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A Phenomenological Study of Mal de Debarquement Syndrome

Divina T. Johnston

Antioch University Santa Barbara

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**EXPERIENCES OF INDIVIDUALS WITH MAL DE DEBARQUEMENT
SYNDROME: A PHENOMENOLOGICAL STUDY**

A dissertation presented to the faculty of

ANTIOCH UNIVERSITY SANTA BARBARA

in partial fulfillment of
the requirements for the
degree of

DOCTOR OF PSYCHOLOGY
in
CLINICAL PSYCHOLOGY

By

DIVINA T. JOHNSTON, MS
MARCH 2017

MAL DE DEBARQUEMENT SYNDROME

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SYNDROME: A PHENOMENOLOGICAL STUDY**

This dissertation, by Divina T. Johnston, MS, has been approved by the committee members signed below who recommend that it be accepted by the faculty of Antioch University Santa Barbara in partial fulfillment of requirements for the degree of

DOCTOR OF PSYCHOLOGY

Dissertation Committee:

Salvador D. Trevino, PhD
Chairperson

Brett Kia-Keating, EdD
Second Faculty

Yoon-Hee Cha, MD
External Expert

MAL DE DEBARQUEMENT SYNDROME

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MAL DE DEBARQUEMENT SYNDROME

Abstract

The objective of this study was to understand the life experiences of individuals who have been diagnosed and live with the symptoms of Mal de Debarquement Syndrome. This is a rare and incurable neurological disorder that creates a feeling of imbalance and that can lead to symptoms of depression and anxiety. This study involved a phenomenological investigation of the study participants in order to obtain data and increase awareness of this rare disorder. Eight women participated and shared their experiences with onset, diagnosis, and living with MdDS. The electronic version of this dissertation is available free at Ohiolink ETD Center, www.ohiolink.edu/etd.

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Chapter I: Introduction

When disembarking onto stable ground from a cruise ship, individuals commonly continue to feel sensations of rocking for a short time, as if they are still on the ship at sea. This condition is known as land sickness. In rare cases, the sensations of movement continue beyond 24 h. Some individuals have reported feeling these sensations for months or even years (Brown & Baloh, 1987; Cha, 2009; Clark & Quick, 2011; Hain, 2013; Murphy, 1993). The persistence of these symptoms is referred to as mal de débarquement syndrome (MdDS) (Brown & Baloh, 1987). MdDS is a rare neurological disorder that results in a “continuous feeling of swaying, rocking, and/or bobbing” and “considerable distress” (Dai, Cohen, Smouha, & Cho, 2014, p. 1). Researchers are investigating possible treatments that involve repetitive transcranial magnetic stimulation (rTMS; Cha, Cui, & Baloh, 2013; Ding, Shou, Yuan, Urbano, & Cha, 2014; Pearce, Davies, & Major, 2015) or specialized vestibular physical therapy (Dai et al., 2014; Dai, Raphan, & Cohen, 2009). Nonetheless, individuals who have developed the symptoms of MdDS continue to have to deal with its consequences.

MdDS is associated with a poor quality of life and psychological distress that can lead to symptoms of depression and anxiety (Arroll, Attree, Cha, & Dancey, 2014; Clark & Quick, 2011). In addition, the symptoms of MdDS are associated with economic consequences, such as a loss of employment and the costs incurred from diagnosis and treatment (Cha, 2015; Clark et al., 2013). The most challenging aspect of MdDS is its diagnosis by medical professionals who are largely unaware of the syndrome. The lack of knowledge of this syndrome results in delays and significant costs due to the multitude of

diagnostic tests that are performed for individuals who are experiencing the symptoms of MdDS.

My Interest in the Topic

In April 2011, I experienced a sudden and severe case of vertigo that was triggered by head motion while I was lying in bed. Over the next few weeks, I began experiencing sensations of bobbing and swaying while sitting up, standing, or walking, as if I was on a boat in rough seas. The vertigo continued for about four months until it gradually decreased in intensity until it was completely gone. However, the bobbing and swaying sensations continued. I saw several doctors and specialists, including a local primary care physician, ear-nose-throat specialist, hearing specialist, and neurologist, about the continuing sensations of unbalance and movement. I was surprised to learn that none of the medical professionals that I consulted with could provide any answers or treatment for the unbalance and rocking sensations that continued after the vertigo symptoms stopped. After undergoing various diagnostic tests, my primary care physician finally provided a referral to a specialist at the University of California-Los Angeles Medical Center. The specialist examined me and diagnosed me with MdDS.

In the following weeks, I searched the internet for information on MdDS. I found the website of a non-profit organization called the MdDS Balance Disorder Foundation and spent hours perusing the information presented on this website. The website offered a wealth of MdDS-related information, including the recommendation to participate in online support groups for individuals with the symptoms and/or diagnoses of MdDS. I quickly joined the support groups and found relief in connecting with similar individuals.

I underwent vestibular physical therapy, which was recommended by the doctor at UCLA. Eventually, my symptoms subsided. I returned to work after a 7-month medical leave and felt normal again. Approximately 9 months later, I began to experience increased work-related stress as well a slight wobble while sitting still, and I started commuting twice a week to attend my university classes. Eventually, I had developed recurrent symptoms of MdDS. I consulted with my primary care doctor, obtained orders for physical therapy, and underwent treatment for a month. However, the physical therapy did not work. Two years after the initial diagnosis, I returned to UCLA to see the specialist, who examined me again and confirmed that my MdDS had not resolved, and unfortunately, there was no cure. The doctors advised me to focus on living life as normally as possible, as if MdDS did not exist, which I continually strive to do to this day.

Consequently, I became interested in the experiences of others with MdDS. Were their experiences similar as they developed symptoms, sought answers, and received their diagnoses? Did they experience the same frustrations and feelings of aloneness when trying to help others understand what they were experiencing? What did they experience when they tried to explain their symptoms to doctors who did not know about MdDS?

To answer these questions, I decided to study MdDS in this research project. This study utilized a phenomenological research design to examine the lived experiences of individuals with MdDS. This qualitative research was expected to yield information on what it is like to live with the symptoms of this rare disorder. The research questions of this phenomenological study were the following:

1. What does it mean to have MdDS?

2. How do individuals who have been diagnosed with MdDS describe their symptoms?

Relevance of the Topic for Clinical Psychology

Multiple studies have shown that the symptoms of MdDS are highly intrusive and negatively affect the quality of life, even though they are not obvious to others. Recent studies have indicated that persistent MdDS leads to the development of depression and anxiety (Arroll et al., 2014; Clark et al., 2013). In addition, the lack of awareness of MdDS in both the medical and public realms is problematic. In my experience, many professionals, including physicians, specialists, therapists, and psychologists, have stated that they had no knowledge of the syndrome. The same is true for the general public. Therefore, one goal for conducting this phenomenological study was to increase the awareness of MdDS. I hope that the addition of qualitative data to the existing body of literature on this disorder will increase the awareness of the disorder and its potential impact on mental health and thereby decrease the amount of time needed to reach a diagnosis (Brown & Baloh, 1987; Cha, 2009).

Chapter II: Literature Review

This partial literature review will summarize the basis of a phenomenological approach to MdDS. Publications on persistent MdDS are relatively rare. Other than brief case studies, the current literature is mainly quantitative in nature, and it lacks descriptions of the impact that MdDS has on individuals with the syndrome.

After disembarking from a ship, such as an ocean cruise ship, onto land, it is common for individuals to feel as if they are still on the ship on the water. These sensations typically resolve in a few hours or days. A portion of the existing literature on MdDS refers to these transient symptoms, which can be confusing to researchers concerned with the more persistent symptoms. To differentiate the transient symptoms from the persistent symptoms of MdDS, this review will first present the literature on the transient symptoms. This section will include the work of Cohen (1996); DeFlorio and Silbergleit (2006); Gordon, Spitzer, Shupak, and Doweck (1992); and Gordon, Spitzer, Doweck, Malamed, and Shupak (1995).

This review will then survey published case studies of persistent MdDS. This section will review the work of Brown and Baloh (1987); Cha, Brodsky, Ishiyama, Sabatti, and Baloh (2008); Hain, Hanna, and Rheinberger (1999); Lewis (2004); Murphy (1993); Mair (1996); and Moeller and Lempert (2007).

A review of the literature related to the cause and treatment of MdDS will then follow. This section will include the works of Dr. Yoon-Hee Cha at the Laureate Institute for Brain Research in Tulsa, Oklahoma and Dr. Mingjia Dai at the Mount Sinai School of Medicine in New York, New York.

Finally, this literature review will discuss publications that have described the psychological and economic consequences of MdDS. This final section of the literature review will discuss the work of Arroll et al. (2014); Clark et al. (2013); and Macke, LePorte, and Clark (2012).

Common Transient Symptoms

The transient and persistent symptoms of MdDS have been reported to be similar, except for their duration and the affected demographics. Both leave individuals feeling as if they are still on a boat at sea after they have returned to stable ground. The sensations include “swinging, swaying, unsteadiness, and disequilibrium that appears after disembarking from a ship” (Gordon et al., 2014, p. 363). The transient symptoms usually resolve quickly and last no more than a few days (Cohen, 1996; Gordon et al, 1992; Gordon et al, 1995). Gordon et al. (1992) conducted a study of the transient symptoms and cited Brown and Baloh (1987) as the only publication at the time that addressed the symptoms of motion perception after exposure to water-related activity, which highlighted the absence of publications on the temporary symptoms. Gordon et al. (1992) closed this gap by surveying Israeli Navy seamen who frequently engaged in ocean travel. The term *mal de débarquement* was used to describe both the persistent symptoms described by Brown and Baloh (1987) and the transient symptoms detailed in the Gordon et al. (1992) study. The study participants ranged in age from 18 to 38 years and served as crew members of small seagoing vessels. Although this study did not report the gender of the participants, a follow-up study of the same population identified the participants as male (Gordon et al., 1995). This is important to note, as persistent MdDS primarily affects women (Cha, 2015). The researchers asked the participants to report if they had

ever experienced motion sensations after returning to dry land and how much time had passed after disembarkment before the symptoms developed. Of the 234 participants surveyed, 171 reported that they developed motion sensations after returning to stable ground. The durations of the symptoms ranged from a few min to 24 h (Gordon et al., 1992). The brief duration of the symptoms noted in that study is important to note as the symptoms of persistent MdDS can persist for years (Brown & Baloh, 1987; Cha, 2009).

Gordon et al. (1995) conducted a follow-up study, and the participants were identified as males ranging in age from 18 to 33 years. As in the 1992 study by Gordon et al., this study described the brief durations of the symptoms (one min to two days). This latter study briefly mentioned that only one case had symptoms that persisted for months to years, which was explained “in terms of probable failure to readapt to the natural conditions on land” (Gordon et al., 1995, p. 364). The researchers did not discuss the single case with persistent symptoms that was noted in their study any more.

Cohen (1996) conducted a study involving a convenience sample of 36 men and 23 women with an average age of 44.3 years who participated in annual week-long sea trials of a restored 117-year-old ship. That study cited case studies of persistent MdDS (Brown & Baloh, 1987; Murphy, 1993) and pointed out that the cases with persistent symptoms were primarily women, which suggested that perhaps more women seek medical assistance for sociological reasons (Cohen, 1996). While the symptoms lasted no more than a few hours in the participants in the Cohen (1996) study, the symptoms reported by the participants in the Brown and Baloh (1987) case study lasted considerably longer and ranged from three months to five years. The Cohen (1996) study did not reference the age differences between the patients in the Brown and Baloh (1987) case study and the

studies led by Gordon (Gordon et al., 1992; Gordon et al., 1995) as well as the subjects of her own report concerning transient symptoms.

DeFlorio and Silbergleit (2006) presented the case of a 22-year-old male who had experienced unsteadiness for a week after a six-day sailing trip in the British Virgin Islands and visited an emergency department for treatment. In their introduction, DeFlorio and Silbergleit (2006) acknowledged varying definitions of mal de débarquement in the literature and stated “most authors describe the disorder as short-lived and with spontaneous resolution” (DeFlorio & Silbergleit, 2006, p. 377).

Case Studies of Persistent MdDS

The first reference to persistent MdDS appeared in the literature with the report published by Brown and Baloh (1987). This report reviewed six cases to define persistent MdDS and differentiate it from transient land sickness. The researchers described a set of patients who experienced continual phantom movement upon returning to land from water-related activities. The durations of the exposures to the water-related activities in these six cases ranged from a few hours to 70 days with a symptom duration of three months to five years (Brown & Baloh, 1987). One participant had slept in a moored boat for one night; one had taken a short five-h boat ride; and the others had gone on ocean cruises. An interesting point made in this article was that individuals reported symptomatic relief when they returned to a boat or ship at sea.

In 1993, Murphy published more information on the persistent symptoms in their case study of four females who had been exposed to four different types of water-related activities (one night sleeping on a waterbed, a week-long cruise, a scuba-diving trip, and swimming and floating on a raft in a lake). Murphy (1993) further defined MdDS by

differentiating it from motion sickness and stated that it is “not to be confused with motion sickness, which causes nausea and vomiting during sea travel, or true vertigo, which gives a sensation of spinning” (p. 10). Murphy (1993) stated that mal de débarquement is common and normally short-lived; however, the symptoms may persist for months or years. This statement was supported by the presentation of four women whose symptoms of phantom movements lasted from four weeks to one year. In addition, the difference between the common transient symptoms that disappear in a short period of time and the less common persistent symptoms was more clear. Murphy (1993) noted that persistent MdDS mainly affected middle-aged women and hypothesized that hormones may play a role in the development of the symptoms of MdDS. Murphy’s (1993) report mentions that returning to sea has an effect, but this is mentioned only as a possible treatment and not as a hallmark feature of MdDS.

In an effort to expand research on MdDS, Mair (1996) noted that the studies that had been published at that time only described a total of 10 cases: six in the study performed by Brown and Baloh (1987) and four in the study done by Murphy (1993). Mair collected data over a period of 30 months and described 10 more cases of persistent MdDS. As with Murphy’s (1993) report, all 10 cases presented by Mair were women who ranged in age from 15 to 66 years with symptom durations ranging from three days to two years. The inclusion of a 66-year-old woman who had symptoms that lasted only three days broadened the definition of persistent MdDS, although the researcher noted that the symptoms occurred after the subject had spent only two hours on a ship. Mair’s (1996) paper, however, did not present MdDS as a condition that was distinct from other conditions, as he sometimes described MdDS as motion sickness.

Hain et al. (1999) hypothesized that MdDS was more common than the literature suggested at the time. At that time, all of the publications presented only 20 subjects (Brown & Baloh, 1987; Mair, 1996; Murphy, 1993). To better understand the incidence of persistent MdDS, the researchers conducted a patient survey and identified 27 individuals with symptoms of persistent MdDS. Contrary to Mair (1996), these authors suggested that MdDS is not motion sickness that is treatable with medications, such as meclizine hydrochloride and transdermal scopolamine, neither of which have any effects on the symptoms of MdDS. The findings from that study supported previous reports that persistent MdDS mainly affects middle-aged women (Mair, 1996).

Cha et al. (2008) reported more findings on MdDS when they reviewed their data, including follow-up interviews with patients who had previously presented symptoms of MdDS, from 64 individuals spanning 27 years. Their long-term study described novel features of MdDS. One new feature was the longer an individual experienced MdDS, the less likely the symptoms would resolve. Additionally, they found that subsequent episodes could spontaneously appear and last longer than the initial episodes. Migraine headaches appeared to be associated with individuals who experienced subsequent spontaneous episodes. They reiterated that individuals with active symptoms found relief when they were again exposed to passive motion, such as riding in a moving car (Cha et al, 2008). In a 2009 report, Cha added that re-exposure to passive motion temporarily worsened the symptoms after the exposure was over (e.g., after the drive) and that individuals with MdDS could not tolerate visual motion while they were symptomatic. Other symptoms that were reported to be associated with persistent MdDS were depression, anxiety, working memory difficulties, and excessive fatigue (Cha, 2009).

Causes and Treatments of MdDS

Discussions of the root cause of MdDS vary in the literature. For the most part, the symptoms experienced by individuals with MdDS are associated with travel by ship or boat (Brown & Baloh, 1987; Cha et al., 2008; Murphy, 1993; Teitelbaum, 2002). As described previously, Brown and Baloh (1987) presented six patients who had traveled by ocean on trips ranging from three- to five-hour boat rides to a 70-day ocean voyage. Murphy (1993) reported on four patients with MdDS with various origins: case 1 resulted after one night of sleeping on a waterbed; case 2 resulted from a week-long ocean cruise; case 3 resulted from a scuba-diving trip; and case 4 resulted from swimming and floating on a raft in a lake. Hain et al. (1999) conducted a larger study of 27 participants whose symptoms were triggered by either boat or airplane travel. Of these 27 participants, 21 identified boat travel as the trigger and anxiety and stress as the most common exacerbating factors, which were followed by positional changes, rapid head movement, and other factors ranging from environmental factors to sweet foods (Hain et al., 1999). A study at UCLA conducted in 2008 surveyed 64 patients and found that the top three triggers of MdDS were boats/cruises, airplanes, and cars/trains (Cha et al., 2008).

Persistent MdDS can be debilitating, and researchers are working to determine the causes of MdDS and ways to consistently treat it. Many research articles have suggested that dysfunction of the vestibular system causes MdDS. For instance, Murphy (1993) suggested that the balance systems of the inner ear and hormones are involved because most of the known cases of MdDS were female.

Cha, Chakrapani, Craig, and Baloh (2012) examined the brains of patients with MdDS with positron emission tomography and magnetic resonance imaging in order to localize

the source of the symptoms in the brain and better understand the underlying pathophysiology of MdDS. Twenty participants (15 women and 5 men) ranging in age from 27 to 66 years with active symptoms of MdDS took part in the study. Compared to age-, sex-, and handedness-matched healthy controls, the researchers reported the following finding.

We show that MdDS, a disorder of continuous self-motion perception is associated with hypermetabolism of the left EC/AG, decreased prefrontal and temporal lobe metabolism, increased functional connectivity with posterior spatial processing areas, and decreased connectivity with several prefrontal areas. Functional connectivity was reduced between all homologous regions in frontal, temporal, and parietal lobes in MdDS subjects while being preserved for posterior temporal (V5/MT) and primary visual cortex (V1) (Cha et al., 2012, p. 5; EC/AG, entorhinal cortex/amygdala).

Researchers have recently described treatments that relieve the symptoms of MdDS, but a cure is not known (Cha, 2012; Dai et al., 2014). Typical motion sickness medications, such as meclizine, are not effective (Cha, 2012; Hain, 2013). Hain (2013) reported that the “usual treatment strategy for MdDS is to attempt to make the patient comfortable, while waiting for the MdDS to end by itself” (p. 9). The current literature suggests that some individuals suffering from MdDS find some relief from low doses of benzodiazepines, such as clonazepam, but these medications have a risk of dependence (Cha, 2012; Hain, 2013).

Researchers are working to develop non-medicinal treatments for patients with MdDS. In order to determine the root cause of internal motion perception, Cha et al. (2012)

utilized functional neuroimaging to determine the parts of the brain that were involved in the perception of movement that is associated with MdDS. The brain imaging results indicated that a neuromodulatory strategy might be used to treat MdDS (Cha et al., 2012). In a pilot study, researchers tested the usefulness of rTMS as a treatment for 10 participants who had been diagnosed with MdDS. Although they found that the treatment was less effective on participants with longer symptom durations, some experienced symptom relief following the treatment (Cha et al., 2013). Dai et al. (2014) treated 24 participants who had been diagnosed with MdDS with a procedure involving head rolling and visual stimulation. The participants were seated in a circular room, and they viewed a projection of vertical stripes that were moving from right to left while an examiner moved their heads from side to side to try to readapt the vestibulo-ocular reflex. They reported that 17 of the 24 participants had complete or substantial recoveries for as long as one year after the treatment. However, the symptoms recurred for some, and one patient failed to respond to the treatment at all (Dai et al., 2014). Other research offers hope for treatments involving rTMS. The application of rTMS to specific cortical areas results in positive changes in patients with MdDS (Ding et al, 2014). Controlled studies on rTMS and transcranial direct stimulation have provided further promise of a treatment for MdDS, and the development of a home-based treatment is expected (Cha, Deblieck, & Wu, 2016; Cha, Urbano, & Pariseau, 2016).

Consequences of MdDS

MdDS affects the quality of life of individuals experiencing symptoms (Arroll et al., 2014; Cha, 2012; Clark et al., 2013; Clark & Quick, 2011; Macke et al, 2012; Nachum et al., 2004). Macke et al. (2012) administered quality-of-life and economic-burden surveys

to individuals diagnosed with persistent MdDS and found that the biggest impacts of MdDS on them were the role limitations caused by the symptoms and the consequent physical problems. The worst economic burden was related to the wages lost by the individuals whose symptoms made it difficult to keep up with occupational work demands (Macke et al., 2012). Clark et al. (2013) conducted an in-depth study of individuals with MdDS that included an exploration of their psychological traits, including their kinesiophobia (fear of physical movement) and fatigue. Their findings indicated high levels of both traits in individuals suffering from MdDS. In another study, the researchers noted high levels of depression and illness intrusiveness among 66 participants with persistent MdDS (Arroll et al., 2014).

Chapter III: Method

In this chapter, I review the methodology of this study, including the phenomenology (the primary method), participant recruitment, instrumentation, ethical concerns, researcher bias, and data validation. The research questions for this project were the following:

1. What does it mean to have MdDS?
2. How would a person diagnosed with MdDS describe their symptoms?

History of Phenomenological Research

In her review of the history of phenomenology, Lavery (2003) noted that Edmund Husserl developed phenomenology through his research, which involved methods that were initially focused on mathematics that later required more philosophy-focused methods, which eventually led to phenomenology. His interests evolved to a search for a universal foundation for both philosophy and science (Lavery, 2003). Wertz (2005) reiterated that Edmund Husserl developed phenomenology as a research method aimed at reversing the dehumanization of psychology, which was also discussed by Lavery who said Husserl “criticized psychology as a science that had gone wrong by attempting to apply methods of the natural sciences to human issues” (p. 4). Vagle (2014) added, “For Husserl, there was no way for subjects to be separated from the world. That is, the subject (the individual “I,” ego, self) was always connected meaningfully with everything else in the world” (p. 35-36).

Phenomenological researchers examine the experiences that human beings have in this world. While exploring those experiences, they intentionally attach to the world through a principle known as intentionality (van Manen, 1990). An interesting point in discussions

of intentionality and intentional analysis is that consciousness, which is always *of something*, does not exist without the consciousness of a subject. An intentional analysis is relevant to psychology because it “provides knowledge of human situations, their meaning, and the processes that generate those meanings” (Wertz, 2005, p. 169). This concept is fundamental for my efforts to investigate the life experiences of individuals who live with, and are conscious of, persistent symptoms of MdDS.

Finlay (2012) examined the problem of how to unite various phenomenological approaches, such as rigorous scientific methods and more poetic flourishes, and concluded that the essence of phenomenological research involves the following five processes:

1. Embracing the phenomenological attitude,
2. Entering the lifeworld through descriptions of experiences,
3. Dwelling with horizons of implicit meanings,
4. Explicating the phenomenon holistically, and
5. Integrating frames of reference.

While discussing the first process, embracing the phenomenological attitude, Finlay (2012) highlighted the challenge of a researcher to be open to a new understanding of the phenomenon. Because I have my own experiences with MdDS, my challenge was to set aside my own experiences with the disorder and be open to the experiences of the study participants. The second process identified by Finlay (2012) involves interacting with study participants in an empathic way that invites them to describe their experiences, even to the point that they again experience them. Finlay’s third process, dwelling with horizons of meaning, entails delving into the data to not only review their superficial

contents but also search for implicit meaning. The fourth process identified by Finlay, explicating the phenomenon holistically, involves “unwrapping layered understandings” (p. 188) and “creating rigorous and evocative findings” (p. 190). Finlay’s last process, integrating frames of reference, involves “engaging phenomenological philosophy” (p. 192).

Wertz (2005) described a process through which researchers approach data in a meditative way and extract the details without judgement. I tried to keep this approach in mind as I conducted open-ended interviews of the participants, and I attempted to extract the finest details in order to better comprehend and appreciate the rich details of their experiences.

Phenomenological research captures evidence of “the primacy of experience over the concept of world, the evidence that each reality cannot exist if not as a presence in consciousness” (Armezzani, 2009, p. 105). Primacy is defined as “the state of being first (as in importance, order, or rank)” (Primacy, n.d.). This concept is particularly important because I have been diagnosed with MdDS and have my own set of experiences. My challenge was to set aside my own knowledge and experiences and put the experiences of the study participants first, in the state of primacy, so that the resulting data would be examined with a fresh perspective and not be influenced by my own experiences.

Many researchers studying a diverse array of topics have utilized phenomenology as a research method. For instance, Sites (2008) used phenomenology to study the meaning and practices of how university professors integrate faith and learning. The author described phenomenology as the “method of choice when one is seeking to learn how

participants understand a phenomenon and how they experience it” (Sites, p. 67). As van Manen (1990) stated,

“Lived experience is the starting point and end point of phenomenological research. The aim of phenomenology is to transform lived experience into a textual expression of its essence--in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful: a notion by which a reader is powerfully animated in his or her own lived experience (p. 36).”

The goal of this study was to capture the lived experiences of individuals who have experienced MdDS and publish information on those experiences in order to increase awareness of MdDS. Nolte (2014) used phenomenology to study the experiences of participants in an experiential psychoeducational learning group and wrote, “The use of the phenomenological framework allows the researcher to understand and interpret the essence of a phenomenon by listening to the accounts of people who have experienced a phenomenon” (p. 47).

Weaknesses of Phenomenological Research

Phenomenological research has several limitations. The data obtained from the participants are personal and private. Although this research can provide deep insights into an individual’s experience of a phenomenon, it cannot be generalized to the whole population because the information is deeply personal to the study participants. Their experiences, which can only be related through language, cannot be observed by others and, therefore, cannot be operationalized. A study cannot be replicated if its data cannot be operationalized (Hanford, 1975).

Participant Recruitment

Eight participants were selected for this study. Participant selection was an important part of this study because the participants needed to be able to describe, in their own words, their experiences and what their experiences meant to them. To recruit participants, the internet, specifically online support groups for individuals with MdDS, was used. The MdDS Balance Disorder Foundation, which is a non-profit organization dedicated to finding the cause and cure for MdDS, endorses two online support groups: one on Facebook and one on Yahoo! Groups. The participants in this study were recruited through these two online support groups. I obtained permission from the Foundation to recruit participants at the appropriate time, and the Foundation offered to assist with participant recruitment. In both groups, I posted a message that was approved by both the Foundation and the university's Institutional Review Board that asked for participants who would be willing to take part in the research via Skype. Only adult males and females who had at least an eighth-grade education, could describe their experiences, spoke English, and had been diagnosed with MdDS, were accepted as participants. Although MdDS predominantly affects women in their 40s and 50s (Cha, 2009), the participants had to be at least 18 years old. The participants were also required to have no history of mental illness.

Research Instrumentation

No measurement instruments were involved in this study because it was a qualitative phenomenological study that involved in-depth interviews. The interviews of the participants were conducted via Skype, except for Participant 8, who the researcher was able to interview in person. The interviews were recorded directly from Skype with

Supertintin (<http://www.supertintin.com>), which is a computer program that records the audio and video data of Skype video calls. The interviews were transcribed with HyperTranscribe and then analyzed with HyperResearch. The data were stored on a flash drive that was kept in a locked box for the duration of the study and that will be destroyed seven years after the completion of the study.

Ethical Concerns

Participating in the study had a potential risk of harm. The participants might have experienced increased stress when they recalled their experiences and/or shame while they talked about their disorder. Discussing their symptoms might have upset the participants emotionally. The participants might have felt that they were being criticized or judged and/or that they were vulnerable, which could have affected their ability to trust others while discussing their problems. Participation and answering the research questions might have resulted in a decrease in the self-esteem of the participants.

If the participants appeared to have been harmed in the study, they were referred to the online support groups and the MdDS Balance Disorder Foundation for additional resources. Additionally, I am a doctoral student studying clinical psychology and therefore have knowledge, experience, and training in identifying emotional and psychological problems. My dissertation committee, which included a medical doctor and licensed psychologist with whom the researcher could consult, was also available.

The selection criteria for the participants included confirmation that each participant had access to professional mental and physical health care providers. Confidentiality was addressed in the informed consent process. The interviewees using Facebook and Yahoo! email were informed of the limitations that electronic communication places on

confidentiality. To protect participant identification, the researcher assigned a numerical value to each participant to replace their names. The participants are referred to by number in the reports of the results. All participants were informed that the data would be kept for seven years following completion of the study in a secure, locked location that was accessible only by the researcher. Furthermore, because some individuals might have been experiencing debilitating symptoms, I made sure that the participants completely understood the informed consent and had access to services in case they experienced any emotional or physical distress because of participation in this study.

My Bias

Because I am an individual who has been diagnosed with MdDS, I had my own personal experiences with symptom development and diagnosis. As I proceeded with this research project, I needed to separate my own personal experiences from the experiences of the study participants so that the study captured the implications of *their* experiences and were not influenced by my own experiences. I conducted skillful and disciplined interview during which I asked only open-ended questions that did not encourage any specific answers. For example, when the participants were asked about their symptoms, they were asked to describe their symptoms instead of being asked to confirm their symptoms.

Chapter IV: Results

After transcribing and reviewing the recorded interviews of all eight participants, responses to the research questions were analyzed for their relevance to the experience of living with MdDS. I excluded information that was not considered relevant to the research questions and findings and ultimately discarded information that was considered irrelevant. The relevant responses were compared and then categorized according to their relevance to each research question. In addition, the responses were divided according to the main features of the research questions. The features of the experience of living with MdDS were decided by comparing the answers to uncover the patterns and common threads among the participants' responses. The responses were summarized and analyzed according to my perception of the participants' meanings.

Relevance to the Research Questions

Research Question #1: What does it mean to have MdDS?

Participant 1 said:

“I think I’ve come to the conclusion I felt that it’s never going to go away. That’s how I feel. I think maybe that’s to stop myself from hoping that tomorrow, when I wake up, it will be gone. I’ve just had to accept it. That this is it. This is how it is.”

“I think when I got it, I thought, ‘This has the potential to ruin my life.’ I really had to start making the decision that it wasn’t going to ruin my life. There are things that are a lot worse that I could have wrong with me. I can still enjoy life, and do everything that I want to do. I just have to learn my limitations and set boundaries and virtually pace myself.”

Participant 2 said:

“Yes, this is what life’s throwing up, and what are the positives? I’m actually doing the work that I want to do. That’s an enormous positive. I’m actually sitting down to do it. I’ve got a deep, deep, spirituality. I feel very grounded in myself as Spirit, and so that gives me a strong sense of who I am and a bigger picture and a solidity and an acceptance and an equanimity and a joy in just living my life. I mean, I’m sitting here and my view out the front window here is just a bush and trees and the sunshine and flowers and the birds, and it’s just exquisite. And so, why should I get upset about having this when it’s just joyous every day?”

Participant 3 said:

“I work from home now. I kind of had to come to a point where I gave up my managerial job. I worked in a hospital, and it was just becoming way too much with the dizziness. There were a couple incidents, and it was just too hard to continue on. So, I came to the decision to take a job working at home, which was probably hard. I did that in 2013. But every day, well, at least I would say, sometimes it’s a big struggle. It’s also a struggle because people don’t understand, as much as you can try to make them understand why one day you feel fine, and the next day you don’t.”

Participant 4 said:

“I’m a stubborn person. I really don’t want it to rule my life. But it does.... So, it’s altered my life. And then when I really think what have I given up? I’ve given up a lot. I just won’t do any more. You know, I won’t go anywhere by myself. So, it has taken away my independence for sure.”

Participant 5 said:

“I feel like I can’t—not that I feel incompetent. I just feel like you can try and try. But let’s just say everything takes a lot more effort than it used to. Just your daily activity.”

Participant 6 said:

“I choose not to let it affect me. When I do feel it, and it might be bothering me if I think sometimes I might be... My stomach might be bothering me or something, I just make it a point to move.”

She expressed what it means to have MdDS socially, stating:

“When you try to explain it to somebody that does not have it, they kind of look at you like, ‘Whoa, they’re losing it,’ or, ‘Okay, she’s really flipped out.’ I don’t think people, because they can’t see something visible, and there’s nothing they can run to the internet... Or, used to be, they can’t go look it up to see what it was, they really thought you were crazy.”

Participant 7 said:

“I just never feel good. I never feel normal. It’s very life altering, like I’ve told everybody. I used to be very social. I’m in sales, so I was always, ‘Let’s go here, let’s go there, I want to go somewhere after work.’ I was always out, out, out.

Now I don’t hardly go anywhere because I don’t feel well.”

Participant 8 said:

“I can remember the first time I felt the gravitational thing. It’s like, ‘Oh my gosh, what is this?’ I feel like I’m being shoved down.... I remember thinking, ‘oh my gosh, I’m losing my mind.’ And then I went on the support group and see people talking about it. They’re calling it G-forces or gravitational. [I thought] I’m not

losing my mind, that I'm not crazy for feeling like that. Because I'll tell you, I don't know anybody else and, I mean, my family tries to understand, but they don't, really. Who can understand unless you've got it...I have to correct people because they all think I'm spinning. No, the room is not spinning. I'm rocking. Some of them have even had an experience of the spinning or feeling dizzy. They try to equate it to that. It isn't that."

Research Question #2: How would a person diagnosed with MdDS describe their symptoms?

Participant 1 said:

"It's just a constant swaying. I have a heavy head with a dragging down sensation. It's the only way I can describe it.... Other times, I feel like I'm walking on a trampoline. I feel like I'm going up and down when I walk. Like moon walking or something."

She also noted a peculiar experience when walking:

"I noticed when I was walking uphill, all the levels get mixed up in my head if we're going uphill or downhill. When I was going down a hill, I felt confusion. It's like what my eyes are seeing and doing, my brain isn't matching the sensation up with what I am doing. I'm walking flat, but I feel like I'm going uphill. It's just really weird."

Participant 1 had also experienced frustration with the unpredictable nature of her symptoms, saying:

“I have periods when I don’t feel too bad, but, most of the day, I have symptoms. I do still have periods where I can think, ‘Oh, I feel quite good right now.’ Then, 10 minutes later, it might all start up again.”

Participant 2 said:

“I’ll just describe what I’m feeling now. I’m rocking from side to side, unevenly. And then, occasionally, my body will feel like it’s lurching forward. Then, I’ll sort of rock this way, and then it’ll start on an angle a bit. It’s not steady. It’s all over the place. And then there will be a gravitational thing to the right. I can feel it in all of my body. I feel it. Like, at the moment, I can feel my body’s sitting on a chair, but I’m going like this, like this (hand moving). It’s moving absolutely everywhere. It’s a complete feeling of no steadiness.”

Participant 3 said:

“Anytime I would be in any type of vehicle with motion, I always feel a continuation of movement.... So, it still feels like I’m moving afterwards. And, a lot of times, when I would sit still, I would just feel like that was my actual worst symptoms. If I sit still, or I’d be walking and stop, it still feels like I was moving.”

Participant 4 reported:

“My head feels miserable.... Dizzy is not the correct term. Because when people think of dizzy, they think spinning around this way (moving finger in a horizontal circle). I do not do that. I rock back and forth, to and fro. And just that feeling inside of my head. Honestly, it just feels like my brain is moving. It’s frightening.”

Participant 5 said:

“I went with my girlfriends on a trip, and we stayed on a yacht for, I think, three days. I was fine when I was on it, fine when I got off. Then I remember I came home and I was just like, why do I still feel like I'm on a boat? And then it got worse to where, I remember, I'd be at church and I had to hold on to things to walk.”

Participant 7 said:

“I feel like I'm always moving and if I move my head, it's not a ...It's an off balance. It's an off balance...I have to be careful how I walk because I bump into things all the time. If I'm at a store and I turn around too fast, I'll trip over myself. I just always feel off balance. I describe it as being dizzy, and maybe that's not the correct word. Now if I'm looking at something, I just feel like it's moving, so I just associate that with dizzy, I guess. Dizzy, off balance.... It's hard to describe everything.”

Participant 8 said:

“There was a spell at a birthday party and we were outside and I thought well maybe it's because I was in the sun or something and I felt light headed. Then a couple months after that I just started the floating kind of an off balance...I don't know if this is meaningful or not because I go on the support group and most everyone feels better when they're driving but I don't. I feel like I'm at Disneyland on an amusement ride. I feel like the car and I are bouncing.”

She later added:

“I always feel like I'm moving. It's not the rocking like some people describe. It's not up and down rocking. I just feel like if I wasn't looking at somebody

straight...if I'm looking at you, I feel like I'm going like this (moving). I just feel like I'm moving, just slightly.”

Many participants used the term trampoline to describe the symptom of bobbing while walking. Participant 3 added, “I would have the trampoline walk that people talk about. You just kind of feel like your feet aren't touching the ground. You feel like you're sinking in.” Participant 4 said, “I feel like I'm walking on water, or a waterbed, a trampoline.”

In addition to the sensation of the trampoline walk, the participants complained of difficulty walking a straight line. Participant 2 first noted this soon after she developed the symptoms of MdDS while she was stopped at a campground. She noted:

“We'd be in camping grounds, and I'd try to walk to the toilets. And I couldn't walk in a straight line. I'd see the toilet block over there, and I'd try. I can walk in a straight line now, but at the time when I was first adjusting, I'd sort of veer off.” She later added, “If a person's coming toward me in the shopping center on an aisle, I'll find it very hard to keep walking in a straight line. If they're coming toward me, I tend to walk into the shelves.”

Participant 1 noted a gravitational pull on her head, and other participants reported a similar experience. Participant 2 experienced the sensation while at a table with friends:

“I was sitting at the table, peeling prawns. I just felt I was going to drop headfirst onto the table the whole time. It was the same feeling as the sea.... I felt like, ‘Oh, no, I'm going to fall into the table. Why can't I just sit straight and peel prawns like everybody else?’ ” Participant 8 described her head as feeling “extremely heavy.”

Elements of the Lived Experience of MdDS

Onset

Research on MdDS has indicated that the onset of symptoms is most often triggered by ocean travel (Cha, 2009; Hain, 2013), but other forms of travel were noted by study participants who reported different triggers of their symptoms. Participants 1, 4, 5, and 8 related that they began experiencing their symptoms after partaking in some form of water-related travel. Participants 1, 4, and 8 had gone on a cruise, while Participant 5 had spent a few days on a yacht.

Other participants reported the onset of MdDS symptoms after nonwater-related travel. Participant 2 reported onset after an extensive automobile trip. Participant 3 started to feel symptoms after a flight to Las Vegas, and Participant 6 noted the onset of symptoms after air travel to Paris. Participant 7 stated she had been using a whole-body vibration plate for a couple of years and first noticed dizziness after using a defective vibration plate that “shook too much.” The common factor in all of these experiences was that some form of motion was involved in triggering the symptoms, which was consistent with the existing literature.

Most participants expressed that they had feelings of confusion at the initial onset of the symptoms. The most common reaction to the onset was anxiety. Participant 1 reported feeling a sense of panic when her sister-in-law and her husband, who had accompanied her on the cruise, both reported that the sensation of movement stopped for both of them, while she continued to feel as if she was still on the ship. She reported spending five days in bed in reaction to her continuing symptoms, but she found that her symptoms worsened, which, in turn, worsened her anxiety, until she was correctly diagnosed.

Participant 2, who reported that she had symptom onset after a long car trip while she was on vacation, said that she felt a great deal of anxiety after symptom onset, and she even felt frightened by her symptoms. She recalled getting out of the car she was traveling in, being unable to walk, and then getting increasingly anxious. During that vacation, she recalled stopping at two different emergency rooms looking for answers as to why she was feeling the unsteadiness and imbalance. As she went from doctor to doctor without finding answers, her anxiety increased to the point that she began to question her mental health.

Participant 4 experienced the onset of MdDS after returning home from a cruise. She recalled waking up the next morning and getting up to go to the restroom, “I literally fell into all the walls. It was miserable trying to get there, and I couldn’t figure out what was wrong with me.”

Participant 5 spent three days on a yacht with friends and recalled that she felt like she was still on the boat after she returned home. She related that she continued to feel like that for three weeks, and she found information on the Internet about MdDS prior to getting an official diagnosis from a doctor. She recalled reading that the symptoms of MdDS never end for some people, which concerned her. She remembered saying to herself, “Oh, my gosh, I cannot live like this!”

Participant 7 said that, because she didn’t feel well due to her sensations of dizziness, she experienced anxiety. She expressed feelings of anger when a neurologist told her that her problem was anxiety. She stated, “Of course, I’m anxious, I’m dizzy!” Participant 8 experienced the onset differently than the others, in that she felt a gravitational pull while driving, as if the car was going to roll over. She described the sensation as “scary.”

Seeking a Diagnosis

One of the frustrations that the participants experienced was trying to obtain a diagnosis from medical professionals who were not familiar with the disorder. Participant 2 was very expressive of to the frustration she experienced trying to obtain a diagnosis. Her experience with looking for answers began with visits to the emergency department where she underwent a number of medical tests that she found very invasive and that increased her anxiety. All of the medical tests reporting normal results only served to worsen her hopes in obtaining answers. Because the tests were inconclusive, she began to experience more anxiety and even began to doubt her mental health. She said:

“It was bewildering. I doubted myself. It was miserable, it was confusing, it was frightening, actually. I was quite scared because it didn’t feel like a physical problem. I felt like it could have been a mental problem, because I was sort of healthy otherwise in my body.”

In her pursuit of a diagnosis, Participant 2 related visiting the emergency department five times, seeing a neurologist and a balance specialist, and then finally seeing her general practitioner. Fortunately, her general practitioner had personal knowledge of MdDS, which had stricken her grandmother, and she was finally able to tell Participant 2 the name of the disorder that she was experiencing.

Participant 4 reported undergoing several tests before doctors reached a diagnosis of MdDS, but she was offered few treatment options:

“And they put me through the series of tests that I’m sure you’ve had people tell you about. The rotary chair, the air in the ears, watching the bars going around. The three-sided wall, where the floor moves. I fell completely out of that one.

When they got all done, and it was an eye specialist, and I think the other one was a neurologist; they both agreed. ‘You have MdDS. No clue what to do. Well, we’ll try you on valium.’ ”

Participant 5 related that she began seeking a diagnosis from an ear, nose, and throat doctor:

“I actually started off with my kid’s pediatrician. I was in the office. I’m like, ‘just look in my ear.’ It started there. Then he gave me a good ear, nose and throat doctor. Went to the ear, nose and throat doctor and then went to Memphis to see that ear, nose and throat doctor. Came back again to the doctor here... Then I went to the regular doctor, got all sorts of blood work just to see is there anything off in my blood work. That was fine. And then also had an MRI of my brain. You start thinking, ‘Oh, you have a brain tumor,’ you know. Everything has been fine. Everything.

Participant 3, who experienced onset in 2009, reported that she finally obtained a diagnosis in 2013. She saw several doctors and recalled that, when she first started seeking answers from doctors, she was told that she was just stressed out and to go home and rest. She related feeling dismissed. As she continued seeking answers from other medical providers, she was further frustrated when doctors had no explanation to offer. She added:

“When I started exhibiting actual symptoms, then it was, ‘we’re not sure what it is.’ I kind of ran the gamut of maybe a thyroid issue. ‘Let’s send you to otolaryngology, let’s go to endo.’ So, I did the whole ‘go all over to all the different specialties.’ Neuro would tell me to go back to oto. Oto would say I

think it's a neurological issue. So, I just spent a lot of time actively searching out a diagnosis, which was, I would say, probably a low point because it's just so frustrating. You kind of get your hopes up. And, then, afterwards, you really don't have any answers."

Participant 7 related that she experienced anger after reading one doctor's diagnosis after ruling out a brain tumor. She recalled, "He kept saying, 'You don't have a brain tumor, you didn't have a stroke, you're fine, you're just anxious.'" She added:

"After reading that, I was so mad, because I got his notes afterward. I don't have an underlying anxiety disorder. I was anxious because I don't feel well. I'm always dizzy, and I didn't know what was wrong with me."

Participant 7's experience was consistent with documentation in the literature that some doctors attribute the symptoms to anxiety and overlook the possibility that the anxiety is a result of a separate disorder (Arroll et al., 2014), which therefore delays the true diagnosis, while others, like Participant 6, reported getting a diagnosis in about four to six months and related that the time frame was "fairly quickly."

Some participants considered themselves lucky when they obtained a quick diagnosis, and they sometimes found information on MdDS after conducting an Internet search of their symptoms. Participant 1 related that her sister found information on MdDS on the Internet that she was able to bring to her general practitioner who then gave her a referral to a neurologist. The neurologist was familiar with MdDS and was able to give Participant 1 a quick diagnosis. Participant 1 stated, "We went to the GP and got a referral to the neurologist, and, luckily, the neurologist knew about MdDS. Lots of them don't." Participant 4 went to see her general practitioner within a week of onset and was

told to put her head between her knees. When this did not work, she returned to her GP who then referred her to a neurologist. Fortunately, the neurologist had knowledge of MdDS and was able to give her a diagnosis.

Factors

Stress

The participants identified stress as a major factor that affects the frequency and intensity of their symptoms. Participant 1 stated, “All I can say is that the symptoms escalate. My head starts being out of control. Rocking, spinning. It’s just too much. I can’t cope with it. Stress will do that to me.” Participant 2 said, “If I stress myself out at all, the symptoms get worse.” She added, “I know, for me, that what caused it was stress. Absolutely. The combination of stress and travel.” Participant 5 stated, “If I start to feel overwhelmed, that affects it as well.” Participant 6 stated, “I think mine definitely was brought on by stress.” Participant 8 related that she experienced several major stressors, including moving to a new home and transitioning into two new jobs, prior to her onset. She said that stress continued to be a factor that affected her symptoms.

Exposure to passive motion

There were varying accounts regarding exposure to passive motion, such as riding in a moving car, or returning to a boat or air travel. Participant 1 reported feeling fine when riding in a car, but she reported a negative reaction to being in a moving airplane, while Participant 2, whose symptoms appeared to have been triggered by extensive car travel, said that she was perfectly fine during car travel but experienced symptoms upon exiting the car. This was also the case for Participant 3, who reported that she can drive just fine without feeling symptoms, but she then has trouble walking once she reaches her

destination. Participant 5 related, “When I get in the car, it goes away.” She later added, “I’ll feel great in the car, and I’ll just have a really hard time once I get back home.”

Participant 6 stated:

“I notice my symptoms sometimes if I drive my car around town and stop at a light, and I sit there and I’m still, then my head starts rocking. But as soon as I move, and I’m in the car, I’m fine. I travel a lot on airplanes now. When I’m in the airplane, it’s almost like heaven, because I can sit still and I’m not rocking.”

Participant 7 related:

“When I ride in a car, I feel much better.... If I’m going on the freeway, I feel great driving in the car. It’s almost like.... ‘Oh my god, I feel good!’ Actually, I just feel so good. I can’t do much turning in a parking lot or something because I’m like, ‘Oh, that’s not so good.’ Going straight, or just a couple turns is fine.”

She later added, in regard to a long-distance car trip, “We’ll drive up for nine hours, and I’ll feel great. I feel great in a car. And then I get out, though, and I have to stop and not feel good for a couple days.” She also said:

“I wouldn’t even attempt to go on the carnival ride. Just passive, a big boat. I don’t know about a small boat, but a big boat, because it’s just barely moving. When it starts rocking, I don’t feel so good, like when it’s rocking a lot. Just the passive motion, I’m just like, ‘Ah, I feel good.’ ”

Repetitive motion

The participants reported that repetitive motion seems to exacerbate their symptoms.

Participant 1 cited that cleaning a window, sweeping, and vacuuming, which are all activities that involve back-and-forth motions, are factors that can make her feel worse.

She added, “The worst is when people are swaying. If you tell someone about what’s going on, they imitate what it’s like for you. They start swaying. That sets me off.”

Participant 2 also cited vacuuming as an activity that worsens her symptoms. She stated, “The symptoms are just so much worse afterward that I think I do a sort of questioning, like, is this worth doing? Am I gonna be exhausted afterwards?” Participant 3 added, “A lot of bending or looking up and down, I have to kind of stop and regroup and sit back down.” Participant 7 also cited vacuuming as a negative factor “because I’m looking at the lines. I don’t know what it is, but I’m moving my head up and down. I can’t move my head up and down, especially up.” She went on to add, “Putting dishes away is very hard, because I’m having to look up and down and up and down.”

Water in motion

A peculiar aspect of MdDS appears to involve the movement of water. Participant 1 said that washing dishes is challenging. She stated, “It’s the swishing around in the sink when I fill the sink up, and the water’s swishing from side to side while doing hand washing. That escalates the symptoms.” Participant 2 was particularly affected by ocean waves. She described her experience while traveling along the coast:

“I recall sitting at the beach, and the movement of the water almost pulled me in. It was bizarre. It freaked me out! It’s the feeling I would get now if I were in the bath. I can’t find any solidity...and, with the waves, it was sort of like that feeling that there was nowhere solid to come back to.”

She continued:

“I recall sitting eating dinner. We’d got take away, and we’d parked the car at the beach and were in the car on a beach. The car was just above the waves, and it

was just exquisite. Except I was sitting in the car, and I just could not help but feel that my whole body was moving into the waves.”

Participant 5 related a negative experience with moving water while bathing her infant, in that the filling of the tub with water and bathing her infant in the tub made her symptoms worse.

Aisles

Navigating aisles was another common theme that emerged during the interviews.

Participant 1 stated:

“I found that the business of going into a shopping center escalates my symptoms. If we’re at a big shopping center, I usually push a trolley around everywhere because it’s something to hang onto. Going down the aisles of a supermarket, that seems to escalate the symptoms. It’s something to do with the aisle. I think vision plays a big role in it.”

Participant 2 described a similar experience with aisles:

“If a person’s coming towards me in the shopping center on an aisle, I’ll find it very hard to keep walking in a straight line. If they’re coming towards me, I tend to walk into the shelves. It’s hard work.”

Participant 4 related experiencing misery going to church:

“To go to church is miserable because almost all churches have aisles that go down and the lighting chandeliers are, I feel they move and I move. By the time I get out of mass, I’m just beside myself. It hurts so bad in my head. I feel like my brain hits my forehead, hits the back of my head, hits the side of my head, and hits the other side. Just constant like that.”

She added:

“Aisles trip me up, I mean worse than I am. I will get ready to go to mass this evening. I might be doing well at 3:00 when we’re getting ready to go. But if I went to my own parish church, whew! I’d be a mess when I come out of there because it does have an aisle way. And [I] go get up and go to communion, I have to walk down an aisle where people are moving. It just increases all my symptoms, makes me worse.”

Participant 4 also included aisles as a factor in not attending movie theaters, stating, “I don’t go to movies because they’re loud, and they’re dark, and you have to go down an aisle, then you have to climb steps.”

Computer work emerged as a factor that can exacerbate symptoms. Participant 3 made the decision to give up her managerial position due to MdDS, relating that:

“I came to the decision to take a job working at home, which was hard. I did that in 2013. Part of it’s good, and then part of it’s bad, ‘cause I work on a computer all day, which does increase my symptoms.”

Participant 5, who also works on a computer at home, stated, “I do work from home and I’ve just almost had to stop completely, because almost everything is computer based, and looking at the computer makes me really, really.... It just zaps me for the rest of the day.” Participant 8 also cited computer work as a factor that worsens her symptoms.

Participant 6 cited elevators as a factor that worsens her symptoms of MdDS. She said, “I do think that elevators also are a problem because you’re moving and you stop.” Her experience with elevators occurred when her husband was in the hospital:

“I was constantly going to the hospital and going up and down in the elevators, and I noticed it a lot then, too. It would be when I get off the elevator, go to his room, and sit, then I would feel the boat rocking in my head, back and forth.”

She added that going up and down stairs also has a negative effect on her. She related visiting her first grandchild in a two-story house, where the baby’s room was upstairs. “I was going up and down the stairs a lot. I got violently sick, throwing up from it. Dry heaves and everything.” Participant 7 said that she avoids elevators. “Going up and down an elevator, I get off and, ugh!” She reported that after an elevator ride, she continues to feel up and down movement as if she is still on the elevator.

Participant 1 also mentioned visual stimulation, or the lack thereof, as a factor that worsens her symptoms. She stated, “I think vision plays a big role in it. If I’m in a situation with poor light, my symptoms escalate.... I think busy situations, like shopping centers.” Participant 2 expressed something similar regarding shopping centers: “The visual stimulation is all bright lights and lots of people.”

Life Changes

Adopting a slower pace

Living with MdDS has meant adopting a slower pace in life for some. Participant 1 begins her day at a slower pace:

“When I wake up, I still get up slow and I sit up and I sit on the bed for a minute before I go any further. I just try and let my head adjust to sitting up from laying down.”

She related that she has had to slow down:

“I pace myself. If I have to rush or have any sort of stress, the symptoms just escalate. I found I have to move slowly around the house. If I walk really quick and turn a corner, my head will just keep going around the corner. It just takes off on me. I have to be conscious not to make any sudden movements.”

Participant 2 said:

“I used to push myself really hard. I just don’t anymore. I do what I need to do...I’ve got to do everything more slowly...I can’t do quick movements cause if I turn quickly, I’ll lose my balance...I enjoy gardening, so I just know I have to garden more slowly and take care of what I’m doing. I can’t just do things without thinking. So, there’s a process inside where I’m much more conscious of what I’m doing.”

Cooking

Participant 1 related that cooking has become difficult for her. She said:

“I can’t cope with cooking very much. [My husband] does most of the cooking now. I can do some things, but if I have to do a lot of chopping up on a chopping board, that spins my head. I also get stressed with how long it takes me to make anything in the kitchen. Then it’s usually running late, so then I get stressed. It just sends everything in a spin.”

Participant 2 did not express as much concern about cooking, but did state,

“Cooking’s fine, I’m just a bit messy. Yeah, I drop more things. I’m not as coordinated as I used to be. So, yeah, a lot more stuff goes on the floor. I’m fine with cooking, just messier.” Participant 3, like Participant 1, expressed having difficulty with cooking: “If I’m chopping a lot of vegetables, I’ll have to go sit

where I'm looking more at it than standing over it." Participant 5 cited cooking as difficult when it involves standing up straight. Participant 8 cited "brain fog" as a factor that makes cooking more difficult.

Employment

MdDS has affected many participants' ability to work, which is consistent with research findings (Arroll et al., 2014). Participants 2 and 3 both work from home now. Participant 3 reported that she had to give up her job as a manager. Participant 5 related that MdDS has put a limit on the amount of income she brings home. Participant 3 reflected on how MdDS has affected her career. She described what it was like to work with MdDS:

"That was difficult. My immediate boss, 'cause we worked so closely together, she knew. She didn't understand completely, but she did the best she could. There were a couple times that I had to have time off because of it. It was difficult. It was hard for me. Couple times when we would be interviewing people, things would happen. Just was embarrassing.... It was really hard, 'cause I was feeling all the symptoms that I was having. It just got to a point where I knew I wouldn't be able to effectively do it anymore.... I would definitely be on a different career path because I was kind of working my way up the ladder. I probably would be in some sort of corporate job by now because I did go to college, and I have all the capability. Or I had all the capabilities to do that....These are just things that I think. I don't know if this really would happen. That's where I was going, or headed. Now I have a job that I'm definitely overqualified for."

Changes in travel

Participant 2, who experienced the onset of MdDS as the result of extensive car travel, stated, “I won’t travel again, I think. We do shorter holidays to the beach or something like that, but I just don’t want the stress. I miss overseas travel.”

Social Life

Many participants reported that living with MdDS has decreased their social interactions. Participant 1, for example, said that she has withdrawn from socializing outside of her home. She related that social interactions became difficult because of the invisible nature of her MdDS. She said:

“They just forget that you’ve got it because you look normal. You look well. They just make no compensation for it. I think that’s what upsets me the most. It’s not that I want them to keep asking me how I am. That would be really bad. I don’t want to talk about it. I don’t want them to, every time I see them, to say, “How’s your head?” I just want them to have acknowledged that they know that I’m not 100% and that I can’t be expected to do everything that they can or I used to be able to do.”

Participant 2 stated that, because conversations with people are difficult to handle due to her MdDS, she has also reduced her social interactions, stating, “Because I just don’t have the energy. I’ve had to make decisions about what’s important to me.” Participant 7 stated, “Well, I don’t go out too much anymore. I can only do a few things at once. My social activity has decreased tremendously.” Participant 4 stated:

“I am really self-conscious of it in a social setting. I don’t want people to look at me and wonder what’s wrong. We went to a cocktail party one night this week. I had to hold on to my husband, of course, to get in a big hotel, to get down the

hallways, and to get in the room. Everyone was standing at high tables, which, I did that briefly. Then I had my husband get me seated at a chair, just because you're so self-conscious of looking clumsy or disoriented....You're just real self-conscious how someone's going to perceive you...."

Participant 3 related, "Social situations can be hard. People can't understand why you can't do something one day, and you can the next. I used to get embarrassed if there's large crowds and something would happen to me."

Participant 2 expressed particular frustration in social interactions when others would assume that she was experiencing vertigo. She said:

"What I say is my brain has adjusted wrongly to the movement, and so I just generally say it's a neurological problem. I mean, I don't know what it is, really. But I just say it's a neurological problem, it's in my brain.... And then the next time you see them, they say, 'Oh, you know, so it's an ear problem. A friend of mine had an ear problem and she had an operation....' I find it really frustrating."

Participant 3 related similar experiences about others' mistaking her symptoms for vertigo:

"Most people, not only do they not understand it, but you'll get advice or the stories. So, a lot of times, I don't like to talk about it 'cause I don't want to hear about their aunt who had vertigo once or whatever's happening. It gets old."

MdDS and Age

The effects of MdDS on quality of life appears to differ according to age. Participant 1 stated:

“I would hate to get this as a young mother with small children and trying to run around with the busyness of children. I don’t know how people would when they’ve got it. We’re really blessed that I got it at the age that I did. I was 47, nearly 48, when I got it. We retired young so that’s been a real blessing for us that we’ve just been able to stay home and cope with it and adjust to our lifestyle.”

Participant 2 similarly stated, “I wouldn’t have liked to have this younger.” She also expressed gratitude that she is not raising children while dealing with MdDS.

Participant 3 had a different experience because her onset occurred while she was in her 30s. She said:

“It’s hard. I think my symptoms started in my early 30s, ‘cause I didn’t really know what to call it or what it was. I’m 39 now, and it was hard because I kind of had to come to a point where...this is the new me. I’m not the old me.”

In regard to children, she said:

“Also, family-wise, I was very career-oriented in my 20s. I think when I finally thought about settling down and having a family, it kind of coincided with me starting to have symptoms. Not like right at the same moment, but probably within six months to a year of each other. So, I decided not to have children.

Because at the time, my symptoms were so bad. And, I still feel like I wouldn’t be able to actively care for somebody else. I feel like...it’s hard enough for me. I know there’s other people who are able to do it, but I don’t think I could.... That was one decision that I made.”

Participant 4 noted, “.... there’s a few women on our support group that are very young and they have little children.... I feel so sorry for them, because I just don’t know how.”

Coping

The participants in this study expressed a great deal of frustration related to living with the symptoms of MdDS, sometimes experiencing symptoms of depression as a direct result. Participant 1 reported that she received her diagnosis from a neurologist and was told that there was no cure. When her symptoms persisted, she returned to the neurologist who told her that everyone is different, and there was no way to know how long symptoms would last. Note the inconsistency for the patient who now has to decide and evaluate how this will affect her life personally. Is it incurable, or is there a chance because “everyone is different?” And, what’s to happen to me. Upon hearing this, Participant 1 described her reaction as “devastating.” She stated, “I couldn’t cope with the symptoms so I went back to the GP and he put me on antidepressants.” She stated that she derives relief from gardening, although it can be difficult: “Gardening is hard because you’re always bobbing up and down. It’s hard on my head, but I also find that it’s good in another aspect. It’s calming. You can just let your head relax and enjoy the peace of the garden.”

Participant 2 also expressed that gardening helps her to cope and that she has had to develop a positive view and resilience to cope with the constant sensations of movement. She stated:

“I enjoy gardening, so I just know I have to garden more slowly and take care of what I’m doing. I can’t just do things without thinking. So, there’s a process inside where I’m much more conscious of what I’m doing. I take it more easy. I’m much more gentle on my body that I was. Yeah, there’s a sort of element of just being more aware of what I’m doing and how that’s gonna impact me. So,

I've slowed down, which is not a bad thing, I think.... You can see everything in a positive or negative light.... I don't like having it. The day it goes away will be a celebration. But, while I've got it, I'll just make the most of it and just say, "this is life." I think there's lots and lots worse things to have."

Participant 4 expressed frustration with MdDS affecting her daily life, but she stated, "I'm still doing my own cooking, my baking, all of that. A lot of people on the support group, they claim they can't do that and they go to bed. I refuse. You know, it's not going to whip me." Participant 5 has learned to cope with MdDS with the help of a close friend who also has MdDS. She reported learning certain exercises that help her symptoms. She showed me one particular exercise in which she holds her thumb up at an arm's length away from her face:

"I don't ever lose focus but move my head as fast as I can, back and forth, but focus on my thumb. I just do that like a hundred times, as fast as I can. I don't know what it is about it, but it's been a huge, huge help. That, and I'll walk down a hallway and just move my head back and forth while I'm walking."

Participant 5, who is one of the younger participants and who has four young children, included her children in her coping strategy, stating, "So my kids, they're super sweet with me.... They'll call out, like, five words, and I will walk while moving my head back and forth and put those words in alphabetical order. Just getting my body to multitask."

Chapter V: Discussion

The experience of living with MdDS can have a significantly negative impact on one's quality of life, as MdDS is itself an intrusive disorder with potentially debilitating, incapacitating, and physically draining symptoms that can lead to depression (Arroll et al., 2014; Macke et al., 2012). The experiences reported by the study participants were congruent with current research, as at least one participant reported experiencing symptoms of depression and anxiety as a result of the stress of living with the phantom movement sensations of MdDS.

For the study participants, seeking a diagnosis for the unusual symptoms of MdDS marked the beginning of many frustrations that were directly related to having the disorder. Cha (2015) reported that patients with MdDS paid an average of 19 visits to medical professionals before finally receiving a correct diagnosis. Some participants were fortunate enough to find knowledgeable medical professionals early in their search for a diagnosis, while others were frustrated by a series of diagnostic tests that yielded no answers, only more questions, and worse, sometimes led to the doubt of their own mental stability while having to still cope with this affliction. This is likely to be the experience of others who develop the disorder and seek answers, as there is, to date, no definitive diagnostic test, other than the exclusion of other disorders through a series of diagnostic tests (Cha, 2015). Undergoing all of the tests is time-consuming and often requires multiple visits to multiple medical providers. Furthermore, even if other disorders are ruled out, there are still a significant number of medical professionals who are not familiar with MdDS and who are apt to provide an incorrect diagnosis or attribute the

symptoms to anxiety or vertigo, as was the experience of some of the participants in this study. Thus, one of the goals of this study was to increase awareness of not only the existence of MdDS but also the impact that MdDS can have on daily living, social interactions, and mental health. It is my hope that this research project will help to achieve that goal.

My personal experience is congruent with that of the study participants. In seeking treatment for my imbalance, I was seen by many medical professionals, from well-known neurologists with the finest of intentions and reputations of the highest integrity to ear-nose-throat and inner ear specialists at some of the most prestigious institutions, only to be misdiagnosed again and again, which left me increasingly frustrated, anxious, and depressed, like the participants in this study. Other than Dr. Robert Baloh, who diagnosed me with MdDS, I have only encountered one other medical provider who was familiar with the disorder “with a fancy French name.” When I met with new health providers, I always reported MdDS in my list of health concerns, only to be met with a puzzled, bewildered look, which is followed by my spelling out the name. At times, I have even had to provide my new health care providers with supporting literature and materials to educate them on the disorder, an action I will continue in order to do my part to raise awareness.

Identifying the malady behind the constant rocking, swaying, and bobbing sensations, however, does not end the ordeal of living with MdDS because, as of this writing, a cure for MdDS remains to be found. Treatment options are geographically unavailable for many and can be costly with no guarantees of their effectiveness. Furthermore, physicians are reluctant to prescribe certain medications that provide relief but that are

highly addictive. Therefore, many individuals who are stricken with MdDS who may or may not have received a diagnosis, may not have any means to alleviate their symptoms. This adds to the intrusive nature of MdDS and likely contributes to the symptoms of anxiety and depression. Fortunately, anxiety and depression, which are the collateral consequences for individuals who live with MdDS, can be treated in order to improve the individuals' quality of life.

The unique symptoms of MdDS were another source of frustration for the eight study participants who largely felt misunderstood by others who were not able to relate to the sensations of the phantom movement associated with MdDS. Participant 8 said it best: "Who can understand unless you've got it." Many participants expressed frustration when others cite vertigo as well as offer tips and tricks that worked for people they knew who dealt with vertigo, having to listen to this diatribe from the well-meaning individual, only to have to smile politely and try to then explain the true nature of these, at times, unbearable symptoms. This aspect of living with MdDS is congruent with my experience as well. Whenever I tell an individual about my experience with MdDS, the individual will invariably use the word "vertigo" or mention some other inner-ear-related vestibular disorder, which is often accompanied with advice on what worked for them or a family member or "someone they knew." In the past, I would attempt to provide education about the difference between vertigo and MdDS, but I became frustrated with the looks of confusion that were sometimes laced with condescension and disbelief. For this reason, it is important to increase the public awareness of MdDS as a neurological condition that is uniquely different from vertigo or other vestibular disorders.

The participants reported having to make significant changes in their lives, particularly with their employment. I was particularly struck by one participant who chose to give up her career path and settle for working beneath her full potential afforded to her by her college education and work experience. Arroll et al. (2014) reported that a significant number of depressed individuals with MdDS had continued to work, despite living with their symptoms. They hypothesized that many individuals with MdDS continue to work because they feel that it would be difficult to apply for disability benefits because MdDS is so unknown (Arroll et al., 2014).

The most common change reported by the study participants was the need to slow down, both in their daily pace of movements and their activities. Some cited the need to physically move slower in order to avoid falling or bumping into things, and some cited the need to reduce their activities and adopt a slower-paced lifestyle. For older participants, especially those of retirement age, this transition was easier. Each of them expressed relief that they did not experience onset in their younger years. It seems that the younger study participants felt more challenged by the MdDS, especially Participant 5, who has four young children. Having MdDS led Participant 3 to decide not to have any children as she felt that her self-care that was required for the MdDS would take away from her ability to care for children.

I would have to agree that slowing down has been beneficial. Because I often find myself rocking as I move about, I have noticed that I bump into things more often, sometimes painfully. Slowing my movements and becoming more mindful of my surroundings has helped me to decrease the number of bumps and bruises I sustain.

I would also have to agree that I am blessed not to have experienced the onset of MdDS while my children were young. I do have grandchildren that I have been afraid to hold unless I am in a sitting position due to the fear of imbalance caused by MdDS. It is difficult for me to imagine giving up motherhood, which I have found so rewarding, but I can understand the fear of dealing with children when one's balance is affected and when a frenzied pace of life exacerbates MdDS.

Although the treatment options for MdDS are limited in availability and effectiveness, many interventions help individuals deal with depression and anxiety. Individuals living with the symptoms of MdDS may benefit from talk therapy, including learning mindfulness skills, which are well-known ways to quiet anxiety and ease depression, and participating in MdDS support groups, such as the Facebook and Yahoo! groups.

Conclusion

What is the lived experience of having MdDS? As an individual diagnosed with MdDS myself and never having heard of it prior to my onset, I found myself feeling curious about how other individuals experience this strange disorder. Like myself, I found that the participants had accepted that living with their symptoms of MdDS was now a part of their daily living. Life without the constant feeling of imbalance now seems foreign. Many of the study participants expressed a resilience and determination to not let MdDS completely change their lives and to maintain some quality of life. I gained an enormous amount of respect for each of these eight women for their courage and flexibility in not only dealing with this challenging and, at times, debilitating disorder that, as of this writing, has no cure but also in their willingness to share their stories with a stranger. My hope is that our collective effort to increase the awareness of MdDS will pay off in the

form of decreased costs and times of diagnosis as well as an increased quality of life through appropriate interventions.

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Appendices

Appendix A: Recruitment Letter

Hello,

My name is Divina Johnston, and I am a doctoral-level psychology student at Antioch University in Santa Barbara, California. I am seeking 8 individuals to participate in a study of Mal de Debarquement Syndrome (MdDS). This study will be qualitative and will aim to describe the experiences of people who have been diagnosed with MdDS and who continue to live with the symptoms. The purpose of this research is to increase the awareness of MdDS by adding qualitative data to the existing literature. Participation in this study will require a 60- to 90-minute interview during a Skype video call in which you will be asked to share your experiences of MdDS. Your participation in this study is voluntary, and you have the right to withdraw from the study at any time. If you would like to participate in this study, you can reach me by email at djohnston1@antioch.edu.

Thank you for your interest and your time. I look forward to speaking with you.

Sincerely,

Divina T. Johnston, M.S.
Clinical Psychology
Antioch University Santa Barbara

Appendix B: Informed Consent

You have been invited to participate in a study conducted by Divina T. Johnston, a doctoral student at Antioch University in Santa Barbara, California, USA. This study is going to ask you to share your experiences with Mal de Debarquement Syndrome. You are eligible for this study if you meet the following criteria:

- (1) You are at least 18 years of age
- (2) You have been diagnosed with Mal de Debarquement Syndrome
- (3) You are currently experiencing symptoms
- (4) You are free of mental illness.
- (5) You have access to a computer, the Internet, and Skype

Participation in this study will involve a 60–90-minute interview that will be conducted via Skype. The interview will be recorded and transcribed, and you will be given a participant code number in place of your name to protect your privacy. The recordings of the interviews will be destroyed upon completion of the study. If you would like a copy of the recording, you can let me know when we meet via Skype for the interview. You will receive a copy of your transcribed interview for review so that you can verify the accuracy of the transcription. You can request to be informed via telephone or email if any part of your interview will be quoted in the final study so that you can verify that I have quoted you correctly and that I have correctly understood the meaning of your comments.

The Institutional Review Board of Antioch University will have access to all signed informed consent forms, but the actual information you share for the study will be kept confidential. Code numbers will be put on the forms and paperwork in place of your name to ensure that you will not be identifiable. The informed consent forms and other documents will be kept in a locked file cabinet and destroyed after five years. The video recordings will be destroyed after the study is completed. If you request a copy of your taped interview, it will be made available to you before it is destroyed. You will also have the opportunity to choose a false name to be used for any quotes that may be used in the study. This study may be published in a journal or book for professionals in the social sciences or other professional journals that may be related to Mal de Debarquement Syndrome.

There is no financial compensation for participating in this study. The benefits you may gain from this study are the ability to share your experiences in a meaningful way and feelings of satisfaction resulting from participating in a project designed to increase awareness of MdDS. The risks to you are minimal. In the unlikely event that you experience any emotional discomfort as a result of this study, you will be referred to resources listed on the MdDS Balance Disorder Foundation's website.

Your participation in this study is strictly voluntary. You may withdraw from the study at any time, and, if you decide that you do not want to participate, there is no penalty. If you withdraw from the study, your data will be destroyed immediately. If you have any questions or concerns, please address them with the researcher at xxxxx.

Name of Participant	Signature of Participant	Date
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Name of Researcher	Signature of Researcher	Date
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Appendix C: Research Questions

Research Questions

What does it mean to have MdDS?

How would a person diagnosed with MdDS describe their symptoms?

Interview Questions

Can you describe your experiences when you started feeling symptoms?

Can you describe your experiences when you were diagnosed?

Can you describe your experiences in daily life as you continue to live with MdDS?

In your own words, how would you describe your experiences with symptoms of MdDS?

In your own words, what factors do you feel contribute to your experience with MdDS?

In your own words, how would you describe your experiences with symptoms of MdDS in social situations?

In your own words, tell me about your experiences in dealing with MdDS at your age?