to many areas of sleep medicine.

Application of the Repair and Restoration Theory of Sleep

The RRTS was important to this study due to the lack of sleep needed for proper brain functioning, as supported by Genzel, Spoormaker, Konrad, and Dresler (2015). This theory included significant information about how NREM sleep is important for restoring physiological functions, while REM sleep is essential for restoring mental functions (Sammons, 2012). According to an article by Venter (2012), testing the repair and restoration theory of sleep consisted of studies in which periods of REM sleep were followed by periods of sleep deprivation and strenuous physical activity. During sleep, the body also increases its rate of cell division and protein synthesis, further suggesting that repair and restoration occur during sleeping periods (Underwood, 2013).

Recently, researchers have uncovered additional information suggesting that sleep allows the brain to perform "housekeeping" duties (Sammons, 2012; Underwood, 2013). Housekeeping duties consist of clearing metabolic waste products of neural activity such as neurotoxic waste products that accumulate in the awake central nervous system from the brain (Sammons, 2012; Underwood, 2013; Xie et al., 2013). This process concluded at a faster rate while sleeping than when awake. Thus, the restorative function of sleep may be the purpose of the enhanced removal of potentially neurotoxic waste products that accumulate in the awake central nervous system (Sammons, 2012; Underwood, 2013; Xie et al., 2013). Researchers also indicated that the brain utilized sleep to flush out

waste toxins (Xie et al., 2013). Another researcher indicated that the brain's limited resources forced it to choose between two different functional states: awake and alert or asleep and repairing (Nedergaard, 2013).

The repair and restoration theory of sleep is important for many reasons. The support for this theory is as follows: (a) REM was necessary for mental growth and reorganization; (b) increased overall sleep was necessary for growth of the human body, especially during repair and growth stages; (c) more timespans for catch up were necessary from incidences of sleep deprivation; and (d) mental and physiological consequences resulted from poor habits, including insufficiencies and sleep deprivation (Dement, 2005).

RRTS has been used as a foundational theory for other studies involving narcolepsy and sleep health studies. For example, in a quantitative study completed by Roth et al. (2013), the researchers used the RRTS to properly understand the effects of disrupted nighttime sleep (DNS) in narcolepsy patients. Researchers examined the RRTS's concepts while observing narcolepsy patients who also suffer from cataplexy and concluded that parts of the RRTS are needed in order to create management strategies for paralysis (Dauvilliers, Siegel, Lopez, Torontali, & Peever, 2014). I used the RRTS in this study to guide the first research question and to explore the perceptions of employees with narcolepsy.

The Disability Theory

The disability theory offered a way to redefine the identity of individuals with disabilities (Goodley, Hughes, & Davis, 2012). This theory viewed disability identity not

as the property of an individual, but as a form of social theory that represented the social and political understanding of disabled people (Goodley, Hughes, & Davis, 2012).

Narcolepsy is a neurological disability that can affect some people physically and mentally (Vignatelli, Plazzi, Peschechera, Delaj & D'Alessandro, 2011). These types of disabilities are often difficult to categorize because the disorder is not visible or is a non-apparent disability (Santuzzi, Waltz, Finkelstein, & Rupp, 2014). The disability theory used in this study dealt with the social impact on people with disabilities. Moreover, researchers have indicated that living with narcolepsy in a social environment may cause fear, anxiety, depression, stress, and other emotional issues (Harvey, Gehrman & Espie, 2014; Stores, 2015). Because of the negative social implications associated with narcolepsy, the disability theory can help create social pathways in the work environment for employees with narcolepsy and the employers.

Application of Disability Theory

This study could serve as a foundational basis for employers, after having gained an understanding of the participants', in this study, personal experiences and perceptions of employment with narcolepsy. Furthermore, subsequent research and application of the disability theory, as related to narcolepsy and employment, may have offered guidance about ways patients coped and dealt with their working environments.

The disability theory has been used in two ways. One way was to identify the sources of oppression within the law and legal institutions. Once disability activists exposed and identified the sources of oppression, they used the disability theory in

conjunction with law to relieve the burdens of oppression the disabled experienced (Goodley, 2013).

The second way of identifying the sources of oppression was by recognizing the potential positive role of the law: creating laws, using existing laws, and enlisting legal institutions in the struggle for the emancipation of disabled people (Goodley, 2013). According to the disability theory, current laws have helped to recognize disabilities as social constructs and not only as the result of physical impairments (Siebers, 2013). Disability is a complex inter-relationship between impairment; an individual's response to that impairment; and the physical, institutional, and attitudinal environment (Goodley, 2013). The social disadvantages experienced by many disabled people are the result of the failure of the social environment to respond adequately to the diversity of experience presented by disability (Goodley, Hughes, & Davis, 2012). Application of the disability theory also examined the ways oppression affected disabled people through a failure to live up to the Disability Act of 1990 promises of equality and justice.

Both quantitative and qualitative studies utilized the disability theory in order to explore the social connection of people with disabilities. A quantitative study by Watson (2012), applied the disability theory to examine recent health developments, including education, to provide for and understand the lives of disabled children.

The disability theory assessed the vulnerability of disabled people in two globally significant disasters: Hurricane Katrina of 2005 in New Orleans, Louisiana and the Asian tsunami of 2004 from the Indian Ocean (Hemingway & Priestley, 2014). The results of this study showed that in both cases, disabled people experienced adverse conditions that

affected their physical safety, access to immediate aid, access to shelter, access to evacuation, and access to relief (Hemingway & Priestley, 2014). The applications of the aforementioned theories have proven to be relevant for this study. ((In what way? Please clarify)

Relevance of the Theories to Research Questions

The repair and restoration theory of sleep and the disability theory are relevant to this study because I sought out to answer the three research questions that concerned narcolepsy as a disability and the lack of sleep due to narcolepsy. The repair and restoration theory of sleep is relevant to a study concerning people with narcolepsy because it can provide an explanation relating to the lack of NREM sleep needed for proper brain functioning. This addressed this study's focus on the adaptations used by employees with narcolepsy in order to successfully become and remain employed.

For example, the research question, what are the perceptions of narcolepsy employees toward coworkers and employers? This research question could use the disability theory as a theoretical framework to help understand the possible responses of the research participants. To predict the facilitating conditions and/or the barriers for employees with narcolepsy, the disability theory was beneficial to this study. The research question, what are the perceptions of employees with narcolepsy toward barriers in the workplace?

To explore the lived experiences of employees with narcolepsy, various concepts synthesized, determine their applicability to the research study. I used the Giorgi (1985) approach to analyze the collected data from the interview transcripts, and this approach

used systematic steps in the data analysis procedure and guidelines for assembling the textual and structural descriptions. The primary concepts applied to this study built upon Oswald (1966), repair and restoration of sleep theory and Siebers (2008) disability theory. Other concepts such as sleep disorders, narcolepsy, clerical and office, employment, and unemployment served as additional foundational concepts. These concepts described some of the lived experiences of people with narcolepsy. The different categories developed common themes among the participants.

Literature Review

Narcolepsy

In 1877 and 1878, two physicians began to notice that their patients regularly showed episodes of muscle weakness triggered by excitement and sleepiness (Morley, 2013). In 1880, Jean Baptists-Edouard Gelineau codified the disorder and named it narcolepsy (Todman, 2007). Evidence of the physician observations showed that many of their patients regularly displayed episodes of muscle weakness triggered by enthusiasm and drowsiness (Morley, 2013). This led the physicians to believe that not only was heredity a factor in the disorder, but emotion could also trigger narcolepsy and cataplexy symptoms as well (Morley, 2013; Schwarzt, 2011).

The literature in the following sections expounded on the key variables and concepts that included living with narcolepsy, employment and narcolepsy, perceptions of narcolepsy and sleeping disorders, narcolepsy studies, narcolepsy statistics, health care administration concerns, direct and indirect costs, possible solutions, and organizations.

Narcolepsy as a Sleeping Disorder

Narcolepsy is a neurological disorder of sleep regulation that affects the control of sleep and wakefulness (Han, 2012; Sagili & Kumar, 2014; Stanford Medicine, 2016.) According to data from the National Sleep Foundation (2014), individuals who suffer from sleeping disorders often deal with the consequences of sleepiness and dysfunction during the daytime. Some people with narcolepsy experience sudden muscle weakness with laughter or other emotions (De la Herrán-Arita & García, 2014; Morley, 2013). According to important information from the University of Arkansas Medical Center (2014), symptoms of narcolepsy, usually starts expressing themselves in people who have the disorder between the ages of 15 and 25, but can become apparent at any age. Additionally, narcolepsy may remain undiagnosed and untreated (Karjalainen, Nyrhila, Maatta, & Uusiautti, 2013), which could potentially lead to greater problems because the person is unsure of what is causing the symptoms and problems.

The Causes of Narcolepsy

Although the exact cause of narcolepsy is unknown, researchers continue to seek out the root cause. One notion of the cause is that genetics, accompanied by an environmental trigger of some sort, may have affected a person's brain chemicals and caused narcolepsy (Burgess & Scammell, 2012). According to Silber (2014), scientists have discovered that people with narcolepsy lack hypocretin, a chemical in the brain that activates arousal and regulates sleep. Additionally, research conducted by Willie et al. (2012) noted that one cause of narcolepsy can result from traumatic injuries to parts of the brain associated with REM sleep or from tumor growth and other disease processes in

the same regions (Willie et at., 2012). Researchers from the University of Maryland Medical Center (2013) provided data that also supported the suggestion that there may be a connection between narcolepsy and brain injury. A study conducted in Beijing, China by the Peking University People's Hospital included information about how the occurrence of narcolepsy is seasonal and significantly influenced by the month and calendar year (Fang et al., 2011). The aforementioned study was an analysis of narcolepsy onset ranging from September 1998 to February 2011 (Fang et al., 2011).

The difference in opinions from researchers determining the cause of narcolepsy indicated that there might have indeed been various ways for developing the disability. Due to researchers' limited understanding of the causes of the disorder, it may be hard for people associated with a person with narcolepsy to have a proper understanding or perception of the disorder.

Perceptions of Narcolepsy

According to Flygare and Parthasarathy (2015), the public's perception of narcolepsy is inaccurate and incomplete. Consequently, family, friends, educators, and employers find it difficult to understand narcolepsy (Chapman et al., 2012).Many people view narcolepsy as a social custom, thus associating narcolepsy with sleepiness that is harmless or even humorous rather than a medical condition requiring medical attention (Flygare & Parthasarathy, 2015). Hence, leading to the judgments of others who do not understand and have false perceptions of the people who are suffering from the disorder.

Narcolepsy Studies

Many studies conducted throughout the years helped discover the foundation and possible causes of narcolepsy. A studies conducted by researchers at the University of Maryland (2013) combined narcolepsy and genetics in an attempt to explain whether individuals could inherit the narcolepsy trait. Different researchers are directing investigations utilizing models to recognize neurotransmitters that may counteract the lack of hypocretin, which may help reduce or resolve the symptoms of narcolepsy (Silber, 2014). A more noteworthy understanding of the complex hereditary and biochemical basis of narcolepsy, led to the detailing of new treatments to control the side effects of narcolepsy and may have prompted a cure, based on ideas from Silber (2014). Likewise, sleep specialists have been examining the modes of activity of wake-advancing mixes and other therapies used to stay awake, to extend the scope of accessible remedial choices (Silber, 2014). Each of these studies supports the concept that understanding sleeping disorders can promote a healthy work environment for those with the disability.

Narcolepsy Statistics

Narcolepsy affected approximately 200,000 people in the United States however, fewer than 50,000 are diagnosed with the disorder (Hans, 2012). Narcolepsy has occurred in all countries and among all racial and ethnic groups (Han, 2012), thus the prevalence rates differ among populaces (Schoenstadt, 2013). Some examples of these differences could come from a comparison of the USA with some selected countries. The USA prevalence rates for narcolepsy is 1 in 3,000 Americans citizens, in comparison with Israel’s 1 in 500,000 Israeli citizens and to Japan’s 1 in 600 Japanese citizens

(Schoenstadt, 2013). Whatever the period of onset, individuals with narcolepsy have found that their side effects have a tendency to have gotten worse over two to three decades after the first indications manifested (Schoenstadt, 2013).

According to Alshaikh, Tricco, Tashkandi, Mamdani, Straus, and BaHammam (2012) the prevalence of narcolepsy with cataplexy is between 25 and 50 per 100 000. Studies have shown that 65% to 75% of patients with narcolepsy have cataplexy (Alshaikh, Tricco, Tashkandi, Mamdani, Straus & BaHammam, 2012). Another study shows that 60% to 80% of people with narcolepsy have cataplexy (Hale, Guan & Emanuele, 2016). According to data from the Narcolepsy Network (2012), diagnosis of narcolepsy generally happens between the ages of 10-30. After diagnosis, a large peak occurs around puberty and a smaller peak between occurs around 35 and 45 years of age (Han, 2012). Although there was no strong gender disparity in the prevalence of narcolepsy, newer data suggest that narcolepsy occurred 1.6 times more frequently in men than in women (Han, 2012). These statistics justified the need to examine employees with narcolepsy viewpoints toward becoming or remaining successfully employed.

Sleeping Disorders

Narcolepsy is a chronic sleep disorder marked by excessive daytime sleepiness, cataplexy, sleep paralysis, and hypnagogic hallucinations (Arango, Kivity, & Shoenfeld, 2015). Sleep apnea is a disorder in which people who suffer from the condition have pauses in their breathing or exhibits shallow breaths when they sleep (Park, Kannan & Olson, 2011) Sleep Apnea may impair daily function, induce or exacerbate cognitive deficits, and increase the likelihood of errors and injuries (Pearlman, 2014). Another

sleep disorder is insomnia, which is the inability to fall asleep and is common among many people (Locke, 2011). Insomnia also occurs in people who experience restless leg syndrome, which is a genetic disorder resulting in prickly or tingling sensations in the leg that cause patients to want to move their legs and often resulting in wakefulness (Rye & Trotti, 2012). Although the selected sleeping disorders are different, they continually affect the daily lives of each person stricken by the disorder or disability.

According to data from the Institute of Medicine approximately 50 to 70, million adult Americans have a chronic sleep disorder (Centers for Disease Control, 2011). Moreover, approximately 1 in 3 adult Americans are sleeping less than 7 hours per night (Centers for Disease Control, 2011; Luyster, Strollo, Zee, & Walsh, 2012). This article also included information about the states with highest incidence of sleeping disorders are Mississippi with 29.4 %, Tennessee with 31.4% and Alabama with 29.7% and Kentucky with 34.9%. States with lower incidence of sleeping disorders are North Dakota with 22.94%, South Dakota 23.9%, and Oregon with 23.6 % (CDC, 2011).

Sleeping Disorders and the Workforce

Past studies have utilized perceptions of their employees to understand how sleep disorders affect their working environment (Bajraktarov et.al, 2011). Narcolepsy is a rare disorder, but it has important social and occupational consequences (Vico, Monzó, Cuenca, and Luis, 2012). A better understanding of the disorder and some work place accommodations can help improve the quality of life for affected workers (Vico, Monzó, Cuenca, and Luis, 2012). Sleep is essential to health and well-being, and it is important to schedule adequate time for sleep (Wilson & Nutt, 2013). Research has proven that poor

sleeping habits is a burden on the society (Leger, 2011; Wilson & Nutt, 2013). Furthermore, the rates of poor sleep have increased with urbanization, noise, shift work, increasing connection time and, especially in young adults and adolescents, with the increasing use at night of mobile phones and the internet (Leger, 2011).

Since employees with narcolepsy appeared to be unproductive, managing the effects of narcolepsy in the workplace, both employees and employers should fully understand the symptoms, (Santuzzi, Waltz, Finkelstein, & Rupp, 2014). Research has suggested that narcolepsy is compatible with success both at school and in the workplace, and proper accommodations for students and employees create a successful working environment (Nishino, 2011). Additionally, a study with nurses and teachers helped recognize the symptoms of narcolepsy. By doing this, students living with the narcolepsy disorder get a fair chance in life's academic, social, and career arenas (Gow, 2013).Sleep is a major part of the human condition and the lack of sleep or too much sleep continues to be a problem for many (Xie et al., 2013).

According to a study conducted by Kessler et al. (2011)) insomnia-related workplace issues are more common than narcolepsy-related workplace issues. The effects of insomnia on next-day functioning, health, safety, and quality of life, as related to sleep health results in a substantial societal burdens and economic losses (Sivertsen, Lallukka & Salo, 2011). The annual direct cost of insomnia is in the billions of U.S. dollars yearly and attributed to the association of insomnia with the increased risk of certain psychiatric and medical comorbidities that result in increased health care service utilization (Kessler et al., 2011; Swanson et al., 2011). Additionally, research conducted by Sivertsen,

Lallukka and Salo (2011) surveyed 7,428 American workers and found that the annual losses in work performance due to insomnia amounted to $367 million a day, which is equivalent to $91.7 billion per year. Lastly, one study included information regarding how insomnia was significantly lower among working people who were ages 65 and older than those who were younger and higher among women than men were (Kessler et al., 2011). In comparison, both narcolepsy and insomnia sleep disorders generate high cost for the workforce industry due to the physically and mentally effects on employees (Kessler et al., 2011). Additionally, just like narcolepsy, those who suffer with insomnia feel tired much of the time and often worry a great deal about not getting enough sleep (Sivertsen, Lallukka & Salo, 2011). Still other disorders cause people to receive inadequate sleep they need to function optimally.

The American Sleep Apnea Association estimated that 22 million Americans suffer from sleep apnea, and it estimates that fatigue costs employers $100 billion per year in lost productivity and workplace accidents (Pearlman, 2014)). In comparison with narcolepsy, sleep apnea has just as many costly effects on the workforce due to incidents According to Leger (2011), 20% of the workforce around the world works shifts or at night, and it established that these work conditions affect the biological clock and the quantity and quality of sleep. On average, night workers sleep one-hour less than daytime workers, which affected sleepiness and increased the risk of cardiovascular disease and some forms of cancers (Leger, 2011). 20 percent, of the work force works shift work and night work that are associated with a higher rates of absences related to sickness and an increased risk of traffic and work related accidents (Leger, 2011; Pearlman, 2014).

Within the reviewed literature, significant percentages of issues related to sleep disorders, yet the gap existed for perceptions of employees with narcolepsy toward their working environment.

Disability and the Workforce

The Americans with Disabilities Act specified that one person with a particular sleep disorder had a disability while another person with a different sleep disorder was not considered to have a disability, which was completely depending on the Equal Employment Opportunity Commission's (EEOC) regulations (Santuzzi, Waltz, Finkelstein, & Rupp, 2014). Employees with non-visible disabilities faced a decision with every new employer, co-worker, supervisor, and client about whether to disclose or not to disclose their narcolepsy disability (Santuzzi, Waltz, Finkelstein, & Rupp, 2014). According to the EEOC, a person has a disability if the person has a physical or mental impairment that substantially limits one or more major life activities (Santuzzi, Waltz, Finkelstein, & Rupp, 2014). This may be why certain sleep disorders are not specified as disabilities (Santuzzi, Waltz, Finkelstein, & Rupp, 2014), which may in turn led to negative work outcomes (Santuzzi, Waltz, Finkelstein, & Rupp, 2014). A study conducted by Swanson et al. (2011) addressed chronic sleep deprivation as being common among workers, and is associated with negative work outcomes, including absenteeism and occupational accidents. Due to the regulations of the EEOC, employers will need to make adjustments for those who suffer with narcolepsy in order to lower the risk of occupational accidents. Lastly, Vico, Monzó, Cuenca, and Luis (2012) indicated that an analysis of occupational hazards related to the jobs of employees with narcolepsy

is imperative for safety. Once the analysis is completed then the employer can make accommodations for the employees, these accommodations can help decrease healthcare concerns.

Health care Administration Concerns

Employment accompanied with narcolepsy is an important public health concerns because many people with narcolepsy remain undiagnosed and, therefore, are not receiving the treatment and support they need (Naiman, 2012). As a result of this, employees who are unaware that they have narcolepsy may not fully understand why there is a struggle on the job (Naiman, 2012). Even though little has been published about the economic implications of sleep disorders, in the year 2000, Hossain and Shapiro (2002) reported the cost implications of sleep disorders were estimated to be $15.9 billion in the United States. The direct and indirect costs implications of people with narcolepsy average approximately $21,000 per year per person. (Jennum et al., 2012). Studies has shown that those who suffer from narcolepsy have greater health care expenses associated directly with general practitioner services, hospital care, medication, and indirect expenses consistent with the risk of losing their employment (Jennum et al., 2012). A quantitative study revealed the rate of total annual drug transactions doubled from 13.3 % to 26.4 % in narcolepsy patients versus patient without narcolepsy. The yearly health care costs were significantly higher in narcolepsy patients at $8346.00 compared to $4147.00 for patients without narcolepsy (Black et al., 2014).

Sleep loss and medical errors are important concerns within the health care industry. (Alireza, Jafar, Fatemeh, Samad & Neda, 2014). The consequences of sleep

deprivation among doctors have been that surgical complications increase when attending surgeons had less than a six-hour window for sleep between their final evening procedure and their first procedure the following day (Breus, 2012). The next section includes information concerning social change implications.

Review of Methodological Literature

Perspectives of Participants

Similar studies have utilized the same methodology as my current study. The first study dealt with views and experiences of people with dementia and their caregivers (Prorok, Horgan, & Seitz, 2013). Examined aspects of the health care experience of people with dementia and their caregivers to understand ways to improve care for this population. In comparison to my study, both studies researched perspectives of individuals who may be dealing with a common health care issue. Both studies created themes derived from interviews. Nevertheless, in contrast, the narcolepsy study is a phenomenological qualitative study; the current study is an ethnography study.

Another qualitative study that used a similar methodology dealt with promoting patient-centered care (Luxford, Safran, & Delbanco, 2011). This study investigated organizational facilitators and barriers to patient-centered care in U.S. health care institutions renowned for improving the patient care experience. Like my narcolepsy study, this study also used semi-structured interviews to convey the perceptions of patients. In contrast, this study interviewed 40 people, whereas the narcolepsy study only interviewed 15 people because narcolepsy represents a small percentage of the population.

Social Change Implications

This study may add insight and additional benefits for family, friends, employers, and co-workers by allowing them to utilize the results from the study as a means of gaining understanding and becoming active support systems to the employee suffering with narcolepsy. This study informed society and the public about the challenges employees with narcolepsy faced in an office or clerical setting. The study allowed for positive social change by sharing the lived experiences of employees with narcolepsy. The study offered information for people who may or may not be aware that they suffer from a sleep disorder such as narcolepsy and provided some education about the symptoms. According to Scammell (2015), approximately 1 in 3,000 Americans have some form of narcolepsy, and only approximately one-fourth of them are aware that they have narcolepsy. The following chapter described the design and nature of the study, including the use of phenomenology, the disability theory, and the sleep theory as theoretical frameworks.

Summary

The most important themes associated with this literature review consisted of sleep disorders, narcolepsy, clerical and office employment, and disabilities. Additional research endeavors have made considerable progress in understanding the original diagnosis and management of the disorder. There have been few studies conducted that related to the perceptions of employed people with narcolepsy; thus justifying this study. Chapter 3 consists of information concerning research methods, design, rational, and the role of the researcher. Chapter 4 entails summaries of the demographics, data collection,

data analysis, evidence of trustworthiness, and study results. Finally, Chapter 5 consists of the discussion, interpretation, conclusions, and recommendations.

Chapter 3: Research Method

Introduction

This qualitative phenomenological study examined the perceptions of employees with narcolepsy. This chapter includes a discussion of the qualitative approach used, the purpose of the study, the context in which the study was conducted, a description of the study participants, and details about the data collection procedures. The problem associated with this study was that employees with narcolepsy have not been able to offer their perceptions of their working environments and issues related to becoming or remaining successfully employed. The employment concerns for many people with narcolepsy included employers who reprimanded, terminated, or passed over them for employment promotion. The purpose of this study was to gain understanding about the lived experiences of employees with narcolepsy as a means to better understand their perceptions of employment situations.

Research Design and Rationale

According to Bayar (2015), a qualitative methodology produces descriptive data from a subject has written or spoken words and observable behaviors (Bayar, 2015). In this humanistic approach, all participants' perspectives are valuable to the research study (Bayar & Kerns, 2015). While some results are better measured quantitatively, these only serve to enhance the study, while maintaining the humanistic approach to qualitative research.

The central focus of this study was to explore the perceptions of employees with narcolepsy. The rationale for the use of this qualitative design was that I did not have

computable variables to quantify in relation to this study's research questions. Phenomenology is a philosophy and a research method that explore experience and perception (Shosha, 2012). According to Zenobia et al. (2013), phenomenology is a philosophy-based research method for the exploration and understanding perspectives of people.

I used this methodology to understand a phenomenon and obtain deep and rich descriptions provided by employees with narcolepsy. I selected a qualitative research design with semi-structured, open-ended interviews to answer this study's research questions as recommended to obtain in-depth information pertaining to participants' experiences and viewpoints as recommended by Gill, Sander, Robins, Mazzei and Struchen (2011). The rationale for choosing descriptive, phenomenological, qualitative research methods over other approaches and methods was that this approach supported my goal of understanding the nature of human experiences that are difficult or impossible to quantify mathematically.

Research Questions

To examine the work place perceptions of employees with narcolepsy this qualitative study had three research questions:

RQ1: What are the perceptions of employees with narcolepsy toward their risks of secure employment in the workplace?

RQ2: What are the perceived barriers to remain employed for people with narcolepsy?

RQ3: What are the perceived facilitators to remain employed for people with narcolepsy?

Role of the Researcher

This study used snowball and purposive sampling from employees with narcolepsy in the United States. The research participants were interviewed in scheduled and recorded telephone calls. I had no existing personal or professional relationships with the employees with narcolepsy. I recorded the interviews of the research participants with a digital voice-recording device and took thorough notes.

In order to protect all research participants, I ensured that research controls were in place, managed biases, and followed the study's protocol in the most ethical manner possible. Research controls were set in place by following all protocols for recruitment, data collection, and data analysis outlined in my study. Biases were managed primarily through organizing data in brackets, clusters, themes, and trends. Bracketing, according to Zenobia et al. (2013), managed at the outset of the study and used throughout the data analysis process, can control biases. Organizing data into brackets clusters, themes, and trends includes acknowledging judgmental or subjective preconceived ideas and putting those ideas aside so that personal experiences did not interfere with the emergent themes identified in the data. I managed biases by conducting a pilot study and by limiting acquaintances and friends' participation in the interviews.

My role as the sole researcher for this study was to design the semi-structured interview guide, to ask open-ended questions, to encourage elaborate answers, and to interact and collaborate with the participants during the data-gathering process, as

recommended by Moustakas (1994) and Patton (2002). To increase the reliability of the qualitative data collected, transcriptions were compared, interviews were recorded, and notes were taken during the interviews and the data was coded. I developed a comprehensive guide that included essential components such as the heading, interview instructions, debriefing and next-steps, and interview and probing questions. This interview protocol is located in Appendix A.

Methodology

The participants for this research study were employees 18 years or older who had been diagnosed with narcolepsy and had been employed for at least 3 years in an office, clerical, health care, or educational setting. The employees with narcolepsy had to speak English fluently. Application of workforce data was important to provide information to the reader and individuals who suffer with narcolepsy based on the description of the qualitative interviews (Louch, 2014).

This qualitative study began once approval was received from the Walden University Institutional Review Board (IRB) 12-23-15-0281111 and concluded when the 15 participants had provided sufficient interview data. As a means to limit the time allotted for collecting data, the interview process was limited to 30-60 days, taking into consideration availability of participants and unforeseen circumstances.

Inclusion Criteria

The inclusion criteria consisted of employees in an office, clerical, health care, or educational setting who were 18 years or older who have been diagnosed with narcolepsy and employed for at least 3 years. The employees with narcolepsy were able to speak

English fluently. The study targeted a population of 15 employees with narcolepsy utilizing purpose-based sampling, selected across the United States.

Exclusion Criteria

Study exclusions consisted of my students and co-workers to protect the research study from bias. Non-English speakers were also excluded. Finally, those who did not want to provide informed consent could not participate in the study.

Sampling

The sampling strategies for this phenomenological research study were purposive sampling and snowball sampling. Purposive sampling is criterion-based selection in which the particular persons is purposefully selected from the qualitative research participants (Purposive sampling, 2012). This sampling process allows the researcher to select the participants best suited to answer the research questions (Purposive sampling, 2012).

Snowball sampling is a sampling strategy based on referrals that are made by the current research participants (Heckathorn, 2011). Snowball sampling is used to recruit potential research participants when finding qualified research participants is difficult. Snowball sampling is also beneficial for difficult to reach populations or populations that are small and are at a disadvantage (Cohen & Arieli, 2011). The sampling method must consider the possibility of sampling errors, which are variations around the accurate significance stemming from the fact that random samples may differ from the population as a whole (Cleary, Horsfall & Hayter, 2014).

Sample Population and Procedures

The sample size for this qualitative research study was 15 research participants. This was a significant amount of participants, as the ninth research participant reached data saturation. Data saturation was important because it ensured that adequate and quality data support the study when the data is collected (Walker, 2012). Data saturation is determined when there is no more new information obtained by analyzing each qualitative interview on an ongoing basis.

Instrumentation and Tools

The data collection instrument used for this study was a semi-structured open-ended interview protocol via telephone. According to Chenail (2011), instrumentation is as critical in qualitative as in quantitative research. I learned proper interviewing skills and practiced writing semi-structured open-ended questions. I focused on retaining the open nature of the questions when actually conducting the interview. A clinical sleep technologist, a human resources director, and a disability expert validated the interview questions. Additionally, the disability expert suggested ways, such as interviewing with sensitivity, to ensure that the participants experience no emotional harm during the interviews.

I used the interview protocols based on McNamara's 2009 implementation of interviews to ensure proper etiquette. These protocols were: (a) if used, occasionally verify the tape recorder is working; (b) ask one question at a time; (c) attempt to remain as neutral as possible; (d) encourage responses with occasional nods of the head; (e) be

careful about the appearance when note; (f) provide transitions between major topics; and (g) always guide the interview properly.

Semi structured interviews have been used in various qualitative research endeavors. Research conducted by Cridland, Jones, Caputi, and Magee (2014) utilized semi-structured interviews in order to convey a study concerning families living with autism spectrum. On another note, a research study conducted in Australia utilized interviews to explore physical activity during physical education lessons (Bennie & Langan, 2014). Last, Hanna (2012) conducted a study that used Internet technologies as a research medium, mainly focusing on Skype communication interviewing as a medium. The aforementioned study was relevant to the current study because I conducted the interviews via telephone with Skype as a backup.

Pilot Study

Before conducting the main study, the pilot study is responsible for determining if the interview method was appropriate and determined the reasonable length of the interviews (Chenail, 2011) for an exploration of the lived experiences of the employees with narcolepsy. The purpose of the pilot study was to test the quality of the interview protocol and to identify researcher biases. The pilot study included two research participants who pretested the understanding of the interview questions as a means to answering the research questions. Two pilot study participants or 10% to 20% of the research participants from the main study are required (Simon, 2011). The reporting of the pilot study was separate, and those participants were not included in the main study.

I recruited two participants for a pilot interview via email. The initial email to the research participants, which consisted of the information related to the purpose of the study, is located in Appendix B. The participants received an informed consent form via email. Both participants agreed on a mutual day and time for the interviews to take place once the participants submitted the informed consent forms. The interview procedures outlined in the pilot study were transcribed in a way similar to the transcripts in the main study. I kept a reflective journal on a personal computer in order to bracket researcher bias.

The NVivo software analyzed the qualitative data from the pilot study and compared the research findings with the transcribed data against the audio recordings to ensure accuracy and validation. In addition, the research findings from the pilot study were not included in the actual research study.

Recruitment Strategy

To locate potential participants for the study, I emailed various social media sleep study groups. Other contacts, such as former co-workers, and previous nursing and health care colleagues helped to locate potential participants. The contacts roles simply distributed the research invitation, and did not recruit research participants or encouraged participation on my behalf. Additionally, the contacts did not answer questions regarding the study. In the consent form, which is located in Appendix C, I included the purpose of the research study, expectations from the participants, IRB approval information, and the possibility of publishing or even a specific quote or two being. My affiliation was solely with Walden University, the informed consent, included that research confidentiality was

guaranteed. The benefits and risks included, the possibility that the participants could withdraw at any time and the need for voluntary participation. The potential participants understood that there were no costs or compensation for participating.

Data Collection Procedures

To collect qualitative data to explore the lived experiences of employees with narcolepsy I implemented a process using best practices, recommendations, and used semi-structured open-ended interviews. Keeping a self-reflective journal helped remove biases after each interview. I collected data from the qualitative interviews from a minimum of seven participants after the participants submitted informed consents (Morse, 2015). After the tenth qualitative interview with the research participant, the data saturation was assessed starting from the eighth, ninth, and tenth participant, and so on (Morse, 2015). The ninth research participant should obtain data saturation, and the qualitative phenomenological interviews can culminate.

I partially analyzed the qualitative data collected simultaneously during the semi-structured interviews with the research participants to increase the trustworthiness of the research data. In addition, the research data and the private digital recordings were stored securely in a private folder in my computer, so that no one else could access the research data obtained. I maintained confidentiality by storing the names of the research participants securely in the computer. As a means to limit the data collected, the interview process was limited to sixty days, from October 2015 through December 2015.

Data Analysis Plan

The data analysis process took place once the data collection process and management techniques were completed. In order to identify data saturation, the data collection method required analysis of the qualitative interviews, according to views of Walker (2012). The NVivo10 software, for content analysis and coding processes, used the semi-structured interviews and information from the reflective journal (Smith & Firth, 2011). I analyzed the qualitative data by recording raw data, reading the data, and coding the data. The data was composed of categories, and the compilation process determined if new ideas or themes emerge. I appropriately categorized and assembled the qualitative data by using descriptive words for each group. The coding process defined the setting, participants, and themes for this study. This process included developing descriptive information in table format about each participant through the NVivo10 software (Smith & Firth, 2011). Giorgi's data analysis is the coding strategy for this study and theoretical frameworks.

I utilized Giorgi's data analysis techniques and modified step 5; Giorgi's strategy has five steps. The steps were (1) assume the phenomenological attitude, (2) read the entire written account for a sense of the whole, (3) delineate meaning units, (4) transform the meaning units into psychologically sensitive statements of their lived-meanings, and (5) synthesize a general structure of the experience base of the constituents of the experience (Broome, 2011). Research conducted by Robinson, Giorgi, and Ekman (2012) utilized the Giorgian, an analysis tool and interviews to convey the lived experiences of people who suffer from early stages of Alzheimer's disease. Another study that utilizes Giorgi's

strategy of coding concerns interviews focused on the dominance of chronic pain in patients (Ojala et al., 2014). Last, this study utilized the same interview and analysis approach in order to properly code and analyze the perceptions of employees with narcolepsy.

Knowledge gained from the research study allowed for further discussions and explained perceived perceptions based on quotations from the research participants. I triangulated and compared the research information to the current literature. Instead of performing member checking where the participants confirmed the transcribed responses from the oral interviews, I compared the transcribed data against the audiotapes to ensure accuracy and validation. The employees completed an informed consent using the standardized form.

Credibility and Trustworthiness

Issues of Trustworthiness

Due to the possible issues related to the quality of this research study, I applied the principles of Lincoln and Guba (1985) as cited by Elo et al. (2014) to resolve quality issues within my study. The trustworthiness of this study involved credibility, transferability, dependability, and confirmability, according to Elo et al. (2014). Credibility is the confidence that veracity of the research participants responses to interview questions are true and in-depth, by investing sufficient time into the understanding of the lived experiences of the group under study, and by testing for misinformation and distortions of the qualitative data collected (Elo et al., 2014).

The second concept that increased the trustworthiness of this qualitative data was transferability. I obtained transferability by understanding the extent to which the qualitative research findings can transfer to another setting or group. Thick descriptions of the qualitative data from this study could enable interested readers to apply the research findings to other contexts, settings, or groups at their own volition based on ideas from Goldberg and Allen (2015). I established transferability protocols to the degree that other researchers may be able to generalize more studies to investigate the perceptions of employees with narcolepsy. Replication of this study is important in other areas of the United States such as the northern states or states that have a higher incidence of narcolepsy diagnosis. In addition, I will established possible dissemination of a one to two page result summary for transferability to health care administrators, corporate offices, human resources directors, and sleep medicine journals with examples of employees with narcolepsy viewpoints to promote positive health maintenance of the disability.

The third concept that increased the trustworthiness of this qualitative research study was dependability, which was the stability of the qualitative data over time and over conditions (Elo et al., 2014). The fourth concept that increased the trustworthiness of this qualitative data was confirmability. Confirmability referred to the objectivity or neutrality of the qualitative data, which derived from the semi-structured interviews, established by maintaining neutrality when analyzing, and interpreting the data collected, based on ideas from Elo et al. (2014). I kept a reflective journal also in order to eliminate researcher bias. By implementing the procedures from Lincoln and Guba's framework as

cited in Elo et al. (2014), I increased the quality and trustworthiness of this qualitative research.

Finally, in order to increase the trustworthiness of the qualitative data, I compared the hand-coded results with that of NVivo10 content analysis and the literature review. I verified that the research findings from the research participant's responses were accurate. The qualitative research findings and interpretation, based on the theoretical frameworks of this research study helped to confirm the trustworthiness of the research.

Ethical Considerations for Conducting the Research Study

I made certain, as a researcher, that ethical issues promoted the objectives of the research, such as knowledge, truth, and avoidance of error. The study participants understood that fabricating, falsifying, or misrepresenting research data was unethical and could have damaged the overall study, according to concepts of Resnik (2011). The ethical considerations related to this research study were included in the informed consent letter, which participants received the document via email, their physical address, or hand delivered. The informed consent included the identification of the researcher, the sponsoring organization or institution, the purpose of the research, benefits for participating in the study, and described the level and type of participant involvement, in accordance with observations from Wiles (2013). The informed consent letter is located in Appendix C.

The research participants understood that there were no costs or compensation for participating in this study. The approval number from the IRB to conduct this research study involving humans is 12-23-15-0281111, with an expiration date of December 22,

2016. The research participants received the IRB approval number at the time of the interview, which also is contained in the informed consent letter. I informed the research participants that they could withdraw at any time before or during the phenomenological interviews. The participants also had the option to opt out of the completed interviews and request that I delete their information.

The participants understood that there is a possibility of publishing the research information from the interviews. I informed the research participants of their anonymity to protect their identity. I offered a digital copy of the published study to those participants who expressed interested. The confidentiality of the participants' recorded and transcribed interviews and the qualitative notes are stored on my computer in a private file, which assist in the security of the data while limiting accessibility to the data,. After 5 years, I will delete the qualitative data on the computer, and I will shred the printed copies. I compared the transcribed data against the participant recordings to ensure accuracy and validation.

Summary

The information discussed in this chapter included methods about how I collected qualitative data to explore the lived experiences of employees with narcolepsy in a southwestern region. I manually analyzed the qualitative data through thematic analysis according to Giorgi's stages of coding and through content analysis using the NVivo10 software. In chapter 3, I addressed the research design and rationale, role of the researcher, methodology, participant selection logic, instrumentation, the pilot study procedures, recruitment, participation, data collection, data analysis, issues of

trustworthiness, and ethical procedures. Chapter 4 consists of the results of my research study. Chapter 5 includes a discussion of the outcomes, including the implications for social change and recommendations for further action.

Chapter 4: Results

Introduction

The purpose of this phenomenological qualitative study was to explore the perceptions of people with narcolepsy of becoming or remaining employed. The objective of this study was to focus on perceptions held by employees with narcolepsy and understand how their experiences as employees may influence others to promote positive health maintenance of the disability. This study is unique because it allowed people with narcolepsy to express their personal perceptions as they pertain to employment in an office, educational, health care, or clerical setting. The research questions that guided this study were the following:

RQ1: What are the perceptions of employees with narcolepsy toward their risks of secure employment in the work place?

RQ2: What are the perceived barriers to remain employed for people with narcolepsy?

RQ3: What are the perceived facilitators to remain employed for people with narcolepsy?

This chapter provides an overview of the key results, which include the perceptions of people with narcolepsy. This chapter includes a brief description of the pilot study, settings, demographics, data collection and analysis, evidence of trustworthiness, results, and summary. Then, chapter 5 contains final discussions, conclusions, and recommendations.

Pilot Study

After the IRB approved my research proposal, two participants outside of the projected sample participated in the pilot study, which was conducted on December 27, 2015. As stated by Simon (2011), the rationale for conducting a pilot study was to test the quality of the interview protocol and identify if the proper execution of the proposed interview method took place as initially planned prior to proceeding to the main study. The pilot study took place separately, and the results not reported in the dissertation. Two participants received and completed informed consent forms. The pilot participants scheduled their interview day and time and I analyzed their data.

After completion of the two pilot interviews, I established that no changes with the interview questions were necessary. Due to the outcome of the pilot interviews, I used the same data collection and analysis procedures for the study's participants as for the pilot participants. Prior to conducting the pilot study, I consulted with three subject matter experts: a medical doctor, a clinical sleep technician, and a hospital human resources director, to determine whether the interview questions were aligned with the research questions for valid responses from the participants. Additionally, if any major issues had arisen during the pilot study that required modification of the interview tool, I would contact the IRB to request approval for any deemed modifications

Setting

The phenomenological interviews used in this study for employed people with narcolepsy took place via the telephone. At the time of the study, the participants did not express experiencing any personal or organizational conditions that influenced their

perceptions. Additionally, no outside influences effected the interpretation of the study results. For interview scheduling purposes and organization of the telephone interviews with the employees, I kept a participant log chart that included documented dates, times, states in which the participant resided, phone numbers, and informed consent forms. During the data collection process, one participant cancelled his interview due to illness, but another research participant rescheduled in his place.

Demographics

The table below represents the research participants' demographic information to include gender, age, education levels, current job titles, and the number of years of employment at their current jobs. The figure below table 1 illustrated the locations of each participant across the United States.

Table 1

Characteristics of the Participants

Participant #	Gender	Age	State	Education	Current Job Title	Years at Current Job
1	Female	44	TN	Masters	Registered Dietician	4
2	Male	29	NY	Some college	Health Coordinator	6
3	Female	27	MI	Some college	Controls Engineer	4
4	Female	22	KA	Bachelors	Beauty Advisor	4
5	Female	40	GA	Masters	Librarian Mgr.	16
6	Male	51	WI	Bachelors	Controller	4
7	Male	43	OK	Some college	Restaurant Mgr.	15
8	Female	63	MA	Bachelors	Occupational Therapist	30 +
9	Female	24	OH	Bachelors	Case Manager	3 ½
10	Male	52	VA	Bachelors	Supervisor	5
11	Female	34	FL	Juris Doctorate	Attorney	5
12	Male	85	TX	Masters	Teacher	30+
13	Female	47	NM	Bachelors	Medicaid Specialist	3
14	Female	36	CO	Some college	Sales Representative	8
15	Male	32	NV	Bachelors	Software Developer	5

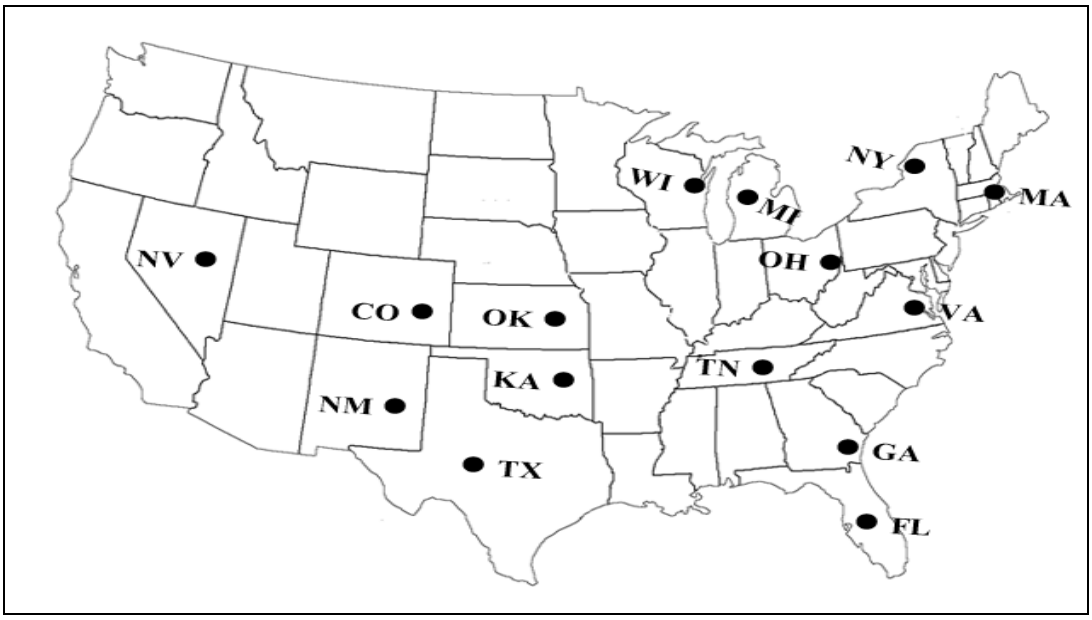

Figure 1. Map illustrating the states in which study participants reside

Data Collection

Fifteen research participants volunteered for the study. I used purposive sampling to recruit volunteer participants. Employees with narcolepsy who were interviewed by telephone were 18 years or older and had been employed at least 3 years in the United States. The phenomenological approach allowed me to gain firsthand knowledge related to the lived experiences, perceptions, and views of employees with narcolepsy regarding successfully remaining employed with narcolepsy.

Participant Demographic Summaries

At the time of data collection, I created a profile summary of each participant. The profiles acted as a guide for review of further results. The profiles include participant age, state of residence, years of employment, education, and any other pertinent information that may be beneficial to this study and results.

Participant 1 was a 44-year-old woman who had been employed at her current job for 4 years. She received her diagnosis of narcolepsy while working at her current place of employment. She was a registered dietician and resided in Tennessee. Her highest level of education was a master's degree. She identified herself as being extremely lucky to have such a supportive group of co-workers and supervisors.

Participant 2 was a 29-year-old man who had been employed at his current job for 6 years. He received his diagnosis of narcolepsy in 2012. He was a health care coordinator and resided in New York. He had some college experience. He identified his job as being neither supportive nor unsupportive of his condition. He also had never met anyone else with narcolepsy thus far.

Participant 3 was a 27-year-old woman who had been employed at her current job for 4 years. She received her diagnosis of narcolepsy about 1 year ago. She was a controls engineer and resided in Michigan. She had some college education and felt as though she had done very well in her life without a college degree. Participant 3 believed she was very blessed to have support from her supervisor and workplace.

Participant 4 was a 22-year-old woman who had been employed for 4 years as a beauty advisor. She received her diagnosis of narcolepsy at the age of 16. She had a bachelor's degree and resided in Kansas. She had learned to work around the disability. She believed that her supervisor and work environment support her and her diagnosis with narcolepsy. Participant 4 believed that staying positive concerning the disability helps her cope with the overall effects of narcolepsy.

Participant 5 was a 40-year-old woman and had been employed for 16 years. She received her diagnosis of narcolepsy over 9 years ago. She was a library branch manager, lived in Georgia, and had a master's degree. She has learned how to manage her symptoms efficiently. She believed her workplace and supervisor support her and her diagnosis with narcolepsy.

Participant 6 was a 51-year-old man and had been employed for 4 years. His highest level of education was a Bachelor's degree and worked as an assistant controller. Participant 6 lived in Wisconsin, does not drive, and listens to music when he feels tired or sleepy at work. He had a supportive work environment and supervisor. So supportive that his supervisor was willing to work with him in any way she can.

Participant 7 was a 43-year-old man and had been employed for over 15 years as a restaurant manager. He received his diagnosis of narcolepsy 2 years ago. He was from Oklahoma. When he was sleepy or tired at work, he takes a walk. He had not revealed to his supervisor about his narcolepsy condition, but feels as though his supervisor would be supportive of him.

Participant 8 was a 63-year-old woman from Massachusetts. She had been an occupational therapist for over 30 years and had a bachelor's degree. In addition to narcolepsy, participant 8 also suffers from cataplexy. Because of her cataplexy condition, she schedules her patients around her symptoms. She had revealed to her coworkers that she had cataplexy, so that they are aware.

Participant 9 was a 24-year-old woman from Ohio. She was a case manager and had a bachelor's degree. She has been on her current job for over 3 years. Some of her

narcolepsy symptoms include memory loss. She had not disclosed her condition to her co-workers; however, her supervisor is aware of her disability. She believed that her supervisor and work environment support her condition with narcolepsy.

Participant 10 was a 52-year-old man from Virginia. He had a bachelor's degree and was a supervisor. He has been at his current place of employment for 16 years. Participant 10 revealed that one of the barriers to having narcolepsy is multitasking, which had become difficult for him to accomplish. He believed his coworkers are concerned for him and he believed his supervisor thinks that he is a good employee. Overall, participant 10 feels very lucky to have support from his coworkers, supervisors, family, and friends.

Participant 11 was a 34-year-old woman from Florida. Her highest level of education was a Juris Doctorate and had been an attorney for 5 years. She believed that her barriers of narcolepsy are being prompt for meetings when she is tired and increasing unpredictable sleeping spells. She has not informed her supervisors of her narcolepsy condition because it has not affected her job performance.

Participant 12 was an 85-year-old man from Texas. His highest level of education was a master's degree. He was an educational consultant and had been in the education industry for over 30 years. When he was tired or sleepy, he took a walk or smoked a cigarette. He also believed that his work environment and school supervisor were very unsupportive of his condition.

Participant 13 was a 47-year-old woman from New Mexico and had been employed for 3 years. She was a Medicaid specialist and her highest level of education

was a bachelor's degree. She received her diagnosis of narcolepsy 1 year ago and had supportive coworkers. She believed that her supervisor and work environment are supportive of her and her diagnosis with narcolepsy.

Participant 14 was a 36-year-old woman from Colorado. She was a sales representative for 8 years. She had some college education and had a desire to complete college. The participant was embarrassed about her condition. She had not disclosed her condition to her supervisor. She was unsure if her work environment and supervisor would support her diagnosis.

Participant 15 was a 32-year-old man from Nevada. He had a bachelor's degree and had been a software developer for 5 years. He received his diagnosis of narcolepsy 3 years ago. He has not revealed to his coworkers and supervisor about his narcolepsy condition. Participant 15 believed if he discloses his condition to his supervisor, they will begin to feel sorry for him and he did not was not special attention.

Interviewing

Fifteen employed people with narcolepsy interviewed for this study via recorded phone conversation, from December 27, 2015 until January 15, 2016. The in-depth interviews lasted about 30 to 45 minutes with the phenomenological interview questions having little repetition. This means, when the research participants answered the research questions, I did not repeat the question to them. My phenomenological interview protocol and questions are located in Appendix A. I recorded the data through a digital recorder installed on the researcher's cellular telephone. Some unusual circumstance, which occurred, was one of the research participants became ill, and had to cancel their

telephone interview. Another participant scheduled an interview to replace the canceled interview, this occurrence happened once throughout the entire study.

Data Analysis

Report Process Used

After implementation of data collection and management techniques, I analyzed the data collected for this qualitative research study through Giorgi's five stages of qualitative data analysis of hand coding for thematic analysis and through NVivo 10software for content analysis. Data saturation occurred after interviewing the ninth research participant. Therefore, the phenomenological interviews and data collection was complete. The collected data were compiled into categories and repeating the compilation process to see if new ideas or themes emerge. I assembled the qualitative data in the appropriate category, and recorded the data as needed.

Themes Identified

I identified themes by finding recurrences of codes, similarities of data, metaphors and analogies, indigenous typologies, transitions, missing data, and linguistic connectors. Finally, I added my interpretations of the raw data by identifying the significance of the coded categories in relations to the research questions and literature review. The formulated codes were not too broad or narrow in meaning. The less relevant information for having broad categories could not be included and the contextual data could not be lost for having narrow categories.

Evidence of Trust Worthiness

Credibility

There were threats to the quality of this research study. I addressed threats of the study by applying the principles of Lincoln and Guba (1985) as cited by Houghton, Casey, Shaw, & Murphy (2013). I ascertained credibility by interviewing only the qualified research participants. In addition, I established credibility by prolonged engagement, through investing sufficient time in understanding the lived experiences of employees with narcolepsy and by testing for misinformation and distortions of the qualitative data collected. I improved the credibility of the qualitative study through data triangulation from the participant interviews and literature findings. The primary source consisted of interviewing several employees with narcolepsy. Finally, I developed qualitative data by comparing the transcribed data against the audiotapes to ensure accuracy and validation. I implemented several attempts to improve credibility through prolonged engagement, by testing of misinformation, by reviewing the literature, through data triangulation, and by comparing the transcribed data against the audiotapes.

Transferability

The second concept that increased the trustworthiness of qualitative data was transferability (Houghton et al., 2013). The research findings of this qualitative research study cannot be transferred to another settings or groups. Though, sufficient descriptive data or thick descriptions in the presentation of the research findings, such as through several quotations of what the research participants stated during the interview process were demonstrated (Houghton et al., 2013). Rich and thick descriptions of qualitative

data can enable the interested readers apply the research findings to another contexts, settings, or groups at their own volition.

Within this study, transferability protocols recognized that other researchers might be able to generalize more studies to investigate the perceptions of employees with narcolepsy. Replication of this study is crucial in other areas of the United States such as the northern states or states that have a higher incidence of narcolepsy diagnosis. Additionally, I will develop a result table for possible dissemination to health care administrators, corporate offices, human resources directors, and sleep medicine journals with examples of employees with narcolepsy viewpoints promote positive health maintenance of the disability.

Dependability

Dependability determined the relevancy of the qualitative data concerning the research findings based on the literature review (Houghton et al., 2013). Dependability also established audit trails and using triangulation. I compiled the recorded interviews and the data analysis reports to justify the conclusions. I triangulated the information in the data analysis process with Giorgi's strategies. Allowing the NVivo, software to organize a collection of interviews, questionnaires, and surveys into themes and trends for possible synthesis and interpretation.

Confirmability

I maintained confirmability by upholding neutrality when analyzing and interpreting the raw data collected. I kept a reflective journal, in order to be aware of researcher's bias. In order to increase the trustworthiness of the qualitative data, I

triangulated the research findings comparing the hand coding results with that of NVivo10 content analysis and the literature review. I verified the research findings by comparing the transcribed data against the audiotapes to ensure accuracy and validation. I interpreted the qualitative research findings based on the conceptual and theoretical frameworks of this research study in order to confirm the trustworthiness of the research findings.

Final Results

Results of RQ1

For RQ1, I investigated the perceptions of employees with narcolepsy toward their risks of secure employment in the work place with corresponding interview questions IQ1, IQ4, and IQ5. With IQ1 corresponding with RQ1, I explored how narcolepsy can affect employees' ability to find and/or retain employment. In Table 2, I illustrated the top 7 perceptions employees with narcolepsy reported including:

Table 2

Results of Narcolepsy Challenges to Find and Retain Employment

#	Common themes reported by narcolepsy participants	Frequency
1	Restrictions to types of jobs I can work	13
2	Already employed when diagnosed	12
3	Employer may not want to accommodate	7
4	Uncertain if you can perform job duties	5
5	Have to find a job that's flexible	4
6	Diagnosed right before starting job	2
7	Concerns about finding the right job	2

A more comprehensive listing of all common themes that occurred associated to employees with narcolepsy is located in Appendix E.

The table above shows the themes and the frequency associated with the top 7 theme. I have added the relation of each theme listed above in this section: restrictions (13 out of 15); diagnosed prior to employment (12 out of 15); accommodations (7 out of 15); uncertainties (5 out of 15); flexibilities (4 out of 15); diagnosed after employment (2 out of 15); and right job (2 out of 15).

I selected five participant quotes from the interviews that correlated with IQ1. Participant 1 stated, “If I had not already had my job before I was diagnosed a huge concern for me would have been that I need to find a job that’s flexible and/or if I will find a job at all.” Participant 1 also mentioned, “In terms of finding, it has not affected the finding a job because I already had my job when I was diagnosed.” Participant 2 referenced, “My perspective has changed since being diagnosed but either way I feel that is creates a huge productivity gap.” Participant 4 indicated, “Retain employment has not affected me at all. My ability to find employment? I think the only effect that it had on me, really, is what jobs I choose to apply for and not apply for.” Participant 15 explained, “Prior to being diagnosed with narcolepsy, I never worried about the type of work I did. After my diagnosis, it was all I could think about.”

With IQ4 corresponding with RQ1, I examined the thoughts of how coworkers view you as an employee with narcolepsy. In Table 3, I illustrated the top 7 perceptions employees with narcolepsy reported including:

Table 3

Results of Coworkers Views Toward Narcolepsy

#	Common themes reported by narcolepsy participants	Frequency
1	Coworker has misconceptions	10
2	Coworkers do not know	7
3	Coworkers believe I am lazy	4
4	Coworkers believe I am unproductive	4
5	Coworkers could care less/ do not understand	4
6	Coworkers assumes I sleep at work	3
7	Coworkers does not believe it is a real issue/disorder	3

A more comprehensive listing of all common themes that occurred associated to employees with narcolepsy is located in Appendix H.

The table above shows the themes and the frequency associated with the top 7 theme. I have added the relation of each theme listed above in this section: coworkers have misconceptions (10 out of 15); coworkers do not know (7 out of 15); coworkers believe I am lazy (4 out of 15); coworkers believe I am unproductive (4 out of 15); coworkers could care less (4 out of 15); coworkers assume I sleep at work (3 out of 15); and coworkers do no not believe it is a real disorder (3 out of 15).

I selected five participant quotes from the interviews that correlated with IQ4. Participant 2 stated, “Everybody thinks I have insomnia, but nobody understands that insomnia and narcolepsy are very different things. The challenge is to get people to understand what narcolepsy is, so I can’t take Benadryl or over the counter medicine to solve the problem.” Participant 4 mentioned, “The ones that know... it does not really

affect them that much. They are... so far they've been understanding." Participant 5 referenced, "They feel I'm not a very good employee, at times, like, I hide it well, or... not necessarily, but I try to do everything I can to make it not affect my job." Participant 7 indicated, "A lot of businesses lack understanding about narcolepsy, and some of the confusion associated with how narcolepsy presents and the impact it can have on somebody's life." Participant 15 explained, "I have only disclosed my narcolepsy issue to two coworkers and they do not believe it is a real issue. Like, how can sleeping be an issue…sleeping is natural right."

With IQ5 corresponding with RQ1, I explored thoughts of how your supervisor views you as an employee with narcolepsy. In Table 4, I illustrated the top 7 perceptions employees with narcolepsy reported including:

Table 4

Results of Supervisor Views Toward Narcolepsy

#	Common themes reported by narcolepsy participants	Frequency
1	Supervisor is very accommodating	10
2	Supervisor is very understanding	10
3	Supervisor wants to be educated on disorder	8
4	Supervisor likes me and is willing to work with me	3
5	Supervisor could care less as long as the work is right	3
6	Supervisor extends deadlines	2
7	Supervisor assumes I won't work as hard/not enough	1

A more comprehensive listing of all common themes that occurred associated to employees with narcolepsy is located in Appendix I.

The table above shows the themes and the frequency associated with the top 7 theme. I have added the relation of each theme listed above in this section: supervisor very accommodating (10 out of 15); supervisor very understanding (10 out of 15); supervisor wants to be educated on disorder (8 out of 15); supervisor likes my work and is willing to work with me (3 out of 15); supervisor could care less as long as the work is right (3 out of 15); supervisor extends deadlines (2 out of 15); and supervisor assumes I will not work as hard (1 out of 15).

I selected five participant quotes from the interviews that correlated with IQ5. Participant 1 stated, "I think that I often wonder because I have to write notes in the evening and we get 24 hours to write our notes…she allows extra time." Participant 2 mentioned, "I feel that, from my perspective, my supervisor doesn't feel that I am doing enough. I have developed an anxiety of how I am performing a because of the challenges with narcolepsy. I push myself just to make up for my perception of inadequacy." Participant 4 referenced, "I'm pretty sure he likes me." Participant 13 indicated, "My main supervisor is very, very accommodating." Participant 14 explained, "No one really cares. If the work is right, my supervisor is happy."

Results of RQ2

For RQ2, I investigated the perceived barriers to remain employed for people with narcolepsy with corresponding interview questions IQ2 and IQ3.

With IQ2 corresponding with RQ2, I explored the perspectives on how narcolepsy may be a barrier to being an effective employee. In Table 5, I illustrated the top 7 perceptions employees with narcolepsy reported including:

Table 5

Results of Narcolepsy Being a Barrier as an Effective Employee

#	Common themes reported by narcolepsy participants	Frequency
1	Invisible disability	15
2	Unfocused	15
3	Sleep attacks	15
4	Late for work	15
5	Unable to multi-task	13
6	Not alert	12
7	Late for meetings	12

A more comprehensive listing of all common themes that occurred associated to employees with narcolepsy is located in Appendix F.

The table above shows the themes and the frequency associated with the top 7 theme. I have added the relation of each theme listed above in this section: invisible disability (15 out of 15); unfocused (15 out of 15); sleep attacks (15 out of 15); late for work (15 out of 15); unable to multitask (13 out of 15); not alert (12 out of 15); and late for meetings (12 out of 15).

I selected five participant quotes from the interviews that correlated with IQ2. Participant 1 stated, “Though, it can be a barrier if I fall asleep while talking or being 1 on 1 with my patients or even in the group setting. So I have to make sure that I get a lot of good quality sleep.” Participant 6 mentioned, “It can disrupt concentration. It can also cause lateness, oversleeping, and a possibility. I think you know, at least for me, is in concentration. If I’m tired enough, I become not so effective.” Participant 8 referenced, “I

also have cataplexy, and I think that is a larger barrier in my field, that I have had to change jobs or change what I'm doing because of fear that I might drop somebody or injure somebody if I had cataplexy while I was supporting them or holding a baby or whatever." Participant 10 indicated, "Multitasking has gotten tremendously harder and just wearing down." Participant 11 explained, "It's a barrier because it can be unpredictable even if you are medicated. Some days are better than others are. Some days are difficult to sleep at night, which, in turn, makes it difficult to wake up and remain at work."

With IQ3 corresponding with RQ2, I examined how employees with narcolepsy accomplish tasks at work when feeling sleepy or tired at work. In Table 6, I illustrated the top 7 perceptions employees with narcolepsy reported including:

Table 6

Results About Strategies to Accomplish Tasks When Sleepy or Tired at Work

#	Common themes reported by narcolepsy participants	Frequency
1	Get some fresh air	10
2	Expose self to bright lights	9
3	Take a walk outside the building	4
4	Do not get overwhelmed	4
5	Take a walk outside	4
6	Stretching	3
7	Eat proper foods-not sweets/sugars while working	3

A more comprehensive listing of all common themes that occurred associated to employees with narcolepsy is located in Appendix G.

The table above shows the themes and the frequency associated with the top 7 theme. I have added the relation of each theme listed above in this section: get some fresh air (10 out of 15); expose self to bright lights (9 out of 15); take a walk outside the building (4 out of 15); do not get overwhelmed (4 out of 15); take a walk outside (4 out of 15); stretching (3 out of 15); and eat proper foods and avoid sugars at work (3 out of 15).

I selected five participant quotes from the interviews that correlated with IQ3. Participant 2 stated, “A lot of caffeine. I usually have a cup of coffee in the morning or I will have a red Bull, I even have caffeine pills at my desk but sometimes they just don’t work. I walk for maybe 5 minutes.” Participant 5 mentioned, “I get up and walk around, mostly. Sometimes I’ll just go outside and go for a walk for a few minutes, and then I’ll come back and I’ll feel a little better. Participant 7 referenced, “My job allows me to get up and move around, as I need to or want to, so if I find myself getting particularly sleepy, I will get up and walk around the office. I’ll go outside the cooler weather might help me wake up a little bit.” Participant 8 indicated, “I generally try to work my schedule so that I’m not sedentary. If I can walk around, if I can remain active, I am less likely to fall asleep. I drank about twelve cups of coffee a day and smoked a lot of cigarettes.” Participant 12 explained, “Yeah, go to the restroom a minute, take me a smoke and then come back, and smoking would help me, arouse me, you know, keep me from being sleepy.”

Results of RQ3

For RQ3, I investigated the perceived facilitators to remain employed with narcolepsy with corresponding interview questions IQ6 and IQ7.

With IQ6 corresponding with RQ3, I explored communication between employees with narcolepsy and their supervisor about the narcolepsy condition once the job was offered. In Table 7, I illustrated the top 7 perceptions employees with narcolepsy reported including:

Table 7

Results About Supervisor and Work Support Toward Narcolepsy

#	Common themes reported by narcolepsy participants	Frequency
1	Did not disclose	8
2	Am prepared to tell if need be	4
3	Will disclose if symptoms get worse	4
4	Did not disclose because not effecting job performance	3
5	Informed co-workers, not supervisor	3
6	Not sure if disclosing will help or hurt me	3
7	Told supervisor in passing	2

A more comprehensive listing of all common themes that occurred associated to employees with narcolepsy is located in Appendix J.

The table above shows the themes and the frequency associated with the top 7 theme. I have added the relation of each theme listed above in this section: did not disclose (8 out of 15); am prepared to tell if need be (4 out of 15); will disclose if symptoms get worse (4 out of 15); did not disclose b/c not effecting job performance (3

out of 15); informed coworkers, not supervisor (3 out of 15); not sure if disclosing will help or hurt me (3 out of 15); and told supervisor in passing (2 out of 15).

I selected five participant quotes from the interviews that correlated with IQ6. Participant 1 stated, “I actually developed it after I had already been working there. So they know it, but I already had my job.” Participant 2 mentioned, “I didn’t say it necessarily during the offer. I randomly brought it up during casual conversation within my first month there. But there was never really any formal conversation about it.” Participant 11 referenced, “No, actually, I got diagnosed after I already got the job, but at this point, I don’t feel it’s something that I need to disclose. I don’t feel it’s really affecting my work or something that I need an accommodation for.” Participant 14 indicated, “I am a little embarrassed about my condition. Mainly because I do not fully understand it myself, so why would my boss. As long as it is not affecting my job performance, I’m good.” Participant 15 explained, “I do not really know if telling my supervisor will help me or hurt me. I do not want them to feel sorry for me.”

With IQ7 corresponding with RQ3, I explored the perception of employees with narcolepsy toward supervisor and work environment support. In Table 8, I illustrated the top 7 perceptions employees with narcolepsy reported including:

Table 8

Results About Disclosure About Narcolepsy to Supervisor

#	Common themes reported by narcolepsy participants	Frequency
1	Workplace is extremely supportive	8
2	Lucky to have such a great job	8
3	Work environment very supportive	6
4	Work environment not supportive	5
5	Supervisor unsure about making accommodations	2
6	School was very unsupportive	1
7	Workplace is neither supportive nor unsupportive	1

A more comprehensive listing of all common themes that occurred associated to employees with narcolepsy is located in Appendix K.

The table above shows the themes and the frequency associated with the top 7 theme. I have added the relation of each theme listed above in this section: workplace is extremely supportive (8 out of 15); lucky to have such a great job (8 out of 15); work environment very supportive (6 out of 15); work environment not supportive (5 out of 15); supervisor unsure about making accommodations (2 out of 15); school was very unsupportive (1 out of 15); and neither supportive nor unsupportive (1 out of 15).

I selected five participant quotes from the interviews that correlated with IQ7. Participant 2 stated, “I don’t necessarily want to say that they support it, but I don’t want to say that they react adversely. It’s just…you know it’s just basically something that is understood and there is really no positive or negative umm reaction to it.” Participant 6 mentioned, “Yeah, absolutely. In fact, I take the commuter bus and I get off at the last

stop, and the bus drivers know me. If they know I'm getting off and I'm asleep, they wake me up." Participant 7 referenced, "I believe they would. If my supervisor was aware of the sleep issues I've had along with – I know of other people who have had different medical conditions, and we were supervisors, and my supervisor were automatically supporters." Participant 9 indicated, "I know that my supervisor does. My work environment, I think, can be sometimes challenging just because it does change from day to day and it is mostly visits with clients in their home." Participant 11 explained, "I would say, I already see speculating at this point, I do not believe she would be. I think that it would kind of put, like, a target on me, like, just to keep track to make sure that I'm being as productive or meeting some kind of guideline."

Summary

After conducting a pilot study of two research participants, fifteen employees with narcolepsy participated in this study to explore their lived experiences regarding how to become or remain successfully employed. The pilot study implemented the same proposed research methodologies as the main study. I searched various social networking websites to find potential research participants. The in-depth interviews of the 15 employees with narcolepsy took place from December 28, 2015 until January 15, 2016, implementing the data collection methods proposed in Chapter 3. Seven total themes emerged from the transcribed interviews analyzed through Giorgi's five stages of hand coding and the NVivo 10 software. These emerging themes are similar to the subset questions asked of the employees with narcolepsy, which are included in the phenomenological interview questions. The theoretical framework helped develop the

subset questions utilized in the research study. The seven emerging themes or categories from the transcribed interviews resulted from the perceptions held by the employees with narcolepsy.

Chapter 5: Discussions, Conclusions, and Recommendations

Introduction

The purpose of this study was to explore the perceptions of employees with narcolepsy by using a descriptive, phenomenological, qualitative approach. The descriptive approach allowed me to gain deep, rich, exhaustive details specific to the phenomenon, as prescribed by Shosha (2012). Little research has been directed toward understanding the perceptions of people with narcolepsy in the workplace. The goal of my study was to focus on perceptions of employees with narcolepsy concerning becoming and/or remaining successfully employed. This study will help researchers, employers, friends, family members, medical providers, and educators had better understand how to utilize various maintenance processes in order to support people with narcolepsy.

Interpretation of the Findings

The findings from this descriptive, phenomenological, qualitative study may enhance treatments and offer strategies to improve the employment situations for many people with narcolepsy. These findings provided meaningful examples and viewpoints from employees with narcolepsy regarding their lived experiences with employment and narcolepsy. This information was provided in the literature review section in Chapter 2 pertaining to narcolepsy. The themes consisted of perceptions of employees with narcolepsy, living with narcolepsy, employment and narcolepsy, perceptions of narcolepsy and sleeping disorders, narcolepsy studies, narcolepsy statistics, health care administration concerns, direct and indirect costs, possible solutions, and organizations.

Chapter 4 illustrated the results of each of the seven interview questions in tables and introduced personal quotations from the participants. The tables displayed the results and findings from employees with narcolepsy against the frequency reported by each of the 15 employee participants. Chapter 4 reported the top seven themes for each of the seven interview questions that were aligned with each of the three research questions.

In order to interpret the findings from the interview questions, I summarized the results from the interviews reported in Chapter 4 as conclusions outlined in Figure 2. In Figure 2, I depicted the seven topic thematic conclusions for each of the research questions. First, I investigated risks in RQ1 and the findings were assumptions, disclosure, misconceptions, misunderstanding, restrictions, unawareness, and uncertainties. Next, I explored perceived barriers of working with narcolepsy in RQ2 and findings were disability, environment, exercise, focus, nutrition, sleep habits, and work tasks. Lastly, I examined perception of facilitators of the workplace in RQ3 and findings were accommodations, coworkers, disclosure, job performance, supervisor, symptoms, and work support.

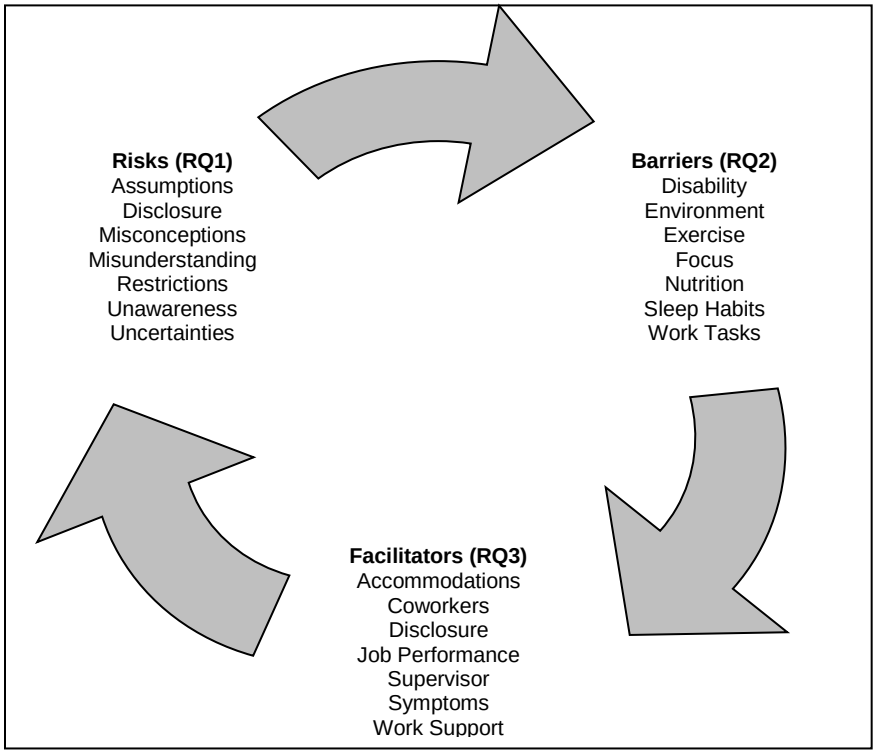

Figure 2. Conclusions of perceptions of Employed people with narcolepsy

Repair and Restoration Theory of Sleep

The RRTS developed by Oswald (1966) stated that sleep is crucial for revitalizing and restoring the physiological processes that keep the body and mind healthy and properly functioning (Sammons, 2012). This theory suggested that NREM sleep is important for restoring physiological functions and REM sleep is essential for restoring mental functions (Sammons, 2012). Due to the lack of physiological and mental restoration of the brain, daily activities become difficult tasks for employees with narcolepsy.

This study addressed many ways narcolepsy affects daily employment. Employees with narcolepsy described experienceing sleep attacks, having the inability to multi-task, being unfocused, arriving late for work or appointments, and being unalert;

which are associated with the RRST for the participants. The study results of RQ2 explored the perceptions of employees with narcolepsy when dealing with barriers in the work place. I used IQ2 to support the RRST, which indicated the various barriers faced by employees with narcolepsy due to the lack of sleep. IQ3 indicated a result of experiencing lack of sleep; the participants described alternatives, such as getting fresh air, exposure to bright lights, and moving around to help them accomplish their tasks. A comprehensive listings of these findings are listed in Appendix G and Appendix H.

Disability Theory

The disability theory addressed how to redefine the identity of individuals with disabilities (Goodley, Hughes, & Davis, 2012). This theory views disability identity not as the property of an individual, but as a form of social theory that represents the social and political understanding of disabled people (Goodley et al., 2012). Narcolepsy is a neurological disability, which can at times affect a person's physical and mental state. These types of disabilities are often difficult to categorize because the disorder is a non-apparent disability (Santuzzi, Waltz, Finkelstein, & Rupp, 2014). Because of the negative social implications associated with narcolepsy, disability theory can help create social pathways to help accomplish positive maintenance skills for people and employees who have narcolepsy.

Employees with narcolepsy described experiencing misconceptions of narcolepsy, appearing to be unproductive, expressing a lack of understanding, and having the appearance of being lazy from coworkers. These themes relate to the disability theory by demonstrating how employees with narcolepsy believe their coworkers view them. The

study results of RQ3 explored the perceptions of employees with narcolepsy when dealing with how coworkers and supervisors view them in the work place. I used IQ4 to support the disability theory, which indicated the various perceptions of how coworkers view the participants from the employee's point of view. Particpants also described experienceing lack of support and accomodations from their supervisors in IQ5. A comprehensive listings of these findings are listed in Appendix I and Appendix J.

Limitations of the Study

Limitations pertaining to the design of this descriptive, phenomenological, qualitative study included time, financial resources, and administrative management for obtaining a representative population of employees with narcolepsy. In addition, the purposive base sample of 15 employees with narcolepsy may not consistently represent the broad spectrum of perceptions of employees with narcolepsy globally. The possible drawback of purposive based sampling was that the data collection might not represent the viewpoint of the entire participant population (Earl, 2013). Phenomenological studies are specific to a group of individuals who have experienced the same phenomena of research inquiry. As the researcher, I proportionally recruited participants throughout the United States. For reasonable measures to address limitations, I adhered to the parameters identified within the scope of this study. I also kept a reflective journal before the qualitative interviews in order to record my possible biases during the interview process.

Recommendations

After exploring the perceptions of employed people with narcolepsy in the United States, I recommend collecting data concerning the perceptions of additional employees

with narcolepsy throughout other areas of the United States. I recommend that researchers from other countries with a high percentage or incidence of people with narcolepsy conduct this study for employment and industry purposes. Other recommendations include investigating the perceptions of employed people with narcolepsy versus the common clusters, themes, and trends noted from the data collected in order to understand the coping mechanisms for employees with narcolepsy. Many of the participants expressed concerns that their employers and human resource departments are unaware of the non-apparent disability. I recommend a guide for non-apparent disabilities be a part of the human resources training across the United States.

Implications

Potential Positive Social Change

Positive social change includes dissemination of study results to individuals who suffer with narcolepsy. As this may help those with narcolepsy better, understand their condition and ways to maintain their symptoms. This study may also improve awareness for people with narcolepsy in general and support their lived experiences. The implication of these findings for positive social change are to inform employers, policy makers, coworkers, and health care administrators of how people with narcolepsy perceive their work environments.

Potential dissemination includes providing a manuscript of this study and results to health services, health care administrators, employers, families, and sleep medicine journals. This study may extend the literature by addressing the research gap through dissemination in peer-reviewed journals. The findings from this study may provide a

better understand of the views of employed people with narcolepsy. Further, health professionals may advocate social change by encouraging improved work environments of employees with narcolepsy. The scope of this descriptive, phenomenological, qualitative study targeted potential transferability. The population identified for this study was employed people with narcolepsy in the United States. This population was justified and significant for exploring the missing gap in literature covered in Chapter 2.

Recommendations for Practice

Recommendations for practice of this descriptive, phenomenological, qualitative research study could possibly provide potential contributions to advance knowledge, practices, policies, and positive social change implications within health services, health care administration, disability services, and sleep medicine. Unfortunately, the general global population lacked awareness of sleep health standards (NSF, 2015). Perceptions of employed people with narcolepsy may enhance the understanding of past and future research involving narcolepsy and non-apparent disabilities. Distribution of this type of information may be in the form of pamphlets, poster presentations, and/or peer reviewed journals.

Conclusion

Exploring the lived experiences of employees with narcolepsy regarding their perceptions of becoming or remaining successfully employed allowed me to better understand and recognize the stigma associated with the disorder. Understanding perceptions of employees with narcolepsy is an important contribution to sleep health and employment. Sleep health can benefit the work environment by increasing attention,

concentration, decision-making skills, and memory. Without proper sleep health, daily functions can become difficult to accomplish.

The findings from this study offer important examples and perspectives from employees with narcolepsy. The lived experiences of the employees with narcolepsy can contribute insights into the adjustments needed to their lifestyles in order to improve their working environments. The results of this study may bring forth concepts for educational purposes for employers or companies with employees with narcolepsy. Additionally, the results of this study may also offer tools that employees with narcolepsy can recognize and utilize to create a successful working environment.

The results of this study may provide awareness for the general population concerning sleeping disorders and the effects they have on employees. Health care administrations may benefit from this study because the results could possibly increase health service resources, control cost, offer additional narcolepsy maintenance techniques, and encourage preventative measures for employees with narcolepsy.

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Appendix A: Phenomenological Interview Questions

Introduction

Hello my name is Chantelle L. Jones, and I am a Ph.D. student in Health Services at Walden University. The purpose of this interview is to explore the perceptions of people with narcolepsy on becoming or remaining employed, and the IRB approval number is 12-23-15-0281111.

The interview will take 30-45 minutes to complete.

Demographic Questions

1. What is your gender?
2. How old are you? 18-19, 30-39, 40-49, 50-59, 60 and up
3. What is your highest level of education? Some high school, GED/high school diploma, some college, associate degree, bachelor degree or higher
4. What is your current job title?
5. How many years have you been employed at your current place of employment?
6. What state do your reside in?

Study Topic Questions

1. How has your narcolepsy condition affected your ability to find and retain employment?
2. What are your perspectives on how narcolepsy may be a barrier to being an effective employee?
3. When you feel sleepy or tired at work, how do you accomplish your task?
4. What are your thoughts of how your coworkers view you as an employee?
5. What are your thoughts of how your supervisor views you as an employee?
6. Did you tell your supervisor about your narcolepsy condition once the job was offered to you? When?
7. Do you think your supervisor and work environment support you and your diagnosis with narcolepsy?

Conclusion: Final thank you to the research participant.

Appendix B: Initial Letter to the Research Participants

January 2016

Dear Prospective Research Participant,

My name is Chantelle L. Jones, a Ph.D. student in Health Services, and I am currently conducting a research study through semi-structured interviews related to the lived experiences of employees with narcolepsy. I am looking for people with narcolepsy who have been employed for at least 3 years in an office setting. The employee should be able to speak English fluently. Examples of narcolepsy employees who are the potential research participants for this study are but not limited to secretary, receptionist, lawyers, Managers, Administrators, etc.

If you agree that, you meet the prerequisite to become a research participant for this research study and you want to participate, please let me know. The participation in This research study is voluntary, and the research participant can withdraw from the interview at any time. The interview can take from 45 minutes to one hour. The informed consent form is attached with this letter. Please read the informed consent, and by replying to the e-mail with the words “I Consent” you are agreeing to participate in the study.

Thank you in advance.

Appendix C: Narcolepsy and Sleep Disorder Organizations and Resources

Brain Resources and Information Network (BRAIN)
National Institute of Neurological Disorders & Stroke
P.O. Box 5801
Bethesda, MD 20824
braininfo@ninds.nih.gov
http///www.ninds.nih.gov
Tel/ 800-352-9424
Fax/ 301-402-2186

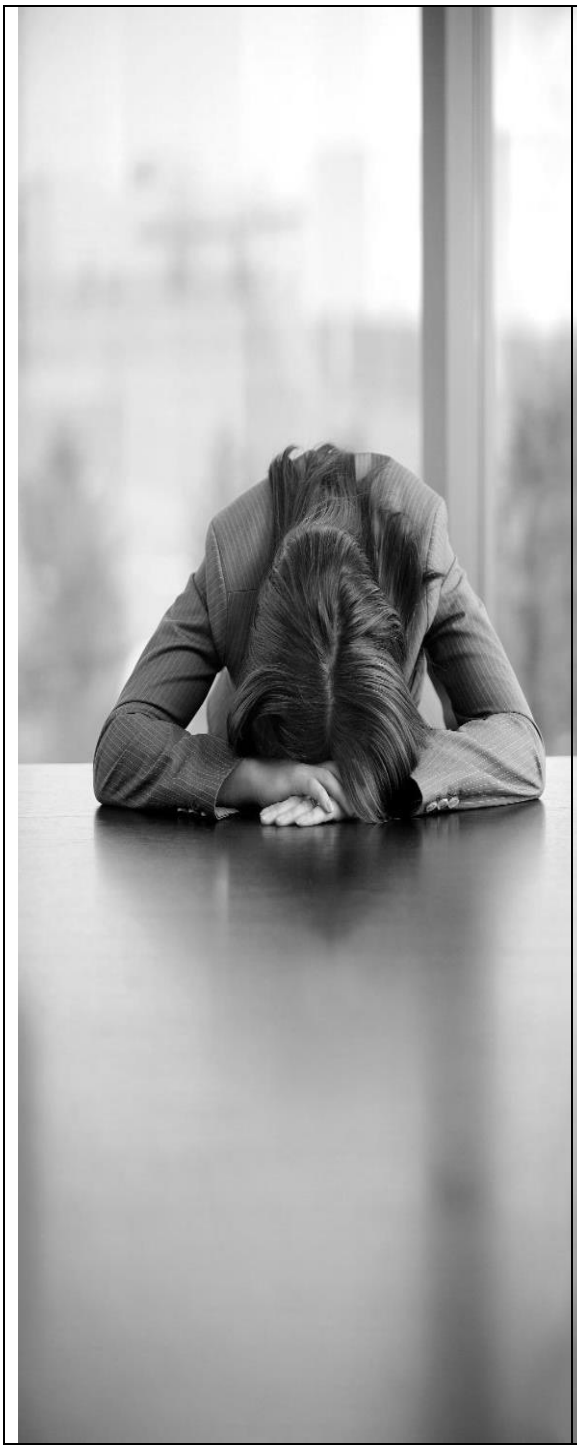
Narcolepsy Network, Inc.
129 Waterwheel
North Kingstown, RI 02852
narnet@narcolepsynetwork.org
http///www.narcolepsynetwork.org
Tel/ 888-292-6522 401-667-2523
Fax/ 401-633-6567

National Sleep Foundation
1010 N. Glebe Road
Suite 310
Arlington, VA 22201
nsf@sleepfoundation.org
http///www.sleepfoundation.org
Tel/ 703-243-1697
Fax/ 202-347-3472

National Heart, Lung, and Blood Institute (NHLBI)
National Institutes of Health, DHHS
31 Center Drive, Rm. 4A21 MSC 2480
Bethesda, MD 20892-2480
http///www.nhlbi.nih.gov
Tel/ 301-592-8573/240-629-3255 (TTY) Recorded Info/ 800-575-WELL (-9355)

Wake Up Narcolepsy
P.O. Box 60293
Worcester, MA 01606
info@wakeupnarcolepsy.org
http///www.wakeupnarcolepsy.org
Tel/ 774-364-4965

Appendix D: Participant Recruitment Flyer



Doctoral Research Study

My name is Chantelle L. Jones, a PhD candidate in Health Services at Walden University. I am conducting a research study related to the lived experiences of employees with narcolepsy in the United States. I am seeking employees with narcolepsy to interview with by telephone.

Requirements are:

- Diagnosed with narcolepsy
- 18 years and older
- Employed for at least 3 years
- Clerical, health care, or education setting
- Speak English fluently

The participation in this research study is voluntary. The participant can withdraw from the research study at any time without penalty.

The Institutional Review Board (IRB) approval number from Walden University for this study is 12-23-15-0281111 and expires on December 22, 2016. If you agree that, you meet the qualifications to become a research participant for this research study and you want to participate, please let me know.

Note: Photo Reprinted with Permission from iStock

Appendix E: IQ1/Narcolepsy Challenges to Find and Retain Employment

#	Common themes reported by narcolepsy participants	Frequency
1	Restrictions to types of jobs I can work	13
2	Already employed when diagnosed	12
3	Employer may not want to accommodate	7
4	Uncertain if you can perform job duties	5
5	Have to find a job that's flexible	4
6	Diagnosed right before starting job	2
7	Concerns about finding the right job	2

Appendix F: IQ2/Narcolepsy as a Barrier Being an Effective Employee

#	Common themes reported by narcolepsy participants	Frequency
1	Invisible disability	15
2	Unfocused	15
3	Sleep attacks	15
4	Late for work	15
5	Unable to multi-task	13
6	Not alert	12
7	Late for meetings	12
8	Depression	11
9	Extremely tired	10
10	Lethargic	4
11	Feeling unproductive	3
12	Cataplexy	3
13	Not performing as well as other employees	3
14	Muscle weakness	3
15	Develop a complex	3
16	Hallucinations	2
17	Memory loss	2
18	Attitudinal	1
19	Anxiety	1
20	Negative reactions to medications	1

Appendix G: IQ3/Strategies to Accomplish Tasks When Sleepy or Tired at Work

#	Common themes reported by narcolepsy participants	Frequency
1	Get some fresh air	10
2	Expose self to bright lights	9
3	Take a walk outside the building	4
4	Do not get overwhelmed	4
5	Take a walk outside	4
6	Stretching	3
7	Eat proper foods-not sweets/sugars while working	3
8	Drink a coke	3
9	Drink coffee	3
10	Switch/change task	2
11	Take a 15 min nap	2
12	Splash water on face	2
13	Do not schedule appointments between hours of 2-4pm	2
14	Quick exercise in office	1
15	Play a game on computer	1
16	Schedule appointments with 30 min breaks in between	1
17	Quick exercise in office	1
18	Smoke a cigarette	1
19	Chew ice	1
20	Take a 20 min nap	1
21	Take caffeine pills	1
22	Listen to music	1
23	Stay hydrated	1

Appendix H: IQ4/Coworker Views Toward Narcolepsy

#	Common themes reported by narcolepsy participants	Frequency
1	Coworker has misconceptions	10
2	Coworkers do not know	7
3	Coworkers believe I am lazy	4
4	Coworkers believe I am unproductive	4
5	Coworkers could care less	4
6	Coworkers assumes I sleep at work	3
7	Coworkers does not believe it is a real issue/disorder	3
8	Coworkers wants to know more about the disorder	2
9	Coworkers wakes me up from my daily naps	1
10	Coworkers confuses narcolepsy with insomnia	1
11	Coworkers feel sorry for me	1
12	Coworkers makes fun of the disorder	1
13	Coworkers suggest I take more vitamins	1
14	Coworkers thinks immune system is too low	1
15	Coworkers thinks narcolepsy is a form of sleep apnea	1

Appendix I: IQ5/Supervisor Views Toward Narcolepsy

#	Common themes reported by narcolepsy participants	Frequency
1	Supervisor is very accommodating	10
2	Supervisor is very understanding	10
3	Supervisor wants to be educated on disorder	8
4	Supervisor likes me and is willing to work with me	3
5	Supervisor could care less as long as the work is right	3
6	Supervisor extends deadlines	2
7	Supervisor assumes I won't work as hard	1
8	Supervisor does not understand	1
9	Supervisor how can sleeping be hard	1
10	Supervisor feels sleeping is the easiest task on earth	1
11	Supervisor makes me feel like an orphan child	1
12	Supervisor treats the disorder like it is nothing	1
13	Supervisor wants me to stay, even though I want to quit	1
14	Supervisor was very unsupportive	1
15	Supervisor did not want to read the doctors note	1

Appendix J: IQ6/Disclosure About Narcolepsy to Supervisor

#	Common themes reported by narcolepsy participants	Frequency
1	Did not disclose	8
2	Am prepared to tell if need be	4
3	Will disclose if symptoms get worse	4
4	Did not disclose because not effecting job performance	3
5	Informed co-workers, not supervisor	3
6	Not sure if disclosing will help or hurt me	3
7	Told supervisor in passing	2
8	Wanted supervisor to know before any issues developed	2
9	Supervisor/HR wanted a formal letter	1
10	Not prepared to tell anyone at work	1
11	Afraid supervisor will feel sorry for participant	1
12	No-doesn’t want special treatment	1
13	Embarrassed to have the disorder	1
14	Not prepared to tell anyone at work	1
15	Only revealed having a sleeping issue not narcolepsy	1

Appendix K: IQ7/Supervisor and Work Support Toward Narcolepsy

#	Common themes reported by narcolepsy participants	Frequency
1	Workplace is extremely supportive	8
2	Lucky to have such a great job	8
3	Work environment very supportive	6
4	Work environment not supportive	5
5	Supervisor unsure about making accommodations	2
6	School was very unsupportive	1
7	Workplace is neither supportive nor unsupportive	1