

The Emotional Experience of Women with Multiple Sclerosis in the Postpartum Period

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Abstract:

Background: The postpartum period is a time of increased risk for MS relapses and emotional distress in women. Women with MS are already at increased risk for emotional distress, particularly depression. The functional impact of MS on physical health and wellbeing and ability to care for an infant can create further emotional distress. **Purpose:** The purpose of this study was to examine and understand the emotional experiences of women with MS in the postpartum period. **Method:** This phenomenological study utilized Colaizzi's (1972) seven-step method for conducting phenomenological research. Thirteen women with MS who had delivered a child 1-10 years prior to their participation in the study provided a narrative description of their emotional experiences in the postpartum period. Their narrative responses were typed by the participants in an anonymous and secure online survey and were analyzed for meaningful themes and then incorporated into an exhaustive description of the emotional experience of women with MS during the postpartum period. A total of six themes and five subthemes were identified. **Findings:** Women with MS felt that their health care providers did not adequately understand the complexities of having MS during their postpartum period. Participants noted that there was a lack of available information for them about managing MS in the postpartum period and what to expect during this time. Women described that their emotional experiences varied highlighting anxiety, general emotional distress, and positive emotional experiences. Participants reported that support was crucial to their experience in the postpartum period. They also reported a variability in MS symptoms experienced ranging from very mild to more debilitating relapses. Lastly, women felt that

they had to choose between their own MS treatment and breastfeeding their child.

Conclusion: Women with MS have unique emotional experiences during the postpartum period that are impacted by lack of information, lack of knowledge by health care providers, availability of psychosocial support, MS symptoms, and decisions regarding breastfeeding.

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The Emotional Experience of Women with Multiple Sclerosis in the Postpartum Period

Chapter 1. Significance of the Problem

Introduction

One of the key indicators of a healthy society is the health of mothers. Currently, the World Health Organization (WHO) (2018) recognizes maternal health, both physical and mental health, as a priority. With advances in health care and greater understanding of chronic disease processes, more women with chronic medical conditions and physical disabilities are able to become mothers. This includes women with multiple sclerosis (MS), a group of women who were historically discouraged from pursuing pregnancy (Coyle, 2016; Fabian, 2016; Houtchens, 2013). At times, therapeutic abortion was even suggested (Houtchens, 2013). Currently, there are estimated to be 1 million individuals living in the United States with MS (National Multiple Sclerosis Society [NMSS], n.d.). Coyle (2014) estimates 2.5 million people living with MS worldwide. MS tends to affect more women than men, with the incidence of cases in women on the rise (Dunn, Gundy, & Lee, 2015). The proportion of women with MS compared to men has been estimated at 3:1 (Coyle, 2016; Christianson, Mensah, & Shen, 2015). The age of onset of MS tends to be during the childbearing years and over half of women with MS will develop the disease while they are still able to bear children (Buraga & Popovici, 2014). This means that MS is a serious concern for women and their health care providers who will be tasked with managing their pregnancies, deliveries, and postpartum periods safely (Coyle, 2016).

MS can present unique challenges to women in the postpartum period and has been linked to increased emotional distress during this period (Gulick & Kim, 2004).

Although pregnancy has been demonstrated to be a time of decreased MS relapses for women, the postpartum period is associated with increased risk of MS relapses (Vukusic et al., 2004; Hughes et al., 2014). MS relapses can include symptoms of ambulatory difficulties, visual disturbances, extremity weakness, paresthesias, fatigue, and bladder dysfunction (Gulick & Kim, 2004; Selvadurai & Ghaffar, 2018). There is a lack of research regarding the emotional experience of the postpartum period for women with MS, a time unique to them in both their disease process and in life transition, including the unique need to balance a chronic potentially disabling condition with a new role and the needs of a dependent newborn (Rankin & Bove, 2018). As more women with MS choose to become pregnant and have biological children, health care providers require increased understanding of the emotional experiences within the postpartum period for this population of women to provide quality and safe care.

Statement of the Problem

According to the current body of literature, pregnancy is a protective time against MS relapses, but the postpartum period has been associated with increased risk of MS relapses (Coyle, 2016; Gulick & Kim, 2004; Buraga & Popovici, 2014; Vukusic et al., 2004; Hughes, et al., 2014; Fragoso et al., 2015; Portaccio et al., 2014; Ghezzi, Annovazzi, Portacci, Cesari, & Amato, 2013; Beaber, Chi, Brara, Zhang, & Langer-Gould, 2014; Gulick, 2007; Hellwig, 2014). Relapses of MS reflect the inflammatory and demyelination process within the central nervous system that is the hallmark feature of the disease. Symptoms can include paresthesias, weakness, vision loss, optic pain, blurred vision, decreased dexterity, fatigue, spasticity, bladder dysfunction, and gait changes (Gulick & Kim, 2004; Selvadurai & Ghaffar, 2018). Relapses of MS symptoms are more

likely to occur in the postpartum period because of the diminished amounts of estrogen, which has a neuroprotective effect (Christiansen, Mensch, & Shen, 2015). Gulick (2007) noted that the neurological symptoms associated with MS can present functional difficulties for the new mother. These difficulties have been demonstrated to cause emotional distress in mothers, even when they had social supports (a variable that has been shown to diminish postpartum emotional distress) available to them (Gulick & Kim, 2004; Gulick, 2007). Iezzoni, Yu, Wint, Smeltzer, and Ecker (2015) found that pregnant women who had chronic physical disabilities, including women with MS, were more likely to experience emotional distress than their pregnant peers without disabilities. However, the findings of Iezzoni and colleagues were limited to women who were pregnant, not necessarily those in the postpartum period. Anderson and Wallace (2013) conducted a qualitative study that examined the childbirth experiences of 9 women with MS and found that women with MS often worried about how their disease would affect their ability to care for their children. The results of the study by Anderson and Wallace demonstrated that women with MS have unique emotional concerns related to their physical disease.

Although treatments exist for MS, the ability of women to take disease-modifying treatments (DMT) and experience subsequent decreased symptomatology is limited and a topic of debate in pregnancy and postpartum (Ghezzi et al., 2013; Portaccio et al., 2014; Frago et al., 2014; Coyle, 2016; Bove et al., 2014). Some have speculated that strict and sole breastfeeding in the postpartum period could decrease the risk of MS relapse, but that has not been widely supported (Vukusic & Confavreux, 2013). As a result, the postpartum period is still considered a high-risk time for MS relapses.

Although literature exists to support the risk of MS relapses in the postpartum period, there is a lack of information on the emotional experience of mothers with MS during this period. Some researchers have studied the functional experience of women with MS in the postpartum period. Gulick (2007) conducted a descriptive quantitative study on the impact that MS relapses have on the functioning of postpartum mothers. A total of 172 mothers with MS participated in the study and were contacted for assessment at 9 and 12 months postpartum. Function was measured through the Activities of Daily Living scale to assess for personal care, socialization, recreation, and intimacy. MS symptoms were measured using the MS-Related Symptom Scale. MS relapses were associated with lower functioning ($p < .01$) and social support was associated with improvement in functioning ($p < .01$).

The postpartum period has also been associated with a time of increased risk for depressive symptoms. According to the Centers for Disease Control and Prevention (CDC) (2018), estimates for postpartum depression range from 1 in 9 to 1 in 5 women. MS has long been associated with an increased risk for depression (Feinstein, Magalhaes, Richard, Audet, & Moore, 2014; Patten, Marrie, & Carta, 2017; Selvadurai & Ghaffar, 2018). According to Patten, Marrie, and Carta (2017), up to 50% of individuals with MS have symptoms of depression. Currently, there is a lack of research on the incidence of postpartum depression in women with MS. However, Mitra, Iezzoni, Zhang, Long-Belil, Smeltzer, and Barton (2015) conducted a study examining postpartum depression among 287 women with physical disabilities compared to 3,440 women without disabilities. The participants studied had physical disabilities but not specifically MS. Mitra and colleagues (2015) found that women with disabilities were at increased risk of

experiencing symptoms of depression in the postpartum period (28.9%, n=83) compared to women without disabilities (10%, n=344) ($p<0.001$). The results of this study need to be interpreted with caution as the women with disabilities were only 8.3% of the 3440 women studied and women with disabilities and postpartum depression represented 2% of the participants. Gulick and Kim (2004) studied emotional distress in women with MS (n=174) in the postpartum period and found that women with MS were at increased risk for experiencing emotional distress in the postpartum period ($p<0.05$). This finding, while important, examined emotional distress, rather than examining the entire emotional experience which, may include both positive and negative emotions.

A study by Smeltzer, Mitra, Iezzoni, Long-Belil, and Smith (2016) examined the perinatal experiences of 25 women with physical disabilities. Similar to the study by Mitra and colleagues (2015), this study was not specific to women with MS but women with MS were included in the study. This qualitative study demonstrated that women with physical difficulties encounter unique challenges during the perinatal experience. Women reported that their clinicians did not understand their specific concerns, did not respect the knowledge women had about their own strengths and limitations, and did not recognize that women with physical disabilities had reproductive concerns and desires. Thus, the perinatal experience was demonstrated to be unique for women with physical disabilities. There has not yet been a study that examines the complete, both positive and negative, emotional experience for these women.

Significance

Multiple Sclerosis

MS is a chronic, progressive, and debilitating disease that affects the central nervous system (CNS) (Selvadurai & Ghaffar, 2018). The CNS is comprised of the brain and the spinal cord. The CNS is comprised of specialized cells known as neurons that communicate with one another through the process of neurotransmission which involves both chemical and electrical changes that generate or inhibit action potentials. When action potentials are generated or inhibited, a series of neurotransmitters or hormones that are involved in the process of neurotransmission are either released or inhibited. This causes further changes to chemical signaling. Neurons send messages through a part of the cell known as the axon and receive incoming neurotransmission signals through parts of the cell known as dendrites. As neurons become specialized, many of them will have axons that are covered by a substance known as the myelin sheath that is produced by special types of neuronal cells known as oligodendroglial cells. The myelin sheath makes the process of neurotransmission more efficient and increases speed of transmission of impulses. Cells can create myelin sheaths, in a process called myelination, well into adulthood (Sadock, Sadock, & Ruiz, 2015).

In MS, there is an inflammatory process that is strongly suspected to be autoimmune, that destroys the myelin sheath and promotes degeneration of axons and destruction of neurons (Correale, Gaitan, Ysraelit, & Fiol, 2017). Demyelination slows the process of neurotransmission. MS also causes axonal destruction, cerebral white matter loss, and the presence of lesions in the CNS (Doshi & Chataway, 2017; Selvadurai & Ghaffar, 2018). This disease process results in a variety of functional neurological deficits and impairments including changes to sensation, mobility, bowel/bladder control, vision, and cognition (Brownlee, Hardy, Fazekas, & Miller, 2017). The disease tends to

begin around age 30, affects women more than men, and is most common in North America (Brownlee et al., 2017; Doshi & Chataway, 2017).

Several types of MS exist. MS often starts with a subtype called clinically isolated syndrome (CIS), which is essentially an acute attack of MS symptoms. At that point, magnetic resonance imaging (MRI) is usually conducted to look for the presence of CNS lesions. Following the initial episode of MS symptoms, patients can develop relapsing-remitting MS (RRMS). This subtype of MS tends to occur more often in females and onset of this subtype is around childbearing age. Relapses are characterized by the presence of MS symptoms described above including weakness, sensory and motor deficits. Between acute symptomatic relapse episodes, patients generally return to baseline level functioning. However, about 10 years after diagnosis, patients can develop a type of MS known as secondary progressive MS in which there is destruction of neuronal cells and symptoms become more chronic and worsen over time. A third subtype of MS is less common than RRMS and is known as primary progressive MS (PPMS). This type of MS has a later age of onset than RRMS and tends to be more common in men than in women. This type of MS is characterized by spinal cord disease and in this type of MS symptoms are chronic and the classic pattern of symptom presence and then remission is not observed (Doshi & Chataway, 2017). There are pharmacologic options available to address MS but treatments primarily target RRMS. However, their use during pregnancy and postpartum periods (if breastfeeding) is not well supported (Ghezzi et al., 2013; Portaccio et al., 2014; Fragoso et al., 2014; Coyle, 2016; Bove et al., 2014). Therefore, many women have been encouraged to cease using disease-modifying treatments during this period, although the current trend is to balance the risks and

benefits of what is known about teratogenic effects of these medications with the severity of the mother's disease (Rankin & Bove, 2018). This leaves many women with MS who choose to bear children without treatment options during the childbearing process.

Postpartum Period

Recently, the importance of the postpartum period to the health and well-being of both mother and baby has been emphasized. Some even refer to this as a “fourth trimester” of the perinatal experience. The postpartum period begins with childbirth and is generally considered to last from birth to 6 or even 12 weeks following delivery. During this period, women undergo a variety of physical, social, and emotional changes (Tully, Stuebe, & Verbiest, 2017). Many women feel that they are not prepared for the changes that will occur during this period and feel that there is a lack of support from the health care community surrounding these changes (Martin, Horowitz, Balbierz, & Howell, 2014).

From a research perspective, the length of the postpartum period can extend through the first year. Gulick (2007) examined functioning in the postpartum period among women with MS (n=172) and found changes in functioning were still occurring at the 9- and 12-month marks post-delivery. Gulick and Kim (2004) found that women with MS (n= 174) were still experiencing emotional distress up to 6 months postpartum. MS relapses are more likely to occur in the first 3 months postpartum (Vukusic et al., 2004; Hughes et al., 2014; Coyle, 2016). Given that women with MS have demonstrated emotional distress up to 6 months in the postpartum period (Gulick & Kim, 2004), this study considered the postpartum period to be the first 6 months after delivery.

Additionally, using a 6-month postpartum period of study will allow for the capture of the emotional implications of MS relapses in the postpartum period.

The postpartum period can be fraught with emotional changes. According to the National Institute of Mental Health (NIMH), postpartum depression occurs in about 15% of women (2018). Postpartum emotional distress can include depression but can also include postpartum anxiety (NIMH, 2018; Rados, Herman, & Tadinac, 2018). Postpartum anxiety and depression commonly occur together but are distinct from one another and can occur independently as well (Rados, Herman, & Tadinac, 2018). The biggest risk factor for postpartum depression and/or anxiety is experiencing these conditions either before or during pregnancy (Stewart & Vigod, 2016). Depressive disorders, including Major Depressive Disorder, are more common in individuals with multiple sclerosis (Patten, Beck, Williams, Barbui, & Metz, 2003). Individuals with multiple sclerosis have a 50% prevalence rate of depression in a lifetime, which is triple the prevalence in the general population without multiple sclerosis (Feinstein, 2011). The risk of depression increases with severity of multiple sclerosis (Chwastiak et al., 2002). Individuals who experience depression in conjunction with multiple sclerosis may also experience several other distressing symptoms as a result. Newland, Fearing, Riley, and Neath (2012) found that individuals who experience depression and multiple sclerosis also experience pain, cognitive difficulties, sleep disturbance, and fatigue. Wood et al. (2013) also found that depression tends to occur with anxiety and fatigue as a symptom cluster making the burden from both MS and depression possibly more severe than either one of these conditions independently. Given that individuals with MS are more likely to experience depression than individuals without MS, that having depression prior or

during pregnancy is the biggest risk factor for emotional changes postpartum, and that the combination of depression and MS may be more impairing than either condition alone, health care providers need to understand the emotional experiences of women with MS in the postpartum period.

Purpose Statement and Research Question

The purpose of this phenomenological study was to examine the emotional experience of women with MS in the postpartum period. The research question was: What is the emotional experience of women with MS in the postpartum period?

A phenomenological approach was chosen for this study as phenomenology is both a philosophical tradition and research approach that examines the meaning of a phenomenon to those who experience that phenomenon (Englander, 2016; Abalos, Rivera, Locsin, & Schoenhofer, 2016; Beck, 2012; Munhall, 1994). In the disciplines of psychiatry and psychology, the phenomena under study are often more abstract and deal more with the human experience than with a concrete object or situation. When one is attempting to study human experience, phenomenology as a philosophy and research tradition has been a natural choice for researchers because the core beliefs of this philosophy are consistent with the interplay between the physical world and conscious thought and phenomenologists seek to understand the meaning of the physical world and its experiences to a person (Englander, 2016; Giorgi, 1997; Ulanovsky, 2008). The concept of the postpartum experience in women with MS is therefore aligned with both philosophical principles of phenomenology.

There are two main schools of thought related to phenomenological research and philosophy. Edmund Husserl was the first to discuss phenomenology as a philosophical

world-view (Munhall, 2019). Husserl's desire was to increase overall understanding of the world as it is lived by man (Abalos et al., 2016; Munhall, 1994). According to Husserl's philosophy of phenomenology, to be able to truly embark on the discovery of this understanding, researchers first must suspend their thoughts and beliefs about a particular phenomenon to be open to understanding the experience of reality as it is (Munhall, 1994; Beck, 2012; Englander, 2016; Abalos et al., 2016). This idea has been known in the literature as "bracketing", epoche, or phenomenological reduction and has been incorporated into methods of phenomenological research that follow the Husserlian tradition (Munhall, 1994; Beck, 2012; Abalos et al., 2016; Englander, 2016).

Influenced by Husserl's philosophy, Martin Heidegger, a student of Husserl, is another well-known philosopher of phenomenology (van Manen, 2017). Influenced by and expanding upon Husserl's views, Heidegger's focus was instead to understand the meaning of the experience rather than to reduce it through the process of bracketing (Abalos et al., 2016). Although following a similar root, the philosophical theories of Husserl and Heidegger branch off from one another and are typically understood to differ in the concept of phenomenological reduction. From these two main philosophies of phenomenology, various research approaches have emerged (Munhall, 1994). However, as attempts to use this philosophy as a research method have grown, it has become clear that the researcher needs to think in ways in accordance with this philosophy (Ulanovsky, 2008; Munhall, 1994). Thus, it is not simply about following steps that have been identified as a process for conducting research, but rather understanding the foundational and conceptual elements of the philosophy and allowing the central tenets of this theory

to occupy one's world view. For the researcher, the philosophical theory of phenomenology becomes a lens through which one can view the world (Munhall, 1994).

Several methods of phenomenological inquiry that have been incorporated into nursing research, and they are identified by the researchers who developed and used the various methods. Colaizzi, Giorgi, and van Manen have all developed methods of phenomenological research which have been utilized by nurse researchers (Beck, 2012). The differences between the methods lie in the interpretation of the main philosophy that is used to guide the method. Based on a review of different research methods, phenomenology, specifically Colaizzi's method of phenomenology, was selected for this study as this approach will result in a description and interpretation of meaning of the emotional experience that is verified by the very women who have experienced this phenomenon (Beck, 2012). Colaizzi's (1972) method includes seven steps for data analysis which include reading all narratives, identifying statements of meaning, organizing statements of meaning into clusters, comparing the clusters of meaning to the original narratives for accuracy, creating a description of the results, condensing that description into a statement about the phenomenon, and providing that description to participants for their feedback.

Each of these seven steps is a crucial part of piecing together a description of the entire concept or experience of a phenomenon, truly descriptive phenomenology. The seventh step increases rigor of the study by validating with the participants themselves if the researcher's understanding and description of the experience accurately reflects what the participants intended to convey. This step helps to ensure that the analysis has

accurately captured and recorded the human experience of the phenomenon of study. Methodology is discussed further in Chapter 3.

Summary

Women with MS have traditionally been discouraged from pursuing pregnancy. With recent advances in research and treatment it is becoming more widely accepted for women with MS and other disabilities to deliver children. However, there is a lack of information and unmet needs for this population during the perinatal period. Women with MS are at an increased risk for a relapse of their symptoms within the first 3 months postpartum. Additionally, few studies have identified that women with MS have lower postpartum functioning and increased emotional distress, including postpartum depression, than women who do not have MS. To date, there has not been a study that specifically examined all aspects of the emotional experience of women who have MS in the postpartum period, including both positive and negative emotional experiences. This study is a necessary first step to understanding what the postpartum period represents, means, and looks like emotionally for women with MS so that health care providers can best provide care for these women. Outcomes of this study will add to nursing and medical knowledge with the goals of providing evidence for screening guidelines for postpartum women with MS and improving the quality of care for this population.

Conclusion

Women with MS represent a population of women who are likely to experience worsening of a disease process, lower functioning, and greater emotional distress in the postpartum period. Yet, there remains a lack of understanding on the part of the health care community regarding the postpartum emotional experience of women with MS.

Without adequate understanding of their experience, nurses and other healthcare professionals cannot begin to fully meet the postpartum needs of this population. This phenomenological study, guided by the methods developed by Colaizzi, furthered the health care community's understanding of the experience of postpartum women with MS to provide suggestions to improve nursing care. A review of the literature is presented in Chapter 2 and summarizes the current state of the science on the postpartum period in women with MS.

Chapter 2. A Review of the Literature

To determine how to approach the topic of the postpartum experience of women with MS, a thorough review of the literature was required. Several large databases were utilized to explore topics related to MS and pregnancy and the postpartum period. Although some information regarding this topic was written in the early 1990s, most of the research has taken place from the mid-2000s to the present day. Articles were obtained both from the direct results of searches and by ancestry searches of articles obtained from database searches. PubMed and CINAHL were the databases utilized. Articles were reviewed for their relevance to the study and articles that were found to be irrelevant were excluded. To understand the entire scope of literature on the study, articles were not excluded by date. The literature presented explores topics related to pregnancy and postpartum in women with MS.

Related Literature

Biological Considerations of MS in Women

Women are about 2-3 times more likely to develop MS than men, and the onset of MS is likely to occur during the period between menarche and menopause (Coyle, 2016; Voskuhl & Momtazee, 2017; Fabian, 2016; Ghezzi et al., 2013; Christianson, Mensah, & Shen, 2015). Female gender is one risk factor for MS. Other risk factors include a genetic propensity for the disease, living in northern climates, smoking, and experiencing certain neurological infections. The most well supported scenario is a transactional model for acquiring the disease which involves the combination of genetic and lifestyle factors (Olsson, Barcellos, & Alfredsson, 2017). Although MS will most likely be present during a woman's fertile years, MS does not affect a woman's ability to conceive or carry a

pregnancy (Voskuhl & Momtazee, 2017). Estrogen, a female sex hormone, has systemic effects throughout the body and has been demonstrated to exert an influence on neuronal cell development and growth in the central nervous system. Estrogen can also have an effect on the inflammatory and immune responses (Christianson, Mensah, & Shen, 2015). One of the main components of MS is the inflammatory response of the disease that can cause far reaching systemic effects. Women are more likely to experience autoimmune diseases in general, not just in the case of MS (Airas, 2015). This has led to a theory that the female sex hormones may have an influence on the development of inflammatory and autoimmune diseases. In particular, estrogen is known to have a protective effect on neuronal cells, including growth and development, in the central nervous system (Airas, 2015; Christianson, Mensah, & Shen, 2015). Pregnancy results in higher levels of estrogen, which directly mediates the immune response, decreasing the potential for relapses of MS symptoms during pregnancy (Christansen, Mensch, & Shen, 2015). Due to the neuroprotective effects of increased levels of estrogen, pregnancy is considered an immunotolerant state and the presence of MS symptoms is decreased during this time (Coyle, 2014). If a woman does experience a relapse of MS during pregnancy, it is more likely to occur earlier as opposed to later in the pregnancy (Coyle, 2016; Vukusic et al., 2004).

Several studies have examined the theory that MS relapses are less likely during pregnancy as the result of increased estrogen circulating in pregnancy and its subsequent neuroprotective effects. Alroughani, Alowayesh, Ahmed, Behbehani, and Al-Hashel (2018) analyzed 99 pregnancies among 87 women with MS for the occurrence of MS relapses during pregnancy. This cross-sectional study used a national MS registry to

identify pregnancies occurring in women diagnosed with MS. The researchers collected demographic data, the use of disease modifying therapies (DMT) as a treatment strategy for MS, and qualities of the relapse including timing and duration of symptoms. Using multivariate analysis, the researchers found that the relapse rate during pregnancy to be 17.2% (n=17). The researchers surmised that the relapses they identified during pregnancy were potentially related to stopping DMTs prior to pregnancy, meaning that these were rebound relapses as the result of stopping DMTs rather than being related to the experience of MS and pregnancy (Alroughani et al., 2018).

The following year, in 2019, Alroughani et al. conducted another study examining relapse rates of MS during pregnancy. The researchers used data from 132 MS patients who had 164 pregnancies that were identified through two national MS registries in Kuwait and Lebanon. During this study, in addition to collecting data on demographics and DMT use, the researchers also collected data on the washout periods, or periods without DMT use, and examined associations between DMT use, DMT washout, and relapses. The researchers found that a longer washout period was associated with increased risk of relapses in the first trimester of pregnancy. They also found that if a relapse was going to occur during pregnancy, it was more likely to occur in the first or third trimester. These findings were unexpected given that most research that has been conducted on MS relapses in pregnancy suggested that the relapse rate during pregnancy is quite low and that it is lowest in the third trimester. Further, the findings did not support the long-held theory that pregnancy is a protective time for MS.

Jalkanen, Alenen, Airas, and the Finnish Multiple Sclerosis and Pregnancy Study Group (2010) examined pregnancy outcomes in women with MS in Finland. A total of 60

women with MS, who had 61 pregnancies, over a period of 3-5 years were assessed by researchers for relapse occurrence, disability status, the presence of certain conditions related to pregnancy, and delivery modality. The majority (65%, n=40) of the participants had their relapses confirmed by a neurologist. The researchers found that 70.8% (n=43) of participating women did not have any relapse of MS during pregnancy. Additionally, among the participants who experienced relapses, the rate of relapses in the third trimester was lowest when compared to relapses during other times in pregnancy.

Albrecht, Fischer, and Moser (2010) administered a questionnaire to determine what women with MS knew about pregnancy after being diagnosed with MS. In addition to examining the information the participants had about pregnancy in the context of MS, they also examined the reported relapse rates among women with MS who had been pregnant. The researchers analyzed data only from women who had at least one child after they were diagnosed with MS. Of 150 total participants, 36 women (24%) had at least once child after they were diagnosed with MS. Among these women, 74% (n=26) experienced a lower relapse rate during their pregnancy than their pre-pregnancy rate. The researchers also mentioned that the women who did report a relapse during pregnancy also had a higher rate of relapses, or a more active disease, prior to pregnancy.

Hellwig et al. (2015) conducted a study to examine the impact of breastfeeding on postpartum MS relapses. Using two national registries in Germany for MS and pregnancy, the researchers identified 201 women with relapsing-remitting MS. The researchers compared women who only breastfed for first 2 months with women who did not or only partially breastfed for the first 2 months on the length of time to first postpartum MS relapse. They found no significant difference in time to first postpartum

relapse in women who exclusively breastfed and those who did not ($p=0.60$). The researchers only considered time to the first postpartum relapse within the first postpartum month. They did not examine the impact of exclusive breastfeeding on later postpartum relapses or number of postpartum relapses.

Most of the literature to date links estrogen's effect on MS with clinical presentation and times when estrogen is known to be higher or lower. Few studies were found that attempted to measure estrogen's impact on MS. Pozzilli and colleagues (1999) conducted a small study with only eight women who had RRMS. Each woman had MRI examination of MS brain lesions at different times in their menstrual cycle. The researchers found that during the luteal phase, which occurs immediately after ovulation and results in larger quantities of progesterone, MS lesions were increased in amount and size. The researchers note that the ratio of progesterone is greater than estrogen during the luteal phase. The number of lesions was significantly more during this phase ($p=0.03$) as was the volume of the lesions ($p=0.009$). These findings certainly provide further support for the link between MS relapses and female sex hormones but the sample size of 8 women is a serious limitation.

Triantafyllou and colleagues (2016) measured levels of several different sex hormones in pre-menopausal women, post-menopausal women, and men, and correlated those findings with disability status as measured by the Expanded Disability Status Scale (EDSS). All participants had RRMS and were recruited from an outpatient MS clinic. Of the participants, 52 were men, 66 were pre-menopausal women, and 15 were post-menopausal. Estradiol, or estrogen, levels were not correlated with any changes to the EDSS in men ($p=0.816$), premenopausal women ($p=0.259$), or post-menopausal women

($p=0.103$). The only female sex hormone that was correlated with worsening MS disability status was follicle-stimulating hormone (FSH) and only for pre-menopausal women ($p=0.038$). For men ($p=0.596$), FSH correlation to disability status was similar to post-menopausal women ($p=0.543$). One important limitation to note is that only one measurement of estradiol was taken for pre-menopausal women and estrogen levels fluctuate during the menstrual cycle. Thus, this correlation is occurring only at one point in the menstrual cycle and it may not be the same point for all participants, which could influence the results.

Trenova and colleagues (2013) studied the levels of estrogen, progesterone, and inflammatory markers in 35 women with RRMS. Levels were obtained when patients were in a MS relapse and during remission periods. The researchers also completed baseline levels and found that a group of women had low levels of estrogen and progesterone at baseline ($n=21$). They separated the participants into two groups, the first group with normal baseline levels of female sex hormones ($n=14$) and the second group with abnormally low levels of estrogen and progesterone ($n=21$). For the group of women who had low baseline levels of the female sex hormones, the concentration of estrogen was significantly lower during relapse than during remission ($p<0.01$). For women with normal levels of female sex hormones at baseline, there was no difference in estrogen concentrations between relapse and remission ($p>0.05$).

Deciding to Have Children in Women with MS

Deciding to have a child can be a major decision for many women but it is especially meaningful for women who are struggling with a chronic, progressive, and potentially debilitating illness. Several studies conducted in recent years have examined

the considerations or factors that influence women with MS in their decision to bear a child. Fabian (2016) noted that women will most likely be diagnosed with MS during their childbearing years, so this will be a decision that they will have to at least consider. Historically, pregnancy among women with MS was discouraged (Fabian, 2016; Houtchens et al., 2013). In the past, women with MS were even encouraged to consider a therapeutic abortion (Houtchens et al., 2013). As knowledge about MS progressed, the evidence demonstrated that MS does not have any impact on pregnancy, delivery, or fetal development and thus pregnancy in women with MS can not only be considered but also can be successful (Coyle, 2014). Although pregnancy in women with MS is more accepted now than it was in the past, there are still unique challenges for women with MS who decide to bear a child. Ghezzi and colleagues (2013) noted that women with MS need to consider additional factors, such as how they will care for the baby while experiencing a chronic and potentially physically debilitating illness, how they will continue to mother with a progressive disability, the presence of social supports who will help them during periods of increased disease activity, and the potential for a genetic inheritance of MS.

Despite these concerns, pregnancy in women with MS is on the rise. Houtchens, Edwards, Schnieder, Stern, and Phillips (2018) conducted a retrospective study using the IQVIA Real-World Data Adjudicated Claims-US Database to compare rates of pregnancy in women with MS and those without MS. Data from January 2006-June 2015 were included in analysis. From the database, data from 5,374,616 women without MS and 274,501 women with MS were analyzed. The researchers found that the rate of pregnancy in women with MS increased from 7.91% to 9.47% while the rate of

pregnancy in women without MS actually decreased from 8.83% to 7.75%. A limitation of this study is that the authors only presented the percentages of pregnancy rates without including the numbers of women who were pregnant for each year from 2006-2015.

Using a t-test, the researchers reported a statistically significant difference ($p < 0.0001$) in pregnancy rates between the two groups.

Although the rate of pregnancy in women with MS is rising, women with MS continue to exhibit greater rates of childlessness than women without MS (Ferraro et al., 2017). Ferraro and colleagues intended to examine both the rates of and potential contributing factors to childlessness among women with and without MS. They conducted a study using a questionnaire with a sample of 303 women with MS and 500 women without MS who provided information about their childbearing status. Women with MS were more likely to be childless (13%, n=67 out of 500) compared to women without MS (22%, n=66 out of 303) ($p=0.001$). The researchers also found that women with MS were more likely to have elective abortions and were less likely to be in stable and healthy relationships. Women with MS identified reasons for their childlessness and these included: being concerned about their future disability status, concern about genetic inheritance of MS, inability to receive treatment with DMTs if they were to become pregnant, their current level of disability was too high, or they were discouraged from pregnancy by their physician. Women without MS gave reasons for being childless as lack of a relationship, struggles with fertility, or simply not wanting children. All reasons for childlessness given by women with MS were all related to their MS diagnosis. Thus, having MS can be a barrier to women who may otherwise want to have a child.

There have been other studies that have addressed the topic of deciding to have a child among women with MS. Smeltzer (2002) conducted a qualitative study to explore the decision-making process to have children of women with MS. Fifteen women with MS participated in semi-structured interviews that discussed their concerns about their pregnancy, their child, their own health, and MS. Five themes were identified through content analysis: concerns about pregnancy, effect of MS on future childbearing, labor and delivery concerns, concerns about breastfeeding, and concerns about parenting. Smeltzer focused on the theme of deciding to have children for this study. Women identified that they struggled to make the decision to have a child. The participants identified a lack of information about pregnancy in MS and often sought out information from many sources including their health care providers and through their own literature searches, but often were frustrated at the lack of information that was readily available. Once women did get some information, they found that a lot of the information was unclear or even contradictory. Women described concern that pregnancy could have a deleterious effect on the clinical course of their MS. Women also identified that support from their partners was an important factor in their decision-making process. One very interesting finding was that women identified having a child as a psychologically positive event for them; one woman even described this as bringing some normalcy to her life since being diagnosed with MS. Women also described that a longer time of being diagnosed with MS prior to considering pregnancy was beneficial in that they felt more confident in how to manage their symptoms and that they were already well acquainted with the clinical course of their MS. The results of this study demonstrated that there are specific MS-related concerns to considering pregnancy for women with MS.

Prunty, Sharpe, Butow, and Fulcher (2008) conducted a qualitative study to assess the decision-making process for childbearing in women with MS. A total of twenty-two women with MS were divided into four focus groups based on their child-bearing status. The first group consisted of women who wanted children, the second of women who already had children, the third group of women did not want to have children, and the fourth group of women was unsure if they wanted to have a child. A total of six themes emerged from the focus groups related to deciding to have a child. Women noted that they were worried about how their disease would affect their ability to function physically in the postpartum period and throughout the life of the child. They were also worried about their own health as they realized they would need to stop their MS treatment prior to conception. Women with MS noted that they would feel guilty if the child developed MS later in life or if their child had to become their caregiver as their disease progressed. They cited symptoms of MS that would affect parenting including the level of fatigue they would feel or fear that they would fall with their child or drop their child due to MS. Many women noted that they needed extensive support from family and friends if they were to decide to have a child. Women also felt rushed in their decision, because there was such a limited time in their lives when having a child would even be possible. Finally, women felt that their family members and health care providers had negative attitudes toward their desire to pursue pregnancy.

Anderson and Wallace (2013) also conducted a qualitative study using semi-structured interviews to explore the experience of pregnancy in women with MS. Women with MS reported that when they interacted with others who knew their diagnosis they were labeled as selfish because they decided to get pregnant while dealing with a

progressive and potentially debilitating illness. Another concern highlighted in this study was that women identified a lack of readily available information about pregnancy and MS from lay sources or from their health care providers. In addition to a lack of information, women also felt that their health care providers did not support their decision to have a child. Women worried about the potential for a postpartum relapse and about how they would manage caring for their infant and later child if the symptoms of MS interfered with their functioning. Lastly, women felt that they had to choose to either breastfeed their infant or care for themselves by restarting DMT-treatment, which was a difficult choice for them. Again the decision for a woman with MS to have a child has been demonstrated to consist of very specific concerns unique to their disease process.

In the study by Anderson and Wallace (2013), women identified a lack of information and knowledge about pregnancy and MS. A study by Mitra and colleagues (2016) also identified a lack of information related to pregnancy as a concern for women with physical disabilities who were pregnant. This qualitative study involved phone interviews with twenty-five women with physical disabilities who had a baby within the past decade. Women with physical disabilities reported that clinicians often lacked knowledge about their specific disability and needs in general and during pregnancy. Clinicians were also inconsistent in their support for women with physical disabilities and were sometimes surprised that women were pregnant. Women cited a lack of information available to them about what they could expect to experience during pregnancy and postpartum while having a disability. Lastly, women noted that they struggled to just find health care offices with accessible equipment or equipment that would enable them to safely care for their babies at home with their physical limitations. Although these

women were not specifically MS patients, this study demonstrated the existence of unique and unmet needs for women with physical disabilities of all types who become pregnant.

A qualitative study by Payne and McPherson (2009) analyzed data from interviews with nine women with MS to explore their experiences related to pregnancy, birth, and mothering. Six themes were identified through semi-structured interviews and analysis of transcripts. One semi-structured interview was completed for each participant. The first theme involved the decision to have a child being both public and private in the case of women with MS. Rather than the decision just involving the woman and her partner, women described having to include extended family as they anticipated needing the support of extended family after delivery as well as their health care providers' input. Another theme was keeping the baby safe. Women with MS identified that they had to consider aspects of their disease and whether it was compatible with sustaining a pregnancy and breastfeeding after delivery. They had to weigh the risks of helping their own health with MS treatment versus how that would affect the health of the baby. Support was another important factor for women with MS. They noted that they all needed some support in the postpartum period. Some women found that they needed extended family support. Others found that they relied upon their partner to provide total care for the baby after they returned home from work because they were too fatigued to continue. Some women felt that they needed support for the physical aspects of caring for the baby, while others felt that they needed support from loved ones at helping to monitor their own MS symptoms. Fatigue was also a significant concern for women with MS. They found that the more fatigued they became, the more likely they were to experience a

relapse of MS. Thus, many women noted that conserving energy was important, and they had to implement strategies to do so, such as staying organized or scheduling rest periods. From a psychological standpoint, women felt worried about their ability to be an ideal mother or at least what they considered an ideal mother should be. They were concerned that they would be perceived as poor mothers if they were physically unable to keep up with certain demands such as housework and mothering, due to their illness. Lastly, women identified that throughout their pregnancy and postpartum experiences, MS was always a factor on their minds. They noted that during these experiences, they experienced symptoms of MS that affected their family lives and required support from family and friends. The results of this study demonstrated that women with MS certainly have unique experiences and concerns in the peripartum experience that need to be considered in their decision to pursue childbearing.

Albrecht and colleagues (2010) conducted a study to determine knowledge strengths and deficits about pregnancy among women with MS. A total of 154 women with MS completed a questionnaire that was structured to ask women knowledge-based questions about MS and pregnancy. The results highlighted a concerning knowledge deficit in this population. Only 4.8% (n=7) of women answered all the questions about MS and pregnancy correctly. A startling 33.6% (n=49) of women did not answer any questions about MS and pregnancy correctly. The researchers noted that women who had a previous pregnancy performed better and demonstrated more knowledge than women with MS who had not been pregnant before ($p<0.001$). This study further highlighted the fact that women with MS who are of childbearing age are not being educated by health

care professionals or perhaps are not even having discussions with health care professionals about pregnancy and their disease.

Women with MS need to be engaged in discussions about pregnancy with their health care providers. Pregnancy is biologically possible in women with MS, and MS does not have an effect on fertility (Coyle, 2014). Amato and colleagues (2017) recommended that a planned pregnancy is best among women with MS. In addition to the usual health care providers who are involved with managing pregnancy, a patient's neurologist should be informed and part of the pre-conception discussion as well as involved as a crucial member of the health care team throughout the pregnancy, with a recommended frequency of neurology follow ups every 3 months during pregnancy. Amato and colleagues also recommended that each woman be considered as a candidate for pregnancy on an individual basis, taking into account the severity of her disease and her desire and motivation to manage symptoms of MS during motherhood. Although pregnancy is no longer overtly discouraged in women with MS, health care providers need to recognize that women with MS who desire to become pregnant will have unique considerations and challenges, need a more intensive pregnancy planning discussion, and need information tailored to their specific disease activity. This requires that there are health care providers who are knowledgeable enough about pregnancy in MS to provide this level of guidance, education, and support (Amato et al., 2017).

Outcomes of Pregnancy in MS

An essential component of increasing education and information that is provided to women with MS who are considering pregnancy, is to understand the obstetrical outcomes in women with MS who are pregnant. Several studies have examined obstetric

and neonatal outcomes in women with MS and physical disabilities in general. A study by Houtchens and colleagues (2018), discussed in the previous section, reported increasing rates of pregnancy among women with MS. In their retrospective study, the researchers not only collected data on the rates of pregnancy among women with MS, but also examined obstetric and fetal outcomes. Houtchens and colleagues examined data from 2006-2014 and looked at each year individually. The numbers of women with MS included in the study varied by year but ranged from 36,361 to 58,218 per year. These outcomes were compared to those of the comparison group to determine if there were any negative outcomes more likely in women with MS than in women without MS. The results of the study demonstrated that women with MS had statistically significant differences in obstetric and fetal outcomes in comparison to women without MS in several areas. Obstetric outcomes in women with MS demonstrated that compared to women without MS, women with MS were more likely to experience premature labor ($p=0.005$) and maternal infection ($p=0.016$). Pregnant women with MS were more likely to also have cardiovascular disease ($p=0.028$), anemia and coagulation disorders ($p=0.007$), neurologic complications ($p=0.005$), and sexually transmitted diseases ($p=0.045$) than women without MS. Related to fetal outcomes, women with MS were more likely to have babies with congenital fetal malformations ($p=0.004$) and acquired fetal damage during birth ($p=0.002$).

A study conducted in Finland by Jalkanen and colleagues (2010) also examined outcomes of pregnancy in women with MS. This study was prospective in design and had a total of 61 MS patients whose birth data was compared with statistics from the Finnish Medical Birth Register, which contains information about pregnant women in Finland.

The only significant difference in obstetric outcomes identified in this study was that women with MS were more likely to require assistance during a vaginal delivery than women in the Finnish Medical Birth Register without MS ($p=0.0017$). The other outcomes that were examined were pre-eclampsia, gestational diabetes, type of analgesia, C-section, gestational age, birth weight, infant death, and infant malformations. Women with MS did not demonstrate any statistically significant difference in these outcomes when compared with information collected from the Finnish Medical Birth Register.

Morton and colleagues (2013) examined birth outcomes in women who had physical disabilities. The participants were not limited to women with MS but included women with physical disabilities as the result of other neurological conditions as well. A retrospective design with matched controls was used and data were obtained through hospital chart review. Data were collected from a total of 25 women with physical disabilities who had 34 pregnancies. In comparison to matched controls without physical disabilities, women with physical disabilities were more likely to experience maternal infections ($p=0.003$), particularly urinary tract infections (UTIs) ($p<0.001$) throughout the pregnancy. Women with physical disabilities were also more likely to have low birth weight infants ($p=0.023$). The researchers noted that women who had infections during pregnancy were more likely to have low birth weight infants ($p=0.023$) and experience preterm birth ($p=0.009$).

Jesus-Ribeiro and colleagues (2017) collected data on 97 women who were diagnosed with relapsing-remitting MS to examine obstetrical outcomes and the postpartum period in women with MS. There was no control or comparison group in this study, so only the frequencies of certain obstetric outcomes among the sample group was

reported. In this sample, 4.5% (n=4) of the women were diagnosed with fetal growth restriction and 3.6% (n=3) with gestational diabetes. In terms of delivery, the majority of patients delivered vaginally so MS was not associated with an increased frequency of Cesarean section (C-section). There were delivery complications in about 14% (n=14) of the infants delivered to women, with the two most common being birth asphyxia (6.4%, n=6) and low birth weight (6.1%, n=6.).

Van der Kop and colleagues (2011) compared obstetric and fetal outcomes among women with MS and women without MS as identified through the British Columbia Perinatal Database Registry. Through the registry, the researchers identified a total of 321 women with MS who had 432 births and compared them to 2,958 women without MS who had a total of 2,975 births. The database contained information from 1980-2008. Women with MS were only included in this group if their MS was identified and diagnosed prior to their pregnancy. The researchers measured the following outcomes: birth weight, gestational age, assisted vaginal delivery, cesarean deliveries, and Apgar scores. There was a small number of births (n=4) to women with primary progressive MS; most births were to women who had relapsing-remitting MS (n=428). There were a few significant differences between the comparison group and the group of women with MS. Women with MS tended to have higher BMI ($p=0.01$), to be hypertensive during pregnancy ($p=0.05$), to have smoked prenatally ($p=0.03$), and to be primigravid ($p<0.001$) and nulliparous ($p=0.01$). Women with MS also had a greater number of previous therapeutic abortions ($p=0.01$). In terms of obstetric and neonatal outcomes, there were no significant differences between women with and without MS. Women with MS had a higher rate of cesarean deliveries, but the difference was not statistically

significant ($p=0.63$). There was no difference between groups on outcomes of assisted vaginal delivery ($p=0.61$), birthweight ($p=0.43$), gestational age ($p=0.98$), or duration of second stage of labor ($p=0.57$). Infants born to mothers in both groups had the same 5-minute Apgar scores with the median Apgar score at 9 in both groups. Thus, the authors concluded that there was no association of MS with these adverse birth outcomes.

A more recent article by Yalcin, Yalcin, Yavuz, Akhurt, and Sezik (2017) also compared delivery and neonatal outcomes in women with MS and women without MS; however, the sample size was much smaller than the earlier study by van der Kop and colleagues (2011). The sample in Yalcin and colleagues' study consisted of 43 women diagnosed with MS prior to pregnancy and 100 case controls of women without MS. Participants were identified through hospital files. There were no significant differences demographically between the two groups. The researchers also compared health status through laboratory tests (complete blood count and urinalysis) and there were no significant differences between the two groups on those measures either demonstrating similar overall health status between the two groups. Outcomes studied included gestational age, birthweight, gestational diabetes mellitus, pre-eclampsia, fetal growth restriction, C-section, use of general anesthesia, stillbirth, congenital malformation, maternal UTI, and 1- and 5-minute Apgar scores. The researchers concluded that women with MS were not more likely to experience a Cesarean delivery ($p=0.594$) but were more likely than women without MS to require the use of general anesthesia for the Cesarean delivery ($p=0.002$). Similar to the findings of Morton and colleagues (2013) women with MS were significantly more likely to experience a UTI ($p=0.04$). Neonates birthed to women with MS were more likely to have a low 1-minute Apgar score

($p=0.04$), but a significant difference was not found for the 5-minute Apgar score ($p>0.05$).

Lastly, Frago and colleagues (2009) examined information from a Brazilian database they compiled by asking MS researchers in Brazil to share data concerning pregnant MS patients within the past 5 years of the study. Their information database grew to include a total of 49 pregnancies from 47 women with MS. The researchers paid particular attention to the fetal exposure to treatments for MS in pregnancy and looked at outcomes in general but also in groups of exposure to specific treatments including interferon beta, glatiramer acetate, corticosteroids, immunoglobulin, methotrexate, or combination treatments that women utilized while pregnant. About half of the women did not use any MS treatment during the third trimester pregnancy ($n=87$). Of the women ($n=47$) who did use MS treatment, either interferon beta, glatiramer acetate, or combination treatment was used. Among these pregnancies, there were no reported cases of fetal malformation, including among fetuses exposed to various MS treatments during the pregnancy. The researchers noted that the incidences of low birth weight and premature birth were as expected for the country. Among 49 births, three complications (spontaneous abortion, hemorrhage, and intrauterine growth restriction) were potentially associated with exposure to MS medications. Having MS alone did not increase the risk of adverse neonatal outcomes.

MS Relapses in Postpartum

Although maternal MS is not considered to be a source of severe maternal or neonatal outcomes in delivery, there is concern that MS can have a negative impact in the postpartum period, particularly the early postpartum period. Within the first 3 months

after delivery, women with MS are likely to experience an exacerbation of their MS symptoms, more commonly referred to as a relapse (Vukusic et al., 2004; Coyle, 2014; Coyle, 2016; Fragoso et al., 2013; Houtchens, 2013; Jalkanen et al., 2010). MS relapses can include neurologic symptoms that can make it more difficult to care for an infant and even contribute to mental health concerns (Rankin & Bove, 2018; Langer-Gould, 2019).

In 1998, a landmark study by Confavreux, Hutchinson, Hours, Cortinovic-Tourniarie, and Moreau was conducted with women with MS and pregnancy. The study included 254 women with MS across Europe. They were followed during pregnancy and into the first postpartum year to determine relapse rates. For this study the researchers considered a relapse to be “the appearance or worsening of symptoms of neurologic dysfunction lasting more than 24 hours” (p. 286). To assess for neurologic dysfunction, the researchers used the 0-10 scoring of the Kurtzke Expanded Disability Status Scale. The researchers found a statistically significant increase in the rate of relapses within the first 3 months postpartum ($p < 0.001$). After the first 3 months postpartum, the researchers found that the rate of relapse returned to baseline, or what it was pre-conception, for each woman. This was one of the first studies conducted to determine the relapse rate among pregnant and postpartum women with MS and heavily influenced the theory that the first 3 months postpartum was a high-risk time for MS relapses.

Birk and colleagues (1990) conducted a prospective study to examine the course of MS throughout pregnancy. A total of eight women with MS completed the study, along with six women without MS who served as controls. The women were examined twice during pregnancy and twice during the postpartum period at 6 weeks and 6 months. At each point, a neurologist assessed disability status by neurological examination and T

cells and plasma protein measurements were obtained. Seven of the eight women experienced clinical worsening of their MS, a relapse, in the first 6 months postpartum. Researchers reported a 17-fold increase in relapse rates for the first 6 weeks postpartum and a 10-fold increase for relapse rates in the first 6 months postpartum. The researchers discussed that the rates of postpartum relapses in this study were higher than expected. All but one of the participants experienced a relapse in the postpartum period.

Using the same sample described earlier, Smeltzer (1994) explored the concerns of women with MS. A total of 15 women participated in semi-structured interviews about their concerns related to the pregnancy itself and childrearing. Women identified several concerns prior to pregnancy including treatment for MS during this period. Women were concerned about how to address symptoms of MS that occurred during pregnancy and fetal exposure to treatments if pregnancy occurred without planning. Women were often left without health care provider guidance about the risks of untreated MS symptoms compared to the benefit of childbearing. Women worried that their MS symptoms would mimic symptoms of pregnancy and vice versa and that this could affect the care they received. Although most of the participants knew the MS symptoms were likely to decrease during pregnancy, they were uncertain about whether or not this would occur and to what extent. The participants noted that they experienced a variety of reactions from others when they disclosed their pregnancy status. Some of the reactions were positive, but many were negative.

Smeltzer (1994) noted that women also had concerns about the labor and delivery process. Many women worried that their MS-related fatigue would affect the labor process in a negative way or that there may be changes to delivery and anesthesia method

due to their MS. Although some women identified that breastfeeding could enhance bonding with the baby, they also noted that there could be negative effects of breastfeeding as a result of their MS. Women were concerned that breastfeeding would exacerbate the fatigue they already felt with MS and some felt that their breast milk was tainted in some way because of their MS. Women worried about the inheritability of MS and potentially passing on this disease to their children. Participants also noted that they were concerned that a postpartum exacerbation of MS would impair their ability to adequately care for their infants. This prompted many women to make extra arrangements for help, beyond what was expected or considered by a new mother without MS. Their concerns about adequately parenting with MS extended beyond the immediate postpartum period as women worried about the potential for long-term disability as their child grew and their ability to adequately participate in their children's lives or that they would not survive to see their children successfully into adulthood. Women also worried about the reactions their children would have to their disability as they grew. The researcher noted that the main finding of this study was that there is much uncertainty for pregnant women with MS, both as it pertains to the actual pregnancy period as well as parenting.

Vukusic and colleagues (2004) sought to identify predictors of postpartum relapses in women with MS. Two hundred and twenty-seven women with MS were included in the study. Inclusion criteria included having MS for 1 year prior to conception and delivery of a full-term live infant. Follow up was conducted at 6 months post-partum (216 women), 12 months postpartum (201 women), 18 months postpartum (182 women), and 24 months postpartum (163 women). When postpartum relapses were

compared to their relapses in the year prior to conception, they were significantly more likely to experience a relapse in the first 3 months postpartum ($p<0.001$). However, the majority of women in this study (72%, $n=160$) did not have a relapse within the first 3 months postpartum. The researchers did find that there were three factors that increased the likelihood of a postpartum relapse: the number of relapses before pregnancy, the number of relapses during pregnancy, and a higher disability score at conception. Therefore, women with more active and severe MS were more likely to experience a postpartum relapse than those with a less active disease.

Hughes and colleagues (2014) also conducted a prospective study using a multi-center international MS database known as MSBase to explore MS relapses in 674 pregnant women (with a total of 893 pregnancies) following them into the postpartum period. Interestingly, within the first 3 months postpartum, most women (86.1%, $n=580$) did not have a postpartum MS relapse. By a full year postpartum, still most women (63.5%, $n=428$) did not have a postpartum MS relapse. The postpartum relapse rate reported in this study was much lower than the relapse rates from the PRIMIS study. Researchers also used logistic regression to determine predictors of MS relapses in the postpartum period and found that women who had higher disease activity prior to conception were more likely to experience a postpartum relapse within the first 3 months ($p<0.001$). They also found that use of DMT prior to conception decreased the potential for postpartum relapses ($p=0.006$).

Although Hughes and colleagues (2014) found that use of DMTs prior to pregnancy can be protective against postpartum MS relapses, a study by Fragoso and colleagues (2015) also examined the impact of MS treatment on pregnancy and found

that the use of immunoglobulin immediately after delivery was not protective against MS relapses. This study was retrospective in design, and data were collected by reviewing medical records of participants. A total of 134 pregnancies were divided into two groups. The first group, which was considered the control group, consisted of 87 pregnancies during which the mother had not received immunoglobulin or corticosteroids in the postpartum period. There were 47 pregnancies among women who received either immunoglobulin or corticosteroids after delivery. In both groups, the mothers did not have any treatment for MS in the third trimester of pregnancy. Both groups experienced an increase in relapses in the postpartum period compared to during pregnancy but in both groups the rates of relapse were lower than the rate of preconception relapses. There was no difference in relapse rates among women who received immunoglobulin after birth and women who did not. This study confirmed the finding from other studies that there is a significant increase in postpartum relapse rates ($p=0.004$); however, they also found that despite the increased rate, the overall relapse rate was significantly lower than what occurred pre-conception.

In 2017, Jesus-Ribeiro and colleagues conducted a study in Portugal of women with MS to determine their relapse rate and obstetric outcomes. This study was discussed in a previous section of the literature review so only results will be provided here. Among 97 women with MS who were included in the study, 38.7% ($n=43$) experienced one postpartum relapse, with 21.6% ($n=24$) of those relapses occurring in the first 3 months after delivery. There was no significant difference between relapse occurrence in the postpartum period compared to preconception relapse rates ($p=0.127$ for first 3 months and $p=0.894$ for 4-6 months postpartum). Predictors of postpartum relapses were found to

be the occurrence of relapses during the pregnancy and a shorter duration of MS prior to conception. This finding demonstrated that women with more active MS disease prior to pregnancy are more likely to experience relapses in the postpartum period.

Alroughani and colleagues (2018) conducted a study to examine relapses during pregnancy among women with MS, as well as the number of relapses in the postpartum period. This cross-sectional study included 87 women with MS who experienced 99 pregnancies. They found that MS relapses increased in the postpartum period, however, little data were reported on postpartum relapses because the focus of the study was on relapses that occurred during pregnancy.

Paavilainen and colleagues (2012) conducted a study that examined the presence of MS lesions in the brain postpartum to further the understanding of the increased incidence of relapses in the postpartum period. They hypothesized a greater number of CNS lesions on MRI imaging in the postpartum period. MRI imaging was obtained on 19 patients with relapsing-remitting MS, once during the last trimester of pregnancy and at 4-12 weeks postpartum. The researchers also studied the apparent diffusion coefficient (ADC) on histogram analysis, which is a measure of brain tissue integrity (Le Bihan, 2013). ADC was hypothesized to increase during the postpartum period. The results of the study demonstrated that there was a statistically significant increase in the number of CNS lesions present postpartum compared to lesions present during third trimester of pregnancy ($p=0.005$), and the ADC was significantly lower ($p=0.026$) in postpartum rather than pregnancy signaling worsening disease activity in the postpartum period. In this study, 58% (n=11) of patients experienced a clinical relapse but even more patients (89%, n=17) had increases in inflammation in the first 6 months postpartum. The findings

demonstrated that there is an increase in disease activity of MS in the postpartum period but it may not always result in a clinically impairing relapse.

Although it has been generally accepted that the first 3 months postpartum is a time of increased relapses in MS, much of the recent research does not consistently demonstrate this. However, taken as a group, these studies suggest that at least for some women with MS, particularly those with more active and more severe MS, the postpartum period will be a time of increased disease activity.

Mental Health and MS

Depression, or Major Depressive Disorder, is the most common psychiatric disorder that occurs in individuals with MS (Feinstein, 2011; Feinstein et al., 2014; Feinstein & Pavisian, 2017; Murphy et al., 2017). The prevalence rate of depression in individuals with MS is estimated to be five times higher than that of the general population. It is also anticipated that about 80% of individuals with MS will meet criteria for a diagnosis of Major Depressive Disorder at some point in their lifetime after being diagnosed with MS (Murphy et al., 2017). The symptoms of MS can overlap some symptoms of depression and this may cause depression to be undetected in individuals with MS (Murphy et al., 2017). Along with increased rates of depression, individuals with MS also tend to have a higher rate of suicide, almost twice the rate of the general population (Feinstein & Pavisian, 2017). Thus, depression is more likely to occur in individuals with MS, and individuals with MS are more likely to attempt to end their lives by suicide.

The postpartum period is already a high-risk time for depression. A recent study by Anokye, Acheampong, Budu-Ainooson, Obeng, and Akwasi (2018) examined the

prevalence of postpartum depression among 257 women in Ghana and found a prevalence of 7% (n=18). Rates have been demonstrated to be as high as 13% of women according to a recent review (Stewart & Vigod, 2016). Knowing that women with MS are more likely to be depressed than the general population, there are surprisingly no data on the rates of postpartum depression among women with MS.

A study by Silverman and colleagues (2017) examined the relative risk of postpartum depression among a large population using the Swedish Medical Birth Register and collecting data from 1997-2008. The results of this study demonstrated that having a history of depression increases the risk for postpartum depression twenty-fold. Although there are no data available on the prevalence of postpartum depression in women with MS, these results suggest that women with MS in Sweden will likely be at an increased risk for depression in the postpartum period.

A study by Iezzoni and colleagues (2015) examined health risk factors among pregnant women with physical disabilities. One of the risk factors that was included in data collection was the presence of any mental health diagnosis. The researchers analyzed National Health Interview Survey Data, which includes responses from over 47,000 women. Information was obtained for women with physical disabilities of all types, including MS. The results of the study demonstrated that currently pregnant women with physical disabilities were more likely ($p<0.0001$) to have any mental health problem compared to currently pregnant women without physical disabilities.

A study by Mitra and colleagues (2015) used the Rhode Island Pregnancy Risk Assessment Monitoring System to assess for the presence of postpartum depression in women with physical disabilities. Again, this study explored rates of postpartum

depression among women with physical disabilities in general, some of who were women with MS. Although the analysis was not specifically focused on women with MS, 6.8% (n=287) of women in the database identified as having a physical disability and of those women, about 30% (n=87) reported feeling down or depressed after childbirth. This was statistically significant with only 10% (n=3) of women without physical disabilities reported feeling depressed after childbirth ($p<0.001$). The authors noted that women with disabilities were about twice as likely to experience postpartum depression than those women without disabilities. They also noted that a diagnosis of depression prior to pregnancy was not associated with an increased risk for postpartum depression in women with physical disabilities. However, being depressed during pregnancy was associated with an increased risk for postpartum depression. The study by Iezzoni and colleagues (2015) reported that women with physical disabilities were more likely than women without disabilities to experience depression during pregnancy.

Only one study has been conducted regarding mental health in postpartum women with MS. Gulick and Kim (2004) conducted a correlational descriptive study among a convenience sample of 174 women with MS in the postpartum period. The study explored emotional distress that was measured with several instruments including the MS-Related Symptom Scale to measure emotions, fatigue, and MS symptoms and they measured social support with the Postpartum Support Questionnaire. The results demonstrated that there was a positive correlation between increased scores on the subscale of the MS instrument that examined MS symptoms and the emotions subscale of the same instrument, demonstrating that there was increased emotional distress with worsening of MS symptoms. This finding, of a relapse of MS increasing emotional

distress, was found at both 1 and 3 months postpartum. The increase in emotional distress with MS symptoms was not significantly decreased by the presence of social support.

Other studies have examined depression and mental health issues among individuals with MS without regard for pregnancy/postpartum status or gender. This is a limitation of the current state of the evidence, but it is worth recording findings here to demonstrate that regardless of gender or child-bearing status, MS itself is associated with increased mental health issues. Gay and colleagues (2017) examined anxiety, depression, and emotional processing among individuals with MS. Their sample was comprised of 189 individuals with MS: about two-thirds ($n=121$) of them were female. Greater than half of the sample (57%, $n=107$) had relapsing-remitting MS, 29% ($n=54$) had secondary progressive MS, and 15% ($n=28$) had primary progressive. Gay and colleagues found that females with MS had more depression than men with MS ($p<0.001$). About 20% ($n=36$) of individuals had both depression and anxiety, and they experienced fewer positive emotions than the general population. The researchers noted that the level of functional impairment with MS had a significant impact on the experience of depression ($p<0.05$). The presence of anxiety also had a significant impact on the likelihood of a person experiencing depression ($p<0.001$).

A study conducted in the United Kingdom by Jones and colleagues (2012) utilized an online portal to administer the Hospital Anxiety and Depression Scale (HADS) and the MS Disease Impact Scale-29 to study depression in individuals with MS. A total of 4,178 individuals with MS responded to the invitation to complete questionnaires through the UK MS Register. Of the individuals who responded, 54% ($n=2256$) had anxiety and 46.9% ($n=1960$) had depression. Similar to the findings of Gay

and colleagues (2017), depression and anxiety were likely to co-occur. Among individuals who had anxiety, 57.7% (n=2268) also had depression. Among individuals with depression, 77.7% (n=1961) also had anxiety. These results demonstrate that both anxiety and depression are problematic for individuals with MS. This study was not specific to women or pregnancy status, which is a limitation for the purposes of the proposed study.

Marrie and colleagues (2015) conducted a systematic review to determine the prevalence of psychiatric disorders in individuals with MS. A total of 118 studies published from 1953 to 2012 were included. These studies were not specific to pregnancy status which is a limitation for the purposes of this proposed study. A total of 71 studies reported the prevalence of depression. According to Marrie and colleagues, the prevalence of depression among individuals with MS was estimated at 23.7% (95% CI: 17.4%-30.0%).

Fatigue and depression are common symptoms of MS. Greeke and colleagues (2017) sought to examine the relationship between fatigue and depression in individuals with MS. The researchers utilized two scales: The Center for Epidemiologic Studies-Depression Scale (CES-D) and the Modified Fatigue Impact Scale (MFIS). A strong correlation ($r=0.62$) was found between depression scores and fatigue scores. Among the individuals studied, 15% (n=65) had high scores on both depression and fatigue. The authors noted that the results indicated that depression and fatigue share many characteristics but that individuals who were not depressed but had high fatigue scores were at higher risk for depression.

Two studies have examined suicidal ideation in individuals with MS. Suicide and suicidal thinking are two concerning outcomes of depression. Viner, Patten, Berzines, Bulloch, and Feist (2014) studied the prevalence and risk factors of suicidal ideation in individuals with MS. Suicidal ideation was assessed by using Question 9 on the depression screen Patient Health Questionnaire-9. Five hundred individuals with MS were invited to participate, and 188 who were eligible participated. The researchers found the point prevalence for suicidal ideation within the past 2 weeks to be 8.3%, which they noted is higher than the general population. The prevalence of suicidal ideation in the past 6 months was even higher at 22.1%. Among individuals with MS, being older (over age 65) and having low self-efficacy were predictors of suicidal ideation. Neither of these studies was explicit in examining depression and suicidal thinking in women of childbearing age, which is an important limitation to note. No studies have examined depression and suicidal ideation among women with MS who are of childbearing age or have been pregnant.

Lewis and colleagues (2017) assessed the interaction between depression, disability, and suicidal ideation in individuals with MS. The sample had 75 participants with MS who were recruited from two outpatient MS clinic sites. They completed the Beck Suicide Scale, the Beck Depression Inventory, Multiple Sclerosis Impact Scale, and Guy's Neurological Disability Scale. Of the 75 individuals, 31 were male and 44 were female. Participants had an average age of 55 years. The prevalence of suicidal ideation in this study was 35%; the researchers did not compare presence of suicidal ideation between genders. Perceived disability was related to suicidal ideation, but the effect was mediated by depression and, when depression was accounted for, there was not a

significant relationship between suicidal ideation and perceived disability. The different types of disability measured through the instrument were not associated with any increased risk of suicidal ideation. Among individuals in the study who were depressed, the relative risk of experiencing suicidal ideation was 3.16. Among individuals with depression and MS, there was a high risk of suicidal ideation. The authors recommended that regular screening for both suicidal ideation and depression be implemented when working with individuals with MS, however, these recommendations are based on male and female participants with a median age that is beyond the childbearing years. There is a lack of information regarding suicidal ideation in women with MS who are in the childbearing years, including the pregnancy and postpartum periods.

Conclusion

The research has demonstrated that women are more likely than men to be diagnosed with MS and are typically diagnosed during their childbearing years. The female sex hormones play a role in mediating the immune response and in the neurological system; thus, the presence of higher levels of estrogen may decrease the likelihood of an MS relapse. Historically, it was assumed that as pregnancy was neuroprotective, postpartum was a time for increased risk of relapses of MS. The research to date on postpartum relapses in MS is mixed, and the postpartum period is still considered be a high-risk time for individuals with MS. Given the many functionally impairing symptoms of a chronic progressive illness, the likelihood of postpartum relapse, and the lack of information readily provided to women with MS, women have indicated that deciding to have a child in the face of this potentially disabling disease has many specialized and unique factors to consider. Additionally, women with MS have

discussed concern about their ability to physically care for a newborn while also managing MS. This is especially concerning since the postpartum period is not only a time of risk for MS symptoms but also for depression. Individuals with MS are more likely than individuals without MS to experience depression and are at greater risk for suicidal thinking. The postpartum period is a time of elevated risk for depression, yet there is a lack of information available about the prevalence of postpartum depression in individuals with MS. Additionally, there is a gap in the literature regarding the overall experience and meaning of the postpartum period in women with MS. This study attempted to establish an understanding of the emotional experience of women with MS in the postpartum period. In order to conduct quantitative studies about the postpartum experience in MS, there must first be an understanding of what that experience is like for the women who live it and live through it. Future research can then focus on the experience of having MS in the postpartum period, promoting healthy behaviors in this population, and addressing mental health issues relating to MS, pregnancy, and parenting.

Chapter 3. Methods

The purpose of this study was to explore and understand the emotional experience of postpartum women with MS. The literature review presented in the previous chapter highlights the lack of information on this topic. This topic needs to be understood as it is experienced to assist the development of appropriate guidelines for nursing care of postpartum women with MS. Phenomenology was chosen as the philosophical framework and method for this study as this method requires the researcher to study the experience of participants. This chapter provides an overview of the method and specific details about how the study was conducted.

Research Method

Phenomenology was the research method used in the study. Phenomenology is a philosophy, a way of viewing the world and the human experience (Munhall, 1989). Phenomenology seeks to understand experiences as they are lived, not in a way that is just descriptive but to truly understand how reality is experienced in the context of a particular phenomenon (Colaizzi, 1972; Munhall, 1989; Giorgi, 1985; van Manen, 2017). Nursing as a discipline is naturally aligned with the philosophy of phenomenology as it uses the individual's experience, the individual's reality in the context of health-related phenomenon, as the focal point of care (Oiler, 1982). In order to provide effective nursing care, the patient's experience and beliefs about a phenomenon need to be understood. Munhall (1988) noted that nursing care centers around the understanding of how a patient will act dependent upon the patient's version of reality or as she more clearly stated "the participant as the expert" (p. 23). In order to add to the body of nursing knowledge, in this case, the body of nursing knowledge surrounding how best to care for

women with MS in the postpartum period, the reality of what that experience is like for the women who live it is essential (Allen & Jensen, 1990). Thus, the purpose and question of the study were matched to the very philosophy of the method chosen.

Phenomenology is commonly thought of as the study of lived experience (van Manen, 2017). However, both the method and the philosophy are more complex than that phrase seems to connote. To conduct research rooted in this philosophy, van Manen (2017) noted that the researcher must first demonstrate an understanding of the philosophy of phenomenology. Phenomenology as a philosophy dates to the turn of the 20th century with Husserl's writings and was later elaborated upon by Heidegger (van Manen, 2017). For much of the early 20th century, science was a quest for true, objective reality. Research that was meaningful and scholarly was designed using a positivist model that assumed there was an objective reality to be uncovered or explored if only other factors were held in check or controlled. Despite the best efforts of scientists to discover objective reality, it soon became clear that the human experience is more complex than what a positivist model allows for (Colaizzi, 1972). The human experience is complex and is dependent upon time, culture, interactions with the environment, and interactions with other people (Munhall, 1989). This level of complexity cannot be adequately explored using the positivistic or reductionistic approach. However, by acknowledging the philosophical tenets of phenomenology as a basis for conducting research, the philosophy can be expanded into a method (van Manen, 2017). This allows for the enhanced understanding and new concepts to be identified that can directly influence nursing care (Munhall, 1989).

The core feature of phenomenology is that it acknowledges that reality or experiences are tied to humanity. As humans interact in an environment, aspects of the environment interact back in a reciprocal relationship. These interactions create unique situations and experiences for each individual human, leading to the presence of a similar but slightly unique reality for each person. Rather than reality existing independently from individuals, reality only exists when there is an interaction between human beings and their inner world (consciousness) with the outside world. Thus, it is impossible to reduce an experience to an objective universal truth because the experience cannot exist in isolation; it is tied to the person. As Colaizzi (1972) stated, “experience is there, for all of us, and it cannot be objectively eliminated” (p. 52).

Colaizzi provided a guide for how to convert the philosophy of phenomenology into a method of data analysis to extract the meaning of a phenomenon. Colaizzi stated that data collection is completed by obtaining narratives from participants who have experienced the phenomenon or situation of study, focusing on the meaning and reality of the experience. Colaizzi identified seven steps of analyzing the transcribed or written narratives. The first step of data analysis is to read the narratives once through to become acquainted with the content. Then a second reading of each narrative is required to highlight statements or sentences that directly relate to the phenomenon of study. Each of these statements is then carefully considered for its meaning, which is then stated. These meaning statements are then grouped together into clusters in which the same meanings are represented. These clusters are then compared to the original narratives to ensure that they adequately represent what the meaning statements are intending to convey. Those clusters are then arranged in a way that describes all aspects of the phenomenon and then

this is reduced into a more concise statement. Lastly, the description is then sent to the participants themselves who provide feedback on the validity of what was found (Colaizzi, 1972).

Internet-Based Qualitative Research

According to Pew Research Center (2019a), 100% of adults aged 18-29 in the United States use the Internet and greater than 85% of adults aged 30-66 use the Internet. The Internet can be a viable and valuable source of rich qualitative data (Beck, 2005). The ability to reach a wide range of participants in geographically diverse areas makes Internet-based qualitative research attractive to researchers (Neville, Adams, & Look, 2016; Wilkerson et al., 2014). Additionally, online research can allow for greater time for individuals to ponder their responses in qualitative research (Neville et al., 2016). The enhanced confidentiality that online research can provide may also allow for individuals to be more comfortable disclosing sensitive or personal information and lead to richer data (Neville et al., 2016; Wilkerson et al., 2014). This was thought to be true for this study's population of interest. Women who experience mental health concerns in the postnatal period face significant stigma that limits their desire to seek care (Moore & Ayers, 2017). Stigma may also limit their desire to participate in health-related research. An online format may allow for greater anonymity and increase the likelihood that women will feel more comfortable participating in research on this topic. Additionally, Internet-based research can eliminate errors resulting from transcription (Wilkerson et al., 2014).

Synnot, Hill, Summers, and Taylor (2014) compared the results of traditionally conducted in-person focus groups with the responses of participants in an online format.

The sample was comprised of individuals with MS and the purpose of the study was to investigate their information-seeking behaviors. There were 27 participants in the in-person focus groups and 33 participants in the online format. There were no significant differences between those who participated in-person and those who participated online in regard to gender ($p=0.93$), age ($p=0.42$), educational level ($p=0.83$), or disability status ($p=0.39$). The researchers analyzed the responses from the focus group and from the online group separately and found that the themes that emerged were very similar. Additionally, they found the online responses to be more succinct and less likely to deviate from the topic of investigation. The researchers concluded that the online method did not result in different data than the in-person interviews and it is a viable research method for individuals with chronic illnesses. They further stated that online research can “enable participation by many people who would not otherwise be able to attend” (p. 437).

Pang, Chang, Verspoor, and Clavisi (2018) examined preferences for research participation among individuals with musculoskeletal conditions. The researchers conducted semi-structured phone or in-person interviews with 23 individuals who had musculoskeletal disorders and 10 researchers who had experience working with this population. The themes identified by researchers supported that individuals with musculoskeletal disorders wanted to participate in research that would potentially benefit their conditions but noted that their participation in person would be limited due to pain, travel, and time factors and would prefer to participate in research that occurred online.

Beck (2005) conducted an Internet-based, phenomenological study regarding the experience of birth trauma among women. A total of 40 women were recruited through a

self-help organization for women with birth trauma in New Zealand, but participants were from all over the world and were not limited to this geographical location. Beck completed a secondary analysis regarding benefits of participating in this research that emerged in the responses of the participants. Beck found that women felt that sharing their experience of birth trauma in narrative form helped them to process their experience and was also cathartic, allowing them to express their feelings and move forward. Completing these narratives also helped them to make sense of what happened and record the important details. Participants indicated that they found this empowering. They were finally given an outlet to share their story. Women described that just knowing there was a study on this topic decreased their sense of isolation because it assured them that other individuals experienced a similar phenomenon.

Beck identified some disadvantages to online research including the requirement for participants to have computer literacy and inability to evaluate non-verbal communication. However, the findings from Beck's study indicated that women who participated in an online study in which they were asked to write a narrative of their experience, obtained similar benefit from this method as has been reported to occur with face-to-face qualitative interviews. The women reported that writing an online narrative had an emotionally beneficial impact on them. They felt that the process itself was therapeutic, and were glad to be participating in a study to help others (Beck, 2005).

Narrative Phenomenological Research

Colaizzi (1972) noted that the phenomenological method was initially based on analyzing written words but was then expanded to include in-person interviews. Thus, for Colaizzi, the process of phenomenological research was traditionally conducted using

written narratives. Van Manen (2017) also indicated that phenomenological data can be obtained in the form of written descriptions or accounts of a phenomenon. That phenomenological data can occur in form of written narrative rather than interview is long established (Colaizzi, 1972; van Manen 2017a; van Manen 2017b; Matua, 2015). The most important component of data is not the manner in which they were collected (interview vs. written narrative), but rather that the collection of data adheres to the philosophical principles of the method and is reflective of the experience of the participants in a way that demonstrates their reality as it occurred to them (Matua, 2015). Thus, although much phenomenological research has occurred through verbal interviews, the use of written narrative descriptions has been widely accepted. The use of written narratives for phenomenological research in a female, child-bearing population has been further demonstrated through Beck's (2005) study discussed previously.

Recruitment of Sample

Women were recruited through social media sites with Facebook being the primary recruitment site. According to Pew Research Center (2019b), 69% of adults use Facebook. Through a search of Facebook, several Facebook pages dedicated to supporting mothers with MS were identified. Initially, four main group pages were identified as places to post recruitment flyers for the study. Two of the groups, Moms with MS, and Mothers with MS-MWMS, were closed groups. The principal investigator contacted the administrators of these groups to request permission to join these groups and post the recruitment flyers on the groups' pages. The Moms with MS group had 973 members as of September 2019. The Mothers with MS-MWMS group had 7,300 members as of September 2019. The Mother's with MS-MWMS group did not accept the

researcher's request but had an informational open page associated with the group that the researcher was able to post information about the study. At one point, the information page re-shared the post, without being requested by the researcher, to provide support for the study. Two other groups, which were open groups, were identified: Moms with MS Information and The MS Mom life. The researcher posted recruitment flyers on the groups' pages. As of September 2019, Moms with MS Information had 1,600 people who "liked" the group, indicating that they received updates when something was posted on the group's page. The MS Mom life page had 1,200 people who "liked" the group as of September 2019 and were alerted when a new message was posted on the group page. Recruitment flyers were posted weekly on these Facebook pages.

Initially, in early March 2020, several participants responded and accessed the survey and members of the social media groups posted support for the study. One woman who responded commented on the study posting thanking the researcher for exploring the topic. Other members indicated that they were happy to see a health care provider asking the people who had MS about their experience. Unfortunately, by mid-March 2020, it became clear that a deadly pandemic known as COVID-19 or Sars-CoV-2, had struck the United States (World Health Organization [WHO], 2020). COVID-19 is a highly contagious respiratory disease that by September 2020 has caused about 1 million deaths worldwide (WHO, 2020). By mid-March 2020, localized lockdowns began in the United States to decrease the spread of Covid-19 and its associated morbidity and mortality (Dunford et al., 2020). Because the population of interest in this study involves women with disabilities who have young children (at least 10 years of age or younger based on the inclusion criteria), it was not surprising that as lockdown orders spread across the

United States, participation in the study stalled. When the study was initially posted in early March 2020, 6 participants completed the study within the first month. From early April 2020 to June 2020, only one response was received, although some participants accessed but did not completed a survey in this time period. In an effort to increase recruitment and participation, the researcher submitted an IRB modification to posting of the study to other social media forums on Facebook, Twitter, Health Unlocked MS blog postings, as well as the National Multiple Sclerosis Society participation in research page. Following IRB approval of these modifications, the researcher posted the study to the other social media forums (Twitter and blog posting) and the study was posted on the NMSS participation in research page by May of 2020.

The recruitment flyer (Appendix A) for the study provided a description of the study including inclusion and exclusion criteria, the purpose of the study, what the study hoped to accomplish, and how the study was conducted. Women who were interested in participating clicked a link posted with the recruitment flyer that directed them to the Qualtrics survey platform and the informed consent page. Participants read about the study; if they chose to consent, they selected “yes” and they were taken to the actual study survey. If they chose not to consent, they clicked “no” and they were not directed to the survey. Participants who consented were given the option to save and return to their survey questions at a later time to allow for adequate reflection on their experience. Their responses remained “saved” in Qualtrics for 1 month until they hit “submit”.

Additionally, participants were asked if they were willing to be contacted with the results of the data analysis to provide feedback on their accuracy. If a participant indicated willingness to be contacted, she was asked to provide an e-mail address to be used to

contact her to request her to review and provide any comments on the final analysis.

Participants then submitted their comments back to the researcher via the researcher's

Villanova University e-mail address.

Sample

The study consisted of a sample of 13 adult women ages 29-43 who had experienced childbirth after they have received a diagnosis of MS. There are several opinions on the size of the sample in qualitative research. Most qualitative researchers have suggested that for individual narratives a sample size of at least 20 must be recruited (Vasileiou, Barnett, Thorpe, & Young, 2018). A sample size of 25 was initially selected to account for the possibility of attrition. Participants had to be able to read, write, and comprehend written English and be residents of the United States. The sample included women who were at least 12 months past the childbirth experience to allow for women to reflect upon their experience during the first 12 months postpartum in total and to avoid capturing women who are currently in the postpartum year. According to Gulick and Kim (2004), women with MS can experience postpartum emotional distress up to the first 6 months after delivery. By restricting the sample to women who were at least 12 months past delivery, women who were no longer in active emotional distress and were able to reflect upon their experience were recruited. Women who had given birth up to 10 years before their participation in the study were eligible to participate in the study. A longer time period since the women gave birth was utilized to adequately recruit a sample of women who have had these experiences. A study by Mitra and colleagues (2016) demonstrated the effectiveness of asking women with physical disabilities, including MS, about their birth experience up to 10 years after giving birth. Exclusion criteria for the

present study included male gender, inability to read, write, and comprehend written English, residing outside of the United States, under the age of 18, and not having a diagnosis of MS. Women who had multiple births prior to the diagnosis of MS with at least one birth after the diagnosis were eligible and were asked to limit their responses to discussing only the postpartum period that occurred after their MS diagnosis. Participants were not excluded from participating on the basis of race, ethnicity, or other sociodemographic characteristics.

Protection of Human Subjects

Participation in this study was completely voluntary. Once a participant had indicated interest in participating in the study, she was able to access the study's informed consent through a Qualtrics link. The informed consent form served to inform the participant about the research, including the risks and benefits of participating in the study. When a participant consented to participation, she clicked "yes" and was taken to the online survey. When a participant did not consent, she clicked "no" and was not directed to the online survey. Only when the participant selected "yes" to the informed consent on the Qualtrics survey, indicating that she agreed to participate in the study, was she able to access the survey. The study was completely voluntary and there was no obligation for a participant to provide any information if she later decided not to complete the study. By allowing participants to save their responses in Qualtrics, the participants were able to add and reflect on their responses, enhancing the richness of the data. Participants were asked to complete their responses within one month of starting the survey so that the information was received in time for data analysis.

One benefit of participating in the study was that the participants had the opportunity to provide information about their experience with a potential benefit of helping to suggest future research or quality of care improvements for other women with MS who have children. The main risk associated with participation in this research study was the potential for emotional distress as potentially painful memories were recalled. On the question prompt, participants were alerted to the National Suicide Prevention Lifeline 1-800-273-8255. This hotline could be used if individuals experienced a mental health crisis or emotional distress and was not reserved solely for individuals who had thoughts of suicide. Additionally, at the onset and completion of the study, participants were alerted to the Postpartum Support International Helpline 1-800-944-4773, which provides support to participants in the event they are experiencing emotional distress related to the discussion of their postpartum experience. Because many participants were recruited from online support groups, they already had a built-in network of support through that medium. Additionally, Beck (2005) demonstrated that women who participated in narrative phenomenological research found direct benefit both in the idea that they were helping others and in being able to express their own psychologically difficult experiences in a cathartic way.

Participants were asked to reflect upon their previous experiences during the first 12 months postpartum. The researcher did not screen for any active symptoms of depression, anxiety, or other emotional distress. Participants who actively felt distressed were provided with the resources identified above and were able to seek help through those resources. The purpose of the research was to have women provide reflections on past experiences and not on current postpartum concerns. Thus, the participants must

have given birth 12 months or later prior to the commencement of the study to avoid participation of women with active postpartum emotional distress.

Setting and Data Collection

The setting of the study was virtual as participants were recruited on social media and other online platforms and consented to participate and participated through Qualtrics, a secure online survey platform. Participants were able to participate in the study by anonymously submitting their responses in Qualtrics. The study was only advertised via Internet so participants were assumed to have the required Internet access necessary to complete the study.

Data were collected through Qualtrics. The data were maintained as completely confidential. Participant identifiers were not linked to the data in any way. Once a narrative was provided to the researcher, it was saved with a participant number that was not linked to any identifying data. Narratives were numbered by the order in which they were received by the researcher. Participants were asked to provide demographic data about age, marital status at time of postpartum period, whether or not they breastfed during the postpartum period in question, how long before the postpartum period before they were diagnosed with MS, how many children they had prior to the postpartum period in question, how many children they had after their diagnosis of MS, whether or not they had psychosocial support during the postpartum period in question, the use of DMTs during pregnancy, the use of DMTs during the postpartum period, past history of depression prior to pregnancy, level of education at time of postpartum period, and employment status in the postpartum period. Participants were then prompted to complete the narrative portion of the study. Participants were asked to describe their postpartum

experience in as much detail as possible. They were asked to describe their emotional states during that time in as much detail as possible by responding to a narrative prompt. The narrative questions can be found in Appendix D and the demographic questions in Appendix C.

Beck (2005) conducted a phenomenological study on birth trauma using a similar population with this method of requesting written narratives over the Internet. In Beck's study of 40 women, narrative responses were e-mailed or mailed to the researcher. In order to facilitate the richness of data that phenomenological research requires, Beck prompted women to describe their experience in as much detail as they were willing to disclose. A similar approach was utilized in this study. Once participants accessed the Qualtrics link, they had ability to save their responses and return to them later. Participants were asked to return responses within 1 month of accessing the survey. When participants indicated on the demographic questionnaire that they would be willing to be contacted with the summary of data analysis, they were asked to provide e-mail addresses that were saved in a separate confidential file on a locked computer and were provided with the summary of results for their review and asked for feedback. Feedback was provided by participants through e-mail correspondence (see Appendix E). Only participants who indicated their willingness and desire to be contacted again were contacted with the summary.

Data Management

When surveys were completed in Qualtrics, the data were downloaded and stored in an encrypted file on a password-protected laptop in the researcher's possession. The narratives did not contain identifiable data. However, since the experiences contained

personal details that could potentially be identifiable, the narratives were maintained in that encrypted file on the password-protected laptop. Data will be stored in this manner for up to 5 years from the completion of the study. The results of the study will be shared through publications and presentations to add to the knowledge base on the postpartum period of women with MS. An external reviewer was engaged to address trustworthiness of the results of the analysis by assuring credibility and validity. The external reviewer had access to the deidentified data to conduct the external audit. The deidentified data were sent from the researcher to the external reviewer via e-mail.

Data Analysis

Colaizzi's (1972) method of data analysis was utilized. As each narrative was submitted, the researcher read each narrative in its entirety. Following the initial reading, a second reading was conducted with the purpose of identifying statements of meaning or "significant statements" (p. 59). Once the statements were identified, the researcher considered each statement carefully for the meaning it contained. These steps were repeated for each narrative. Once all narratives were submitted and read, and all statements of meaning were identified and described, the researcher organized the meanings into clusters of themes and then re-read the narratives to be certain that the clusters of themes were reflective of what was contained in the original narratives. A description of themes was then crafted and condensed into an exhaustive summary describing the meaning of the phenomenon. Study participants who agreed to review the findings were e-mailed the results of data analysis and the description and were asked to comment on the accuracy of the description (Appendix E). That feedback was then read,

reflected upon, and considered for incorporation into the final exhaustive summary (Colaizzi, 1972).

Credibility and Validity

According to Mackey (2012), credibility in qualitative research is established by engagement of participants throughout the study to hold results accountable to the reality of the phenomenon. By providing participants with the completed description and requesting feedback on the accuracy of the description, credibility was established. Two participants responded and reported that the exhaustive description accurately captured their experiences. The researcher ensured validity by accurately describing the meaning of the phenomenon from the point of the participants (Mackey, 2012). Another method of establishing credibility is for the researcher to document the process of data analysis and how themes were developed for the potential review of other researchers (Cutcliffe & McKenna, 1999). Detailed notes were kept by this researcher on how the themes were clustered and developed throughout the process of data analysis. This type of audit trail also established confirmability as it demonstrated how decisions were made throughout the process of data analysis. The audit trail was also reviewed by an external reviewer not associated with the research project but who had expertise in maternal nursing and qualitative research. The external reviewer agreed that the themes identified by the researcher were consistent with the data.

Summary

The aim of the study was to understand the emotional experience of women with MS in the postpartum period. This was accomplished using a phenomenological approach both in the researcher's orientation and approach to the data and, also in the method. A

total of 15 women with MS who were between one and 10 years post-delivery were recruited through social media for their participation. However, only 13 survey responses from women ages 29-43 were able to be used in the data analysis as will be discussed in Chapter 4. After informed consent was provided by the participants, they were asked to provide a narrative describing their postpartum experience. These narratives were analyzed according to a specific phenomenological framework developed by Colaizzi. Colaizzi (1972) outlined seven steps for phenomenological data analysis, which have been previously described. These steps as outlined by Colaizzi were accomplished with the aim of producing a description of the meaning of this phenomenon in its entirety. Credibility and trustworthiness were established through member checking, in which the participants were contacted and were asked to provide feedback on the final analysis to ensure that it is reflective of their responses. Also, the researcher maintained a detailed audit trail so that decisions made by the researcher through the process of data analysis were clear. The auditor concluded that decisions made by the researcher were sound and that the resulting themes were an accurate representation of the data.

Chapter 4. Results

In this chapter, findings of this phenomenological study of the postpartum experience of women with MS are described. This chapter details the data collection process, description of the sample, the data analysis process, a description of the resulting themes from data analysis, and finally provides the exhaustive description of the phenomenon per Colaizzi's method (Colaizzi, 1978).

Data Collection

Data collection began following receipt of initial IRB approval in February 2020. The study was initially posted to social media forums in early March 2020. The first response was obtained on March 9, 2020. During the initial posting of the study, social media users were enthusiastic about the study. The researcher noted that users were commenting on the posting expressing their wish to participate but explaining that they did not meet inclusion criteria (for example, one user resided outside of the United States and another was within the first 12 months postpartum) or expressing their appreciation that a health care provider was studying this topic and asking women who had MS about their experiences. Four responses to the survey were obtained on March 9, 2020. As noted previously, on March 15, 2020 localized lockdowns to decrease the spread and mortality of COVID-19 virus began in the United States (Dunford et al., 2020). The researcher noted a pattern of slowing responses and dwindling enthusiasm as the COVID-19 pandemic became a focal point of American lives. Although causation cannot be determined, the decreased enthusiasm for the survey closely mirrored the initial lockdown phase of the United States. Lockdown included closure of public spaces including schools and places of employment as well as restrictions in leisure activities. In

May 2020, the researcher sought additional IRB approval of a modification of the recruitment process to expand study posting to other social media platforms and the NMSS website. When this modification was approved, the researcher expanded posting of the study and additional responses were obtained from June to September 2020. By September 24, 2020, COVID-19 cases in the United States continued to increase by thousands daily (Adeline et al., 2020). As a result, the researcher collaborated with the dissertation chair and obtained approval to cease recruitment. Previous patterns of participation demonstrated that with worsening COVID-19 cases, participation would likely wane with worsening COVID-19 cases. Review of the narratives indicated that saturation had been achieved.

Participants completed the study through Qualtrics, an online, HIPAA-compliant survey platform. Survey responses were recorded in Qualtrics. Participants had one month to revisit and revise survey responses before they submitted their responses or they could submit them immediately upon completion by clicking submit. A total of 29 participants started a survey response in Qualtrics. A total of 13 surveys were left blank following provision of consent and were not included in analysis. Two participants failed to complete the narrative portion of the survey and were subsequently not included in the analysis. One of these participants provided her e-mail address. This researcher contacted her via e-mail to invite her to complete the narrative portion of the survey, but there was no response. One participant indicated in the narrative portion that her postpartum period was over 28 years ago, which excluded her responses from inclusion in the study as her postpartum period fell outside of the 10-year requirement for inclusion. A total of 13 completed survey narratives were included in analysis.

As responses were recorded in typed text, transcription of responses was not required. Responses were downloaded in PDF format to the researcher's password-protected laptop where they were stored in encrypted file separate from identifying information. Responses were analyzed in their raw PDF format by the researcher. Narratives varied in their length from a short paragraph to 3 pages in length. Responses were more concise than was anticipated but did yield information pertinent to the study's research question.

Description of Sample

Thirteen participant responses were included in the sample (Tables 1-3). Most participants were in their thirties (84.6%, n=11) at the time of the postpartum period discussed. The majority (84.6%, n=11) were married at the time of postpartum period, the other two participants (15.4%) were unmarried but described themselves as in committed relationships. Eight women (69.2%) breastfed during the postpartum period. Five women (38.5%) had children prior to being diagnosed with MS but only four women (30.8%) had another pregnancy following the postpartum period they described in their responses. All women (100%) indicated that they did have support in some form throughout their postpartum period. Only two women (15.4%) used disease-modifying treatment during their pregnancy and both of those women used glatiramer acetate injection (Copaxone). Eight women (61.5%) used disease-modifying treatment during the postpartum period. One woman indicated that she wanted to use a DMT during the postpartum period, but it was not approved by her insurance carrier. Three women (23%) were treated with glatiramer acetate injection in the postpartum period. Two women were treated with natalizumab (Tysabri) in the postpartum period. One woman was prescribed

interferon Beta-1a (Rebif) in the postpartum period and one woman was treated with ocrelizumab (Ocrevus).

Only two women (15.4%) were previously diagnosed with depression prior to the postpartum period they were discussing. None of the women reported being diagnosed with postpartum depression in this postpartum period. Only one woman reported being diagnosed with postpartum depression but clarified that it was not during this postpartum period. That woman did have a pregnancy prior to her MS diagnosis but no pregnancies after, leading the researcher to conclude that her postpartum depression diagnosis occurred prior to the diagnosis of MS. All of the women had post-high school education with ten (76.9%) having at least a Bachelor's degree. Seven women (53.8%) reported working outside of the home in either a part-time or full-time position. Only one participant reported being disabled from MS at the time of the postpartum period being discussed. Two participants reported being stay-at-home-mothers (SAHM).

Table 1. Demographic Data of Participants (N = 13)

Age	Marital Status	Support System	Educational Level	Employment
34-36	Married	Yes	Some college	Part time
37-43	Married	Yes	Graduate school	Full time
36	Married	Yes	Bachelor's	Retired
29-30	Unmarried	Yes	Bachelor's	Full time
29	Married	Yes	Bachelor's	Full time
29	Married	Yes	Bachelor's	Part time
33	Married	Yes	Bachelor's	Unemployed
33	Married	Yes	Bachelor's	SAHM
30	Married	Yes	Some college	SAHM
30	Married	Yes	Doctorate	Full time
32	Married	Yes	Bachelor's	Full time
33	Unmarried	Yes	2-years of college	Disabled
39	Married	Yes	Master's	Unemployed

SAHM= Stay at Home Mother

Table 2. Obstetric History of Participants (N = 13)

Years before MS diagnosed	Children before MS diagnosed	Number of Children	Children after discussed postpartum period	Number of Children	Past History of Depression	Past History of Postpartum Depression
2	No	0	Yes	1	No	No
9	No	0	No	0	No	No
1.3	No	0	Yes	1	No	No
2	Yes	1	No	0	Yes	No
7	No	0	No	0	No	No
3	Yes	1	No	0	No	No
1.5	No	0	No	0	No	No
4	Yes	2	No	0	No	No
5	No	0	Yes	1	No	No
4.5	No	0	Yes	1	No	No
1	Yes	1	No	0	No	Yes
7	Yes	2	No	0	Yes	No
13	No	0	No	0	No	No

Table 3. Treatments and Breastfeeding Reported by Participants (N = 13)

DMT in Pregnancy	DMT Postpartum	Breastfed
None	Ocrelizumab	Yes
None	Yes but not identified	No
Glatiramer acetate injection	Glatiramer acetate injection	Yes
None	Interferon Beta-1a	Yes
None	Natalizumab	Yes
Glatiramer acetate injection	Glatiramer acetate injection	Yes
None	None	Yes
None	None	Yes
None	None	Yes
None	None	No
None	Glatiramer acetate injection	No
None	Natalizumab	No
None	None	Yes

DMT = Disease modifying treatment

Data Analysis

Transcription of the data was not required as survey responses were recorded in text as submitted. As each response was received, the researcher conducted an initial reading of each narrative for appropriateness of the response. A detailed audit trail was

kept by the researcher and was submitted along with the narrative responses to the external reviewer for credibility. The researcher read each narrative a minimum of three times during the first portion of data analysis. Narratives were read and re-read on different days by the researcher to allow for the continued familiarity with the narratives and to minimize the potential of the researcher to miss any important details in each narrative as each reading was fresh to the researcher. The initial reading phase extended over the course of 7 days with additional readings throughout the data analysis process.

In accordance with Colazzi's method (1978), the researcher next re-read the narratives an additional three times and identified statements of meaning within each narrative. A total of 67 statements of meaning were identified from the 13 narratives. Each statement was recorded on a separate document as it was identified. Following identification of each statement of meaning, the researcher re-read all 13 narratives with statements of meaning as a reference to determine their appropriateness and to reflect on the statements. Once there were no further statements of meaning elicited from repeated readings of the narratives, the researcher organized the statements into themes and subthemes. Each theme was then read with the narratives an additional time to ensure that each theme captured the meanings identified in the narratives. A description of each theme was then developed by the researcher. Following the description of each theme, the researcher condensed the themes into an exhaustive description of the overall emotional experience of women with MS in the postpartum period. Data analysis to this point was conducted over 2 months.

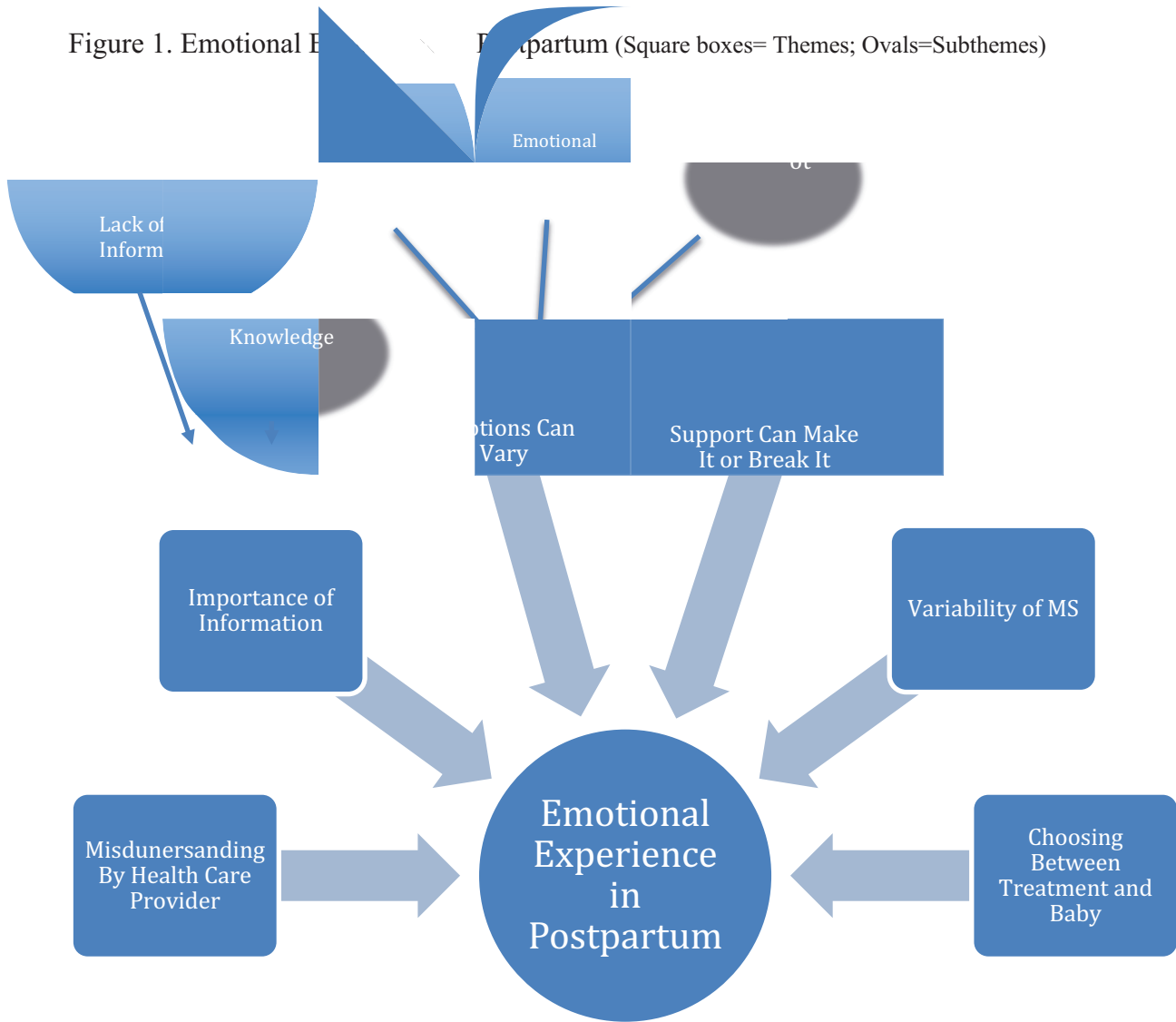
Following the completion of this phase of data analysis, the researcher sent the audit trail which included details on the identification of statements of meaning, how

statements were organized into themes, the description of themes, and the exhaustive description to the independent reviewer to be analyzed for credibility. Additionally, of the 13 women whose responses were included in data analysis, eight of them provided an e-mail address indicating that they wished to be contacted with the results of data analysis and were willing to provide feedback on the results. Each participant was contacted individually by the researcher via e-mail using the e-mail address the participant provided. The subject line of the e-mail indicated the name of the study and the body of the e-mail contained the collective exhaustive description for their review. Appendix E provides a copy of the instructions sent to the participants. The participants were asked to provide their feedback within 10 days. All e-mail correspondence was sent from the researcher's Villanova University e-mail address. Two participants responded indicating that they felt the exhaustive description was accurate.

Description of Themes

The study results clearly identify the postpartum period as an emotional one by the women with MS who participated in this study. A total of six themes and five subthemes related to the emotions experienced by the study participants and issues related to those experiences were identified in data analysis. The following graphic (Figure 1) lists each theme and subtheme. Each theme and subtheme then are discussed individually.

Figure 1. Emotional Experience in Postpartum (Square boxes= Themes; Ovals=Subthemes)



Misunderstanding By Health Care Provider

Several women indicated that their health care providers were uninformed about symptoms or issues pertaining to the postpartum period in the context of MS.

Unfortunately, not one of the respondents identified the types of health care providers

(e.g., nurse, doctor, midwife, nurse practitioner) or their specialty (e.g., emergency medicine, obstetrician, neurology). Women described that the lack of understanding led to the provision of care that was not congruent with their expectations. One woman noted “I was not treated well because of this and I was practically begging to leave. It was not a good experience at all. I have four older children and this was the worst of them all.” One participant described that prior to leaving the hospital after delivery, she was prescribed corticosteroids to prevent MS relapse. She had previously received corticosteroids and experienced mania as a result, a common side effect of corticosteroid treatment. She stated:

They [steroids] caused me to have a manic episode and I was stuck in the hospital room for 4 extra days. Which prompted the hospital to question my ability to parent and also had them call dcf [child services] even though I explained that I was back on meds the day my son was born and that steroids trigger mania.

She stated that she was not treated well by hospital staff because of the side effect of steroids and described it as “the worst experience.” This participant experienced emotional distress because of her MS treatment. Her providers failed to understand that it was her treatment causing these symptoms leading them to question her fitness as a parent rather than providing support for her during this experience. Her description demonstrates that this episode of misunderstanding caused a stressful and emotional situation to be even more distressing.

Another participant described experiencing anxiety symptoms from restarting glatiramer acetate injection in the postpartum period after delivering a stillborn son at 20

weeks gestation. When she restarted glatiramer acetate she noted “my anxiety flared because I wasn’t used (sic) to the Copaxone.” She described a visit to the emergency room for a panic attack expecting that her concerns that this was a side effect from Copaxone would be addressed. However, she reported that this was not mentioned by providers. She reported being told that “it was postpartum because we experienced a loss. I’m sure that played a key [role] but it wasn’t the only factor.” She described feeling misunderstood by providers and stated that they did not understand the entire clinical picture and were focused only on one aspect—the loss of her child. The health care providers did not consider the emotional distress she was experiencing in the postpartum period as a result of MS treatment. She wrote “I had a hell of a couple of months post [partum].” Again, this was another participant who reported an already emotionally charged situation exacerbated by lack of health care provider understanding.

Another participant noted that she had to deliver with the assistance of a provider who was not her “regular doctor.” She wrote “my regular doctor didn’t deliver him and I felt like things were not going smoothly like we talked about.” Although she did not describe the details of this, she did note that she did not feel like her experience proceeded as planned. Her narrative implied that she had previously spoken to the provider she thought would preside over her delivery about specific MS-related concerns and they had developed a plan, but when that provider was not available, a covering provider presided over the birth and likely did not consider her concerns.

One participant described her experience with a health care provider as not only being misunderstood but also as being shamed. This participant had to make a difficult choice between restarting DMT in the postpartum period or breastfeeding her newborn.

She opted to restart DMT. She wrote “I was shamed at the hospital by a doctor for not breastfeeding when it was because I was looking out for the best for my baby...” She explained that she felt being on DMT would allow her to be more physically active, healthier, and therefore, a greater participant in her child’s life. After she considered her options, she felt that she would be the best resource and parent to her child if MS was treated so she chose to feed her child formula. Rather than receiving help in making her decision to resume DMT or to breastfeed, she patient felt that the health care provider’s lack of understanding of this difficult choice was judgmental and caused her to feel ashamed. She felt misunderstood by the provider because she felt she was judged negatively for a decision that she did not feel the provider truly understood.

In each of these examples, women described their experiences with healthcare providers as unfulfilling and sometimes shameful. Their descriptions demonstrated that health care providers failed to understand the complex elements of MS in the postpartum period, including treatment. Two participants described emotionally distressing side effects from MS treatment and found that health care providers questioned their ability to parent or failed to address their concerns regarding MS treatment. In the second example, a participant made a difficult decision to stop breastfeeding in order to resume MS treatment and felt shamed by her provider who did not understand the intricacies of her decision and how her decision was impacted by having MS. These narratives revealed that the lack of support and understanding of MS and postpartum by the health care community exacerbated emotional distress in these women. To use the words of one participant, “It was not a good experience at all.”

Importance of Information

Women described two different experiences related to the importance of information. Some women felt that information regarding MS and pregnancy/postpartum was inadequate and described more negative postpartum experiences. Women who described feeling informed, reported feeling empowered and described more positive emotional postpartum experiences. To encompass these views, two subthemes were identified: Lack of Information and Knowledge is Power.

Subtheme: Lack of Information

Some participants indicated that there was a lack of information regarding postpartum care in the context of MS, including use of DMT and breastfeeding in the postpartum period. Women described that there was not a lot of information available to them regarding how to balance strategies to address their MS disease process with caring for their newborn. Women also identified a desire to participate in future studies that addressed use of DMT in the postpartum period and how to make decisions that addressed their need to balance their own health and the health and well-being of their babies. Most MS treatments are considered to pose some risk when passed through breastmilk. Women felt conflicted about having to choose between their own health by avoiding an MS relapse and breastfeeding their baby. One woman described that by getting back on DMT and not breastfeeding she felt she was doing the best thing for her child. By not experiencing active MS flare, she could be more physically present and active in her child's life. She noted, "would love to help with the poor research and information for mothers with MS, postpartum and dealing with DMT decisions." Another participant wrote that she would "love to see more studies come out on breastmilk and if the medicine can truly pass through the milk to the baby." Women described their

decision about breastfeeding as very emotional. One woman reported feeling “like a failure not being able to breastfeed.” Another noted that she had to stop breastfeeding to restart DMT treatment when MS worsened. She wrote:

I was breastfeeding and had to stop at about two months postpartum so I could go back on my Tysabri. That was the most emotional time since I had planned on breastfeeding at least 6-9 months. I would have loved to have breastfed longer.

Women described that without adequate information regarding compatibility between use of DMT and breastfeeding, they often felt torn in their choice. Women who felt ill-informed about this topic felt more emotional distress.

Subtheme: Knowledge is Power

Not every participant felt inadequately informed about managing MS in the postpartum period. However, those who described being informed noted that their knowledge came from their own research and independently seeking out knowledge, rather than from their health care providers. Again, women did not specify the type of health care provider they expected to provide the information to them. For example, one woman described doing her own reading about how breastfeeding has been associated with decreases in MS relapses. She noted “I did breastfeed for 18 months because I had read some reports of breastfeeding providing some relapse protection.”

When describing the positive impact of information, the topic was not limited to DMT and breastfeeding. One mother indicated that just by understanding her own symptoms and course of MS, she felt that she was able to deal with MS symptoms in a healthier way in the postpartum period. She noted that she had symptoms of MS with a

previous pregnancy but had not yet been formally diagnosed with that pregnancy. Once she was diagnosed and understood the symptoms of MS, she was able to be more understanding of the challenges in her postpartum experience. She reported:

My easiest postpartum recovery was the post-diagnosis recovery. I attribute this to a strong support system and knowledge and awareness of having MS. I was able to allow myself to rest more without feeling guilty I was being lazy.

Due to her knowledge of MS, she knew she would need extra rest periods to compensate for additional fatigue. Once she received a diagnosis and was knowledgeable about the symptoms of MS, she was able to make allowances for her need for extra rest rather than feeling guilty or distressed that she was tired.

Another woman noted that she received her diagnosis of MS prior to starting fertility treatments and had MS with all of her pregnancies. She wrote her narrative response detailing her most recent pregnancy. She wrote about accepting treatment with corticosteroids after delivery and how the knowledge of postpartum within context of MS allowed her to be accepting of this treatment. She describes that the use of steroids “reminded me of what I felt like to be human and I will be forever grateful for being able to enjoy my newborn like a normal happily exhausted mother.” With her first pregnancy, also in context of MS, she noted that she did not receive preventive treatment for MS relapse in the postpartum period. Her increased knowledge allowed her to be more accepting of MS treatment in the postpartum period and experience what she termed a “normal” postpartum period.

Women who were knowledgeable about MS and knew what to expect in the postpartum period not only from their own bodies but also from previous treatment had an easier time making decisions pertaining to MS care and also described more emotionally positive experiences than women who lacked information. Women who lacked information described uncertainty and hesitation that led to some anxiety while women who felt they had adequate information described feeling empowered to make best decisions for their health.

Emotions Can Vary

The narrative prompt used in this study encouraged women to describe their emotional experiences in the postpartum period in as much detail as possible. Unfortunately, the majority of the narratives were brief in their description and did not contain as much detail as the researcher had hoped. However, women described various emotions that occurred in the postpartum period in the context of MS and reported a range of emotional experiences. The most common emotion was anxiety, which is one of the study's subthemes. A second subtheme titled "General Emotional Distress" was used to capture the other range of negative emotions. A third theme "It's Not All Bad" was developed to demonstrate that with MS, women had some positive emotional experiences in the postpartum period.

Subtheme: Anxiety

The most common emotional symptom reported was anxiety. One woman noted that since being diagnosed with MS "anxiety has played a bigger role in my life." Women described experiencing worry and anxiety about having another relapse. One woman had her most serious MS relapse one year after giving birth to her first child. As a result, she

wrote “with my second child I was very scared for a relapse.” Another woman noted that she started to experience “bad anxiety around week 2” of her postpartum period but was able to cope with anxiety because “I had my husband and family for support.” Women also described anxiety about their ability to care for their children because of MS symptoms. One woman noted that because of MS-related gait disturbances she feared “going down the stairs with my baby.” Another noted that although she fared well in the postpartum period, her disability had progressed to point of her occasionally needing a wheelchair, which has increased her anxiety about her role as a parent. One woman noted “having fear of a possible flare up on the back of my mind 24/7.” Another participant indicated that her experience with postpartum anxiety lasted for 6 months and required pharmacologic intervention. Although one participant noted that she was not necessarily anxious, she indicated that had her MS symptoms been more severe, she would have had more anxiety and may have decided not to consider having a child. She wrote “my MS has been very mild which is why we decided to have another child after my diagnosis. Because of this, I wasn’t consumed with worry.” Her quote suggested that if her MS symptoms were more severe, she would have been too anxious or worried to have another child.

Subtheme: General Emotional Distress

Anxiety was prevalent but was not the only emotional experience that was reported by the participants. Women reported feeling like a failure or sadness. These emotions are often associated with experiences of depression. It is important to note that in the descriptive data, none of the participants reported being diagnosed with postpartum depression during the postpartum period they discussed. Only one participant

experienced postpartum depression and noted that it occurred with a different pregnancy postpartum period than the one she discussed in this study. Although none of the study participants described clinically diagnosed depressive episodes, many described symptoms of depression. One mother wrote “I cried every day for a few months.” Another wrote that although she did not think she suffered from postpartum depression, she did experience poor mental health during the postpartum period. She explained:

I didn't suffer from postpartum depression, but my mental health during this time was not great. I kept making myself check in with how happy I was with my baby, how he felt in my arms at that age, because everything else was a mess. My relationship, my family dynamic, and my self-confidence with my body. I tried very hard not to hate my body.

She continued “I think choosing to reframe these situations helped keep me from experiencing depression.”

Many women described feeling that they had failed in some way or that their body had failed them. The same participant quoted above noted:

I had always hated my body, but then it gave me the greatest gift. The body I loathed so much produced my greatest love. I swore to love my body and I tried very hard during these lactation troubles. Though I felt like a failure not being able to breastfeed and give my son the absolute best immune promoting food I could give him, I forced myself to remember that my body may not let me do this one part of motherhood, but it made me a mother.

Another participant wrote that she felt emotionally distressed because she had to stop breastfeeding to pursue treatment for MS during a flare and noted “that was the most emotional time.” Another participant noted that she was unable to massage her breasts to promote breastfeeding due to pain and physical limitations related to MS. She also noted that she was unable to maintain the rigorous schedule of breastfeeding because of her fatigue. She described feeling disappointed that she was unable to breastfeed due to physical issues with her MS. She noted “Giving up on breastfeeding was a very hard decision.”

Subtheme: It's Not All Bad

Although some participants described negative emotional experiences, not all women described their postpartum experience in a negative way. Some women reported experiencing positive emotions as well. One woman noted “I truly loved bonding and nurturing my baby during the postpartum period.” Another noted that she had a positive postpartum experience and was looking forward to having another child. She stated, “very excited for number 2 arriving this September.” One woman noted that she felt positively because she found pregnancy and postpartum to be a time of less MS symptoms. She wrote “But really I felt better with the pregnancy and the breastfeeding than I did before or after the breastfeeding was done. The added hormones made my MS symptoms go away. I am looking forward to being pregnant again.” Another participant described enjoying her postpartum time; she noted “I enjoyed my early mommy time very much (as I do now).”

Support Can Make it or Break It

Women who reported having positive support systems in their lives wrote that support helped them have a more positive emotional experience in the postpartum period. One woman noted that she had a “wonderful” postpartum period and attributed that to her support system. She wrote “I have an extremely loving and supportive husband who helped take care of the household and our family while being the sole supporter of our household.” She wrote about how her husband took on extra roles during the postpartum period to help compensate for her needing rest because of distress or MS symptoms that she experienced. Another participant indicated that the only reason she was able to cope with postpartum anxiety was because of familial support. Another woman noted that her family realized that she needed extra support in the postpartum period following her diagnosis of MS and provided it. She noted “easiest postpartum recovery was the post-diagnosis recovery” because of their support. She continued “I attribute this to a strong support system.”

Other women noted that when support was unavailable they experienced a more difficult postpartum period. One woman described conflict between her mother and her husband which led to decreased support for her. She wrote “the first couple of weeks were so hard interpersonally. The stress was palpable.” Another woman described that her in-laws stayed with her and her husband but were unable to care for themselves and thus detracted from support rather than added to it. She wrote “I was miserable for 10 days failing nursing and pumping before I gave up and the in-laws were there the whole time (they needed care themselves and were unable to help us).” The presence of support tended to help make the postpartum period a positive experience, whereas the absence led to a more negative experience.

Variability of MS

MS is a disease with considerable variability in symptom presentation both among individuals with MS and within one individual at different times, for example, during periods of relapse versus periods of remission. It was not a surprising finding that women reported several different MS symptoms in their postpartum experiences. Women described fatigue and exhaustion beyond what is typically experienced in the postpartum period. One woman noted that in previous postpartum periods she did not have MS treatment but in one she did and described that with treatment she felt “like a normal happily exhausted mother.” She noted that with treatment of MS, she was exhausted but in a “normal” capacity, as in not overly fatigued with MS.

Women also described relapses of MS during the pregnancy up until one year postpartum. One participant noted that with her second pregnancy with MS she noted “worsening MS and new MS symptoms.” She did not, however, elaborate on which symptoms worsened and which symptoms were new. In contrast, other women noted that pregnancy was “a breeze” or that symptoms remitted “around 35 weeks”. Some women noted paresthesia or gait changes. One participant wrote, “I had some numbness and tingling in my right leg and foot.” Another noted “a little bit of tingling in my fingers but nothing major.” Women who had received treatment for MS, with either DMT or steroids, noted that symptoms were less severe, with one woman noting “my neurologist did a 2-day round of IV steroids after my C-section to hopefully avoid any flare-ups or issues.” Another noted that she had symptoms despite DMT treatment; when she experienced a relapse at 8 months postpartum, she made the decision to change her DMT treatment.

Choosing Between Treatment and Baby

Among the most emotionally taxing events in postpartum for the participants were decisions surrounding DMT use and pregnancy and postpartum. Women explained that they had to choose between treatment for their chronic and progressive illness and breastfeeding or in some cases even having a child. One woman noted that she had to stop an oral treatment for MS and stated, “I had to eliminate Abaugio from my system prior to becoming pregnant but chose not to get back on medication due to breastfeeding and wanting another child.” Another participant noted that the most emotional time for her in the postpartum period was when she had to make the decision to stop breastfeeding at two months postpartum to resume DMT treatment for MS. Another participant reported that she had to stop breast feeding at 3.5 months for the same reason.

One participant noted she, “decided not to breastfeed because I wanted to get started on Ocrevus [another DMT treatment for MS] ASAP and be able to rest when needed.” Sometimes, women chose to breastfeed instead of pursuing MS treatment. One participant noted “I made an appointment with my neurologist after a few weeks and he recommended medication but I decided not to start anything” because of her desire to continue breastfeeding. In contrast, another participant noted that she opted to restart her MS treatment immediately after delivery, which meant she could not breastfeed, and she described being “shamed” by a health care provider for her decision to not breastfeed.

One participant made the decision to restart treatment and stopped breastfeeding but her treatment was delayed due to insurance issues. She noted that she had 11 new lesions on imaging due to the break in treatment; this concerned her because such lesions could cause long-lasting physical impairment. The decision to resume MS treatment or

breastfeed is not an easy one and many women received differing opinions from their health care providers, with some women indicating that providers recommended restarting MS treatment immediately after delivery and others emphasizing to women that breastfeeding was most important. Again, women did not mention which types of health care providers were providing these recommendations. Regardless of whether or not they received helpful guidance from providers about the decision to treat MS or breastfeed, the participants noted feeling saddened about not being able to experience breastfeeding at all or having to stop their breastfeeding efforts earlier than anticipated to restart DMT in an effort to minimize progression of their MS.

Exhaustive Description

The phenomenological method used for this study dictates that once all themes are identified, they be condensed into an exhaustive description which is intended to conceptualize the phenomenon as experienced by the participants. After development and revision of themes, the following exhaustive description was developed.

The postpartum experience in the context of MS can vary, particularly in regard to the type and severity of MS symptoms experienced. There are some treatment options that can decrease the severity of MS symptoms during this time, including the use of DMTs and steroid therapy; however, the treatments can also further complicate this experience and the decisions women had to make during the postpartum period. Some women experienced increased anxiety when restarting MS treatment, while others felt that they had to make an emotionally challenging choice between MS treatment to prevent relapse or breastfeeding their newborn. This decision had an emotional impact, with women reporting feeling shamed, saddened, or having failed. Supportive family and

friends were essential in aiding the emotional and overall postpartum experience of women with MS. Women who had support from family and friends reported less anxiety and a less tumultuous MS course than women who did not have such strong support. If support was problematic, it often led to increased anxiety. Lastly, information is an essential component of managing a chronic illness such as MS in the postpartum period. Women felt that they did not have adequate information about MS treatment options and the potential impact of those treatments on their newborns. They also felt a lack of understanding and support from their health care providers. Some women reported that providers failed to recognize that emotional reactions could be related to MS treatment and the women felt judged or shamed by their providers. Women who had information about MS treatment options and ways to reduce MS symptoms in the postpartum period reported more positive postpartum emotional experiences. Despite the challenges, women felt joy over being mothers and many noted that they would have another child if they could.

Conclusion

The postpartum experience among women with MS is individualized and variable but there are a few common themes that were experienced by the participants. Women experienced a range of emotions including anxiety, sadness, and joy, with anxiety being the most common. The quality of support and support systems mitigated the emotional experiences with strong support systems identified as having a positive impact on emotions and weaker or tumultuous support systems leading to more negative emotional experiences. Additionally, the presence or absence of information played a significant role in the emotions experienced. Although the physical symptoms of MS varied in their

experience, many women struggled emotionally with the decision to resume MS treatment versus breastfeeding. Women felt misunderstood by their health care providers when they presented with side effects from MS treatment or when they made decisions that affected their ability to breastfeed or the clinical course of their MS.

Chapter Summary

Participant recruitment and data collection were robust initially but stalled with the beginnings of COVID-19 pandemic in the United States in 2020. Consequently, modifications to the IRB application were made and once approved, recruitment was expanded to other social media platforms and through NMSS. A total of 29 participants accessed the survey, 16 completed some aspect of it, and one participant's response was not considered in analysis due to the participant's not meeting inclusion criteria. Thus, a total of 13 narratives submitted by the women were analyzed yielding six overall themes and five subthemes. Eight women were contacted with the results and asked for their comments. An external reviewer reviewed the audit trail kept by the primary investigator as well as a sample of responses for credibility. Chapter 5 will include a discussion of the findings in relationship to the existing body of literature and will also comment on limitations of the study, as well as suggest directions for future research.

Chapter 5. Discussion of Findings and Implications

A total of 13 participant survey responses of women with MS who recalled their postpartum experiences one to 10 years earlier were reviewed and analyzed for descriptive statistics and themes relating to emotional experiences in the postpartum period. Although a total of 29 individuals accessed the survey, only 16 participants completed at least a portion of the survey. Of those 16, one participant indicated in her narrative response that her postpartum period occurred outside of the inclusion criteria limitation of 10 years previous, and two others did not complete the narrative portion of the online form. Thus, 13 narrative responses were analyzed resulting in 6 themes and 5 subthemes. Each theme will be discussed in relationship to the existing literature. Rigor, limitations, and implications for practice, research, and education will also be discussed.

Health Care Providers

Participants in this study identified a lack of understanding on the part of the health care providers from whom they were seeking treatment and postpartum care. Unfortunately, the participants did not identify the type of health care provider (physician, advanced practice nurse, nurse, etc.) nor the specialty of those providers. Participants in the study discussed that when health care providers failed to understand the complexities of MS during the postpartum period, they felt judged, shamed, or even anxious. This is a theme that is echoed in the current body of literature. Smeltzer (2002) found that women with disabilities who were making the decision to have children were often frustrated by the lack of information available to them by their health care providers. Prunty and colleagues (2008) found that health care providers were often negative and discouraging in their interactions with women with MS who were opting to

pursue pregnancy. Although the Prunty and colleagues study involved women who were deciding to have a child, the negative reactions on part of health care providers appears to continue into the postpartum period for women with MS. Similarly, a study conducted by Mitra and colleagues (2016) identified that health care providers responded in ways that demonstrated a lack of understanding of the experience of women with physical disabilities. Findings of that study described inconsistent support and encouragement in pursuit of pregnancy and even surprise at the desire of women with disability to pursue pregnancy. The results of the present study echoed the concerns that women with MS who are seeking support or guidance from their health care provider in the peripartum period are often met with a lack of understanding of the unique needs and complex issues facing women with MS during this time.

The current recommendation for women with MS who are pursuing pregnancy or are pregnant is for women to partner with their health care provider to discuss how to manage MS during the pregnancy and postpartum periods (Amato et al., 2017; Dobson et al., 2019). This requires that health care providers are familiar with the latest evidence regarding the issues specific to the postpartum woman with MS. Women with MS will be cared for by neurologists, obstetricians, nurse practitioners, nurses, lactation consultants and other health care professionals in these specialties. All of these health care providers need to be aware of the latest evidence concerning pregnancy in MS. This includes treatment options and a discussion of risks and benefits associated with pursuing or not pursuing treatment during the postpartum period as it pertains to breastfeeding status. Additionally, a discussion of the emotional experiences, such as anxiety, that can occur during this time should be included. Recent guidelines from the Association of British

Neurologists support breastfeeding and corticosteroid use for management of MS in the postpartum period (Dobson et al., 2019). Familiarity with current treatment guidelines is essential for the health care providers, who are likely neurologists and/or obstetrical providers, providing care for the woman with MS in the postpartum period to decrease emotional distress among women with MS. A study by Borislow and colleagues (2014) sent questionnaires asking knowledge-based questions about managing women with MS during pregnancy to German neurologists. About half (54%) of the questions were answered correctly by the responding physicians and the authors commented that the more experience providers had treating patients with MS, the more likely they were to answer these questions correctly. Neurologists, who are the specialty physicians providing care for patients with MS, were only able to answer half of the questions about MS and pregnancy correctly. These results highlight a significant knowledge deficit for providers caring for patients with MS. There have not been any studies identified exploring the knowledge of treating women with MS during the postpartum period among obstetric providers. Additionally, a study by Horner-Johnson and colleagues (2020) indicated that women with physical disabilities have longer rates of hospitalization in the postpartum period than is typically expected. This novel finding provides further evidence for the need for health care providers to be well-informed about MS in the postpartum period. Additionally, health care providers must collaborate across specialties to provide excellent care for women with MS.

As the body of evidence for caring for women with MS in the postpartum period expands, providers caring for women with MS need to remain up to date on most recent literature and collaborate with one another, sharing their expertise regarding pregnancy

and MS to merge knowledge. Sources of information and networks can include in-person and virtual conferences, blogs, and publications of medical and nursing organizations. Health care providers must understand the science of childbearing and MS and the needs and concerns of child-bearing women with MS. Only then can they offer realistic and supportive emotional care as women navigate postpartum decisions that will affect their health and the health of their newborn.

Importance of Information

Closely tied to the theme of misunderstanding on part of health care providers, is the importance of information regarding MS and postpartum period. Participants in this study identified that not having adequate information about aspects of MS in the postpartum period could create a negative emotional experience whereas having information about MS and postpartum decisions allowed women to feel empowered and have a positive emotional postpartum experience. Anderson and Wallace (2013) found that women with MS reported a lack of clear and readily accessible information about MS in the postpartum period. Additionally, when women with MS were asked to respond to questions about MS, only 6% (n=49) of women with MS were able to correctly answer any questions about MS and pregnancy (Albrecht et al., 2010).

Borislav and colleagues (2014) conducted a similar study with neurologists in Germany and found that their sample of neurologists (n=56) were only able to answer 54% of questions about MS and pregnancy correctly. Smeltzer (2002) demonstrated that women are often looking to their health care providers for information about what to expect in the postpartum period. Health care providers are often a source of information for individuals with a chronic health condition; however, as noted in the previous

discussion, there is a knowledge deficit among health care providers about MS and pregnancy. This finding is of concern because health care providers who are not knowledgeable about the interaction of pregnancy and MS are likely to be unable to provide adequate information and knowledge.

In this study, women identified that not having information about MS and postpartum created emotional distress, most notably anxiety. Smeltzer (2002) found that when women were unable to access information about their condition and pregnancy, they were often left feeling frustrated. Whether the emotional response is anxiety or frustration, it is clear that not having easily available and clearly stated information about MS and postpartum can result in emotional distress for women with MS.

One important finding that differentiates this study from what is currently available in the literature, is the positive aspects of having information for women with MS. Having information did not just eliminate negative emotional experiences, but also contributed to positive emotional experiences. Women who had some knowledge about MS and postpartum described feeling more empowered. For example, women who were educated about the options available to them in the postpartum period chose to have MS-related treatment in order to diminish MS symptoms, decrease the risk of relapse and be more physically present. One woman noted that she opted for steroid treatment and that it allowed her to feel like a “normal” postpartum mother and enjoy the postpartum period that way. Another woman noted that just having knowledge about MS in general allowed her to better understand the unique needs of her body during this time. She noted that before she knew she had MS, she would feel guilty about being “lazy” when she was overcome with fatigue. Having knowledge about her disease process allowed her to be

more accepting of the increased periods of rest required by her body during the postpartum period and also enabled her to arrange supportive help earlier and be more prepared to accept and be comfortable with accepting help. The availability of adequate information and knowledge about MS in the postpartum period is crucial to improve the emotional experience of women with MS during this time.

Emotions Can Vary

The participants in this study reported a range of emotions during the postpartum period. They described emotions that included anxiety, sadness, feeling like a failure, but also joy and happiness during this time. Most of the research in this population has focused on the experience of negative emotions, primarily postpartum depression. Depression is more common in individuals with MS than in the general population (Murphy et al., 2017). Surprisingly, women in this study reported experiencing more anxiety than depression. A meta-analysis by Boeschoten and colleagues (2017) demonstrated that 58 studies reviewing the psychiatric experiences of women with MS found that the experience of anxiety symptoms was also quite prevalent in 40% of the collective study participants (n >87,000). The Boeschoten and colleagues study also included studies in which anxiety symptoms, not just anxiety disorders, were discussed. This is pertinent as participants in this current study did not discuss being diagnosed with a psychiatric disorder but rather described the experience of feeling anxious. The emotional experience of anxiety was echoed by the findings of the meta-analysis by Boeschoten and colleagues. Anxiety can also be a predictor of depression symptoms for individuals with MS (Gay et al., 2017).

Current evidence supports the high likelihood of anxiety in individuals with MS and this study supported the link of anxiety and MS. Interestingly, a study by Tauil and colleagues (2018) examined prevalence of anxiety in 132 men and women with MS. Using a screening tool for anxiety, they determined that 7.6% of the participants experienced anxiety. They also investigated any link between the presence or absence of anxiety when DMT was used and found that treatment with DMT did not affect the rate of anxiety in this population.

Much research has focused on the experience of postpartum depression in women rather than anxiety. Rados, Tadinac, and Herman (2018) recently examined the experience of postpartum anxiety in women within the general population. They administered several screening tools for anxiety and depression to 272 postpartum women. About 40% of the 272 women in the Rados et al. study were reported to have high anxiety at some point in the postpartum period. The prevalence rates for anxiety and depression were fairly equivalent with both disorders occurring at rates of about 20% and depression and anxiety were likely to occur together. The present study also demonstrated that the experience of anxiety was of concern for women with MS in the postpartum period. Future research further exploring the experience of anxiety for women with MS in the postpartum period is recommended.

Anxiety was not the only negative emotional experience for women in this study. Women described feeling as if they were a failure. Wilson and colleagues (2019) noted that most studies on postpartum emotional experiences tend to focus on depression but there are other distressing emotions that are less often addressed. Wilson and colleagues did not include an assessment for shame or feelings of failing, but they did address other

negative emotional experiences including irritability and stress. In a sample of 78 women in a residential early parenting program, 97.5% of them reported feeling some sort of distressing emotions (Wilson et al., 2019). The authors concluded that simply assessing for the presence or absence of depression is insufficient to capture the range of negative emotional experienced by women in the postpartum period. Gulick and Kim (2004) studied emotional experiences in women with MS and found that women with MS did experience emotional distress in the postpartum period, again noting that there were negative emotions other than just depression. The results of the present study support Gulick and Kim's (2004) findings as women did not describe depression, but did describe anxiety, shame, sadness, and other emotionally distressing symptoms that are not classified or typically considered as part of the depression experience.

Although negative or distressing emotional experiences are certainly of concern, it is important to note that not all of the emotions experienced by women in the present study were negative. Women reported positive emotional experiences, such as excitement and happiness as well. Positive emotional experiences have not been as well studied. Smeltzer (2002) found that although women with physical disabilities had some concerns about pregnancy, they did indicate that it was a psychologically positive experience for them and helped them to feel normalized. In the present study, women did identify great joy with the experience of having a child. Exploring what predicts and can foster positive emotional experiences in women with MS and other physical disabilities will also be an important topic of research moving forward. Greater understanding of the positive experiences of postpartum for women can provide insight into how health care providers

can continue to foster those positive experiences to improve postpartum emotional well-being.

Support Can Make it or Break it

Participants in this study identified that having support in the postpartum period was essential to their physical wellbeing and to the provision of childcare which led to more positive emotional experiences. One participant described that during her postpartum period there was tension between her husband and her mother. This tension detracted from the support that she was able to receive from these family members. She described a more emotionally difficult postpartum period. The concept of support creating emotionally healthier postpartum periods for women is not a foreign concept, especially to women with MS or other physical disabilities.

Smeltzer (1994) found that women with MS anticipated needing extensive support from others in the postpartum period and made arrangements for the procurement of that support in advance. Smeltzer (2002) and Prunty and colleagues (2008) examined the decision-making process about childbearing in MS. Both studies found that women with MS understood that they would need the support of family members to care for themselves and their child after delivery. Both studies also found that the availability of support was a factor that determined whether or not to pursue pregnancy. A study by Anderson and Wallace (2013) also found that women with MS knew that they would need support in the postpartum period but interestingly, women noted that they felt selfish for a decision to have a child knowing that they would require the assistance of others to successfully navigate the postpartum period as a result of their MS. Payne and MacPherson (2009) noted that women with MS required support from their partner and

their extended family networks in the postpartum period. Participants in Payne and MacPherson's study indicated that not only would they need support to physically care for their child but also emotional support during this time. Thus, women with MS in the present study and previous studies recognized their need for support of others because of their disease process and its effects on physical functioning. It is likely that women with MS feel the need for support from others in the postpartum period earlier and more acutely than women without MS. Future research should determine how health care providers can increase support provided to mothers with MS and how health care providers can provide education and preparation to the loved ones of women with MS who may be called upon to offer support in the postpartum period.

Variability of MS

Current literature supports an increased likelihood for MS relapses within the first 3 months postpartum (Vukusic et al., 2004; Coyle, 2014; Coyle, 2016; Fragoso et al., 2013; Houtchens, 2013; Jalkanen et al., 2010). Women in the present study reported a wide variety of MS symptoms. Some reported minor symptoms like tingling or numbness in digits. Most women described severe fatigue beyond what they believe would normally be expected in the postpartum period. One participant indicated that she had severe MS symptoms but did not elaborate on what those symptoms were. Some women reported that with the help of steroids they did not experience any relapses during the postpartum period and described feeling healthy during this time.

A study by Anderson and colleagues (2021) examined the presence of central nervous system lesions and disability in women with MS in the postpartum period. The study included 119 women but of those 119 women, the participants had a total of 155

pregnancies. Of those 155 pregnancies, 31% were associated with new MS lesions on MRI. However, new lesions were not always correlated with changes to disability status as only 16% of pregnancies were associated with changes to the disability rating scale. Thus, even though a relapse may not be manifested with changes in disability status, there is increased likelihood for worsening of MS status and development of new lesions in the postpartum period. Women in this study also indicated that they attributed the increase in lesions to their being off of DMT during their peripartum period.

The results of this present study and the current literature indicate that the experience of postpartum relapses can vary in terms of presence or absence of relapses and severity. Not all women experience a relapse. Additionally, there are some strategies that can reduce the risk of relapse, such as treatment with corticosteroids in the early postpartum period. Women in this study indicated that when they were treated with corticosteroids early in the postpartum period they were able to function and feel physically improved in their ability to meet the physical demands of the postpartum period. Dobson et al., (2019) have supported the use of corticosteroids in the postpartum period for women with MS. Not only do health care providers treating women with MS in the peripartum period need to be aware of these recommendations, women with MS also need to be aware of the impact of corticosteroids on the experience of relapses in the postpartum period in order to make informed decisions and advocate for the best care possible.

Choosing Between Treatment and Baby

One of the most highly emotional and debated topics in postpartum care has been the decision to breastfeed. The CDC (2021) currently supports exclusive breastfeeding

for the first 6 months of an infant's life as the gold standard. However, breastfeeding is not always an easy or even feasible process for new mothers. Gianni and colleagues (2019) found that of 552 mothers who intended to breastfeed 70%(n=338) of them encountered significant challenges to breastfeeding including fatigue and other physical concerns. Of women who experienced challenges in breastfeeding, 189 women (48%) of reported feeling that they had support from their health care providers to persist in breastfeeding. The decision not to breastfeed or to discontinue breastfeeding has been a highly debated topic in the United States for years. An editorial by Mullan (2015) details that social media has continued to allow the debate surrounding breastfeeding to flourish. Women have felt pressure and judgement when they are unable to or decide not to breastfeed. Even in Mullan's editorial, which takes the position that the debate on breastfeeding should never have occurred because breastfeeding is clearly best and health care providers must determine ways to better support women to achieve this goal. However, as the participants in this study have demonstrated, breastfeeding is not always an option for women, particularly those with MS. One of the most distressing events in the postpartum period identified by women in this study was the decision to either breastfeed or to resume DMT treatment. Participants indicated that they often felt conflicted about the decision to resume treatment for MS or to breastfeed. Some women indicated that even when they chose not to breastfeed, they made their decision with their infant's best interest in mind, noting that if they were able to receive treatment for MS, they would be more physically able to be present for and care for their child. Additionally, women with MS already face a high level of fatigue and the demanding schedule of breastfeeding is not always compatible with their increased need for rest.

However, women reported that they often felt shamed or judged by health care providers over their decision to not breastfeed. They noted that often health care providers did not understand the difficult choice to either resume MS treatment or breastfeed their infant. They also noted that health care providers did not understand that often by not breastfeeding and choosing to take DMT, they were making a conscious and difficult decision to treat MS in order to be healthier and better able to care for their infant. Women with MS are not the only group of women who have faced emotional distress over the issue of breastfeeding. Women without MS or physical disabilities who for various reasons have chosen not to breastfeed or are unable to do so have described feeling emotionally distressed over their decision. Hvatum and Glavin (2017) explored the experience of women who did not breastfeed in Norway, a country with a culture in which breastfeeding is highly valued. This qualitative study demonstrated that similar to women with MS in the present study, the mothers ultimately wanted to breastfeed but for various reasons had to make a difficult choice to not breastfeed or were unable to. They felt stigmatized by their decision not to breastfeed and sometimes even felt as if they were so far on the wrong side of society's norms that it felt as if they were breaking a law.

Thomson, Ebisch-Burton, and Flacking (2015) explored the concept of shame and how it is experienced in the context of breastfeeding. In this qualitative study, Thomson et al. found that women who breastfed experienced elements of shame as did women who did not breastfeed. The experience of shame in breastfeeding women was centered around doing so in public. For women who did not breastfeed, shame resulted from others assuming that they were poor mothers who were choosing to deny their infant the

best nutritional option. The results of this study demonstrated that breastfeeding is an emotionally charged topic on both sides of the debate but the decision to not breastfeed is often met with shame and mothers' ability to adequately parent being called into question. Women with MS in this study described that they felt shamed and judged by health care providers when it came to breastfeeding decisions but also to other aspects of their postpartum experience, such as experiencing emotional instability as a side effect of MS treatments.

Although the benefits of breastfeeding are clearly noted by the CDC (2021), the decision to breastfeed needs to be considered within the context of the physical and emotional wellbeing of the mother. Failure to fully appreciate the complex factors that are part of the decision to breastfeed can leave women feeling ashamed and as if they have failed in their duty to their child. Women with MS have an acute and important decision to make regarding breastfeeding as choosing to do so often means that they are sacrificing their ability to receive treatment for a progressive and disabling illness, which may affect their physical health and ability to provide care for their infant in other ways. Health care providers who are caring for women with MS in the postpartum period need to be aware not only of the difficulty making this decision but also of the emotional distress that can accompany this decision for women with MS.

Rigor

A 2017 article by Cypress demonstrated how the components of validity established by Lincoln and Guba (1985) could be determined in a phenomenological study by elaborating on the concepts of credibility, transferability, dependability, and confirmability. The process of determining credibility in qualitative research involves the

extent to which the researcher can demonstrate that the data truly reflected the experience of the participants and that the results were truly reflected in the data. At the time of participation in this study, participants were asked if they would be willing to review the results and provide their opinion on its accuracy. Of the 13 participants in this study, eight provided their e-mail addresses to be contacted with the results to provide their opinion. Those eight women were contacted using their preferred e-mail address using the researcher's Villanova University e-mail address. Two of the eight participants responded and indicated that they felt that the exhaustive description accurately captured their experiences.

Transferability was demonstrated by full immersion in the data through repeated readings of the transcripts for the emergence of themes. Transcripts were read as the study progressed so that as new participants submitted narratives, the researcher was able to identify new concepts within the most recent transcripts. As transcripts were reviewed, the presentation of novel concepts decreased until saturation of the data was reached at a total of 13 participants. The primary investigator made thorough notes to demonstrate this process. These notes and the subsequent audit trail that resulted from them, established confirmability of the data. Lastly, dependability, which requires that the resulting themes are a reliable interpretation of the data, was established by having a third-party auditor who was an expert in maternal child nursing and postpartum care as well as qualitative research, reviewed the raw narrative data and the notes on data analysis. After review, the auditor determined that the themes presented did develop from the data.

Limitations

There are several noted limitations of this study. The first is the small sample size. Qualitative studies in general have smaller sample sizes than quantitative studies, but this study had a smaller sample size than originally intended. An initial sample size of at least 25 participants was proposed. Initially, the response to the study was robust and it was predicted that the expected 25 participant minimum would be obtained. However, about 1 week after the study was posted on social media forums, COVID-19 became a serious health concern in the United States. Participation and enthusiasm for the study dwindled as COVID-19 changed daily ways of life through lockdowns imposed throughout the world. As a result, after 6 months of posting the study weekly, and with the COVID-19 pandemic still a focus of concern and attention, the decision was made to stop data collection. Additionally, the sample was rather homogenous with the majority of women (83%) being married and all women (100%) having post-high school education. Thus, women with a different relationship or educational status may have different experiences. A similar study with a more diverse sample would be valuable.

The homogeneity of the sample may be representative of selection bias, as there are likely common qualities among individuals who chose to participate as opposed to those who did not. Additionally, the method of data collection is in itself a limitation as only individuals with both Internet access and an active online presence in MS-related social media pages or the NMSS website would have had access to the study. Although the online method of data collection has been successful at yielding rich phenomenological data for another study (Beck, 2005), the narratives obtained from this study were not as rich as was hoped for by the researcher. Not all narrative responses contained expansion and elaboration in the spirit of “great detail” requested by the

narrative prompted. Perhaps modification of the method of data collection in future research on this topic will yield a greater level of detail in participant responses.

Implications for Practice

The results of this study demonstrated that the postpartum experience remembered one to ten years after childbearing for women with MS is fraught with unique concerns that are not well recognized or acknowledged by the health care providers who are caring for them. Women with MS will encounter providers in their peripartum journey who are experts in MS and providers who are experts in the peripartum period. It is essential for physicians, advanced practice nurses (including midwives), and nurses in both specialties (neurology and obstetrics) to increase their knowledge of MS in the postpartum period. Providers across specialties and disciplines must also collaborate with one another to share their expertise and inform each other of the most recent recommendations for women with MS in the postpartum period. This includes information on risks of having children for this group, the current recommendations for treatment of MS in the peripartum period, and what women should expect in the postpartum period in the context of MS. Women with MS are looking for clear and accessible information about the intersection of MS in the peripartum period. They look to health care providers to have these answers but are often disappointed at the lack of information. For example, acknowledging that postpartum period has a greater risk of relapse of MS symptoms and how that can affect a woman's ability to care for her newborn is an important topic that needs to be addressed.

Greater awareness of the science, needs, and issues relating to childbearing and MS can be addressed through professional organizations like the National Multiple

Sclerosis Society (NMSS) and the Association for Women's Health, Obstetric, and Neonatal Nursing (AWHONN). Through additional research and clinical reports on this topic, education can be provided to health care professionals through in-person or virtual conferences and publications. Health care providers and organizations dedicated to furthering health of women with MS can also increase societal awareness through media campaigns, online educational materials, and Webinars. Professional and public awareness will serve to increase communication across disciplines about MS and postpartum period and can decrease stigma about childbearing and childrearing in women with MS. As media consultants, reporters, authors, and expert program guests, nurses can disseminate accurate information about MS and MS and childbearing. Nurses have often been a trusted source of information for the lay community and can serve an important and much-needed role in providing education and information to women with MS about the postpartum period. Academic educators for physicians, advanced practice nurses, and nurses should include information about MS and postpartum in curricula to better prepare providers for practice.

Childbearing women with MS are mothers with all the needs of transition to parenthood and an expanding family as women without MS. They also have needs related to MS. An emphasis on health promotion and wellness that also respects special needs of MS may prevent or alleviate some of the negative emotional experiences described by women in this study. All participants in this study were women recalling their experiences one to 10 years after their deliveries. This study highlights the impact of the postpartum experience for women with MS and especially what may be viewed as

enduring traumatic wounding as these negative experiences were recalled even after years had passed.

From a health promotion perspective, health care providers can encourage childbearing women with MS and their significant others to consider how much support they will need during this time and arrange for family and friends to be available to help them. Women should be educated on how to manage the demands of motherhood with the challenges inherent in MS. For example, in this present study, one woman noted that just knowing that MS was going to increase her fatigue allowed her to be accepting rather than self-blaming of her need for rest. Nurses can bridge the information gap by providing education to women with MS about what to expect in the postpartum period. Education can be provided one-on-one between nurse and patient. Nurses can lead educational classes for women with MS who are considering pregnancy. Perhaps a more efficient educational strategy is for nursing and specialty organizations in support of MS and childbearing to provide accessible educational materials in a variety of formats (video, written word, Webinars, etc.) in online platforms. Inclusion of characters with MS in popular media series, books, films, and features can provide education and promote public understanding of childbearing women with MS.

Health promotion must start with primary prevention of negative childbearing experiences, including proper education and information sharing from health care providers to women with MS. This can include encouraging women to increase both their physical and emotional wellbeing prior to pregnancy as well as strategies for how women can enhance both of those areas during pregnancy and postpartum. Emphasizing the importance of partner and family support in the postpartum period and including

significant others in their shared experience can also improve mental health outcomes for women with MS as well as their families.

Women need to be educated about the treatment options available to them for MS during pregnancy and postpartum. This education needs to include a risk-benefit discussion in which women learn about the risks of taking DMT and about other treatment options available to them in the postpartum period, like corticosteroids. A realistic discussion regarding the risk of relapse and how that will affect their ability to physically and emotionally provide care for their infant needs to be balanced with the risks of specific treatment options during this time. While physicians are a traditional choice to provide this education, advanced practice nurses, midwives, and nurses are particularly well suited to this task as they are educated to provide care that focuses on considering a holistic model of care.

Women in this study indicated that they needed more information specifically about the use of MS treatments and breastfeeding. The decision whether or not to breastfeed was an emotional one for women. Women in this study felt that they had to choose between treating their disease and caring for themselves or caring for their infant by providing breastmilk. Often, the decision not to breastfeed was met with feelings of shame and judgement. Clinicians can improve the postpartum experience for women with MS by creating an open and non-judgmental environment with women invited to discuss their concerns about treatment options during postpartum and how that will affect breastfeeding. Lactation specialists should also be provided with education on the unique needs of women with MS in the postpartum period and should support the decisions of women with MS. They are important members of the health care team that can provide

support for women to make the best decisions for themselves regarding how to feed their infants. Women who choose not to breastfeed should never be made to feel as if they are harming their babies or unsuccessful as mothers. In their commitment to breastfeeding, health care providers need to avoid promoting guilt and anxiety and to remember that babies who are formula fed are also healthy and have a great relationship with their mothers and families. As this study highlights, women with MS may have other health needs the supersede attempting to breastfeed. In addition to helping women make a decision that has important implications for their own health, healthcare providers, like physicians, advanced practice nurses, and nurses will be easing some emotional distress by allowing women to feel confident and heard in their decisions.

Implications for Future Research

By providing information regarding the experience of women with MS in the postpartum period, further research is needed to explore the identified themes in more depth. One of the limitations of this study is the homogenous sample. Further research is needed to determine if a more diverse sample has comparable experiences with MS in the postpartum period. Women in this study identified that there were gaps in information available to them both from lay sources and from health care providers. Future research needs to focus on the best way to provide education to women with MS. For example, is information best delivered through some fact-based materials or is a full education session with risk-benefit analysis with a health care provider more valuable. This study also identified that health care providers are often unaware of or lack understanding of the unique needs of women with MS in the postpartum period. Future research needs to focus on both developing guidelines for the treatment of women with MS in pregnancy

and how to best educate health care providers in different specialties (neurology and obstetrics) about the intricacies of MS in the postpartum period. How to best educate providers and how to implement that education into practice will also need to be a focus of future studies.

In exploring the deficit of knowledge imparted to both health care providers and women with MS, the role that nurses and advanced practice nurses can play in this process needs to be further explored. As nurses and advanced practice nurses often have a holistic view of their patients, they are in a prime position to assess the needs and educational deficits of women with MS in the peripartum period and provide that education. Nurses and advanced practice nurses may be able to develop and implement educational programs to impart needed information to women with MS. This includes furthering research to explore how to best provide this education to patients and sharing information professionally at conferences and within publications. Nurses and advanced practice nurses can also develop direct to patient education including media campaigns and Internet based educational tools like Webinars and blogs. Many popular media shows feature the concept of childbearing. Professional organizations, like NMSS, can provide funding for or advocate for the inclusion of women with MS to be discussed or even featured in these programs. Future research can help to guide the development and implementation of such programs by exploring how to best convey this information in an efficient and caring manner.

The focus of this study was on the emotional experience of women with MS who recalled their postpartum experiences one to 10 years after their deliveries. This study found that women with MS experienced a variety of emotions in the postpartum period.

Surprisingly, depression was not described by the participants. Rather anxiety, shame, and feeling like a failure were commonly identified by study participants. Women also reported that they experienced positive emotions along with the negative emotions as well. Often, depression has been a focus of postpartum emotional research. However, this study demonstrates that emotional experiences are more complex and varied than just one type of experience, such as depression. Future research should explore and perhaps attempt to demonstrate quantitatively the negative and positive emotions experienced during this time to further understanding of the totality and complexity of the emotional experience for women with MS in the postpartum period.

Support was an important concern for women with MS in the postpartum period. Future research should focus on the types of support needed by women with MS so that health care providers can understand how to either provide that support or to help women and their families develop that support within their communities. This can also allow health care providers to help educate family members on how they can best support a woman with MS in the postpartum period. The research on support extends to breastfeeding as well. Women felt considerable emotional distress in their need to decide to breastfeed or to formula feed in order to resume treatment for MS. More research needs to be conducted on the most effective way to reduce the likelihood of MS relapses in the postpartum period (medications or through breastfeeding) to assist and support women with MS in making the most informed decision about whether to breastfeed or resume treatment. Lastly, future research needs to examine how health care providers can support a woman's decision to either breastfeed or not breastfeed to decrease the emotional distress surrounding this topic.

Conclusion

The results of this study demonstrated that one to 10 years after delivery women with MS recall unique postpartum experiences that include complex and variable emotions that can range from negative to positive. There is a lack of readily available information to women with MS about what to expect in the postpartum period and often that information is not known or is misunderstood by health care providers women with MS view as the experts. Women with MS require support from loved ones to both have positive emotional experiences during the postpartum period and also to provide care to their infant due to physical symptoms of MS. Women with MS will experience relapses and MS differently in the postpartum period with some women having very mild symptoms to more severe MS relapses. Lastly, women with MS reported that the decision to breastfeed or not was particularly emotionally charged. Women felt that the decision was not simply a choice about what to feed their infant but became a choice of putting their health needs or the needs of their infants first. Many women felt that putting their health needs first allowed them to indirectly prioritize their infants by being more physically healthy and capable of caring for them by resuming treatment for their MS in the postpartum period rather than foregoing treatment to breastfeed. The clinical implications and directions for future research are many. This study presents several topics that require further investigation and represents the starting point of understanding the complex experience of women with MS in the postpartum period. It is hoped that the results of this study will inspire further research to provide specific care guidelines and recommendations for women with MS in the postpartum period to allow women to have an enriching and emotionally positive postpartum experience.

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Appendix A

Recruitment Flyer

Women with Multiple Sclerosis**Wanted for Study Related to Postpartum Experiences**

If you have multiple sclerosis and have had a child after your diagnosis, we are interested in hearing from you. We are interested in hearing about your experiences in the postpartum period, including how you felt emotionally during this time in your life.

This study involves completion of an online survey that will last approximately 40-60 minutes. To participate, you must have had a baby within 1-10 years ago, be over the age of 18, be able to communicate in written English, and reside in the United States of America.

This study has been reviewed and approved by the Villanova University Institutional Review Board.

If you have any questions about the study, please contact Megan Walsh, CRNP, RN by e-mail at mwalsh77@villanova.edu or via phone at 570-814-3007.



Office of Doctoral Student Research

Informed Consent

Consent for Participation in a Human Research Study

Title of research study: *The Emotional Experience of Women with Multiple Sclerosis in the Postpartum Period*

IRB #: *IRB-FY2020-40*

Investigator: *Megan Walsh, CRNP, PMHNP-BC*

Key Information: This section is intended to provide key information to assist in your decision on whether to participate in this research study. More detailed information about the topics covered in this section is included below.

This study intends to further our understanding of the emotional experience of women with MS in the postpartum period. It is a research study and participation in the study is voluntary. Participants will be asked to complete a survey in Qualtrics that involves both demographic short-answer or multiple choice questions and a narrative prompt. The open-ended narrative prompt will ask you to write, in as much detail as possible, about your experience as a woman with MS in the postpartum period.

The researcher is Megan Walsh, CRNP, PMHNP-BC a PhD student at Villanova University.

Part 1: About Research

What should I know about a research study?

- You can contact the researcher with questions about this study at any time. The researcher can be contacted at mwalsh77@villanova.edu
- Whether or not you take part is up to you.
- You can choose not to take part.
- You can agree to take part and later change your mind.
- Your decision will not be held against you.
- You can ask all the questions you want before you decide or at any time.

- You can be assured that we are committed to best practices for safety and the well-being of all participants.

Who can I talk to?

If you have questions, concerns, or complaints, or think the research has harmed you, communicate with the research team at mwalsh77@villanova.edu

This research has been reviewed and approved by an Institutional Review Board (“IRB”). You may talk to the IRB office by calling (610) 519-4228 or writing to irb@villanova.edu if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research subject.
- You want to get information or provide input about this research.
- You feel you have been injured or harmed while participating in this research.

You may also call the EthicsPoint hotline, a third party resource unaffiliated with Villanova, toll-free at 1-855-236-1443 if you prefer not to speak to the researcher or the IRB office.

Part 2: About this Study

Why is this study being done?

This study is being completed to learn more about what it is like to be a woman with MS in the postpartum period. Having MS can change the experience of being a new mother. By learning more about how MS can impact this experience, women are being asked to provide information about their experiences with MS in the postpartum period. A more in-depth understanding of the postpartum period for women with MS will hopefully influence the care provided to women by health care providers by educating them about this time in a woman with MS's life. By participating, you may benefit future women with MS who are in the postpartum period. The study is intending to ask women to reflect on past experiences in the postpartum period. The researcher is not studying postpartum depression.

Why am I being invited to take part in this research study?

We invite you to take part in this research study because you are an adult female at least 18 years of age who has MS, has delivered a child after your diagnosis of MS between 1 and 10 years ago and can communicate in written English. You must currently reside in the United States of America.

What will I see, hear, read, or do in this study?

You will be asked to answer a questionnaire that will ask for some information about you, such as age, length of MS diagnosis, etc, during the postpartum period you are reflecting on. You will also be asked to provide a written description of your emotional experience in the postpartum period. This narrative can be as long as you desire. You will be asked to complete these responses in a secure online survey platform called Qualtrics.

You will also be offered the opportunity to receive the analyzed results of the study and provide your opinion on the analysis. If you indicate that you are interested in receiving the study results for your review and feedback on the demographic questionnaire, you will also be provided with the study results and asked for your feedback.

What happens if I say yes, I want to be in this research study?

If you want to be in this study, please click on the Qualtrics link located with the recruitment flyer.

You will be asked to complete the questionnaire within 1 month. If you have indicated that you DO NOT wish to be sent the results of the study e-mailing the researcher your responses will conclude your participation.

If you have indicated that you do wish to provide comments on the study results, you will be contacted by the researcher at the e-mail of your choosing with the study results and asked to provide your opinion back to the researcher via e-mail within 1 month. There is no financial compensation for your participation.

What happens if I say yes now, but I change my mind later?

You can leave the research at any time and it will not be held against you. If you decide you no longer want to participate in the study, please send an e-mail to mwalsh77@villanova.edu indicating that you no longer want to participate. Any data that have been collected prior to your resigning from the study will be included in the analysis. Upon your withdrawal from the study, you will no longer be contacted by the researcher concerning the study.

How long will the research last?

We expect that answering the questions provided for participation in this study will take about 60 minutes to complete.

If you indicated a desire to provide your opinion on the results of the study, this will likely take 60-120 minutes to complete since it involves reading the study results and providing your opinion.

How many people will be studied?

We expect about 25 people will be involved in this research study.

What happens if I do not want to be in this research?

Your participation in research is completely voluntary. You can decide to participate or not to participate and can leave the study at any time.

Is there any way being in this study could harm me?

As you participate in this study, you will be asked to recall your emotional experiences during the postpartum period. There is potential that recalling these experiences could result in psychological discomfort.

Although unanticipated, it is also possible that there are risks to you we as researchers cannot foresee.

Will being in this study help me in any way?

We cannot promise any benefits to you or others from your taking part in this research. However, possible benefits include providing information that can potentially help to provide information to change or initiate care guidelines for other women with MS in the postpartum period. Participants in similar studies have discussed feeling that the experience of writing about their postpartum emotional experience was therapeutic and helped them to process this time of their life.

What happens to the information collected for the research?

Efforts will be made to limit the use and disclosure of your personal information, including research study records, to people who have a need to review this information. We cannot promise complete secrecy. Organizations that may inspect and copy your information include the Institutional Review Board of Villanova University and other

representatives of this organization. The Institutional Review Board is a committee that ensures research is completed in a safe and ethical manner. Data will be retained for 5 years in order to continue to explore the data for additional research or information. Data will be retained for 5 years in order to continue to explore the data for additional research or information. Data will be stored without personal identifying information within an encrypted file on a locked computer in the researcher's possession. Results from this study will be published or presented to share the findings with the health care community. An expert in the field will be asked to read through a portion of responses that are not identifiable to determine that the principal investigator is drawing appropriate conclusions from the data. This person is known as an "external reviewer".

Additionally, direct quotes, that will not be attached to you in any way or be able to identify you, may be used in publication and presentation.

What else do I need to know?

Identifiers may be removed from the identifiable private information you provide, and after any such removal, the information could be used for future research studies or distributed to another investigator for future research studies without additional informed consent from you.

There will be no costs to you as a result of participating in this research.

There will not be any compensation to you and/or available medical treatment for you in the event of injury from participating in this research. If in the course of participating in this study you would like additional emotional support you can contact National Suicide Prevention Hotline at 1-800-273-8255 and/or the Postpartum Support International Helpline at 1-800-944-4773.

You may print this page for your records.

If you have read and agreed to the informed consent outlined above and elect to participate in this study please indicate Yes. If you have read and do not agree to the informed consent outlined above and do not elect to participate in this study, please indicate No.

_____ Yes –I consent

_____ No—I do not consent

Appendix C

Demographic Questionnaire

Please complete the following questions.

When answering these questions, please provide the information requested as it was **during the postpartum period (first year after giving birth) you will be discussing in the narrative portion.**

What was your age during the postpartum period? _____

What was your marital status during the postpartum period? _____

Did you breastfeed during this postpartum period? _____yes _____no

How long before this postpartum period were you diagnosed with MS? _____

Did you have children before your MS diagnosis? _____yes _____no

If you had children before your MS diagnosis, how many did you have?

Did you have more children after this postpartum period? _____yes _____no

If you had children after this postpartum period, how many additional children did you have?

Did you have any support during this postpartum period? _____yes _____no

If you had support during this postpartum period, who were your supports? ie., partner, parent, sibling, etc.

Did you use any disease modifying treatment (DMT) during pregnancy? _____yes _____no

Did you use any disease modifying treatment (DMT) during postpartum period in question?

_____yes _____no

What disease modifying treatment did you use during pregnancy? If none, put N/A.

What disease modifying treatment did you use during the postpartum period in question?

If none, put N/A.

Were you ever diagnosed with depression prior to the postpartum period in question?

_____yes ____no

Have you ever been diagnosed with postpartum depression?

_____yes ____no

If yes, did that diagnosis occur during the postpartum period you are discussing now?

_____yes _____no

What was your highest level of education at time of the postpartum period? _____

What was your employment status at the time of the postpartum period? _____

Would you be willing to be contacted with the results of this study in order to review and provide feedback as to whether or not it accurately captures your experience?

If yes, please provide your preferred e-mail address of contact below.

If no, please leave blank.

e-mail address : _____ -

Appendix D

Narrative Question

Please respond to the following narrative prompt. Please complete your survey response within 1 month of accessing the survey. As you reflect upon your experiences, if you experience emotional distress please note that you can seek emergent emotional support and assistance by contacting:

National Suicide Prevention Lifeline 1-800-273-8255—which can provide support for emotional concerns other than suicide as well

Postpartum Support International Helpline 1-800-944-4773

Thank you for your participation!

In as much detail as you can, please detail your experiences, including emotional experiences, as a postpartum mom with MS.

Appendix E

Questions for Opinion

Thank you for taking the time to review the results of the study. You will find the results of the study below. Please provide your opinion indicating whether you feel the information accurately reflects your experience. If not, please provide feedback indicating how you think the results could be improved.

Once completed, please e-mail your response to mwalsh77@villanova.edu within 10 days by 3/5/2021. Thank you for your participation.

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