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Understanding the Lived Experience of Health Through the Exploration of Well-being of Women with Multiple Sclerosis in Southwestern Ontario

Jennifer Howard, *The University of Western Ontario*

Supervisor: Dr. Yolanda Babenko-Mould, *The University of Western Ontario*

A thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Nursing

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ABSTRACT AND KEYWORDS

The prevalence of Multiple Sclerosis (MS) is increasing globally with 2.8 million cases worldwide as of 2021, with Canada experiencing the highest incidence for this disease (Multiple Sclerosis International Foundation [MSIF], 2021; Multiple Sclerosis Society of Canada [MSSC], 2021). MS is an autoimmune disease that damages the myelin sheath in the central nervous system (spinal cord and brain) which may result in problematic symptoms such as cognitive dysfunction and lead to physical disability (MSSC, 2021). There are over 90,000 Canadians with MS, impacting women on a ratio of 3:1 compared to men (MSSC, 2021; Statistics Canada, 2013). Current literature suggests that women may experience health, social determinants of health, and disability differently and therefore may benefit from researchers considering gender as a focus for investigation of phenomena (Tobiasz-Adamczyk et al., 2017; Nyberg et al, 2016). The World Health Organization [WHO] (2014) describes health as physical, mental and social well-being, and the WHO definition is the most common conceptualization of health in nursing scholarship (Simmons, 1989; Tariq-Alslman et al., 2015). There is a gap in the literature that currently examines gender from a women's perspective as to how health is experienced (Phillips & Hamberg, 2016). Additionally, there is a lack of qualitative evidence about the lived experience of women with MS to help guide health care practice and future research (VanRuymbeke & Sneider, 2013). Therefore, the study sought to better understand the essence of women's experience of health through the exploration of their well-being as they live with MS. van Manen's (1990, 1997) hermeneutic phenomenology was used as a guiding methodological perspective in this study.

Keywords: Interpretive phenomenology, Multiple Sclerosis, Women's Health, Women with Disability, Nursing, Nursing Practice.

SUMMARY FOR LAY AUDIENCE

This study explored the lived experience of the health and well-being of women affected by Multiple Sclerosis (MS). Health was defined using the World Health Organization definition to include physical, mental, and social well-being. This research is important as it shows how MS impacts being a woman and vice versa. The study participants were living within Southwestern Ontario exclusively, as this area is the most diverse and densely populated area in Canada. Furthermore, having participants in the same area allowed for an understanding of what health care resources were accessed in a specific geographical area. Key themes that emerged during this study were “foundations of vitality for women with MS”, “enhancing wholeness for with women MS”, “obstacles for women with MS”, with subthemes of “barriers to mental well-being”, “barriers to physical well-being”, and “barriers to social well-being” and “caring to enhance wholeness for women with MS”. This study revealed that women with MS who can make their own choices freely, without institutional or financial barriers, were more likely to experience health and well-being while living with MS. This included the ability to make choices surrounding medical decision such as medications, treatment and accessible devices and personal choices such as housing, employment, transportation, and education. The findings from this study may help develop more informed health care practices, policies and education that ultimately impact the health and well-being of women with MS. Furthermore, this study may lead to the development of future research in this area.

CO-AUTHORSHIP STATEMENT

Jennifer Howard completed the work for this research project under the direct supervision of Dr. Yolanda Babenko-Mould and with her doctoral committee members, Dr(s). Kim Jackson and Tracy Smith-Carrier. Dr(s). Babenko-Mould, Jackson, and Smith-Carrier are co-authors with Jennifer Howard on all publications and presentations that arise from this study.

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CHAPTER 1
INTRODUCTION: MULTIPLE SCLEROSIS AND
WOMEN'S HEALTH AND WELL-BEING

“The energy of the mind is the essence of life.” ~ Aristotle

Introduction

In Canada, approximately one in 340 people have Multiple Sclerosis (MS), which affects more than 90,000 Canadians (Multiple Sclerosis Society of Canada [MSSC], 2021; Statistics Canada, 2013). MS affects people aged 15-60 and is more likely among those who are Caucasian or of Northern European decent (MSSC, 2021). Women experience MS more frequently than men at a 3:1 ratio. If a sibling or parent has MS then there is a slightly higher chance for MS to develop, although the direct genetic linkage is currently unknown (Multiple Sclerosis and Neuroinflammation Centre, 2021). MS is an immune-mediated disease that affects the central nervous system, which consists of the optic nerves, spinal cord and brain, and is potentially disabling (National Multiple Sclerosis Society [NMSS], 2018; Mayo Clinic, 2017; MSSC, 2018). The onset of MS occurs when the myelin sheath covering nerve fibers in the brain and spinal cord are attacked by the immune system resulting in deterioration or damaged nerves (National Institute of Neurological Disorders, 2018; NMSS, 2018; Mayo Clinic, 2017). When the myelin sheath is damaged, it forms scar tissue (sclerosis), hence the name of the disease (NMSS, 2018).

Exact causes for MS remain unknown but are believed to be triggered in individuals who have several activating factors (outlined below) and are genetically susceptible to developing this condition (NMSS, 2018; Mayo Clinic, 2017). The presence of specific autoimmune diseases such as thyroid disease, inflammatory bowel disease or

type I diabetes may increase the likelihood of experiencing MS (NMSS, 2018). There are various factors that may increase the chances of an individual developing MS, these include both modifiable and non-modifiable factors. Non-modifiable factors include age, sex, genetics, family history, people living in the Northern hemisphere and previous exposure to the Epstein-Barr virus (NMSS, 2018; Mayo Clinic, 2017). Potentially modifiable factors include geographical location and lifestyle factors. Lifestyle factors, such as a history of smoking, may also increase the chances of developing MS (NMSS, 2018; Mayo Clinic, 2017; Multiple Sclerosis and Neuroinflammation Centre, 2021). Although there are numerous factors demonstrated to be associated with MS, direct causation remains largely unknown.

The signs and symptoms that an individual with MS will experience vary significantly depending on the location and severity of nerve damage (Fox et al., 2019; Mayo Clinic, 2017). Symptoms of MS may include: extremity numbness, tingling, weakness or loss of function, vision issues, tremors or unsteady gait, fatigue, slurred speech, dizziness, bladder or bowel dysfunction, and mental and cognitive changes (Fox et al., 2019; Mayo Clinic, 2017). Exacerbations, also referred to in the literature as 'attacks', 'flare-ups' or 'relapses', may differ among those living with MS, and the variation of symptoms experienced as a result of an attack may wax and wane but are generally progressive over time (NMSS, 2018; Multiple Sclerosis and Neuroinflammation Center, 2021). The diagnosis of MS is focused on identifying lesions in the central nervous system seen on magnetic resonance imaging (MRI) combined with clinical and para-clinical diagnostic methods (McDonald et al., 2001). Currently, there is no cure for MS, however, various treatments may aid in managing MS and lessening MS related symptom exacerbations (Mayo Clinic, 2017).

Background and Significance

MS is an autoimmune disease that damages the myelin sheath in the central nervous system (spinal cord and brain) which may result in very troublesome symptoms such as vision problems, extreme fatigue, bladder problems, cognitive dysfunction and the lack of coordination (MSSC, 2021). The prevalence of MS is increasing globally with 2.8 million cases worldwide as of 2021, with Canada experiencing the highest incidence of this disease (MS International Foundation, 2021; MSSC, 2021). There are over 90,000 Canadians with MS and women represent more than three times the number of men living with this disease, and there is evidence suggesting MS rates may further increase among women (Christiano et al., 2016; Magyari, 2016; MSSC, 2021; Statistics Canada, 2013). The MS Society (2021) posits that although men and young children may be diagnosed with MS, women are more likely to be diagnosed during their peak years of reproduction, education, and career development. Current literature suggests that women and men may experience health, social determinants, and disability differently and therefore may benefit from researchers considering gender as a focus for investigation of phenomena (Malmusi et al., 2014; Nyberg et al., 2016; Tobiasz-Adamczyk et al., 2017). Lawson and Marsh (2017) support the need for robust qualitative inquiry into how women experience health to help promote the unique perspective of women in clinical health research. Furthermore Tobiasz-Adamszyk et al. (2017) argue that men and women may have different health needs and interventions may be different for men and women. Additionally, gender may intersect with health and MS as there may be differences with how women and men experience health (Bilalic et al., 2009; Franconi & Campesi, 2014). Gender may be further impacted by sociocultural factors such as the environment a

person lives in and may further influence how women and men experience health (Bilalic et al., 2009; Donaghue, 2015).

As a social construct, gender has been found to be a strong predictor of health and how illness is experienced (Ohlman et al., 2015; Phillips & Hamberg, 2016). Identifying as a woman was found to be a reliable predictor of having unmet health needs (Bryant et al., 2009). Also, gendered power relations have been identified as the most influential inequality for experiencing social determinants of health (Gen et al., 2007). Brown et al. (2016) suggest that women have lowered mortality rates compared to men but exhibit worse health in regards to having higher morbidity rates and diminished quality of life. Bird and Rieker (2008) note that these differences may be related to gendered social expectations and social roles. Gender is an important construct influencing how health is experienced, however, this is not always adequately investigated in clinical trials (Phillips & Hamberg, 2016). There is a gap in the literature examining how women experience health from their own perspective (Phillips & Hamberg, 2016). Therefore, due to the overall increase in MS rates in women (MSSC, 2018), and the gaps identified in the literature, this study will focus on the experience of living with MS among adult women (over the ages of 18) in Southwestern Ontario.

Nurses are not always adequately meeting the health needs of people with MS. As Abma et al. (2005) contend, nurses are commonly unable to meet the health needs of patients living with chronic illnesses such as MS as they may not understand the special needs of people with this disease, and therefore may not readily attend to their biopsychosocial needs like challenges with social connections and employment. As nurses support individuals living with varying chronic health issues, they must acquire an expansive knowledge base to help meet the unique needs of their patients. This study

seeks to better understand the essence of women's experience of health through the exploration of their well-being as they live with MS. As such, van Manen's (1990, 1997) hermeneutic phenomenology will be used as a guiding methodological perspective in this study. Through the collection of qualitative data, researchers can garner rich, in-depth information that is detailed from the individual's point of view on what really matters to them (Denzin & Lincoln, 2011). van Manen (2011) notes that formative knowledge may be gained from phenomenological inquiries, which can enhance readers' perceptions and insight about human relationships, such as the therapeutic nurse-client relationship. It is proposed that nursing practice and quality of care provided, in relation to caring for women living with MS, may ultimately be enhanced through findings that emanate from the application of a research approach that provides interpretation of a phenomenon (Leipert et al., 2008; Pope et al., 2002).

Purpose of the Study

The overall purpose of this hermeneutic phenomenological study is to understand the lived experience of health in the context of physical, social and mental well-being for women living with MS in Southwestern Ontario.

Research Question

What is the lived experience of health in the context of physical, social, and mental well-being for women living with MS in Southwestern Ontario?

Significance of the Study to Nursing

Although Canada has the leading incidence of MS in the world, limited evidence is currently available about Canadian women living with MS and their perceived physical, social and mental well-being (MSSC, 2021; VanRuymbeke & Schnieder, 2013). As such, little consideration has been given to how women living with MS experience

health and well-being from a multi-dimensional and contextualized perspective. Consequently, the Canadian healthcare system, current nursing education, and best practices may not necessarily be meeting the key health needs of this population. As such, this proposed study may inform how nurses approach best practice care needs for women with MS within a Canadian context (VanRuymbeke & Sneider, 2013).

Declaration of Self

My interest in and appreciation for individual well-being stems from my personal and professional view of the need to emphasize holism for the full embodiment of health. Since I was a young child, I have always been drawn to various holistic practices, such as yoga or mindful meditation or the arts to calm my mind and give me a sense of inner peace and well-being. I truly believe that one's being reaches beyond the physical realm of health and absence of disease, and extends to factors such as socioeconomic, relational and environmental factors. When I explore my own life challenges, either personally or in my career as a Registered Nurse (RN), I know that I thrive when my mind, body, and soul are aligned. An example of this would be with experiencing not one but two motor vehicle accidents (MVA) just months apart several years ago. These experiences unfortunately resulted in potentially life-long musculoskeletal health issues, including a reduced ability to engage in the physical activities I once previously enjoyed. Although I experienced several complications as a result of the injuries I sustained, I was also able to have the meaningful benefit of experiencing many aspects of the health care system through the lens of receiving versus providing and administering treatment. These unique experiences enabled me to develop a deeper sense of appreciation for my own well-being and for practitioners who display warmth, empathy and compassion toward their patients. I truly valued those who cared about my concerns beyond treating my medical diagnosis.

As a result of incurring musculoskeletal injuries and being placed on light duties as a RN while working in the operating room, I was provided the opportunity to spearhead a small pilot research project. This also gave me time to evaluate and reflect upon my nursing career and allowed me to ponder questions I needed to ask myself. Did I really want to try to endure an entire career in a heavy and physically demanding practice area while being told I was on permanent light duties? Or should I try to rise to this challenge that life has presented me and pursue a higher level of education and pursue a career in research and academia? I really enjoyed the research project I had participated in, so I decided to choose the latter and have not looked back since. Since returning to school I have been able to go from starting my first year in a Master's program at Western University to accelerating into the nursing doctorate of philosophy (PhD) program within the nursing education stream. During my time as a graduate student at Western University, I have been able to gain experience as both a teaching and graduate research assistant. In my role as a teaching assistant, I have been able to learn more about teaching others to understand the basic tenants of research, including various methodologies and research methods; something which I value and enjoy immensely. My latter experience as a graduate research assistant led me to an exciting opportunity to help conduct an interpretive phenomenological analysis for elderly people with dementia who had participated in a garden therapy program. This experience allowed me to develop and refine my abilities to analyze existing data using an interpretive phenomenological lens.

Through my academic pursuits I have been able to take several research methodology courses in both interpretive and post-positivist paradigms. Although I appreciate post-positivism, I see myself as a future mixed methods researcher – I sensed from an early start that I was strongly drawn to phenomenology as a methodology and

research method. I personally view phenomenology as a methodology that empowers the subjective experience of research participants; something that I can appreciate given my personal experience with several injuries and complications from the MVAs and my meaningful nursing experience with MS patients. In addition, phenomenology allows for the future development of informed qualitative, mixed methods or quantitative studies; something I intend to employ in my forthcoming research program upon the completion of my PhD studies.

My experience in academia has been both challenging and fulfilling, and has provided ample opportunity for growth and development as a budding researcher. I was able to find another practice area for my nursing career to support myself while in school that was physically light, exciting, and thoroughly stimulating for my strong desire to be constantly learning and expanding my nursing knowledge.

My recent clinical setting experience was in a community clinic working with immune-mediated illnesses. Generally, I see the same patients on a routine basis for biotherapy administration (a form of immune therapy); as a result, this has allowed me to develop meaningful therapeutic bonds with patients who visit the clinic. Although a majority of the care I am prescribed to administer is in the form of injections or biotherapy infusions, I am able to take the time to actively listen to my patients and develop meaningful therapeutic relationships with them. More often than not, I am blessed to hear stories about patients' loved ones or personal stories about their lives and how they cope and manage struggles with various illnesses. Of particular interest for me is my work with MS patients, an overwhelming majority of whom are young woman around the same age and life stage as myself (young adulthood and childbearing years).

Working with MS patients has allowed me to be privy to many confidential discussions about how MS has affected their lives on a daily basis. Some of these dialogues have included patients' voicing their frustrations about barriers to access care, financial costs, and burdens with obtaining funding for their disability. Furthermore, some patients have divulged a lack of understanding and empathy from friends and loved ones or vented about the impact of MS-induced fatigue or the side effects of related treatments. Additionally, some patients have discussed personal challenges that impacted their decisions about their education, career or family planning, as well as issues with relationships and breakdown familial structures. Conversely, sometimes my patients share their personal triumphs as to how they manage and cope with such a devastating diagnosis like MS. There are times when my patients express the desire to have more effective connections to those around them, including in their personal lives, and to be able to connect in a meaningful way with others who share the same diagnosis, such as with MS groups that are led by people living and coping well with MS. I was surprised to see this is not always reflected in the current literature, which piqued my interest in focusing my doctoral research in this area.

Although these issues have been observed in my nursing practice, these emerging trends appear to be under-represented in current scholarly literature about MS. I am aware that having this knowledge prior to conducting the proposed study may create inherent bias that all women living with MS struggle and face many challenges. Furthermore, I am aware that this may influence the data being collected by creating a bias in quantitative research towards limitations of what factors influence resiliency, coping, or any overall positive implications of having MS.

Organization of the Dissertation

This dissertation is composed of chapters organized in the traditional monograph format, in accordance with Western University's School of Graduate and Postdoctoral Studies (2021). Chapter 1 consists of an introduction to the topic of MS and women's health, the aims of the research and significance of the study. Chapter 2 consists of a literature review about MS in relation to health through a lens of well-being. The literature review provides insight into how the experience of women with MS is explored in relevant scholarly publications. The methodology and research methods used to guide this study are discussed in Chapter 3. The findings are presented in Chapters 4 and 5. In particular, Chapter 4 consists of a contextual narrative for each participant along with a discussion about the research in relation to lifeworld existentials. Chapter 5 reflects the findings through presentation of emergent study themes and sub-themes. The final chapter for this study, Chapter 6 includes implications and recommendations stemming from the findings, and future areas of further research are explored.

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CHAPTER 2

LITERATURE REVIEW

In this chapter, a review of the literature was conducted for the purposes of gaining information about the health of women with MS in relation to well-being as outlined by the WHO's (2014) definition of health as a state of physical, mental and social well-being. This review was conducted using the following databases: Pub-Med, SCOPUS, ProQuest, and the Cumulative Index of Nursing and Allied Health (CINAHL) available through the Western University online library system. Additional grey literature located online outside of University accessible databases were also utilized, such as Google and Google Scholar. Combined keywords used for searching databases included "MS" and/or "women" for core search terms; additionally, search terms of "lived experience", "health", "well-being", "social well-being", "physical well-being", "mental well-being", "wellness", "family", "coping", and "self-efficacy" were applied, which allowed for the retrieval of articles that were relevant to the health and well-being of women with MS. Additionally, as MS is an illness that may cause disability, the search terms "disability" and "episodic disability" were also used. Parameters were applied to include links to full text articles published within peer-reviewed journals in the last five years at the original time of retrieval (2013-2018), allowing for the retrieval of recent and relevant articles. Later additional articles were retrieved that fit the aforementioned key terms and databases in 2019 through 2021; thus, allowing for the inclusion of recently published articles that would be relevant to this study. The search resulted in a total of 1,274 articles from Pub-Med, ProQuest, SCOPUS, and CINAHL. Inclusion criteria for articles selected included publications from primary research sources pertaining to health and well-being of women living with MS that were published in English from peer-

reviewed journals within the last five years and links to full text articles to allow for the retrieval of current and pertinent information. Limited information is currently reflected in the scholarly literature on MS through qualitative inquiry or investigating specific matters pertaining to health and well-being, such as the financial or familial impacts of the disease on the individual within a Canadian context. The initial information in the review outlines the way in which concepts have been defined in the literature. Further, the review reflects literature that focused on women with MS in the context of health and well-being. Namely health and physical, mental, and social well-being. Upon review of the literature on well-being and MS, 63 articles on this subject were retrieved that met the inclusion criteria and were selected based on relevancy of scholarly evidence highlighting the health and well-being of women with MS. A majority of available literature located pertaining to the health and well-being of women with MS is from a post-positivist lens employing quantitative methods and is included in this literature review due to the relevancy for this study, while at the same time demonstrates a gap in the literature about this topic from other methodological perspectives that use qualitative methods.

Health

The constitution of the World Health Organization [WHO] (2014) principles describe health as the “complete physical, mental and social well-being and not merely the absence of disease or infirmity” (p. 1). For the purpose of this study, health will be informed by the WHO’s (2014) definition to include that of well-being, and will also take into account that an individual may experience health without “complete” aspects of well-being. For example, an individual may experience some aspects of well-being, i.e., social and mental well-being, while possibly experiencing negative aspects of well-being, such as deteriorating physical well-being (Huber et al., 2011).

The WHO's (2014) definition of health is considered holistic, comprehensive, and the most common conceptualization of health in nursing scholarship (Simmons, 1989; Tariq-Alsman et al., 2015). Health has also been defined in nursing literature as beyond the absence of disease to include multidimensional aspects, including physical, mental, social and spiritual health, and many scholars argue that the term health is synonymous with well-being (Kushner & Jackson, 2019; Labonte, 1993; Pender et al., 2015). Nurses are now taught that optimizing health is through the process of obtaining a high level of well-being (Penque, 2019). Operational definitions of health may vary depending on philosophical views (Berg & Sarvimaki, 2003) and cultural views (Kerns et al., 2003). Kerns et al. suggests that in order to mitigate confusion surrounding the definition of health, that individuals must be aware of their own personal definitions. Furthermore, Habersack and Luschin (2013) propose that concepts and definitions of health should be standardized with the WHO's (2014) definition.

Well-Being

Nursing includes the careful application of learned skills, expert knowledge, and judgement to address the health needs of patients. There is a special quality to nursing practice that extends well-beyond a task orientation to include a holistic concern for the well-being of those requiring nursing care. The Canadian Nurses Association [CNA] (2017) and the College of Nurses of Ontario [CNO] (2006) support the promotion of health and well-being of patients in all practice contexts as a crucial aspect for the enactment of nursing values and ethical responsibilities. Nurses may promote patients' well-being through aiding in their health or welfare, or by removing or preventing harm (CNO, 2009). There are cultural considerations to well-being, where the nature of what it means to experience well-being may be culturally specific. Although there have been

associations made in the current literature between similarities of subjective conceptions for well-being between various Eastern and Western cultural groups of the reviewed literature (McMahan et al., 2014; Ku et al., 2008; Shweder, 1998), it is important to be mindful that culture is dynamic, ever-changing, and must be considered not only at the group level, but from individuals' perspective. Given that well-being is a primary and central tenant of the WHO definition of health, maintaining that, "health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 2014, p.1), well-being may be interpreted in this study as being in a state of health. Well-Being is conceptualized as a positive outcome of a multitude of good living conditions, for example, employment and secure housing (Centers for Disease Control and Prevention [CDC], 2021). There is not a universal definition for well-being that is agreed upon in scholarly literature, however, well-being is generally described as having positive moods, emotions and a fulfilled life that is satisfying (Andrews & Withey, 1976; Diener, 2000; Diener et al., 1997; Frey & Strutzer, 2002; Ryff & Keyes, 1995; Veenhoven, 2008). Additionally, the CDC (2021) indicates that well-being is a positive outcome from having vitality and health.

Episodic Disability

Although not all people affected by MS have the presence of a disability, MS is considered a disabling disease that is episodic, meaning that exacerbations may last less than 12 months and fluctuate over time (Disability Help Center, 2021; Vick, 2013; Vick, 2014). Lightman et al. (2009) posit that there is limited scholarly literature addressing the spaces between wellness and illness for women living with episodic disabilities like MS. Episodic disabilities are both a form and cause of disability that involves periods of variation between wellness and illness and do not follow a predictable disease trajectory,

such as with chronic illness (Banks, 2003; Vick, 2013; Wendell, 1996). The term disability involves a spectrum of embodied experiences and varies by context and therefore, has a fluid and porous definition instead of a fixed and static one (Hughes & Paterson, 1997; Imrie, 2004; Vick, 2013; Wendell, 1996). Women with episodic disabilities experience their disabilities uniquely and define themselves and their disability based on time and context and not how they are perceived by others; symptoms may be invisible and visible, mental and physical and vary over time (Watson, 2002; Vick, 2013). In Ontario, according to the Ontarians Disability Support Program Act (Ontario, 2021) a person with a disability is defined as the following:

- (1) A person is a person with a disability for the purposes of this Part if,
 - (a) the person has a substantial physical or mental impairment that is continuous or recurrent and expected to last one year or more;
 - (b) the direct and cumulative effect of the impairment on the person's ability to attend to his or her personal care, function in the community and function in a workplace, results in a substantial restriction in one or more of these activities of daily living; and
 - (c) the impairment and its likely duration and the restriction in the person's activities of daily living have been verified by a person with the prescribed qualifications. 1997, c. 25, Sched. B, s. 4 (1).

This definition has been critiqued as being too narrow, specifically with the aspect of disability needing to last one year, as it lacks consideration for the fluid nature of episodic disabilities (Chouinard & Crooks, 2005; Smith-Carrier et al., 2020; Vick, 2014). This is further problematic as women with episodic disabilities may have challenges with securing adequate finances through remaining employed, but also be illegible for

disability funding support (Chouinard & Crooks, 2005; Lightman et al., 2009; McAllister, 2020; Smith-Carrier et al., 2020; Vick, 2014).

One aspect of the obstacles to receiving adequate funding for women with episodic disabilities is barriers when engaging with social structures. Societal structures impact women with episodic disabilities, such as limiting employment and funding opportunities (Gignac et al., 2021; Shakespeare, 2008; Vick, 2014). Societal structures, also referred to as social structures or structures, describe elements that influence agency, or human and/or personal agency and are ontologically distinct and frame the experience of disability (Fleetwod, 2008; Sen, 1999; That Ton, 2021; Watson, 2012). Examples of societal structures include laws, politics, institutions (e.g., clinics, hospitals, education), public infrastructure (e.g., transportation), family and marriage (Barone, 1999; Schoon & Heckhausen, 2019; That Ton et al., 2021; Van Wormer & Link, 2018; Watson et al., 2012). Societal structures have been noted in the literature to impede the health and well-being of women affected by episodic disabilities (Chouinard & Crooks, 2005; Lightman et al., 2009; Vick, 2013; Vick, 2014; Smith-Carrier et al., 2020).

Women with episodic disabilities may have their social well-being impeded when experiencing barriers to societal structures, for example when having a barrier to expressing personal agency for employment opportunities (Chouinard & Crooks, 2005; Lightman et al., 2009; Vick, 2013; Vick, 2014; Smith-Carrier et al., 2020). Agency, sometimes referred to as human, or personal agency is comprised of three key elements, which are: defined individuality, actively engaging within an environment and norms within the environment (Barandiaran et al., 2009; Barkey et al., 2009; Christensen & Hooker, 2000). Health in relation to agency is described as involving the pursuit of goals without limitations, such as that of personal goals for well-being and health (Sen, 1992).

Physical Well-Being

The WHO (2014) does not elaborate on a specific definition or provide details to support what constitutes ‘physical well-being,’ and to reiterate, the term health and well-being are often used interchangeably as noted by several authors (Kushner & Jackson, 2019; Labonte, 1993; Pender et al., 2015). Therefore, the terms ‘physical health’ and ‘physical well-being’ were applied synonymously to help aide in providing an operational definition of physical well-being for this study. Khan and Qureshi (2018) propose the WHO’s (2014) definition of physical health constitutes proper physiological functioning, both internally and externally, and allows for individuals to function without limitations. Huber et al. support that physical health may be maintained when a human is confronted with physiological stress and produces a protective response that maintains and restores equilibrium; if this process cannot be achieved then an illness may form. Additionally, a search of the grey literature revealed that ‘physical health’, in addition to physiology, also relates to physical fitness and the capacity to which individuals may perform tasks (Ontario, 2019). Whereas the grey literature revealed that ‘physical well-being’ includes lifestyle choices to ensure health, and is aligned with an individual’s mind, body and spirit (American Association of Nurse Anesthetists, 2019). The WHO (2019) has indicated that physical health is associated with having mental well-being. For this study physical well-being will be defined as having physiological homeostasis in spite of having MS and the physical ability to engage in physical activities, such as activities of daily living (ADL) with or without physical limitations.

Mental Well-Being

The WHO (2018) declares that there are no universally accepted definitions for mental well-being and attributes this to the variations and differences between

individuals, cultures or groups. They do, however, state that mental well-being is “a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community” (WHO, 2014, p. 1). The WHO (2014) supports that mental well-being includes emotional, cognitive and behavioural responses on an individual level. Furthermore, the WHO asserts that the mental well-being of an individual, culture or group should be interpreted in a sociocultural context on an individual basis and supports the use of primary prevention to foster mental well-being. In sum, the WHO (2014) conceptualization of one’s well-being will be used in this proposed study, as it provides an encompassing and broadened context for understanding one’s overall health that extends beyond the physical aspect of disease and infirmity.

Social Well-Being

The WHO (2014) does not specifically outline an operational definition for social well-being. A search of relevant scholarly and grey literature was conducted to ascertain an operational definition for social well-being. Huber et al. (2011) interpret WHO’s (2014) definition of social well-being, used interchangeably with ‘social health,’ to include an individual’s capacity to independently manage their life despite a medical condition and the ability to participate in social activities such as employment. Huber et al. describe ‘social health’ as a balance between limitations and opportunities; meaning that an individual with a medical condition may adapt to their illness and engage in social activities despite their condition. In nursing literature, social well-being has been defined based on the WHO’s (2014) definition of health as being a major factor that demonstrates the function and circumstances within society (Salehi et al., 2017). Keyes (1998) proposes that social well-being has five domains; social integration, social acceptance,

social contribution, social actualization and social coherence. For the purpose of this study, social well-being will be defined as having the ability to participate in meaningful social interactions, including employment and connecting with others, despite being diagnosed with MS.

Health and Well-Being

Health: Well-Being and MS

There have been numerous studies that have examined health and well-being among various populations. For example, the effect of health and well-being were studied in terms of outcomes with Indigenous peoples' engagement in cultural practices (Jones et al., 2018); examining differences in social determinants of health among Black and Caucasian inmates (Blankenship et al., 2017); and adolescents who experienced bullying and weight gain (Greenleaf et al., 2014). However, much of the research literature about health and well-being seems to have been conducted using quantitative methods. As such, limited research appears to be available for studying health and well-being in women living with MS using qualitative methods. A study by Motl et al. (2018) explored well-being with people affected by MS by examining diet, exercise and emotional well-ness; however, the study's authors did not ground their approach in well-being related to health. Given that health is defined by the WHO (2014) as having physical, mental and social well-being, it was apparent that the literature often reflected a perspective of how the components of well-being were interwoven. For example, a study by Vega et al. (2019) examined adults living with a disability and found that less social support may lead to experiences of depression, impacting mental well-being. Research investigating the overall implications of well-being and women living with MS is presently limited with clear operational definitions for gender as a construct, but is starting to trend

towards research exploring the use of alternative approaches to medicine, including the use of cannabis to treat MS symptoms and evaluating the sexual function of women with MS. For example, several studies explored sexual dysfunction in women with MS from a biomedical lens (Conero Contentti et al., 2019), with a majority of the settings particularly in the Middle East, however, due to the cultural considerations of transferability or generalization that to a Canadian population these may not be relevant to exploring the literature on the health and well-being of women with MS from a Canadian perspective (Deghan-Nayeri et al., 2018; Hocaloski et al., 2016; Ghasemi et al., 2020; Nazari et al., 2020; Salhofer-Polanyi et al., 2017; Sazesh et al., 2021; Yilmaz et al., 2017).

Physical Well-Being and MS

Physical well-being in relation to health may be broadly interpreted as not only the absence of disease, but rather the ability to engage in physical health activities such as exercise for people living with MS. Numerous benefits for health, in relation to engaging in physical activities, are outlined in the literature about MS, such as improved physical function, mood, improved quality of life and psychological and physical well-being (Fasczewski et al., 2017; Florindo, 2014). In the literature specifically pertaining to MS, there is evidence to support that physical activity may promote anti-inflammatory properties to lessen the inflammation that promotes MS attacks, meaning acute exacerbations of symptoms related to the disease (Florindo, 2014). For example, White and Costellano (2008) suggest that the promotion of exercise and an active lifestyle could promote neuroprotection, neuroplasticity and neuro-regeneration in people with MS. However, psychological impacts, such as a fear of falling or obtaining an injury, may prevent people with MS from engaging in exercise (Kalron et al., 2018). This is despite

evidence suggesting that people with MS generally tolerate exercise well (Guilamo, et al., 2018; Padgett & Kasser, 2013). Recent literature has demonstrated that women and men with MS may experience PA differently, for example, a study by Pau et al. (2020) determined that men with MS were more likely to be sedentary and attributed this to hormones. The American College of Sports Medicine [ACSM] (2017) recommends that adults with minimal disability should engage in flexibility exercises 5-7 days/week, aerobic exercise 3-5 days/week and resistance exercise 2 days/week.

A systematic review was conducted by Florindo (2014) who examined randomized controlled trials that researched the relationship between inflammatory processes (cytokines) and physical activity for people with MS. A total of five studies examined by Florindo (2014) demonstrated a significant reduction of inflammatory processes and MS for those that engaged in physical activity that lasted over 30 minutes and alternated between resistance training and aerobics. Florindo's (2014) findings suggest that the physical well-being of people living with MS is improved with physical activity. These findings helped frame the discussion physical well-being to provide inclusive interview questions that encouraged participants to discuss their unique perspective with their physical well-being and how this is managed without the assumption that all participants would inherently engage in PA.

People living with MS may experience disability resulting in weight gain and loss of function, as observed in a study by Christie et al. (2013). The study involved women living with MS and the authors noted that the reduction of physical activity (PA) and lower-limb physical function potentially distorted the participants' body composition for adipose tissue. A total of 51 women living with MS were recruited as participants for the study. The participants were assessed for daily step counts and relative fat mass.

Participants' leg lean mass mean was measured using a dual energy X-ray. This group of 25 people were then compared to an otherwise healthy control group of 26 people. The authors noted that women living with MS had a reported 12.5% to 53% function of their lower limbs, and that an increase in relative fat mass and decrease leg lean mass were correlated with a decrease in lower-limb function. The researchers concluded that there was a need for interventions specifically aimed at reducing adiposity such as increasing lean mass and PA levels. However, the study did not capture data surrounding body image or other individual information on how women living with MS perceive their disability, bodies and ability to engage in PA.

Burschka et al. (2014) conducted a two-arm trial examining the effects of Tai Chi with people living with MS. The researchers evaluated the physical well-being of MS patients by assessing participants' balance and coordination, as well as their fatigue and depression. The study consisted of a sample of 32 participants who live with MS that were allocated into an intervention or control group. Burschka et al.'s (2014) study addressed physical and mental well-being indirectly by measuring participants' balance, coordination and levels of depression and fatigue. The results demonstrated that the Tai Chi group showed significant improvements in balance and coordination, as well as depression. However, the study did have several limitations, which included a lack of formal randomized assignment and a small sample size that impacts generalizability. As a result, there may have been some bias introduced into the results. The authors described the need for future researchers to investigate the different components of Tai Chi, such as motion, breathing, and mindfulness to help develop theories about how these impact mechanisms triggered MS symptoms or relapses. This study's intervention group (n=17) were mostly women (n= 10), however, the authors did not appear to control for gender as

a variable, so it is unclear as to whether there are any specific insights for how Tai Chi impacts the well-being of women with MS specifically in comparison to men.

Recent literature about women with MS explore matters related to sexual function and intimacy for this population (Nosrat et al., 2020; Mohammadi et al., 2020). For example, Nosrat et al. (2020) conducted a pre-post intervention clinical trial to assess for the effect of pelvic floor muscle exercises on sexual function for women with MS (n=45). Participants were recruited using purposeful sampling and involved women who were attending an MS clinic in Iran, between the ages of 18-45 years, had literacy skills, were married, diagnosed with MS and had a sexual function score less than 26.5 on the Female Sexual Function Index (FSFI) questionnaire. The FSFI is a validated tool (Cronbach's alpha= .85) that contains 19 questions pertaining to libido, sexual satisfaction, pain, lubrication and orgasm with a score up to 36; a score of 28 points or higher indicates sexual dysfunction. Nosrat et al. (2020) concluded that pelvic floor muscle exercise may improve the sexual function of women with MS (p=0.001). Mohammadi et al. (2020) explored factors associated with intimacy and sexuality for women effected by MS by conducting a cross sectional study using convenience sampling of women less than 35 years old (n=117) with MS who were attending outpatient clinics in Iran. Mohammadi et al. (2020) utilized the Multiple Sclerosis Intimacy and Sexuality Questionnaire-19 (MSIS Q-19) to evaluate how MS influences sexual satisfaction and function, the authors note that the psychometric properties for the MSIS Q-19 are well documented but do not explicitly state what these are. The MSIS Q-19 consists of 19 items evaluating MS symptoms impact on sexual satisfaction and function over the previous 6 months The authors concluded that psychological and demographic factors such as employment and education adversely impacted sexuality and intimacy (p= < 0.001) for women with MS

and that early interventions to support mental health are essential to mitigate these effects. The influence of sexuality or sexual dysfunction and how this is influenced by physical well-being was not a focus of this study and therefore not explored unless mentioned by a participant. However, the quality of relationships is an important aspect of social well-being, including relationships with spouses, partners and previous and was considered for developing the interview questionnaire.

Krysko et al. (2020) conducted a study that examined the literature about the impact of female hormones and MS susceptibility (i.e., relapses of symptoms) during menarche, pregnancy and menopause. The authors indicate that women with MS may have safe pregnancies but may be concerned about stigmatization and require expert support to cease any disease modifying therapies. Furthermore, Krysko et al. discuss the period of ovarian aging (perimenopause) as a time that correlates with secondary progressive MS. A limitation of this study was that gender was not discussed as a study construct.

Zeydan et al. (2020) examined the reproductive history and menopause of women with MS using a cross-sectional study design and a case-control of MS with matched population-based cohort. The authors noted that there was a noted significant relationship for females with MS having less full-term pregnancies than the control group ($p < 0.0001$) and menopause was significantly associated with the onset of progressive MS ($R^2 = 0.359$, $P < 0.001$) and expanded disability status ($R^2 = 0.229$, $P < 0.003$). Results from studies of a similar nature to Zeydan et al.'s reported by Bove et al., (2021), Rankin and Bove (2018), Karageorgiou et al. (2020), and Sparaco and Bonavita (2021) who noted that there is a correlation between menopause and progressive disability in women with MS. As the impact of menses, pregnancy and menopause is not a focus of this study, it

will only be explored if mentioned by a participant during the semi-structured interviews. There is a robust amount of scholarly literature on the biomedical aspects for female hormones and MS for health care professionals to refer to when providing care for women with MS, including pregnancy and menopause. However, this literature review revealed a gap in knowledge for how gender intersects with women with MS, such as the influence from social structures to manage physical well-being are experienced by this population.

Vorobeychick et al. (2020) conducted a systematic review to inform the care of young women with MS in Canada. The authors propose that women with MS in Canada require care that is holistic and addresses concerns like constipation, urinary incontinence, depression and pain. The authors did include gender as a construct in their discussion of the review findings, but did not discuss how gender intersects with the health of this population. The authors noted important aspects about caring for women with MS, including contributing biomedical factors to troubling symptoms such as constipation, but did not discuss social implications for women living with MS, such as the impact episodic disability caused by MS may have on secure housing, employment, or access to basic income for nutritious food (Vick, 2014; Smith-Carrier et al., 2020). For example, the authors note that constipation can be related to poor diet but did not discuss social barriers to food security, such as barriers for eligibility funding, or inadequate financial support for nutritious food available through provincial resources, such as the Ontario Disability Support Program [ODSP] (McAllister, 2020; McDowell & Ferdosi, 2020; Smith-Carrier et al., 2020). The authors indicate that issues with finances may attribute to symptoms such as migraines and exacerbations of mental health issues associated with MS such as depression and anxiety. Additionally, Vorobeychick et al.

indicate that Registered Social Workers can support the care of women with MS, which may help address financial constraints. The authors conclude that multidisciplinary care is needed to support women with MS, however, the term interprofessional care is more commonly used in available scholarly literature pertaining to the working relationship between professional groups (Bainbridge et al., 2010; Khalili et al., 2013).

Although there is a great deal of literature on the evaluation of physical performance in people diagnosed with MS (Christie et al., 2013; Florindo, 2014;), there is a gap in the literature of studies exploring physical well-being on health and barriers within social structures that may be experienced by women with MS; which is one area of focus for this study. Further, a limitation of the studies presented is the primacy given to quantitative approaches that are often from a bio-medical perspective. Personal perceptions of physical well-being in people with MS are not adequately addressed in current literature and therefore will be explored further within this study.

Mental Well-Being and MS

Health is comprised of more than a physical state and involves one's mental or psychological well-being. Psychological well-being and MS have been documented in the recent literature in addition to physical well-being, however, this is still very much a growing area of research that requires further investigation. A study by Strober (2017) examined personality types in people with MS to evaluate the role personality may have on psychological well-being, coping, and overall quality of life (QOL). Strober examined if a distressed or 'Type D Personality' among individuals with MS had an impact on disease management, disease symptoms (including health-related behaviours that are related to mental well-being, such as coping, psychological well-being) and overall QOL. Strober did not provide a robust definition of well-being as a construct nor did the author

utilize a specific measure, although the author did attribute personality types, such as distressed 'Type D Personality', as a determining factor to overall negative well-being. Strober found that people with MS who have 'Type D' personalities reported a higher level of fatigue and pain ($p < 0.05$), lower levels of social and family support ($p < 0.05$) and lower self-efficacy in managing their MS ($p < 0.05$). Furthermore, "Type D" personalities in Strober's (2017) study were more likely to employ maladaptive coping skills, demonstrate behavioural disengagement and engage in substance use. Specifically pertaining to psychological well-being and QOL, 'Type D' personality participants also reported a higher level of depression ($p = 0.001$) and trait anxiety ($p = 0.001$). The author concluded that personality traits may greatly impact one's overall well-being and QOL, and efforts to better understand this area and provide informed education is needed. Additionally, these findings suggest a potential overlap between mental and social well-being that has not been directly addressed in current literature with this population. Strober's (2017) study helps to illuminate the impact personality types might have on the QOL and well-being of people living with MS, including maladaptive coping strategies like substance use. Similar findings were reported by Kar et al., (2020), who noted that women with MS who have established anticipatory coping skills were more likely to adapt to mental stress associated with having MS. Strober's findings helped to inform compassionate dialogue with participants, which included allowing participants to discuss their mental well-being from their own perspective.

MS might influence the QOL and mental well-being of those who are recently diagnosed, however, this may be improved with the initiation of cognitive behavioural interventions, as examined in a study by Calandri et al. (2017). Calandri et al. (2017) used a quasi-experimental design with 85 participants with recently diagnosed relapsing-

remitting MS (RRMS) to study the effect of cognitive behavioural therapy (CBT) on quality of life and psychological well-being. The participants were placed in an intervention group (n=54) and participated in five group format cognitive behavioural sessions held over two months with a six month and 12-month follow-up session. All these sessions were conducted by a psychologist with experience in group cognitive behavioural therapy. Thirty-one participants were placed in the control group and received the usual care for people living with MS, which included routine activities prescribed to newly diagnosed MS patients and interviews with their neurologist, psychologist and MS nurse (Calandri et al., 2017). Participants completed a survey about socio-demographic variables and measurement tools about QOL, depression, affective well-being and optimism (Calandri et al., 2017). The results were analyzed using a repeated measures analysis of variance (ANOVA) to investigate any significant group and time interactions. The results included an increase for positive mental health for the intervention group ($p = 0.036$); well-being was significantly increased in the intervention group ($p = 0.048$); and lastly, optimism had increased in the intervention group at the one-year follow-up ($p = 0.007$). The researchers concluded that the cognitive behavioural intervention had a positive impact on participants' mental health and overall psychological well-being. Similar findings were noted by Pahlayanzadeh et al., (2017) who conducted a clinical trial for cognitive group therapy with women with MS in Iran. The authors found significant relationships for various components of mental well-being including improved stress ($p = 0.02$), anxiety ($p = 0.02$) and depression ($p = 0.03$).

Subjective well-being may vary across the lifespan of a person with MS, as investigated in a study by Stern et al. (2018). Stern et al. (2018) examined the subjective well-being of 57 individuals with MS and classified them into three age groups: 35-44,

45-54, and 55-65, suggesting that examining differentiation across the lifespan in relation to age in people with MS, allows for more targeted screening. The authors conducted an exploratory secondary analysis of cross-sectional data that was originally obtained by one of the authors in a previous study. Depression was measured as an outcome using the Mood and Evaluation scale from the Chicago Multiscale Depression Inventory (CMDI), which is a standardized self-reported questionnaire with 5-items that evaluates mood and somatic symptoms, and the Physical and Mental scale from the Multiple Sclerosis Quality of Life Instrument (MSQOL-54); with no mention from the authors about the validity or internal consistency of either scale. The results from Stern et al. (2018) indicated that the oldest group of people living with MS had significantly less severe depressive symptoms and a better QOL ($p > 0.05$), suggesting that younger individuals diagnosed with MS may potentially be at risk for poorer QOL and depression. The authors addressed the limitations of the study, which included the inherent nature of a cross-sectional design and the limitations on generalizability, as causality cannot be inferred. Literature related to the mental well-being of people with MS and influence of aging helped to increase awareness for how age may affect participants' individual experience of health and well-being. Consideration was given for the unique nature as to how age influences the health and well-being of each participant, including being young and employed or medically retired, or an older adult who may be at the expected age of retirement.

Depressive symptoms are frequently reported and observed in individuals with MS and may be further exacerbated by the experience of pain. However, the impact of pain on depressive symptoms may be lessened when an individual has a sense of spirituality (Nsamenang et al., 2016). Nsamenang et al. (2016) studied the associations

between pain interference, depressive symptoms and spiritual well-being in 81 patients being treated for MS. The authors hypothesized that spiritual well-being would be negatively associated with depressive symptoms and pain interference would be positively associated with this as well, thus an increase in mental-well-being may be experienced with improved depressive symptoms.

Nsamenang et al. (2016) analyzed an exploratory mediation model for possible associations between spiritual well-being, depressive symptoms, and pain interference. Nsamenang et al. (2016) used the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp) to assess the spiritual well-being with chronic illnesses. The FACIT-Sp includes two subscales to assess for meaning and inner peace, and faith (Cronbach alpha= .88). Depression was evaluated using the Center for Epidemiologic Studies Depression Scale (CES-D-R-20), as this measurement assesses the presence and level of depressive symptoms and is noted as having excellent internal reliability (Cronbach alpha = .90). Pain interference was measured using the Pain Effects Scale (PES), which is part of the Multiple Sclerosis Quality of Life Inventory (MSQLI) and includes 6 items that evaluate the impact of pain on mood, ambulation, sleep, enjoyment, normal work and recreational activities. Nsamenang et al. reported the PES had excellent internal consistency among populations with MS (Cronbach alpha = .92).

The authors' results indicated partial support of their hypothesis; greater spiritual well-being was associated with a reduced perception of pain interference ($p < 0.05$); this in turn was associated with less depressive symptoms ($p < 0.05$). The authors noted that their findings indicate a need for a psychosocial approach to the treatment of pain-related symptoms with patients who have MS, and that those working with this population should promote spirituality as a means to positively influence the pain, depressive

symptoms and thus potentially improve the overall mental well-being for people with MS. A limitation of the study is the small sample size that impacted the power of their statistical analysis. Nsamenang et al.'s (2016) study helped provide the necessary foundation of understanding the broad impact invisible physical symptoms associated with MS and physical well-being, i.e., pain, may have on mental well-being. This will help enrich the interview questionnaire and analysis for the current study as the findings from Nsamenang's research highlights the complex relationship and interconnectedness between various forms of well-being.

A study by Senders et al. (2014) assessed the use of mindful-consciousness in people with MS to modify the impact of stressful events and improve health outcomes. Senders et al. (2014) reasoned that stressful life events have been demonstrated to worsen neurological symptoms and decrease the QOL in people living with MS. Therefore, the authors sought to evaluate the associations between mindful-consciousness, perceived stress, coping and resilience in participants with MS and QOL. The researchers used a convenience sampling approach to recruit a sample of 119 participants, men (n=26) and women (n=93), with any type of MS between the ages of 18-90. The authors used the Perceived Stress Scale (PSS) to assess uncontrollable, unpredictable and overloaded perceived stress is, with higher scores indicate increased levels of stress; Five Facet Mindfulness Scale (FFMQ) which consists of 39-items and evaluates mindfulness for 5-items (describing, observing, awareness, non-reactivity and non-judging); Connor-Davidson Resilience Scale (CD-RISC) which measures resiliency characteristics (tolerance, patience, commitment, adaptability and recognition of limits to control); Brief Coping Orientation for Problem Encounters (B-COPE) that consists of 14 subscales to assess various aspects of coping and contains 28-items; and the Medical Outcome Study

Short Form-36 (SF-36) to evaluate the study's variables, which is a general measure of QOL and evaluates components of mental health and physical health. The authors do not provide information for the internal consistency for the measurements enlisted in their study, but do indicate that the SF-36 is noted as being valid, reliable and widely utilized in MS trials.

The study's results demonstrated that participants who reported being mindful were likely to have lower levels of perceived stress and utilized more constructive coping mechanisms to manage their MS, such as information gathering, planning, and seeking out social and instrumental support. These results help provide further insight into the possibility that some participants may or may not participate in holistic care to manage their health and well-being with MS, such as meditation or alternative therapies to help manage the stress. Conversely, this study's findings have helped alleviate some potential a priori assumptions that all participants may either be stressed or lack adequate coping mechanisms in relation to their health and well-being when managing their MS.

Having MS can increase the likelihood of various psychosocial issues that impact mental well-being, such as depression and anxiety (Boeschoten et al., 2017). People with MS have a reported 30% increased chance of experiencing major depressive disorders; which is four times higher than the general population (Schurmann & Margraf, 2018; Weinberger et al., 2018). Between 23.5% to 44% people with MS experience anxiety (Wood et al., 2013). Due to the psychosocial impacts that depression and anxiety can bring, there is a burgeoning amount of research being conducted on alternative therapies to help alleviate the impact of depression and anxiety has on people with MS (Kim, et al., 2018; Sesel et al., 2019). For example, Spitzer and Pakenham (2018) conducted an interventional pilot study with 23 adults (female= 21, male= 2) in a five-week

community-based mindfulness program for people with MS. Spitzer and Pakenham assessed quality of life (QOL) as their primary outcome, and concluded that this intervention may improve well-being. These studies help inform the current study through understanding the complex relationship between mental well-being, mental health and being affected by MS, which may not always be apparent to others. The findings also suggest that not all participants may face challenges with mental well-being, but if this is experienced that they may be engaging in meaningful therapeutic activities, such as mindfulness to lessen these feelings.

Bassi et al. (2014) examined the coexistence of well- and ill-being in people with MS (n= 71, 67.6% female), their caregivers (n=71) and health professionals (n=26) in a multi-centered study that examined depression, QOL, psychological well-being, life satisfaction, hedonic balance, and additionally, gathered demographic information on all participants. Bassi et al.'s study noted that people with MS reported higher levels of depression, lower QOL and lower general well-being. Additionally, the authors reported that the caregivers of people living with MS had a higher level of depression and lower general well-being in comparison to the health professionals caring for these participants, who reported having higher levels of well-being.

Being employed has been shown in the current literature to support positive well-being, and conversely, being unemployed may negatively impact one's social well-being (Stam et al., 2016). Bassi et al.'s finding's demonstrates the connection between mental and social well-being, and may have implications for the quality of relationships for people affected by MS. This helps heighten awareness to explore the nature of relationships for participants who are receiving care from loved ones, or paid professionals and how this influences their social well-being and health.

A departure from the previously noted studies, which focused on quantitative approaches, Cowan et al.'s (2020) study examined the lived experience of the psychological aspects of living with the disease of MS. Fifteen participants (10 with progressive forms of MS) from an inpatient rehabilitation unit where care was provided for people with MS who had disease progression or severe relapse of their illness. The authors interviewed individual participants using a semi-structured interview guide six-weeks post-discharge from the inpatient rehabilitation unit. Emergent themes included: fatigue, independence and dependence. The findings from Cowan's study help demonstrate MS as an episodic illness that changes over time and varies for each individual. This helps inform the study through consideration for how participants experiences may vary depending on their current health status with MS and previous experiences, thus indicating that health and well-being may fluctuate for the investigated population. Much of the research conducted on mental well-being and MS is conducted utilizing quantitative methods and a gap in literature continues to exist about foundational knowledge around women's experiences with MS, their mental well-being and the episodic nature of MS.

Social Well-Being and MS

Social well-being (SWB) is defined by the WHO (2018) as being a central component of overall health. Soleimani et al., (2018) define SWB as an individual's relationship with others and society. Soleimani et al. describe SWB with MS as including social prosperity, adaption, cohesion, acceptance and participation. Social well-being may refer to the sociocultural and environmental factors present in an individual's life. Wojcicki et al. (2014) note that there can be a relationship at the psychological level that appears to exist between mental and social well-being, whereas symptoms such as

depression and anxiety may lessen social relations and affect leisure activities in people with MS. Bassi et al. (2019) further support that perceived coping strategies, such as positive social support, will improve the likelihood of experiencing psychological well-being. Similar findings for self-esteem and social participation were noted by Mikula et al., (2017) and Wilski et al., 2016, which may further suggest the linkage between mental well-being and social well-being.

Social isolation in people with severe MS was examined by Freeman et al. (2020) using a mixed methods approach. The authors recruited 16 people living with MS (female, n=9) who were reported as experiencing a severe level of disability (EDSS > 6.5). The authors conducted individual interviews using a semi-structured interview guide. Themes included: defining isolation, causes of isolation, impact of isolation, potential eases of isolation; which suggests that people with severe MS are more likely to experience aspects of social isolation and less social well-being. Participants with severe MS who reported less meaningful social engagement were noted as having to rely more on others, which created feelings of being burdensome to those providing support. Participants noted feeling a loss of their sense of self, place in life and overall purpose. The authors highlighted that finding ways to promote meaningful social engagement for people living with severe MS may promote social participation and promote a sense of purpose. Meaningful social engagement may not occur during MS group meetings where participants expressed challenges bonding with others over their illness. This suggests that people living with MS may benefit from the development of diverse strategies to facilitate meaningful social connections and was explored in this study.

Employment is noted by Pack et al. (2014) as being important to one's overall social well-being and mental well-being for people diagnosed with MS. Pack et al. (2014)

assert that QOL has been used to describe subjective well-being, life satisfaction and overall happiness. Therefore, the authors sought to evaluate the role of employment in relation to QOL in people diagnosed with MS. Participants consisted of 1,310 people diagnosed with MS, aged 21-89 who were recruited through ten National Multiple Sclerosis Society chapters in the United States of America. The participants were split into three categories of employment, including: full-time employment, part-time employment and unemployed (retired, homemaker, and volunteer employment). An 86-item un-named survey instrument was used to measure participants' QOL. Participants who were employed reported a higher level of QOL than those who were unemployed ($p < 0.05$) (Pack et al., 2014). Similarly, Strober and Arnett (2016) reported that women ($n=17$) with MS who were unemployed reported greater disability ($p < 0.001$), had higher levels of fatigue and substance use. This information will help inform interview questions and dialogue pertaining to employment, including the impact of employment on social and mental well-being, as well as underpinning discussions on participants who may be unemployed and may have faced challenges with this transition.

Invisible symptoms often associated with MS, such as mood disorders, fatigue and cognitive impairment may be problematic for those wishing to engage in meaningful work and socializing (Lorefice et al., 2018). The authors examined the relationship between employment status, social lives, level of physical disability and invisible MS symptoms for fatigue, depression and anxiety with 123 participants ($n=85$ females) in Italy. The study examined demographic data (sex, age and education), clinical data, and disability level. The study then investigated the co-occurrence of invisible symptoms. Fatigue was evaluated using the Fatigue Severity Scale (FSS), which consists of nine-statement interview with Likert scales up to seven (higher scores indicate increased level

of fatigue). Depression was assessed using the Beck Depression Inventory Second Edition (BDI-II) which includes a 21-item, self-reported questionnaire with a maximum score of 63 (depressive symptomology is indicated by scores greater than 14). Apathy was measured using the Apathy Evaluation Scale (AES-S) containing of 18-items for cognitive, behavioural, emotional and general characteristics of apathy. Additionally, participants filled out the Work and Social Adjustment (WSAS) questionnaire to evaluate respondents' ability to work, with higher scores (up to 40) indicating a higher level of impairment. The study revealed a significant relationship between higher education levels and employment ($p < 0.01$) and higher disability was significantly associated with unemployment. The authors did not provide any details for the reliability or validity of the instruments used. Lorefice et al. surmised that there were no significant associations between employment and invisible symptoms, but that invisible symptoms of MS may still negatively affect participants' social life. For example, social structures such as employment or social support (i.e., friends, family) may be impacted negatively as a result of invisible MS symptoms. Other factors that may impact the findings in Lorefice et al.'s (2018) study could also be attributed to positive coping strategies, less barriers experienced by their participants with societal structures in Italy and gender. Holland et al. (2019) evaluated coping in participants with various neurological disorders ($n = 722$), including women with MS has suggested that women and people who are employed are more likely to positively cope with MS through the use of venting and seeking emotional support. Authors have also noted that the episodic nature with MS requires employers to support accommodation of employees' needs in order for them to remain in the workplace, but that accommodation is an aspect that is often neglected (Viek, 2013; Viek, 2014; Vijavasingham et al., 2017). The findings in the literature will assisted in informing

dialogue pertaining to employment, social well-being and the influence on mental well-being. Further consideration will be given to societal structures that may enhance or impede employment during in-person interviews, such as supportive work environments where participants MS diagnosis could be disclosed and accommodations met.

Hunt et al. (2013) conducted an interpretive phenomenological analysis (IPA) on the meaning of engaging in art as a leisure activity for people living with MS.

Participants were recruited via email from MS Ireland and were eligible if they had a diagnosis of MS and participated in any form of visual art making. A total of five participants were recruited for the study, including two males and three females. All participants identified as being Caucasian, retired upon diagnosis of MS, in a relationship, and the length of time from their initial onset of MS varied from one to 30 years. Five themes emerged from the data, which included: 1) adjusting to a new way of life, 2) managing time meaningfully, 3) creative classes - a multifaceted experience, 4) art-making as an affirmative experience, and 5) self-expression of feelings and personality through artwork. The authors noted that the women reported enjoying the social aspect of being involved with art classes while the men in the study did not. Although this finding requires further investigation, it may suggest that men and women may experience social-well-being in different ways, and therefore will be given consideration in the study.

Well-Being and Women with MS

This section will focus studies exclusively published on women with MS. Previously reported studies in this literature review had relevancy for this study pertaining to the conceptualization of well-being and MS but were mostly conducted with both male and female participants who are affected by MS. A pilot study conducted by

Becker et al. (2017) evaluated the use of acupuncture with women living with MS who were attending group sessions about health promotion directed to this population. A total of 14 women diagnosed with MS attended eight classes to learn more about building health promotion skills and overall QOL. The group also received acupuncture immediately before or after each class. The study used a pre-post experimental design, and a self-reported questionnaire about symptoms associated with MS (i.e., fatigue, pain and depression). The authors observed a significant improvement in the areas of self-reported fatigue, anxiety, sleep interference, stress and pain and a significant increase in an overall sense of general or overall well-being (Becker et al., 2017). Becker et al.'s study helped further increase the understanding and appreciation for the interconnectedness between physical, mental and social well-being. However, since acupuncture is not covered by most private insurers or ODSP in Ontario it also heightens the awareness of potential inequities and barriers some participants may experience when selecting treatment options for their MS symptoms.

Kolahkai and Zargar (2015) took a unique approach to investigating the psychological symptoms associated with MS through examining the effects of mindfulness-based stress reduction (MBSR) on stress, depression, and anxiety in women living with the disease. The authors used a randomized controlled trial design in a major city centre in Iran with a convenience sample of 48 women living with MS. Participants were assigned to either the experimental group (n=24 women living with MS) where they engaged in the intervention of MBSR, while the remainder of participants (n=24) were assigned to the control group and received treatment as per usual. Both groups completed the Depression, Anxiety and Stress Scale (DASS-21) during the initiation of the study, at one-month, and then again two-months post implementation of the MBSR intervention

for the experimental group. The authors concluded that the MBSR intervention had significantly reduced participants' mean levels of depression, anxiety and stress scores; indicating that MBSR is an effective intervention for women living with MS. Although this study will explore the need for holistic approaches for managing potential psychological symptoms associated with MS, it will consist of a qualitative element to the study to enable women to define their own meaning of well-being and how this relates to their mental health. A mixed methods study incorporating both quantitative and qualitative methods could advance knowledge in this area further, as recent findings in the literature demonstrate that self-esteem, including positive body self-esteem improved feelings of mental and social well-being for women with MS (Mikula et al., 2017; Wilski et al., 2016). The literature with women with MS and well-being currently focuses on holistic interventions, such as acupuncture or meditation that promotes mindfulness. However, there is a gap in foundational knowledge for how this population experiences holistic treatments from their own experiences and within a Canadian context, which will be addressed in this study. This information may help uncover currently underreported barriers or facilitators such as social structures and how women with MS may express their agency in selecting these treatment options.

One study was located for this literature review that utilized a broad application of phenomenology as an encompassing 'theoretical lens' and explored the perceived influence of targeted group exercise on the well-being of women living with MS (VanRuymbeke & Schneider, 2013). This study was conducted in Southwestern Ontario and involved six female participants. VanRuymbeke and Schneider (2013) highlighted that participants perceived targeted group exercise as beneficial and positive for their well-being, but did not specifically state the areas of well-being being addressed. The

authors note that more qualitative research using qualitative methods to explore the well-being of women with MS would be beneficial to help develop strategies to improve the lives of men and women with this condition. This will be considered in the study for examining how gender intersects with women and MS engaging with, or experiencing various social structures to manage their health and well-being.

Researchers are beginning to put more focus on examining and exploring MS in relation to a variety of facets of social well-being, including motherhood, marital adjustment, and employment (Graziano et al., 2020; Ozturk & Dayapoglu, 2019). For example, the impact of adjusting to MS, identity satisfaction, and motherhood were examined by Graziano et al. (2020) using a cross-sectional study design that evaluated depressive symptoms, affective well-being and identity satisfaction for newly diagnosed mothers with MS (n=74 females). Participants ages ranged from 19-57, n=32 were mothers of children between 2-29 years, all had mild-moderate disability and were diagnosed with RRMS. The authors evaluated depressive symptoms with the Italian validated 10-item Center for Epidemiologic Studies Depression Scale (Fava, 1983). Affective well-being was evaluated using the Positive Affect and Negative Affect Schedule, which has two mood scales for Negative Affect (10-items) and Positive Affect (10-items). Identity Satisfaction was evaluated through the Identity Motives Scale (Manzi et al., 2010), which is comprised of six identity motives (continuity, self-esteem, efficacy, belonging, distinctiveness, and meaning) using 12-items, for both positive and negative aspects of identity motives. Graziano et al. describe measurements in their study as validated in Italy but only provide psychometric information on depressive symptoms with 68 participants (Cronbach's alpha = .87). The authors found that mothers with RRMS experienced greater levels of depression, less affective well-being, and less

identity satisfaction. This included a significant relationship between depression and motherhood with a disease duration of three years ($p < .0001$). The researchers concluded that health professionals need to consider the additional complexity the role of motherhood might have on women diagnosed with MS that have young children.

Graziano et al. noted that their study size was not representative of all women with MS and had limitations for the generalizability of their results and that further investigation is needed for mothers with MS who have more severe disabilities.

Studies by Graziano et al. (2020) and Eid et al., (2021), who conducted a cohort study evaluating the onset of depression and anxiety for women with MS who gave birth ($n = 308$), noted that women with MS who were newly diagnosed had greater levels of depression, with an increased risk of depression developing in their third trimesters and postnatally; this included previous sexual abuse and adverse socioeconomic as risk factors for developing depression. Similar studies were conducted by Calaceci et al. (2021), who explored the lived experience of women with MS ($n = 16$) who were seeking to become mothers, pregnant or had become mothers and found that parental support was an important aspect and key finding. A content analysis was conducted by Ghafoori et al. (2019) in Iran with women affected by MS who were of reproductive age, who noted “lack of social support” as a key theme. This may begin to show the important of social support and well-being for young mothers and thus the social support for participants in this study who are young mothers and how this influences their social well-being were considered. Ghafoori et al., also noted that participants had a fear of failing as a parent, fear of pregnancy concerns and fear of infertility; this resulted in participants postponing motherhood or voluntarily choosing to remain childless. Similar findings were reported by Parton (2019) who conducted semi-structured interviews with women with MS who

are mothers (n= 20) and using a thematic analysis reported themes of fear of failing at motherhood and being judged. Likewise, Ferraro et al. (2017) examined breast feeding and delivery procedures for women in an intervention group (n= 303) and a control group (n= 500) and noted that having MS was associated with higher frequencies of voluntary childlessness. This suggests that mental well-being may also have implications for participants' decisions to become mothers or remain childless. Such findings will be considered through exploring this aspect of social well-being within this current study when addressed by participants. Consideration of participants' unique perspective and attitude towards motherhood are not a focus of the current study, but implications for social well-being and the role of motherhood were noted prior to engaging in semi-structured interviews and will help inform dialogue and prompts if motherhood is addressed by participants as influencing their social and mental-well-being, including participants who may describe voluntary childlessness and motherhood.

Marital adjustment has been found to influence a couple's well-being and satisfaction, the compounding factor of MS has been found to contribute to marital stress and make it twice as likely for a couple to seek divorce (Boland et al., 2012; Gold-Spink et al., 2000). The impact of MS on marital adjustment was noted in a study conducted by Ozturk and Dayapoglu (2019) that involved women with MS who lived in Turkey. Ozturk and Dayapoglu (2019) conducted a cross-sectional study with women (n=154) living with MS who were admitted to a neurology clinic in Turkey. Instruments included a demographic form, MS Features (type of MS, amount and duration of MS exacerbations and hospitalization, etc.), and The Marital Adjustment Scale (MAS). Women's marital adjustment decreased with hospitalizations ($p=0.04$), MS exacerbations ($p=0.00$) and their increased duration for length of having MS ($p= 0.006$). The authors

concluded that women with MS may benefit from professional support to keep their relationships and marriages healthy. In the current study, literature pertaining to marriage and women with MS helped inform respectful and open dialogue pertaining to social well-being, including women who were in partnerships, divorced and single.

The literature review for this study indicates that there is limited research available about the overall well-being of women with MS and how this population perceives their own health through physical, mental and social well-being. As such, this may be problematic as research focusing on bio-medical types of perspectives may not enable nurses or other health practitioners to create and engage in patient-centered and evidence-informed interventions from the perspective of women living with this illness. In this literature review, quality of life (QOL) was explored as a concept related to the health and well-being of the population involved in this study. However, the literature revealed that QOL as a concept involves nuanced differences when compared to the WHO's (2014) definition of health and well-being. Although an important concept to explore, in relation to MS, it was found that literature about QOL with MS did not generally take into consideration more global aspects for social and mental well-being with MS (Vickrey et al., 1995), such as the influence of enacting personal agency within social structures and possible barriers that may pose limitations like finances or accessibility needs as a result of experiencing disability that may impact the health and well-being for this population. As such, the literature review process enabled the research question to be considered from a somewhat more holistic perspective that considered social and mental well-being. Further, the known research found to date in the area of women's health and MS seems to be disjointed in nature, with various topic areas being touched upon in research but not yet pursued to an in-depth and comprehensive level. As

noted, much of the located research literature used quantitative approaches, which demonstrates a gap in foundational knowledge about the experience of living with MS from women's perspectives in particular. Building upon the foundation of what is known, this study can serve to create a body of literature that is comprehensive in nature and includes a variety of methodological approaches that have been used in rigorous studies. By conducting this study, further data on how women experience their health and well-being from their own unique perspectives may be illuminated and better inform nursing care from a holistic approach (Becker et al., 2017). Conducting a qualitative exploration about women and MS, specifically related to health as defined as physical, mental and social well-being, can help develop information to inform nursing and allied health practices and future research that aims to better understand how women with MS ameliorate or manage their illness.

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CHAPTER 3

THEORETICAL LENS, METHODOLOGY, METHODS

To explore health and well-being in women with MS, a methodology was selected to elicit the lived experience and meaning of this phenomenon. Since the purpose of the study was subjective in nature, the focus was on selecting a methodology that would illuminate the lived experiences of individuals, therefore, the study was conducted using an exploratory methodology (Denzin & Lincoln, 2011; Patton, 2012). The study design is within a qualitative research paradigm, as this allows the researcher the ability to utilize lived human experiences as a source of enriched data (van Manen, 1997b). In this chapter rationale for constructivism as a theoretical lens is described as it provides a philosophical account for the research methodology informing the study. This chapter further explores an overview for the application of interpretive phenomenological analysis (IPA) to this study as both a methodology and a research method. Additionally, details of the methods used to collect and analyze data are provided.

Theoretical Lens

Constructivism

Constructivism as a philosophy is based on the premise that the world as experienced by human-beings differs from the physical and natural world and that the human experience is made up of linguistic and cultural constructs that shape an individual's perception of reality (Denzin & Lincoln, 2011; Patton, 2012). Language, as a cultural and social construct, shapes reality from multiple perspectives and is a central focus for constructivism (Patton, 2012; Peck & Mummery, 2018). Constructivism is relative to time and place, and changes with variations of these, meaning that there may be no true expression of absolute reality (Patton, 2012). Denzin and Lincoln (2011)

summarize constructivism as being methodologically hermeneutic (interpretive) and dialectic (investigative), ontologically relativist (truthful) and epistemologically subjectivist (subjective experiences). As a philosophy, it is rooted in ontological relativity, meaning that it is concerned with the way of 'being' as a form of reality derived from individual's subjective experiences that are interpreted as truth (Patton, 2012). The epistemological consideration for constructivism asserts that one's knowledge is shaped by their own personal experience (Crotty, 1998).

In research, constructivism is based on a philosophical perspective and is used to describe the social constructions and perceptions of individuals and viewed as 'reality oriented' from subjective experiences (Patton, 2012). Some questions a researcher investigating a phenomenon may ask from a constructivist paradigm include: "What is the reality of the individuals in this setting?", and "What are the consequences of these perceptions?" (Patton, 2015). When conducting research from a constructivist lens, traditional and positivist paradigmatic concerns such as internal and external validity are exchanged by terms such as authenticity and trustworthiness (Denzin & Lincoln, 2011). The primary assumptions of constructivism in research include the following: 1) Truth or knowledge is directly derived from one's lived experiences; 2) Facts only have meaning when they are within a value framework that change with time and place, therefore, there is no one such 'objective' reality as this constantly changes; 3) Causes and effects do not exist within a subjective reality; 4) Phenomena can only be comprehended within the context in which they are lived and experienced; generalizations cannot occur from one phenomena to the next; and 5) Information derived from constructivist inquiry cannot be assumed to have absolute facts, they can only represent another construction to be considered towards consensus of a phenomenon (Denzin and Lincoln, 2011; Guba &

Lincoln, 1989). Constructivism informs the philosophical underpinnings of this study as the purpose of this study is to construct the truth or knowledge for the lived experiences of women living with MS in Southwestern Ontario and was derived subjectively from people experiencing this phenomena.

Methodology

Phenomenology

As a methodology, phenomenology aims to uncover the meaning, structure, and essence of the lived experiences of a person or group of people and the science of phenomena; it has developed as both a philosophy and methodological research approach (Kant, 1964; Munhall, 1994; Patton, 2015; van Manen 1990, 1997b, 2014a).

Phenomenology is focused on uncovering how language, concepts, and theories provide structure and context to the present living moment (van Manen, 1990). There are two main branches of phenomenology, the first being transcendental, which is also known as descriptive or Husserlian phenomenology, and the other being hermeneutic or interpretive and Heideggerian phenomenology (Rapport & Wainwright, 2006).

Husserlian phenomenology was developed by the philosopher Edmund Husserl (Husserl, 1931) at the Utrecht School in the Netherlands and the latter Heideggerian (Heidegger, 1962) or interpretive phenomenological approach was developed by his student Martin Heidegger (van Manen, 2014b). Husserlian phenomenology refers to the use of bracketing, or suspension of presuppositions through the phenomenological reduction, whereas the Heideggerian phenomenological approach involves the awareness of one's perceptions and thoughts through an interpretive process (Rapport & Wainwright, 2006).

Edmund Husserl (1911-1980) is credited as the intellectual 'father' of phenomenological philosophy. Husserl's descriptive phenomenological approach

involves studying phenomena through unobstructed notions that aims to get to the things themselves (van Manen, 1990). Husserl (1931) defines phenomenology as a philosophy for the essence for pure experience (van Manen, 2014a). In descriptive phenomenology, the aim is to capture lived experience in its essence or primordial origin without theorizing, explaining or interpreting. Furthermore, Husserl posits phenomenology is not a science that aims to uncover matters of fact but is an eidetic science, meaning a science of essences (Husserl, 1931; van Manen, 2014a). Essence is described as the true being and innermost nature of a thing (van Manen, 1990). In ancient Greek philosophy, Plato described essence as the very nature of something, and Aristotle further defined this as a notion of the essential nature of a thing (van Manen, 2014a). Husserl was influenced by these philosophers and linked ‘essence’ to the basic ideals of a thing and believed this was accessible through phenomenological intuiting (van Manen, 1990, 1997b).

Husserlian phenomenology involves describing “how” experiences appear to our conscience and is a retrospective description of the lived experience (van Manen, 2014a, 2014b).

Husserl (1931) believed that in order to practice phenomenological reflection as a researcher one must go “back to the things themselves” (p. 108); therefore, this approach involves studying phenomena through unobstructed notions to prevent preconceived ideas from influencing the description of phenomena. Husserl (1931) defines this process as bracketing, which was also labelled by Husserl as *epoche*; a notion that involves the suspension of one’s natural attitude during the phenomenological reduction. A phenomenological reduction is when a researcher may prevent presuppositions from contaminating the essence of a phenomenon (Husserl, 1931). The term bracketing is a word borrowed from Husserl’s background as a mathematician (van Manen, 1990,

2014a). Heidegger disregarded the notion of bracketing as described by his predecessor's Husserlian phenomenological descriptive approach and shifted the emphasis to understanding and interpreting phenomena, which he termed hermeneutic phenomenology (Heidegger, 1962; van Manen, 2014a). He believed that no description of a phenomena may truly exist without a level of interpretation, which occurs in a cyclical manner, described as the hermeneutic circle (Heidegger, 1962; van Manen, 2014a). The hermeneutic circle refers to the researcher's process of analysis, including the interpretation of themes within the data until the essence of the phenomenon has been revealed. Interpretive phenomenology concedes that no description of a phenomena can be without conscious knowing and interpretation, and this process is never truly complete (Rapport & Wainwright, 2006; van Manen, 1990, 1997b, 2014a).

Hermeneutic Phenomenology

Phenomenology is defined as a description of the lived experience and hermeneutics as an interpretation of the lived experience through a symbolic form such as language or text (van Manen, 1990). Hermeneutics and phenomenology are approaches rooted in philosophy as human science through reflection. Hermeneutics is the practice of interpretation and originates from Greek mythology and the Greek god, Hermes; whose role involved communication between the gods and mortals. As a philosophy, hermeneutic phenomenology represents the individual in contrast to the background of one's personal character in a social context. For example, how people may react differently in a stressful social situation based on their personal values. Hermeneutic phenomenology as a methodology is both descriptive (phenomenological), as this focuses on how things appear, and also interpretive (hermeneutic), as there can never truly be a phenomenon without some form of interpretation.

Heidegger (1962) is credited for developing hermeneutic phenomenology and refers to the notion of hermeneutics as the power to understand the various ways of being in the world (van Manen, 1990, 1997b). Heidegger (1962) stated, “The meaning of phenomenological description as a method lies in interpretation” (p. 37). Interpretation for Heidegger is not an absolute. Meaning that one may only ever partially understand a phenomenon during a lived experience and that this may change constantly depending on the cultural, historical or social context of an experience (van Manen, 2014a). Heidegger (1962) claims the study of phenomenology is the study of being in the world, which is comprised of structures and interpreted through the use of language (van Manen, 1990, 1997b). Heidegger argued that language cannot exist without perception or thought, as these provide the concepts for interaction and meaning within the lifeworld (Munhall, 1994). Hermeneutic inquiry involves the use of the hermeneutic circle, which describes the process of interpretation for a phenomenon to resonate a deeper sense of understanding; this involves continuous examination of suppositions (Rapport & Wainwright, 2006).

Hermeneutic phenomenology and phenomenology have been influenced by other philosophers, who were inspired by Heidegger’s philosophical works about interpretation. Interpretation in relation to phenomenology, as described by Munhall (1994), is the unique perception of what is happening during an individual event. Ricoeur (1976) builds upon Heidegger’s and Gadamer’s (1975) understanding of hermeneutics with a focus on understanding as a human scientific method of hermeneutics, the ontological mode of being (van Manen, 1990, 1997). Merleau-Ponty (1962) describes phenomenology as the study of essence and asserted that phenomenology strives to make the differentiation between appearance and essence (van Manen, 1990, 1997b). One’s

culture and language are handed down in social and historical contexts and form the “background” of one’s being; this provides the meaning of one’s perceptions (Munhall, 1994).

van Manen’s (1990) Hermeneutic Phenomenology

Phenomenology aims to uncover the ‘essence’ of a phenomenon through exploration of lived experience to gain understanding of the meaning for phenomena (van Manen, 1990, 1997b, 2014a). In the study, van Manen’s hermeneutic phenomenology was the method of inquiry used to understand the nature and meaning of health through the exploration of well-being as a woman living with MS. van Manen (1984) describes phenomenology as the study of the individual’s life world as it is experienced and the purpose is to uncover a deeper understanding of the meaning or nature of everyday lived experiences (Munhall, 1994; van Manen, 1990). Hermeneutic phenomenological research is meant to provoke a realization, as it is meant to instill a deep level of understanding and meaning that creates a transformative effect for the reader (van Manen, 2011). The ability for readers to resonate with the research conducted within this methodology is referred to as a phenomenological reverberation (van Manen, 1990).

van Manen’s (1990, 1997b, 2014a) hermeneutic phenomenology is both a descriptive and interpretive methodology. Descriptions are provided through personal life stories of the everyday experiences and then meaning is uncovered. In relation to this study, this allows for greater understanding of what it is like to experience health through the exploration of well-being as a woman living with MS. van Manen supports the application of hermeneutic phenomenology as reflexively uncovering the essence of a phenomenon and thus the cultivation of a deeper understanding of the human experience (van Manen, 1990, 1997b). Reflexivity for van Manen (1997) refers to the researcher’s

previous experiences with the research participant to uncover the meaning of a phenomena though clarifying assumptions or biases.

Rationale for Methodology

The study of health and well-being is well suited to research using an interpretive phenomenological methodology and may provide rich and detailed accounts about the investigated phenomena (Reissman, 2000; Smith et al., 2009). The World Health Organization [WHO] (2014) describe health as having physical, mental and social well-being. Considering this, it would be beneficial for nurse researchers to adopt a research practice, and to also explore aspects of well-being in the presence of illness to gain a better understanding as to how a disease, such as MS, is experienced in relation to health. van Manen (1990) asserts that hermeneutic phenomenological inquiry is not a methodology employed as a method of questioning, but rather a method for answering. As such, with limited evidence and research conducted on the essence or lived experience of health and well-being for women living with MS, there is presently little consideration given as to how to develop tailored interventions and policies to fit the needs of this population (Abma et al., 2005). To capture the essence of women living with MS, van Manen's hermeneutic phenomenology was utilized to answer the question: what is the lived experience of health and well-being for women living with MS? This will allow for a greater understanding of what factors may contribute to health for this population or conversely what challenges are impacting the experience of health and well-being. The study elicited a rich source of data by uncovering the nature of the investigated phenomenon. van Manen's hermeneutic phenomenology, a methodological approach that uncovers the meaning of the lived experience of a phenomenon, is commonly utilized in health care research to gain a deeper understanding of the human experience (Hawley &

Jensen, 2007; van Manen, 1997a). Lastly, nursing knowledge may be greatly advanced through the elucidation of the participants' experience of illness through phenomenological approaches (Rapport & Wainwright, 2006).

Method of Inquiry

“A good phenomenological description is an adequate elucidation of some aspect of the lifeworld - it resonates with our sense of lived life” (van Manen, 1990, p. 27). As a research method, phenomenology emphasizes the study of the essence of phenomena with the aim of understanding the experience of an individual or group and this understanding is only accessible through those experiencing the phenomena (Benner, 1994; Chinn & Kramer, 2015; van Manen, 1990). The first characteristic of phenomenology as a research method is that it always begins in the lifeworld (van Manen, 1990, 1997b, 2014a). van Manen (1990, 1997b) describes the lifeworld through Merleu-Ponty's four rudimentary concepts being spatiality (lived space), corporeality (lived body), temporality (lived time) and relationality. These comprise the basis for the lived experience of a phenomena to occur.

van Manen's (1990, 1997b, 2014a) hermeneutic phenomenology was utilized to provide a foundational perspective to guide qualitative research methods for collecting and analyzing data in this study, thus allowing for the collection of personal life stories of health through the exploration of well-being with women living with MS. van Manen's method of inquiry is guided by reflection, both with the researcher's reflexive use of recording their self-awareness, and their exploration of the structure of the participant's lifeworld through observation and exploration of the lived experience. van Manen posits that there is no such thing as uninterpreted phenomena. The collection of personal life stories through semi-structured interviews that are recorded allows for a first-person

account that accurately depicts the phenomenon.

Hermeneutic phenomenological inquiry uncovers both the semantic and mantic themes within a text; the former captures what the text's meaning conveys, and the latter captures how the texts evoke our understanding (van Manen, 1997a). In *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*, van Manen describes six aspects for his process of phenomenological pedagogical inquiry, which also align with a research data analysis process (van Manen, 1990, p 30-31): (1) Turning to the Nature of Lived Experience: this step involves orienting to the phenomenon, the research question and explicating suppositions, (2) Investigating Experience as We Live It, which includes: obtaining experiential descriptions for the lived experience, (3) Hermeneutic Phenomenological Reflection, this involves: conducting thematic analysis, (4) Hermeneutic Phenomenological Writing, which includes attending to the speaking and writing of language, (5) Maintaining a Strong and Oriented Position, which involves writing in an oriented way, meaning that the researcher is connected to the participant and research and lastly, (6) Balancing the Research Context: Parts and Whole Working the Text, which analyzes for meaningful significant statements and the whole entirety for the text to uncover meaning. When phenomenological research is done well, there can be an enriched understanding of what it means to be human, and it helps make sense of human existence (Munhall, 1994). Ultimately, the goal of interpretive phenomenology is to gain an in-depth understanding of the essential meaning of lived experience (van Manen, 1990, 1997b).

Research Methods

Study Sample

In order to reach the essence of the phenomenon and achieve data saturation,

which refers to a point in the data analysis where the researcher uncovers repetition in themes and is different from having everything revealed since, with this methodology, nothing can ever be fully revealed as it is always changing. In this study, 23 participants fitting the study's inclusion criteria were utilized (see van Manen, 2014b; Morse, 2000). In doing so, the study reflected a sample size similar to studies that have used van Manen's hermeneutic phenomenological methodology (Green & Young, 2015; Hall et al., 2013; Heinonen, 2015; Jacob et al., 2015; van Manen, 1990, 1997b, 2014a). The study sample size allowed for possible attrition of participants should any individuals choose to withdraw or decline from participating in the study, while also ensuring a sufficient number of participants to acquire rich data to reach data saturation. Potential participants were screened for inclusion criteria during a phone call prior to the interview and all potential participants self-disclosed this information. If participants met the inclusion criteria, then an interview appointment was arranged with potential participants, during which the study's letter of information (LOI)-consent was reviewed (Appendix A).

Exclusion/ineligibility criteria for the study included: not fluent in speaking or reading the English language, younger than 18 years, has not been formally diagnosed with MS, does not make decisions independently - for example has a substitute decision maker or legal guardian, does not reside in Southwestern Ontario, self-identifies as a gender other than a woman, does not consent to be audio-recorded for the study interview, and does not consent to the use of de-identified data for future studies.

Setting

The study took place in Southwestern Ontario, Canada; as there are a large number of people living with MS that access this area's resources, such as local MS

Societies (Multiple Sclerosis Society of Canada [MSSC], 2021). Canada's most heavily populated province is Ontario, with most residents residing geographically toward the southern most areas (Ontario Ministry of Finance, 2020). As Canada has the highest incidence of MS in the world, and Southwestern Ontario is the most heavily populated area in the country (MSSC, 2021), the selection of this geographic setting for this study was assumed to support the participant recruitment process.

Recruitment/Sampling Strategies

After securing ethics approval to conduct this study from Western University's Research Ethics Board (REB), permission was requested from the MS Society of Canada to display study posters to recruit research participants from their online research portal. The MS Society has locations across Canada that provide information and support services to individuals living with MS and their families, as well as provides services online. With permission from the MS Society, study related posters were placed online in their research portal, which is an area of their website to notify potential participants of research opportunities. MS Society sites in Southwestern Ontario emailed participants on their listserv indicating there was an opportunity to enroll as a research participant. Recruitment was initiated at the MS Society chapters in Southwestern Ontario by MS Society administrative staff. Administrative staff arranged email correspondence to coordinate the distribution of the study's LOI-consent forms. After receiving the study LOI-consent forms, potential participants were asked to contact me via email or telephone, and I verified if the research candidate met the study's inclusion criteria. Purposeful sampling was used in this study. This technique is commonly utilized in qualitative studies to recruit participants who meet the study criteria and are immersed in the proposed investigated phenomena (Palinkas et al., 2015). Research candidates were

able to share my contact information with others, but they were asked not to provide any identifying information of the other research participants to myself or my dissertation supervisor. This form of recruitment enabled potential participants to consider being involved in the study and to be able to contact me about the study poster (Appendix B) as well as provide a script to their staff (Appendix C). Then, I asked the potential participant questions to ascertain if they met the inclusion criteria for the study (Appendix D).

If the potential participant met the study inclusion criteria, I invited the individual to schedule an interview that could be conducted either in-person, by telephone, or by Zoom on a date and time that was convenient for both the potential participant and myself. If the interview was conducted in-person, a location suitable to both the potential participant and myself would be agreed upon beforehand.

Immediately prior to starting the audio-recording of the interview, I reviewed the study LOI-consent documents with the participant, and if the interview was conducted in-person, I then provided the participant with a \$10 gift card to their choice to either Tim Horton's or Starbucks. If the interview was conducted by telephone or Zoom, I followed a similar process regarding first addressing any study related questions, then reviewing the study LOI-consent and informing the participant that the LOI-consent would be mailed to their preferred mailing address with a stamped and self-addressed envelope so that they could return the signed consent form to me. I explained that unless written consent was obtained prior to initiating the analysis that their data would not be used for the research. They were also informed that the gift card for their preference of either Tim Horton's or Starbucks would be mailed to them with the LOI-consent form. I also made note on the master list that the individual provided verbal consent prior to beginning the interview. I explained that 2-3 participants will be contacted at a later time after the

analysis for a 15 minute follow up interview via telephone to validate the study's findings; all participants verbally consented during the interview to be potentially contacted at a later time for the purpose of validating the findings.

Data Collection and Analysis

A semi-structured interview guide (Appendix E) was used during the digitally audio-recorded interview with each participant, which was approximately 60-90 minutes in length. van Manen (1990, 1997b, 2014a) suggests the interview consist of open-ended questions and serves the purpose of gathering essential information and experiential narrative to uncover the essence of the investigated phenomenon. Demographic data were verbally collected at the start of the audio-recorded interview so that participants were not required to complete a hard-copy demographic form. The verbal responses were collected using a digital audio-recorder and did not include any identifying participant information. Before the password-protected audio recordings were uploaded by secure file transfer into the Western OneDrive study folder, I first listened to each recording and deleted any identifying information. That way, there was not any identifying information for the transcriptionist to hear on the audio recordings, or to transcribe. Immediately after each audio recording was securely transferred to the Western OneDrive study folder, they were permanently deleted by me from the audio recording device. Data was collected prior to the start of the first wave of COVID-19 in Ontario and subsequent lockdown in March 2019. The data collection period occurred during January and February of 2019.

Digital audio-recordings were transcribed verbatim by a professional transcriptionist who prior to engaging with any data signed a confidentiality agreement. Additionally, the professional transcriptionist only had access to the Western OneDrive site for the sole purpose of transcribing the digital audio recordings (Appendix F). I also

made reflective notes in a paper-based field book after each interview. These notes were also considered as data and were used to inform the analysis. Notes included information such as emotional expressions, facial expressions, voice tone, non-verbal gestures, and specific statements made by participants that stood out for me. The transcriptionist was advised that no identifying information was to be included in the transcripts (i.e., name, address, location of MS Society). Once the de-identified and numerically coded transcripts were securely transferred to Western OneDrive by the transcriptionist, the transcripts were transferred to a password-protected NVivo file that were held on my own and my dissertation supervisor's and dissertation committee's password-protected computers. After I verified that the transcripts matched the audio recordings, the audio recordings were permanently deleted from the Western OneDrive study folder and the transcriptionist no longer had access to the folder.

The field notes taken during the study supported the study's accountability through the supply of information essential for a detailed audit trail – a record of detailed documented findings throughout the research process that demonstrates safe and accountable research practices (Patton, 2015). Furthermore, this form of data collection helped to triangulate the research findings by providing data that would allow me to compare my notes with the participants' interview transcripts. Patton (2015) describes data triangulation as the use of multiple methods of data collection in qualitative research to enhance the study's rigour. In conjunction with van Manen's (1990, 1997b) hermeneutic phenomenology, I engaged in reflexivity through the use of presuppositions in the field notebook. Lastly, van Manen (1990, 1997b) suggests phenomenological themes are a reduction of a notion, meaning that data saturation can be achieved through careful analysis of the transcribed interviews and verified with participants by means of

having them reflect further upon emergent themes and their experiences. Therefore, I returned to three participants who consented to providing feedback about the study findings for a 15-minute follow up member checking discussion via telephone or email.

After the interviews were completed and data saturation was reached, I used three approaches to uncover thematic aspects of dialogue or text as either the holistic approach, the selective or highlighting approach and the detailed line by line approach (van Manen, 1990). In the holistic approach, the researcher notes individual judgements, meaning that different individuals may find a diverse fundamental meaning. The selective or highlighting approach encompasses reading or listening to statements made by participants multiple times and the researcher enquires what phrases capture the essential aspects of the experience being described. With the selective approach, the researcher asks him or herself if there are any expressions or statements that stand out as being thematic of the lived experience. The detailed approach involves the researcher vigilantly reading sentence clusters or singular sentences, taking note of any potential revelation for the meaning behind the phenomenon. The researcher then asks themselves what each sentence cluster or sentence exposes about the investigated phenomenon. Finally, the researcher interprets the emergent themes to find meaning within the investigated phenomenon, which ultimately leads to a greater level of understanding, and for this study, the essence of the lived experience of how women with MS perceived their overall health in regards to their physical, mental and social well-being was revealed. The qualitative software package NVivo 12 was used to manage the data and to support the process of illuminating meaning from participants' shared experiences (Green & Young, 2015; Jacob et al., 2015; van Manen, 1990, 1997b, 2014a; QRS International, 2018).

van Manen (1990, 1997b) recommends analyzing themes using reduction, a method of analysis that utilizes deductive thought from the data collected as a means to find multiple meanings or unearthing themes within the text (Patton, 2015). Furthermore, van Manen describes themes in hermeneutic phenomenology as the meaning of the experience or focus and contends these may be understood as structures of experience. van Manen (1990) further posits phenomenological themes are never a single entity to grasp the essence or meaning of a phenomenon, and therefore, supports the need for researchers to discuss emergent themes with participants to ensure the meaning or essence is reflective of their statements. Additionally, van Manen believes phenomenological themes are always a reduction of a notion, meaning that data saturation can be achieved through careful analysis of the interviews and verified with participants by means of having them reflect further upon emergent themes and their experiences, a process known as the phenomenological nod (van Manen, 1990, 1997b).

A summary of thematic findings was reviewed with study participants who consented to a follow-up email or telephone discussion to engage in this process. To validate the study's findings, I carefully selected participants that had rich data from their interviews. I was able to select participants from various demographics, including women of colour, differing marital status, such as single, divorced and a woman in a common-law partnership who provided representation from the LGBT+ community, as well as various forms of ability and disability. There were also commonalities between participants for gender, as all participants identified as being a woman who confirmed having a formal diagnosis of MS. Additionally, the findings from the analysis were reviewed with my dissertation supervisor as well as my committee members as an additional form of data triangulation; doing so also provided support of the findings in the

event that no participants were willing to be contacted for follow-up about the summary of study findings. Lastly, to triangulate the research findings I compared and contrasted these with my field notes that were collected throughout the data collection process (Patton, 2015). At the conclusion of the study, I sent a summary of the study findings to participants who wished to receive them via email, as at the time of conducting the interviews all study participants verbally expressed their desire to view the study's summary of the findings.

Participants

Sample demographic characteristics are noted in Table 1; including pseudonyms that were randomly assigned to provide anonymity, as outlined below in the 'participant narratives' section. Throughout the interview process, some participants described themselves as requiring a myriad of assisted devices, such as the use of canes, crutches, walkers, motorized scooters, wheelchairs, motorized wheelchairs, and chair lifts. Participants also described various activities they engaged in, which included physical activities such as yoga or exercise classes (including classes modified for people with physical disabilities), walking, running, biking, hiking and swimming. Participants also described several social activities that they engaged in such as attending concerts, the theatre, and social events held by the MS organizations, or through their churches. Several participants were still working, some expressed having no concerns with the impact of their MS on their employment; while a majority of participants believed that disclosing their MS to their employer or requesting modifications to their work may jeopardize their job security. Participants' employment status varied from being unemployed, employed casually, working part-time and full-time, to self-employed. This included participants disclosing working part-time hours and engaging in self-

employment to accommodate needs for MS. Some participants disclosed working full-time with their employers aware of their MS diagnosis to receive accommodations, and others described feeling unable to do so out of fear for perceived threat to job security. A diverse sample of housing accommodations was noted, which included rent geared to low-income apartments, condominiums, semi-detached and detached homes; some with modifications to accommodate physical needs brought on by MS, such as chair lifts, automatic opening doors, lowered kitchen cabinets and wheelchair ramps. Several participants also described modifying their homes with devices such as personal lifting devices, shower, toilet and bathtub railings, and bars to get in and out of bed to assist with physical disabilities associated with their MS. Four participants disclosed receiving disability pensions, three disclosed receiving financial support from their spouse, one participant discussed receiving child support (as well as government assistance) and four participants were retired and receiving pensions (including four of these participants disclosing being medically retired due to problematic symptoms from MS).

Table 1

Demographic Characteristics of Participants

Women's pseudonyms	Age	Type of MS	Marital status	Level of education	Number of children
Emalia	62	Secondary ^a	Married	College Certificate	2 ^h
Asha	42	RRMS ^b	Married	Bachelor's degree	2
Sharisse	73	Progressive	Married	Undisclosed	3
Eva	46	RRMS	Married	Bachelor's Degree	2

Darcy	42	RRMS	Married	College diploma	N/A
Audrey	43	RRMS	Married	High school	N/A

Table 1 (Continued)

Women's children pseudonyms	Age	Type of MS	Marital status	Level of education	Number of
Keena	71	Progressive	CL ^c , SS ^d	Master's ^e	N/A
Dakota	60	Secondary ^a	Single	Bachelor's degree	N/A
Clara	29	RRMS	Relationship	Some College	N/A
Bernadette	46	RRMS	Divorced	High School ^f	1
Marcia	56	RRMS	Divorced	College diploma	N/A
Ilana	60	RRMS	Divorced	College diploma	3
Arica	36	RRMS	Single	College diploma	N/A
Felicity	59	RRMS	Married	Professional Cert. ^g	3
Bridgette	51	RRMS	Married	Bachelor's degree	2
Reena	42	RRMS	CL	Bachelor's degree	4 ^h
Cari	54	RRMS	Divorced	Doctorate degree	1
Danika	61	Progressive	Married	College diploma	N/A
Sloan	31	RRMS	Single	Master's degree	N/A
Geneva	52	RRMS	Married	Some high school	2
Arleli	33	RRMS	Married	Bachelor's degree	1
Willow	61	"Unsure"	Married	High school diploma	2
Florence	52	RRMS	Widow	Professional Certification	1 ^h

Notes. ^a Secondary Progressive MS. ^b RRMS = Relapsing Remitting MS. ^c Common-law partnership. ^d SS= Same sex relationship. ^e Master's degree incomplete. ^f High school diploma incomplete. ^g Professional certification. ^h Including stepchildren.

Approaches for Creating Authenticity

To maintain authenticity for the proposed research, application of van Manen's (1990) hermeneutic phenomenological method will be adhered to throughout all stages of the research being conducted. Patton (2015) describes authenticity as being objective and trustworthy. van Manen posits a good phenomenological description provides an adequate elucidation of the lived experience; this resonates with the reader through our sense of the lifeworld and is referred to as the phenomenological nod, meaning that when someone reads a phenomenological account they would agree with, they relate to the experience as if they were the one experiencing the phenomena. Additionally, van Manen refers to this as the validating circle of inquiry, where in qualitative research the researcher returns to the participants and validates emergent themes, thus creating an authentic and trustworthy reflection of their lived experience (van Manen, 1990). As noted in the data collection section, for this study, I aimed to confirm the accuracy of my findings using the phenomenological nod by contacting participants who consented to be followed-up to discuss a summary of study findings by via email or a telephone for 15 minutes. Validating the study findings with participants allowed me to ensure that the essence of the phenomenon was accurately highlighted. As noted, findings were also reviewed with my dissertation supervisor and academic committee - this acted as a form of member-checking to support the accuracy of the findings.

Rigor is another critical component of qualitative research. However, van Manen does not specifically outline ways in which a researcher may enhance rigor, thus Koch's approach to creating trustworthiness or rigor in qualitative and hermeneutic research were applied, as these provide reputable and well-documented criteria for supporting rigor in qualitative research. Koch (1996) describes rigor for the constructivist paradigm as the

necessary inclusion of an audit or decision trail pertaining to the credibility, transferability and dependability of a qualitative study (Guba & Lincoln, 1985; Guba & Lincoln, 1989; Koch, 1996, 2006; Sandelowski, 1986). Koch (2006) describes credibility as the need for the researcher to embody self-awareness throughout the conduct of research and indicates one way of doing so is through the use of a personal journal. The journal became a detailed record for my thoughts, reactions, and decisions. Furthermore, this acted as a form of triangulation and in so doing enhanced the study's rigour by providing an additional source of data to consider and integrate in relation to the study's findings (Patton, 2015). Transferability is also referred to as 'fittingness' and allows for a rich description of the lived experience that is understood by readers to be meaningful and applicable as if they were experiencing the phenomenon personally. Transferability occurred in this study through the employment of member checking. Dependability allows for a detailed account of the process for the research known as an audit trail. Maintaining a written account of the researcher's perspectives and data obtained during the research process is useful in enabling other researchers to understand the context of the research and come to comparable conclusions (Koch, 2006). Dependability was addressed in this study by keeping a written account of my own perspectives in a journal, keeping a detailed audit trail of all data collected during the research process and safeguarding all documents obtained through the study in a secured location at Western University, thus allowing for other researchers to audit the research process, if needed.

Although van Manen (1990) does not specifically outline how to address rigor in his methods, he does discuss how to approach validity in phenomenological research. Validity is achieved with the use of van Manen's phenomenological approach when those experiencing the phenomenon recognize the interpretation as having accurately portrayed

their lived experience, which is a form of member checking (van Manen, 1997a). For example, this is referred in qualitative inquiry as the phenomenological nod and may be exemplified when the researcher returns to participants with their findings and receives statements of affirmation such as, “Yes, that’s it. You really captured it.” (Hawley & Jensen, 2007, p. 664). I ensured phenomenological reverberation through the validation of the findings with participants who voluntarily agreed to be contacted for follow-up to review the study findings, share support of and/or clarify thematic findings. As outlined above, I ensured all areas of the research conducted promoted a deeper understanding of the investigated phenomenon.

Ethical Considerations

Conducting research ethically is an essential component for creating good quality research results (Patton, 2015). For the proposed study, ethical approval was obtained from Western University’s REB. Furthermore, approval was received from local MS Society chapters throughout Southwestern Ontario for the purpose of recruiting potential study participants. Additionally, careful consideration was given to following van Manen’s hermeneutic phenomenological approach in all phases of the research.

In addition to the aforementioned ethical considerations, I diligently ensured confidentiality through the use of coding for all participants’ transcriptions to safeguard their identities. All participants had a pseudonym provided on their transcript, thus preventing the participant from being readily identified. Prior to conducting the in-person interviews, I again reviewed with all participants how the information collected from the study would be stored to ensure they were fully informed as to how their privacy was being maintained. Participation in this study was completely voluntarily and participants could withdraw their consent to participate in the interview at any time. Every participant

for the study returned an original copy of their signed consent. In the event that a participant expressed discomfort or had unsettling emotional reactions during the interview, I asked the participant if they would like to stop the interview and resume when they felt ready to, either after a break or at another time. No participants withdrew consent from this study.

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CHAPTER 4

FINDINGS: PARTICIPANT NARRATIVES AND LIFEWORLD EXISTENTIALS

In this study, van Manen's hermeneutic phenomenology was the method of inquiry used to elicit understanding on the nature and meaning of health through the exploration of well-being for woman living with MS. As a methodology, van Manen (1990, 1997) describes phenomenology as the study of the individual's life world as it is lived. van Manen (1990) highlights the importance of contextualizing information about participants, doing so tells the patient's 'story' through providing a narrative; which van Manen attributes as a basis for all human science. Narratives can be poetic and compelling, allowing the reader a depiction into the lifeworld of participants through storytelling. The purpose of this chapter is to provide participant narratives to contextualize their lived experience both as a human and as someone affected by MS. Consideration for participant's narratives is an important aspect for understanding lifeworld existentials within phenomenological investigation (van Manen 1990, 1997).

The use of phenomenological inquiry involves the exploration into the formation of the lifeworld (van Manen, 1990, 1997, 2014). Lived experiences give rise to structure for themes and meaning in human science research (van Manen, 1990). Every human being belongs to a multitude of 'lifeworld's' which may include our professional and personal roles in society that we occupy at various times throughout any given day. van Manen asserts that there are four fundamental themes which pervade the lifeworld for each unique person in existence and refers to these as 'existentials.' These four existentials of the lifeworld as described by van Manen that act as guides within reflection in the phenomenological research process, including: "lived space (spatiality),

lived body (corporeality), lived time (temporality), and lived human relation (relationality or communality),” (van Manen, 1990, p. 101).

Setting

The study took place in Southwestern Ontario, Canada, as there are a large number of people living with MS that access this area’s health resources, such as local MS Societies (MSSC, 2018). Canada’s most densely populated province is Ontario, with most residents living geographically towards the southern most areas (Statistics Canada, 2020). As Canada has the highest incidence of MS globally, and Southwestern Ontario is the most densely populated area in the country (MSSC, 2018), the choice of this geographic setting for this study supported the participant recruitment processes.

Participants

Twenty-three participants who met the study’s inclusion criteria were involved in this research (van Manen, 2014; Morse, 2000). The participants’ age ranged from 29-73. A majority (17) of participants indicated they had relapsing-remitting MS, five stated they had progressive MS (including both type one and type two progressive) and one participant was unsure of the type of MS she had. Almost all of the participants indicated they were diagnosed with MS in adulthood, except one participant who specified she was diagnosed at the age of 16. The marital status of participants was diverse and included participants who identified as single, dating, married, in common-law relationships, divorced, and widowed. This included one participant who noted they were in a long-term same-sex relationship. Several participants did not have children and for participants who reported having children, the number varied from having one to four, including step-children and one participant who had a deceased child. In addition to some participants describing caregiving roles for children, a few also described their caregiving

responsibilities for other adults, including one participant who was acting as a caregiver for her husband and a parent with a physical and mental disability. Participants' educational backgrounds varied as well - some having high school, college or professional certificates and university undergraduate and graduate degrees. It is important to note that MS varies greatly between individuals for symptoms and experiences, and the findings may vary if reproduced.

Participant's Narratives

In this section, a narrative overview is presented that embodies an aspect of each participant's story that spoke to their lived experience with MS. Through the inclusion of participant narratives, readers are provided an intimate understanding for the human who is experiencing the investigated phenomena, which may enrich the overall understanding of the meaning derived from the lived experience (van Manen, 1990, 1997). van Manen (1990) indicates that story telling is an important aspect of narration, therefore, the participants narratives were derived from my time immersed with them and reflecting on our conversations through careful evaluation with the participants texts gathered during our interviews.

Emalia

Emalia discussed the many ways in which she would work around having physical limitations with MS which evoked her strength and determination, for example she began running when she was first diagnosed with MS as she wanted to experience this in that present moment of being diagnosed knowing that someday she may not have the ability to do so. Additionally, Emalia described purchasing and renovating an old home after her diagnosis with MS and how she currently rearranges furniture independently to promote her own physical independence. Throughout our discussion

Emalia lit up when talking about her personal strengths and determination to remain independent in her home.

“I will find a way... I figured I would start running ‘cause I was pretty sure that one day I wouldn't be able to... what started off as a coping mechanism turned out to be something that I fell in love with.” ~ Emalia

Asha

Asha has a background as an economist and described her spouse as a successful entrepreneur. Asha discussed her choice for working from home after being diagnosed with MS to allow her to focus her energy on her husband and children. She was passionate when discussing her use of essential oils and vitamins as her primary approach to managing her health and avidly shares this information with those in her social group. Asha passionately discussed the importance of homecooked meals she prepares and shares with her family as something rooted in her Italian ancestry. Additionally, Asha described the joy and meaning she has volunteering with her children's extracurricular activities such as their “Brownie” group and described this as her priority now after having MS.

“Well, you know what, the way I look at it is I was given this opportunity to have that MS so that I can educate everybody...” ~ Asha, rationalizing her diagnosis with MS

Sharisse

Upon meeting Sharisse I could see that her eyes had a sparkle and warmth to them that lit up when she spoke. She radiated positivity and described the source of her positive outlook for life coming from her family. When interviewing Sharisse, she discussed how much she has overcome in life, including the traumatic loss of her son, being diagnosed with MS in her older adult years and previously having cancer that has now returned. She was resilient and determined to still find the good in life and every

situation she encountered. Sharisse had a bright personality and described how seeing her own belated mother's optimistic approach to having MS that eventually progressed influenced her own positive attitude. Sharisse described having several networks of meaningful friendships and close familial relationships, including a robust social network of church friends who check on her regularly to help her manage her health and well-being.

"I can't walk anymore... but in every other way I'm healthy. This is... I don't have any other issues, other than the cancer. But that to me is just something that you deal with. Um, I can still get out and about. So, I consider myself actually very lucky health wise, you know." ~ Sharisse musing on her health

Eva

During our interview, Eva discussed recovering from every MS exacerbation she has experienced and believes she will always recuperate. She talked proudly about how living by her own example of personal strength with MS has resulted in her daughters viewing MS with resiliency and courage. For example, she discussed how one of her daughters created a meaningful school project about her experience with MS and how this conveyed a message of hope for people with MS.

"... they don't have this fear of MS because they see it and they see you can have an attack, but you'll get better." ~ Eva speaking of her daughters understanding of MS as learned firsthand from her own experience with MS and strength.

Darcy

Darcy works as a paralegal and spoke of her strong will and determination to manage her health and well-being with MS. Darcy viewed her experience with MS as an opportunity to making her health her top priority. After her MS diagnosis, Darcy started engaging in healthy activities, including exercising and eating a balanced diet. She described focusing on helping the health of others with MS too, and expressed starting a

virtual MS forum over social media where members can share information on how to manage challenges with MS, such as energy conservation. Darcy indicated that she has a strong ability to vocalize her needs with MS to family and friends and that this has helped her manage troubling MS symptoms like fatigue.

“I started to get serious about [my health] and have to just change the way I used to do things. So just sleep, exercise, diet, stress, stress is a big one... Listening to yourself, your body... It works best for me when I'm mindful of things.” ~ Darcy, on how MS changed her approach to prioritizing her health.

Audrey

Audrey and I met for our interview in her place of work. She brought me back to her office where we had privacy to conduct the interview. At this time, Audrey demonstrated vulnerability as she shared several personal struggles in addition to her MS, which include caring for her disabled mother and mentally ill spouse. She disclosed the stress this put on her as she was working full-time and acting as the sole income earner for her household. This complicated Audrey's ability to engage in self-care and manage her own health and well-being with MS, as she disclosed having to put others around her first and take care of her home when she is not working which was causing severe fatigue.

Keena

Keena expressed how she felt like the world was 'dumping' on her. In addition to having progressive MS, she also had a lower leg amputation, which further complicated her ability to independently engage in meaningful activities she enjoyed managing her health like exercising. Additionally, she discussed how having MS caused her to leave a career in nursing leadership that she cherished, which subsequently led to problematic substance use for alcohol and caused her same-sex partner to temporarily leave her. She

was able to move past using alcohol to cope and regain her relationship with her partner. She did express feeling fearful towards her future with MS but is focused presently on using her expertise to volunteer and help others in need. For Keena, health and well-being means having the ability to contribute to the world around her and acts as the chairman of her condominium board to advocate for accessibility needs.

“Well because doing this job... you have a lot of people... talk to you and need help from you for various things. And when I can... help them, then that makes me feel somewhat like it used to when I was still in nursing... then it does make you feel somewhat like you've done something worthwhile.” ~ Keena on deriving meaning from volunteering

Dakota

Dakota described being openly expressive and using poetry and art to convey her thoughts and emotions, including those with her having MS and a disability. She expressed her creativity was supported by her friends, to which she described having a large group of supportive friends. She disclosed using a wheelchair to ambulate and has a personal care worker (PSW) who comes in to assist her with bathing. She was adamant that people see and know her, not her accessibility devices. She described the importance identity and humour were for her health and well-being.

“I'm having a good time and I'm exploring myself through my words, my paintings and my MS. MS is part of the definition that makes up me. It is not who I am. I am not that woman with MS. I am that woman, period. I am not a disabled person and I quite strongly believe this. I'm a person with a disability. I was someone before I had the disease.” ~ Dakota on her identity and having MS and a disability.

Clara

Clara described herself as an “an open book” and “positive” person. She described struggling initially with her MS diagnosis and being away hometown at college when she started having an onset of various neurological symptoms which resulted in her feeling isolated. Prior to MS she indicated she was in excellent physical condition and played triple A hockey. She discussed transitioning her love of sport to her level of ability that was impeded by MS through engaging in parasports, which is a form of competitive sports for people affected by various levels of disability. She also described her passion for yoga and alternative approaches to managing her health and well-being with MS, including the use of essential oils. She has described using essential oils to treat various side effects that were associated with her medication treatment, such as nausea effectively with this approach.

Bernadette

Bernadette disclosed to me that she previously sustained a broken hip and was experiencing barriers to have proper orthopaedic treatment and care, including surgery. During our interview, Bernadette discussed how she was divorced and acting as a single parent for her child with special needs. She described single parenting with MS and a disability as challenging, including barriers for public transportation and living on limited government financial support for her disability. She also described feeling discriminated against while trying to access public sidewalks and transportation during the winter months, a necessary task she must engage in to get her child to and from school. Additionally, her role as a single mother was described as difficult with the challenging MS symptoms, she experiences such as a loss of sensation and fatigue, which has resulted in several concerning injuries for her. Despite the challenges Bernadette described

experiencing she attributed her love for her daughter as her main motivating factor for striving to manage her health and well-being.

“It just gets me frustrated... it does get me emotional... there's days... like I just lose it... I was literally crying myself to sleep every night... And it was just bad... And the only thing that gets me through is it gets me up in the morning is her.”
 ~Bernadette talking about single parenting with MS and a disability; and her daughter as a motivating factor to manage her health and well-being.

Marcia

Marcia passionately discussed her love for her dogs and how she frequently competes in dog shows. She discussed how her two elderly parents lived with her and how she was acting as the sole income earner. With her mortgage, she expressed feeling the need to work, and the importance for her to not disclose her needs with MS to her employer. Marcia provided several examples of people she knew who were terminated after disclosing their MS from the perspective of acquaintances she knew who worked in human resources, or who had MS. She works in information technology and felt that expressing any needs for her MS, or her MS diagnosis may threaten her employment security.

Ilana

Ilana discussed her experiences with immobility and how she required several assistive devices; including a power wheelchair for outside her home and a chairlift in her two-storey home. She described herself as being grounded, family oriented and spending her time frequently with her current common-law partner, children and grandchildren. She expressed missing her role as a palliative personal support worker (PSW), where she had to leave her professional work due to MS against her choosing. She recollected on a harrowing life-threatening experience with her former spouse who was physically and emotionally abusive to her. She described leaving her former husband, who she described

as verbally and physically abusive. She also explained experiencing financial barriers and discrimination from her specialist for her body size which she believed prevented her from managing her health and well-being with MS. She shared several barriers to experiencing health and well-being with myself during the interview, including not having adequate financial government support to obtain necessary MS medication. However, despite experiencing some barriers to maintaining her health and well-being, she described herself as determined.

“My partner will say, ‘take the chair, take the chair up! You’re not going to disturb anybody,’ it isn’t that... I got to climb that mountain so that I can come down another day.” ~ Ilana on her perseverance with managing her health and well-being with MS

Arica

Arica recalled what it was like for her to be diagnosed with MS as a teenager and the impact this had preventing her from engaging meaningfully with her peers in high school. During her teenage years she discussed experiencing feelings of isolation and having body-image issues related to the bruises she acquired from self-injecting her MS medication. She strongly felt that having MS impeded her ability to have a normal life as a teen. She described living at home with her parents, who she expressed do not understand her MS symptoms and accuse her as “being lazy,” when she is experiencing fatigue symptoms. Arica discussed she initially experienced difficulties trying to find others to relate to with her MS. She shared her experience where she attended an MS support group as a teen, but described the group members were older and more ‘advanced’ with their MS and this overwhelmed and frightened her.

Felicity

Felicity reported working with her husband running their family-owned business, which is a small apartment building they own and manage. She expressed wanting to retire from their business as she wants to prioritize spending time with her family enjoying life together before her 'MS progresses'. However, she indicated her husband is not ready for retirement and that he may not fully understand her MS symptoms and disease trajectory. She shared that her beloved mother had MS and that her mother's health declined rapidly. Felicity described approaching health and well-being through engaging in healthy eating and exercise but expressed being limited in the free time she has to engage in self-care.

Bridgette

Bridgette described being married with two young daughters when she was initially diagnosed with MS. She discussed having a "dramatic" MS diagnosis that had affected several areas in her brain which resulted in her losing the ability to walk, see or eat independently during the exacerbation. She expressed fully recovering from her physical symptoms after one year of her initial exacerbation but described experiencing a lot of 'fear' afterward. She expressed managing her health and well-being through engaging in physical activity, such as yoga for balance and eating a healthy diet. Additionally, she reported enjoying her role acting as a volunteer peer-mentor for the MS society. Despite having a severe onset of physically debilitating MS symptoms, she describes her current life with MS as mild with no symptoms. She disclosed sometimes she feels that MS groups and communities look down on people like herself who do not have more progressed or visible disabilities as not being sick enough which results in her feeling a form of "survivors' guilt".

Reena

Reena described having always been active prior to her MS diagnosis and was a professional dancer. Presently, she describes her MS causes her legs to become fatigued but being able to walk and bike daily to keep active but not to her previous level. She shared that her most pressing symptoms with MS are invisible, such as severe neurological pain and impaired cognition, the latter she believes impacts her parenting with having to remember her family's schedules. Prior to her MS symptoms worsening she expressed engaging in meaningful work as a case manager for people with brain injuries and owning a vintage boutique shop. She shared that no longer working outside of her home causes her to experience feelings of isolation and that she valued working outside of her home. She shared having a large social network and enjoys having friends over to her home and but described that she used to organize more events prior to her MS diagnosis. She feels that some people within her social group compare her to others with MS without necessarily comprehending that MS affects people differently. She described managing her health from what she refers to as coming from a place of "privilege," where she is able to engage in self-care activities such as acupuncture for her pain and conveyed gratitude that she is covered by her spouse's benefits for private health insurance.

Cari

Cari discussed how she had a doctoral degree in social work, had been divorced twice and worked in upper administration for a post-secondary institution. Additionally, she disclosed her approach to managing her health and well-being with MS include engaging in cultural treatment modality known as Ayurveda. She disclosed that this decision was not often embraced and supported by her medical practitioners here in Canada. She expressed facing hardships with her identity as a woman of colour who was

also now experiencing disability related to her MS. Her determination to advance her career allowed her to reach her maximum earning potential, she pursued this knowing that she would need to support her own needs with MS. She discussed the importance of self-identity and diversity, which she asserted is not well represented within MS communities and groups. As a woman of colour with a disability she described promoting representation through her new career path in modeling.

“I became a co-creator in my body and my process and my healing. That's how I felt with Ayurveda.” ~ Cari on discussing how engaging in her traditional cultural healing practices helped her manage her health and well-being with MS.

Danika

Danika disclosed that she previously worked as a dancer and owned and operated a dance studio. She defines her health as being able to move which she described is now ‘deteriorating’. She is presently 61 years of age and medically retired due to severe fatigue related to her MS but believes that her dancing has helped maintain her overall physical well-being and core strength. She indicated that because of her MS, she required numerous assisted devices including crutches, walker, wheelchair and a scooter to assist her with her mobility. Additionally, she described needing a chairlift in her home to help her get upstairs as she indicated she can no longer climb the stairs without assistance. She described being frustrated as she narrowly missed the threshold for receiving financial support from the government which resulted in her and her husband needing to purchase the entirety of her assisted devices out of their limited personal finances. Danika expressed concerns over her husband currently not being able to retire because of her financial needs with MS and not receiving financial support from the government. She was upset when disclosing that her spouse was 65 and they were without a retirement plan due to her MS.

Sloan

Sloan is 31 years old and employed as a behavior therapist, and described that she is considering further education to pursue a career advancement in psychotherapy. She discussed the importance of caring for your mental health, as she had depression prior to being diagnosed with MS. She expressed that having a mental illness for anxiety and depression allows her to empathize with others. However, having a mental health history has had negative effects on her experience with MS. For example, she described upon initially experiencing MS symptoms and seeking emergency care and that she was dismissed by her attending physician as they attributed her MS symptoms to her depression. She discussed feeling as though she needed to be brought into emergency care with a wheelchair to be taken seriously for her MS symptoms. She disclosed that she also actively engages in cognitive behavioural therapy to help her manage negative feelings and self-talk. She asserted that managing MS involves the inclusion of a, 'good support system' that empathizes with the invisible nature of MS.

Geneva

Geneva expressed caring deeply for her family and community, including others with disabilities. She described playing an active role on a local committee for people with disabilities that advocates for increased accessibility in public spaces. She expressed seeking out empathetic friends who support her MS and disability, including what she described as a meaningful relationship with her current partner who also has a physical disability. She expressed that she leads an active life that promotes the health and well-being for herself and for other with MS and disabilities. She attributes her health and well-being are largely supported by her social life. She expressed her love of "cheering"

people up in her MS social groups and giving back to her community through activism volunteering for people with disabilities.

“...sometimes if I'm having a really bad day and I go into them groups and there's somebody that's having a worse day than me and then I think, okay let's see if I can cheer that person up.” ~ Geneva on discussing her passion for helping others with MS and disabilities.

Arleli

Arleli provided a detailed account for her personal experiences leading up to her MS diagnosis, including a previous breast cancer diagnosis and an anxiety disorder. She described being diagnosed with MS prior to her wedding and that because of her MS she offered her spouse a ‘way out,’ an offer which he adamantly declined. She described her faith in God and having supportive family as her source of strength. She expressed feelings of uncertainty with having MS and not knowing how this will impact her employment as a Registered Nurse in an acute care setting if she disclosed her MS diagnosis, as well as fears as to what her life will be like for MS and the impact this will have on her family. She described her spouse as grounding her in the present moment and as she learns to cope with these feelings.

Willow

I met Willow for our interview in a private board room at the LTC facility she now resides in. She became teary eyed when talking about the impact MS has had on her life, she is now in her 60's but described that she was in her early 40's when she was first diagnosed with MS. At the time of her diagnosis, she discussed that she was working as a nursing assistant and living in home that her and her husband owned and raising their two young teenage boys. She described the impact of having progressive MS as causing her to medically retire from her career and shared the financial distress her and her family

experienced as a result. She described that this caused her husband to declare bankruptcy and lose their home. She discussed that after losing their home she needed to enter long-term care to meet her physical needs with MS and that her two teenage sons were sent to live with their grandparents; as her disability pension was not enough to sustain a basic level of support for her and her family. She described adjusting to life in LTC, although she expressed crying every night when she first moved to the facility. She remains hopeful for her health and described how she lost weight which has helped her regain some sensation in her legs. Willow also shared her philanthropic endeavours at her LTC residence, where she engages in volunteer work on committees to improve access to nutritious meals and advocates for improved accessibility for people using bariatric accessibility devices.

“Your whole lifestyle changes. You don't have, you don't have a bed to sleep with your husband... you're not home with your family... your children. I was not there to raise them at the time they were teenagers...” ~ Willow on discussing the impact of moving into long-term care (LTC)

Florence

Florence described being widowed, living alone and the impact MS has had on her career as a head journeyman chef. She discussed some of the hardships she faced with MS and her life, including losing her spouse who died from cancer. She described enjoying her life as a head chef at a local golf and country club, but MS caused her to experience several troubling symptoms such as fatigue ultimately led her to losing this position. She expressed not letting this deter her from working and described finding a suitable position as a childcare provider at a local gym. In this position she described finding joy in the children's laughter and expressed also having the ability to be flexible with her attendance to accommodate her physical needs with MS. She described living a

life that embraces simple pleasures and she described enjoying yoga, mediation and engaging in her faith-based community.

“I’m a special person. I’ve been chosen by someone up above to help battle this disease and to help in some way overcome it. I don’t look down on it. I don’t feel sorry for myself about it or anything like that... it’s just a stumbling block I have to get through in life.” ~ Florence on living with MS.

Reflection on the Research Process Guided by Lifeworld Existentials

The four fundamental existentials uniquely form the lived experience for each human being and are fundamental structures to the lifeworld (Merleau-Ponty, 1962). Researchers engaging in phenomenological reflection and writing pose questions while examining the lived experience of a phenomenon for spatiality, corporeality, temporality and relationality or communality to better understand and uncover meaning within the lifeworld (van Manen, 1990). In doing so, the researcher may engage in reflexivity throughout entirety of the research process into how these existential structures encompass the lived experience (van Manen, 1997). The existentials act as universal themes to gain meaning for a particular phenomenon under investigation and guide reflexivity during phenomenological questioning, reflection and writing (van Manen, 2014a).

Lived Space (Spatiality)

Lived space, or spatiality is space that is felt (van Manen, 1990, 1997, 2014). This may include special dimensions such as mathematical measurements for depth, height or length. We discuss spatiality regularly through our day-to-day conversations about distances between locations and when defining dimensions within our workplace or home environments. However, lived space may also be subjective and subconscious as it is mostly pre-verbal, for example, when considering the lived space for our bodies (van

Manen, 1990, 1997). Spatiality also adjusts and shifts to our immediate surroundings, whether we are gazing up at a vast starlit sky or confined to a small, crowded room. Moreover, spatiality may also refer to places that are commonly known to us and may provide a fundamental sense of being, such as the space we occupy within our homes (van Manen, 1997).

van Manen (1990) describes home as place where people are at their most comfortable and can be who they are. For example, a phenomenological researcher may consider how the participant experience of home is altered from experiencing illness (van Manen, 2014). The presence of MS and potential disability, when viewed from van Manen's (1990, 1997) lens of phenomenological reflection for corporeality alters how participants have embodied their lived space in both terms of their bodies, homes and spaces occupied within their home and communities. As van Manen (1990, 1997) attributes lived space for being largely pre-verbal, participants described the presence of MS and disability enhanced the conscious awareness for lived space. For example, Keena disclosed that she, 'became one' with her wheelchair and implied the space for her wheelchair as challenging to maneuver in public spaces and within her home. Keena described owning a dog as therapeutic for her as they provide unconditional love, but the extra embodied space of her wheelchair in her home made it unsafe for her to keep her treasured and beloved pet, which caused her an incredible amount of emotional pain. Several participants, including Cari, Sharisse and Danika, discussed how their lived space was altered as a result of living with MS and subsequent disability by needing to reconstruct their lived space to accommodate their physical needs. This included construction to lower counters or the addition of grab bars throughout their homes. Dakota spoke of spatiality literally when she discussed how she could bring anyone who

discriminated against her use of a wheelchair, as bringing them “down to her level.” This implied that her wheelchair caused her to take a physically lower space in her lifeworld. Bernadette spoke to the lived space of her personal experience with MS when expressing her frustrations with the difficulties and barriers she experienced commuting in her wheelchair while accessing public sidewalks and transportation during the icy and frigid cold winter months of Southwestern Ontario. Therefore, the results of this study would suggest that the presence of MS and disability may increase the level of awareness as to how spatiality is experienced.

Lived Body (Corporeality)

van Manen (1990, 1997, 2014) defines the lived body, or corporeality as our physical bodily presence in the world. Our bodies simultaneous reveal something both within and external to the ‘self’ (van Manen, 1990). The lived body may not always act consciously or deliberately, for example during the presence of an invisible illness. Exploration for the of corporeality guides reflexivity for researchers to ask how the body is experienced in relation to the investigated phenomenon (van Manen, 2014). When considering the lived body as an existential reflection on working with women who have MS, I reflected on my nursing practice where I observed the impact this disease has had on the corporeality for patients I have cared for. My role as an infusion nurse administering biological therapies would not include the careful dissecting and observation of MS cellular structures, or the complex examination of new lesions on magnetic resonance imaging like that of a microbiologist or neurologist. But rather, my nursing care would involve cautious monitoring and administration for biological infusions for people affected by MS while conveying warmth and empathy to meet the needs of patients. Over the course of my time within this role, I would often provide care

for the same patients on a regular basis. I witnessed and listened to how MS manifested for both visible and invisible signs and symptoms in patients in relation to their lived bodily experience with this disease. For example, the lived bodily experience could be observed and readily revealed to me when patients would come into the clinic using assisted devices to manage their ‘visible’ disabilities and physical needs for mobility as a result of their MS. However, I found as a nurse deliberately uncovering the ‘hidden’ aspects for the lived bodily experience with MS requires establishing meaningful therapeutic relationships with patients and may take some time. This necessitates gaining trust from patients and their willingness to share the unseen or ‘invisible’ aspects for their lived bodily experience with MS, such as experiences with pain or fatigue. The experience I have as a Registered Nurse working with this population allowed me to better understand the lived bodily experience with MS and establish a rapport with participants in this study. Additionally, this experience enabled me to reflexively guide the research process from pragmatic experience (van Manen, 1990, 1997, 2014), thus allowing me to better explore the ‘visible’ and ‘invisible’ aspects of living with this disease within a confined timeframe for our interview.

The lived bodily experience was discussed by participants when they shared how MS impacted their physical bodies and innermost being, i.e., mentally and emotionally. For example, Ilana gave a harrowing account for her ‘visible’ lived bodily experience with MS and the compounding challenges with her weight causing her to feel discriminated against for her disability and size. Danika, Clara, Reena and shared their love for physical activity prior to their diagnosed with MS, which included Danika and Reena’s passion for dancing and Clara playing semi-professional hockey. These three participants shared changing physically and overcoming challenges to their lived bodily

experience as a result of MS and adapting to their new sense of corporeality. Danika described having challenges walking but spending private moments she in her kitchen using her counter for support her while she performs small dance movements. Clara shared her new love for parasports where she is learning to play and enjoy competitive wheelchair basketball where she gets the same feeling of euphoria that she did when engaging in sports prior to MS. Reena expressed difficulty with experiencing severe fatigue in her legs but that she is now utilizing a city bike program to get exercise and walks long distances daily to keep active. Participants also shared how MS may adversely impact their corporeality. For example, Keena discussed with great sorrow the physical disability and leg amputation she experienced and how this impacted her sense of self. Participants also discussed how an alteration to their lived body experience enhanced their overall well-being. This included Darcy, who conveyed a sense of gratitude for their current lived-body experience with MS, as she now embraces a healthier lifestyle that includes yoga and healthy eating.

Lived Time (Temporality)

Lived time or temporality refers to time that is felt subjectively and not considered mathematical or an objective measurement for time, such as that on a clock or calendar (van Manen, 1990, 1997, 2014). Lived time changes throughout our lifespan, for example a young person's conception and thoughts towards their sense of time may involve plans for their future, whereas someone in their older adult years may reflect on their past experiences in their childhood (van Manen, 1990). Lived time relates to our sense of being through experiences formulated in our childhood, adolescents and into our adulthood and constitutes a temporal landscape for being (van Manen, 1997). Our sense of temporality also refers to our hopes, fears or aspirations towards the future (van

Manen, 1990). I first gained insight into the lived time for the experience of living with MS when working as a Registered Nurse with a young woman close to my own age. I saw this patient regularly on a monthly basis and after developing a trusting therapeutic relationship she expressed how ‘lucky’ I was to have gone to school and make friends. I realized at this moment how deeply MS and disability may impede temporality with this population. The patient expressed a desire for wanting to go to school and gain meaningful friendships but was unable to do so because of the impact MS had on her life. The temporal impact for this patient including grieving a version of her future ‘self’ she had planned and longed for that she felt could no longer exist.

The thought of how MS impacts the lived experience and specifically lived time was compelling for me and fostered an academic interest in researching MS. Other patients began to explain about how MS altered, ‘where they thought they would be’ with careers, relationships and family planning. The experience I have from my nursing practice allowed me to better understand the lived time experience for women with MS in this study throughout the research process, such as the use of probing questions during the semi-guided interview. For example, several participants within the study disclosed fearing for their future with MS when asked what impacted their well-being. As this came up in interviews, I probed deeper to learn this included fears for projected care that they may require from their children, or in some cases, the potential to need future care from children that did not yet exist. This also included fears projected by participants who were worried as to how MS would affect their health as several participants disclosed being consumed with worry about their uncertain futures with MS. Temporality was also viewed reflexively by some participants, including Sharisse who expressed feeling gratitude for not being diagnosed with MS until her older adult years as she

indicated she had already retired, reared her children, and lived most of her life. Participants shared reflexivity for their lived time through the dividing experience between what life was both before and after their MS diagnosis, most participants sharing stark contrasts between these. Few participants shared a sense of hope for their future in relation to shared lived time. Clare discussed feeling hopeful for her future as she completed treatment that may prevent her from experiencing further progression with her MS and she saw this as allowing her to start planning for her future again.

Lived Self-Other (Relationality or Communality)

Lived self-other or relationality refers to the lived relation to the other, meaning the relationships that we form with others (van Manen, 1990, 1997, 2014). This may include the interpersonal space that we share with those around us. Human beings seek out relationality or communality through a sense of community and to find a greater meaning than our selves (van Manen, 1990, 2014). van Manen's four existentials themes are never fully separated and overlap, for example we create bonds relationally with others in a corporeal way (van Manen, 1997). When we meet someone, we gain impressions through the way they are physically present to us (van Manen, 1990). Relationality may include significant relationships that we formulate throughout life, such as that of a teacher and student, or parent and child. My reflections on relationality as applied to the research process draw from my professional nursing experience for that of the therapeutic nurse- relationship (College of Nurses of Ontario [CNO], 2006; Registered Nursing Association of Ontario [RNAO], 2002). This includes a relationship where there exists an inherited power-imbalance that nurses must be aware of to provide optimal care. Communality may be implored by phenomenological researchers to ask what meaning community holds to the participant in relation to other community

members (van Manen, 1997). A nurse must establish therapeutic relationships with their patients and convey professionalism and trust (RNAO, 2002). When learning about van Manen's (1990, 1997, 2014) thoughts on relationality I intrinsically drew on my experience forming professional nurse-client therapeutic relationships with this population. One aspect of relationality in this study included that of the researcher-participant relationship. I was acutely aware of my role as a researcher and how I may be perceived relationally with the study's participants. This included the use of professionally structured communication over email or telephone correspondence and dressing appropriately for interviews and conducting myself in a professional manner; for example, acting as an attentive listener, maintaining appropriate eye contact and keeping open body language. I observed closely when communicating with participants who requested a phone or videoconference about the way they sounded or communicated to get a sense for who they 'were' in relation to others. van Manen (1997b, 2014a) describes the impact technology has on relationality as providing the ability to indirectly form an impression for others. Furthermore, the study was pertaining to the investigation for the lived experience of health, which is partially comprised of social well-being (WHO, 2014). Relationality was explored and overlapped with probing questions pertaining to social well-being. To learn more about the participants experience for social well-being, I explored directly how participants viewed themselves in relation to 'lived others' by asking probing questions about their social networks, relationships and experiences with others; this included health professionals who provided their care.

Participants shared how MS impacted their lived self-other in several different ways, including the impact their MS diagnosis had on their spouse or partners, family, friends and how they were in relation to their community at large. Most participants

expressed having to rely on someone during an exacerbation for their MS symptoms or with the experience of progressive MS symptoms. For a lot of participants, this led to mixed feelings of gratitude and guilt. The sentiment of guilt was shared by several other participants for needing assistance from loved ones. Most participants had close family and friends who were supportive and helpful for participants needs, however this at times could be overdone without asking permission for offering help. A few participants indicated that they never had a bad experience out in public for using necessary assisted devices, however a majority of participants expressed experiencing discrimination, judgement or a fear of judgement while in their community. Several participants, including Bernadette, indicated that they struggled in their community for their accessibility needs such as when shopping, accessing public transportation, using public washrooms and parking. This impacted participants by leading to feelings of shame, anger, frustration and even humiliation. There was a commonality for numerous participants for engaging in activism through volunteer work to advocate for improved public accessibility within their communities.

There was a deeper and more fulsome understanding for the lived experiences of the women who participated in this study through exploration of the lifeworld existentials and participant narratives. van Manen (1990, 1997) indicates that understanding participants stories can be both compelling and poetic, while enriching the meaning derived from the phenomena of interest. Furthermore, through the careful exploration of the four existentials, I was able to better determine how participants experienced commonalities and important aspects for gender and having MS from the perspective of their individual lifeworld's- which was crucial for deriving an enriched understanding of this phenomena.

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So anytime I just tell or explain MS to anybody... I explain it as a snowflake because every snowflake looks different, every MS patient looks so different, but everybody looks at a snowflake and they can see that it's different. So then they understand that MS is different for everybody, so they don't expect it to look the same. - Clara on the unique nature of living with MS

CHAPTER 5

FINDINGS, PART 2 AND DISCUSSION FOR THE HEALTH

AND WELL-BEING OF WOMEN WITH MS

Health is comprised of physical, mental and social well-being and was explored in this study through the context of the lived experience of women with MS. This purpose of this chapter is to highlight findings, based on data shared by participants during participation in semi-structured interviews with women living in Southwestern Ontario. Findings revealed that a number of factors, including gender, agency and social structures influence women's experience of health and well-being and are presented below. This includes considerations for health care providers who are providing care for women with MS.

Findings

This study revealed how women affected by MS experienced health and well-being, which included exploration of their physical, mental and social and well-being. Although each of the participant's shared unique aspects about living with MS, there were four themes that revealed commonalities between participants' experience of health in well-being with regards to their MS. These themes were: *Foundations of Vitality for Women with MS*, with subthemes for *Womanhood and 'Being' with MS*; *Enhancing Wholeness for with Women MS*; *Obstacles for Women with MS*, with subthemes for: *Barriers to Mental Well-Being*, *Barriers to Physical well-being*; and *Barriers to Social*

Well-Being and Caring to Enhance Wholeness for Women with MS. It is important to note that aspects of physical, mental and social well-being are often inter-related through the findings, which is congruent with literature about health and well-being (Huber et al., 2011).

The study revealed that women with MS who were able to enact personal agency in managing their physical, mental and social well-being, which they described as feeling healthy. Further, the maintenance of health and well-being was influenced by agency and structure, meaning that the two aspects jointly impacted individuals (Schilling, 1992; Schilling, 2006). Agency, which is also referred to as personal or human agency, reflects an individual's ability to effect change in their life and is comprised of three key elements including: defined individuality, active engagement within an environment, and normativity (Barandiran et al., 2009; Barkey et al., 2009; Christensen & Hooker, 2000). Barandiran et al. (2009) discusses individuality as a condition of agency between an individual or system that interacts within a specific environment. How an individual engages with the environment is established by norms, such as the expected behaviour of an individual within a specific environment. For example, the expectation of remaining quiet while within a library. Further, agency related to health is described by Sen (1992) as involving the pursuit of goals, including that of well-being. Agency is closely related to temporality and spatiality, which are components of phenomenology and thus relative to the examination of lived experiences (Abrams, 2017; Barandiran et al., 2009; van Manen, 1990, 1997). Inherently, agency is interconnected with temporality as how agency is dependent on time and is experienced within an environment or 'space' where phenomenon occur (Barandiran et al., 2009; van Manen, 1990, 1997). Agency is conceptualized in research and practices that involve social change, for example,

initiatives to promote social justice (Clark et al., 2019; Craig et al., 2019; Crocker, 2008; Ducey et al., 2012; Heinick-Motsch & Sygall, 2003, Kelman & Stough, 2015). Closely related to the concept of agency, are aspects society referred to as structures that individuals interact with both indirectly and directly through expressing their personal agency.

Structures, or social structures refer to factors that influence agency by enabling conditions for human agency to be enacted (That Ton., et al, 2021). Structures may influence, but do not determine human agency, as agency is closely related to an individual's ability to enact personal decisions within an environment (Fleetwod, 2008; Sen, 1999; That Ton, 2021; Watson, 2020). Social structures are ontologically distinct and frame the experience of disability through providing conditions within an environmental, such as that of the public accessibility of buildings or public transit. Examples of social structures include family, transportation, politics, infrastructure, facilities such as hospitals or clinics and laws (That Ton et al., 2021; Van Wormer & Link, 2018; Watson et al., 2021). In this study, participants highlighted structural factors, including: class, economy, education, employment, politics, law, institutions (e.g., health institutions - hospitals, MS Clinics and MS organizations), and social supports, for example, family (Barone, 1999; Schoon & Heckhausen, 2019). Aspects of agency and social structures and their impact on health and physical, mental and social well-being are integrated throughout each theme and discussed within the findings.

Theme 1: Foundations of Vitality for Women with MS

Women in the study described themselves as feeling healthy while living with the illness of MS. Furthermore, participants who experienced co-morbidities such as various forms of cancer, arthritis, obesity, or mental health disorders, such as depression and

anxiety, all shared the view that they were healthy when they were able to maintain agency over the decisions pertaining to their own health and well-being. Participants defined health with MS in various ways, which included stress management, taking breaks, and focusing on lifestyle factors, such as maintaining adequate sleep, diet and exercise. Health with MS was viewed as all encompassing and was similar to how respondents described well-being. For example, one participant stated how she viewed health as, “I think that'd be pretty much everything... how you... sleep and the way you eat and your exercise and your mental health and stress and everything I think is what I would think of as health.” How some participants viewed health changed after their diagnosis from being initially physical in nature to becoming focused on having healthy mental well-being and being ‘emotionally okay.’

The experience of health and illness was also influenced by factors reflecting a sense of personal agency and the extent of influence for social structures. For example, participants who described having higher levels of education, employment and job security, or meaningful family connections, discussed a sense of autonomy in managing their health and well-being and were more likely to have agency when making decisions for their health. Whereas participants who described being negatively impacted by social structures, such as laws that prevented them from maintaining meaningful employment or inadequate income for accessible housing, challenges in attending to their medical or accessibility needs, or decreased access to institutions, such as MS care, shared that they were experiencing barriers to proactively managing their health. As such, they described limitations related to various aspects of their well-being, which was grounded in experiencing less personal agency.

Several participants described how having MS improved their approach to managing health, including making healthier lifestyle choices such as engaging in more physical exercise, de-stressing, maintaining a healthy balanced diet and activities that promoted cognitive activity. Being able to maintain agency, despite having challenges with physical health such as disease progression or experiencing immobility, emerged as a key finding for being 'healthy'. For example, a participant who was diagnosed with MS after retiring, and who described a high level of social well-being, such as having a supportive family, friends and a church community, stated she was healthy despite living with MS and serious comorbidities, including cancer and lymphedema. Further, she described having a comfortable lifestyle, with access to finances and empathetic social support to help her remain independent while living with MS. This was also true for participants whose MS had progressed, even in the presence of deteriorating physical health, such as experiencing immobility. This was explained by one participant as:

I'm healthy. I just have MS. My body is breaking down. I'm aware of that, but I still feel okay. I still move as best as I can. There are things that I can no longer do, but you know, who wants to vacuum? ... my health is deteriorating because my ability to move is deteriorating, but I still feel healthy. - Emalia

This suggests that participants with advanced MS and the presence of comorbidities may feel healthy despite the presence of medically diagnosed illnesses when having social support and other resources, such as finances.

Age and the process of aging were other factors that appeared to impact health and agency, such as a resistance to using assisted devices when feeling 'too young' for participants who were middle-aged or younger, or when experiencing feelings or reluctance to access services when not feeling as 'worse off' as others with more debilitating cases of MS. Aging with MS was discussed by several participants, which

included aspects of normalizing disability and personal identity with aging. Participants who were diagnosed later in life demonstrated a higher level of agency and appeared to be positively influenced by structures, such as having access to personal finances and funding to independently manage their health needs. This included accessing costly assisted devices and MS medications that were not covered by provincial funding and acquiring meaningful employment. Participants who described employers and coworkers that supported participants' needs for managing their health and well-being at work i.e., through adequately meeting expressed accessibility needs for MS without compromising job security, described experiencing greater aspects of well-being and health compared to participants who experienced structural barriers. Furthermore, one participant described some cognitive decline as possibly more age related than her MS: "I would not say that I have cognition problems but sometimes I struggle to find words and I know that the words are there and it's just a matter of waiting for them to come, so... is that MS, is that aging, I don't know." Several other older adult participants attributed possible age-related co-morbidities such as arthritis for their current physical symptoms, such as pain, that may otherwise be attributed to MS. This indicates normal processes of aging appeared to be experienced similarly to some symptoms related to MS for participants, for example cognitive decline and immobility.

Societal views of MS were noted as an example of a social structure that were described as influencing how others viewed MS and health. One participant described herself as "a white privileged woman" and noted her perception of MS as a "white woman's disease," which may suggest that a person may perceive that race, a social construction, is an influencing factor for how people view MS. The study participants included two women of colour, one of whom was of East-Indian and Guyanese decent

who described a lack of racial diversity at gatherings she attended from her local MS organization - “they're not diverse in any, in any way, shape or form. You know, they're not culturally specific in any way, shape or form.” This viewpoint is that there is a perceived lack of racial diversity at MS related gatherings. That might result from either fewer non-Caucasian people living with MS and/or MS related gatherings may not be as inviting to people of colour or who are Indigenous. This may have implications for mental and social well-being for women of colour living with the disease. For example, one participant identified as being bi-racial of Caribbean and Caucasian descent. She described her racial identity as impacting her social-being as her Caribbean family blamed her Caucasian ethnicity as, “... my mother is black and my father's white, my mother will always blame my MS on my father.” Further research is needed to determine if and how culture and ethnicity influence health and well-being for women with MS.

Participants noted that their personal identity was negatively influenced due to the issue of stigma surrounding MS by members of society and media and that this impacted their health and well-being. Participants described having MS as being stigmatized or ‘labeled.’ For example, one participant who is a woman of colour stated, “... I’m a visible minority and female and now I'm disabled. So that's three of the five prohibited grounds.” The ‘label’ of being diagnosed with MS or experiencing disability did not impact everyone the same way; for example, one participant displayed resilience with the ‘label’ of being diagnosed with MS and described this as:

MS is part of the definition that makes up me. It is not who I am. I am not that woman with MS. I am that woman, period. I am not a disabled person and I quite strongly believe this. I'm a person with a disability. - Dakota

Labels were not always viewed as negative, for example, one participant proudly introduced herself as “not a typical person with MS,” referring to her mobility and lack of need for an assisted device, such as a wheelchair.

Participants also described how knowing others with MS through structures like family and employment shaped their knowledge and perception of MS; this appeared to influence their mental well-being. For example, one participant had a mother with MS who she described as someone who had a positive outlook on life towards having MS. This influenced the participant’s attitude towards MS and she attributes this to her ability to maintain a ‘positive outlook’, despite experiencing a decrease in physical well-being. Another participant who described having a mother with MS who progressed quickly stated that it caused her to be fearful of having MS. She also described feelings which impeded her sense of mental well-being such as a lack of understanding from people within her family,

My mother had MS, she got it at my age and it was very progressive so it was, and it is very scary... I tried to do everything I can, especially the eating, do a lot of reading. But then days when my symptoms are worse, then I go back to when they first told me. And it's scary. - Felicity

This suggests that participants’ well-being is impacted by the ways in which their personal identity as a person living with MS is shaped by societal influences such as stigmatization and structures that reflect depth and quality of social connections.

Womanhood and ‘Being’ with MS

The impact of gender was explored in the study from the lived experience of women living with MS and was found to influence participants’ health and well-being both explicitly and implicitly. Gender was noted as influencing personal agency through the intersection of structures, such as economy, employment, and family. For example, a

majority of women who described working indicated that they were employed in traditional work for women, such as caring and service roles. Traditional gender roles such as caregiving for children or adult parents and marriage were noted as impacting the health and well-being of participants.

Participants discussed how being a woman living with MS affected their sexual and reproductive health in relation to menstruation and menopause. Menstruation and menopause were perceived as contributing to a worsening of MS symptoms. As such, women's physical and mental well-being were impacted temporally during their life-course by MS symptoms. Several participants who were younger adults to middle-aged women described being curious as to how having MS may impact their experience with menopause. One participant described how she felt her MS affected her menses as:

During my cycle, a lot more of my symptoms flare up and so it's like, am I having period cramps or are these cramps muscle contractions in my legs?... For example, my period, it's kind of an ordeal because it looks so different for me and I'm almost terrified of my period coming because I'm going to have a flare up of my MS, my legs are going to go completely numb... but if I was a guy, would I be having this flare up or is it because my body's going through this event?... it hurts. - Clara

Another participant discussed her current experience with menopause as

I think menopause was harder ... with MS... the heat... some of the hormonal things can throw you off with MS. I just think as a woman... there's just some things that biologically happened... with a woman who doesn't have MS that you know, that are difficult enough or it makes transitions harder, I think. - Keena

Participants felt that the impact of menses and menopause and how this relates to their MS symptoms was generally not discussed with their health care providers, although several participants indicated they would like more information for how MS impacts this aspect of their health. These findings indicate that women with MS may believe that

menstruation and menopause may be more challenging with MS and such issues warrants further research.

The impact of fatigue combined with engaging in traditional gender roles, such as caregiving for older adult parents or spouses who were unwell were noted as impacting the health and well-being of participants. A participant noted she was the primary and sole income earner for her household which consisted of four adults, and was also the caregiver for her spouse and an adult parent with a disability. The combination of these roles detrimentally impacted her mental well-being. She attributed her situation as preventing her from being able to seek mental health supports, such as counselling, to enable her to manage her previously diagnosed mental health conditions. Furthermore, she discussed being responsible for chores around the house, such as laundry and yard work, while also taking her mother to her medical appointments. She described experiencing extreme fatigue as a result of her MS symptoms along with the caregiving demands, and although she might benefit from having the ability to work from home throughout the week, she explained she would not be comfortable asking her employer for further accommodations. She worked in the automotive industry and stated that the leadership is male-dominated and her job security may be threatened if she requested further accommodations. She attributed her situation as having less time and energy for engaging in self-care activities to manage her health and well-being.

Having limited time to engage in self-care activities was discussed by another participant who cared for her husband's and children's needs before her own. She discussed receiving little empathy at home when experiencing her own symptoms of fatigue and was expected to cook and clean for her husband and children. Not having the time to engage in self-care activities, feeling guilty for needing time to manage symptoms

of fatigue, a lack of understanding and respect from close social connections, were all noted to decrease feelings of personal agency and decreased participants' ability to maintain their health and well-being. These findings suggest traditional gender roles such as caregiving may exacerbate MS related fatigue and also present challenges for the necessary energy and time needed to engage in preferred self-care activities.

Motherhood was explored by several participants who noted this role was potentially complicated by MS; for example, when experiencing invisible symptoms such as fatigue or engaging in single parenting while dealing with a physical disability. Parenting as a single mother with MS and a physical disability was also noted by some participants as negatively affecting their mental well-being. For example, one participant expressed facing various challenges with being a single mother to a high need's child, these included: challenges with public transportation and accessibility, limited finances, experiences of social isolation, as well as challenges managing household chores, such as cleaning and cooking.

Two participants described their children as having a lack of understanding for their mother living with MS symptoms and described this as being a challenge of parenting with MS. This decreased social well-being for one participant who felt that she may be injured when engaging in physical activities, such as swimming with her daughter, who could not understand her physical limitations. One participant described her role of motherhood with MS as complicated as she experienced invisible symptoms such as physical pain and fatigue. She noted that her children and family do not always understand her MS symptoms and that she had to find creative analogies. This participant also described a scenario that distressed her when her child brought home a picture of her from school. The picture depicted the participant laying in her bed and what it was like

being diagnosed as a young mother, which she described as upsetting. These findings may suggest that there are challenges for mothers of children at various developmental stages, when teaching their children to comprehend and understand their MS symptoms. Furthermore, this may also suggest that women with MS who are young mothers may feel a sense of guilt for needing to accommodate their own health needs, such as resting when experiencing fatigue.

Other women in the study described not wanting to become parents or waiting to start a family until MS medications would not impact a potential pregnancy. Several women described how MS also impacted their opinions about having children. One participant, when being informed by health professionals of the diagnosis of MS, described being told not to have children. Participants noted that fear and anxiety related to potentially caring for someone else and the possibility of offspring inheriting of MS were reasons for not wanting children. A participant described electing to have a therapeutic abortion because of a high degree of anxiety that the MS medication may have caused complications for a pregnancy; the participant indicated this contributed to her experiencing problematic substance use for drugs and alcohol to cope with feelings of distress that resulted from her receiving a therapeutic abortion. There was no professional support offered to her in Ontario, so she personally sought out the use of an 'abortion doula' online in the United States of America to help her cope with the traumatic loss. These findings suggest that women with MS may be internally struggling with issues related to family planning and encounter complicated emotions related to experiencing unplanned pregnancies while undergoing treatment for their MS.

Gender-based discrimination was noted by one participant who identified as a lesbian. Although she did note that she has not recently experienced discrimination from

health care professionals regarding her sexual orientation, she described that her sexual orientation was something that she did not disclose often when seeking health care as she felt that this was irrelevant to most situations when receiving care. She described going to her family physician when first experiencing the onset of MS symptoms, as where she experienced gender-based discrimination from a health professional. She described having felt that her symptoms were dismissed as a result of being a woman, as the physician erroneously attributed her symptoms to being psychological in nature and described this as:

... then when I got these odd symptoms, trying to get somebody to listen, including my own family doctor who was not a good one in [Location], she actually sent me to a psychiatrist. - Keena

This participant noted that this incident was several decades ago and that she felt society's attitudes had improved towards women since this occurred. However, she stated that she had recently experienced ageism and sexism when receiving post-surgical care from a nurse who she felt perceived her as a "whiny old woman." Another participant noted that she was taken less seriously by two neurologists because of her gender and described feeling dismissed because of being a woman. The first instance was during the initial testing and diagnostics process to rule out MS. Despite being told that there were lesions on her brain, the neurologist blamed her stress on her husband and attributed her symptoms to the stress of being a mother; therefore, denying that she had an MS diagnosis. Currently she is seeing another neurologist who she described as an older man who talks to and treats her "like a child." This participant noted that she felt her husband had to be present for her medical appointments to convey her concerns and have them taken seriously because she felt dismissed because she was a woman, despite having the ability to legally make independent decisions with her health. The findings point to how

some participants perceived that their medical issues were not being addressed with importance when accessing health care services because of their gender.

Theme 2: Enhancing Wholeness for Women with MS

Participants noted that their physical, mental and social well-being with MS was supported by a number of factors, for example, the ability to access preferred resources to treat their MS. This included obtaining desired costly MS medication and accessibility devices, as well as alternative therapies like massage therapy, private exercise classes or adhering to special diets. Promoting health involved having limited barriers from social structures to make choices freely for preferred therapies, such as having access to personal finances, private health insurance or financial support provided by the government. Furthermore, women with MS experiencing physical, mental and social well-being were more likely to benefit from structures. Participants with friends and family who were noted as providing empathetic social support to meet their health needs described benefitting from social structures, such as accessing various health professionals or MS clinics to promote their health needs.

Participants described managing their physical well-being through physical activity (PA), diet and having the ability to access various treatments options. Participants who described having the ability to select MS medications indicated this not only impacted their physical well-being through the prevention of further relapses or delays in their MS progression, but it also affected their mental well-being by providing a sense of relief as many participants acknowledged that not everyone with MS in Ontario can access these medications and treatments equitably. Additionally, participants with a strong sense of agency were able to engage in using both traditional medical approaches and alternative approaches to manage MS symptoms and side effects from MS

medications. For example, several participants noted utilizing additional alternative treatments that were accessed through personal finances or private insurance, Such treatments were not often available to participants who disclosed receiving government funding or who were experiencing poverty. Alternative treatments included massage therapy, physiotherapy, modified exercise programs, and yoga classes at privately owned studios. A participant who described being employed and having private insurance benefits noted she chose to take yoga classes at a privately owned studio, meditation, cannabidiol and essential oils to help her manage side effects while taking disease modifying therapy. Meditation, mindfulness, Ayurveda and Reiki were noted by participants as beneficial to physical and mental well-being by physically relaxing the body and providing a sense of balance and, in the case of Ayurveda, a sense of cultural connection. Having the ability to remain physically active and experience agency for decisions of treatments for MS appears to promote physical well-being in women with MS, and have a positive influence on their mental and social well-being. For example, one participant noted that her use of cannabidiol oil for MS-related muscle spasticity allows her to spend more time socializing with her friends and family, and thus enhanced her social well-being. This suggests that women with MS may prefer individualized and tailored approaches to managing the disease including access to pharmaceutical or alternative approaches, which may be beneficial and help meet the unique needs for physical well-being of this population.

Exercise and PA were identified by participants as an important aspect to manage participants' physical well-being, as well as benefitting their mental and social well-being. Benefits of PA were described as experiencing feelings of enjoyment and improved balance. For example, several participants discussed attending yoga classes and

described this as beneficial to managing physical symptoms of MS such as balance disturbance, as well as promoting mental well-being through instilling a calming effect and promoted social well-being through creating a sense of community belonging. This was noted by one participant who was receiving disability funding. The participant disclosed she was able to access a funded class that promoted modified exercise which helped her with her MS hug symptoms, a symptom that causes chest pain and tightness (Wingerchuk et al., 2019). She stated:

I do yoga... I went out on my own and did what they did at a pain clinic. They had ... a six-week course or whatever and I completed it and it had like different, moves. ... it combines meditation and relaxation techniques and I've been doing a lot of the relaxation techniques, which has been really good. And they give you a great big book with the little CD in it to show you to do some chair yoga... I was a little bit nervous and then when I got in there and there were a bunch of friendly people and they showed you how to relax and do things and just some like deep breathes and yeah, it was great. It was awesome. - Geneva

It is important to note that most participants who did not have agency to access modified exercise classes expressed wishing to do so but experienced barriers. This may suggest that this population have a desire to access alternative treatment options for physical well-being that are not currently readily available to them or equitably funded.

Other treatments were used by participants to enhance physical well-being through private insurance or financial resources from employment included acupuncture and massage. Acupuncture was described as the “best treatment” for one participant’s facial pain caused by trigeminal neuralgia. Another participant described receiving massage therapy as the one treatment she “wouldn’t trade for all the money in the world,” and that she would prefer to have more financial support from her private health insurer for this as well as public access through her MS clinic, which may demonstrate a limitation for her agency to further utilize this treatment modality to help her manage her

pain symptoms and enhance her physical well-being. Participants who did not have adequate access to financial resources indicated that they would utilize this type of treatment to help manage their physical well-being with MS. These findings suggest that there is currently an inequity amongst this population to access to these holistic therapies that could help manage troublesome MS symptoms such as pain.

Having adequate resources to obtain accessibility devices, including in the home, for stability and safety and while mobilizing was noted as an important aspect for maintaining physical well-being. Participants described that assisted devices for mobility, including crutches, canes, walkers, wheelchairs and hand devices for operating personally owned vehicles, helped maintain participants' independence. Having agency to select appropriate devices to meet accessibility needs was noted by most participants, but not all. Participants who had access to adequate personal financial resources through employment, private insurance, financial assistance from family or government funding, described having the ability to obtain preferred accessibility devices. For example, some participants discussed purchasing or applying for funding to obtain power wheelchairs or scooters versus manual wheelchairs. Accessibility devices in the home were often paid for by participants' personal income or government funding, and included costly home renovations to allow for easier mobilization in power chairs, as well as improving access to bathtubs, toilets, kitchen counters and power lifts for staircases. However, not all participants had access to funding and some even described being denied funding for equipment despite having a physical and financial need. Participants noted that paying for accessibility devices from their personal finances often came with a stressful financial burden. Furthermore, participants who received funding indicated that the documentation to be filled out to apply for devices was stressful and they experienced lengthy wait times

to obtain the devices, which was noted as burdensome and stressful. These findings suggest that participants' physical well-being is enhanced through accessibility devices, but that the process of obtaining them may cause financial and emotional stress that impacts participants mental well-being.

Having the ability to enact agency to promote mental well-being was noted by participants who expressed managing their mental health and engaging in what they felt were healthy coping mechanisms. This included having the financial means to access counselling and psychological services. Furthermore, this involved being able to engage in alternative therapies such as mindfulness and meditation which were noted as promoting mental well-being, but required free time and adequate financial resources. Promoting mental well-being was noted as enabling participants to experience greater social well-being and health. Additionally, factors that promoted mental well-being were noted when participants described having their physical needs met. Feelings of experiencing physical well-being may help alleviate stress, such as not having to worry about how to pay for costly medications used to treat MS and promote mental well-being. Additionally, factors such as being mindful of physical limitations, staying active and seeking social and emotional support, were noted by participants as effective means for coping with MS and thus helped to increase feelings of mental well-being. Participants who experienced mental well-being noted aspects of how this additionally benefitted social well-being, such as having positive feelings towards friends and family. The findings suggest that mental well-being is closely related to having personal agency when selecting treatments for managing physical well-being and this may further influence social well-being. Furthermore, having access to adequate financial resources through

structures such as employment and government funding may improve the mental well-being for participants.

Social well-being was observed in the findings as being closely related to both physical and mental well-being. Having feelings of physical and mental well-being enhanced participants' ability to engage socially and experience social well-being. Participants described social support as being comprised of romantic partners, family, friends, co-workers, employers, neighbours and community members; and social structures, such as church groups or MS community groups. Several participants described how their social networks and social support changed over the course of being diagnosed and living with MS. Women in this study who described changes in their social networks often discussed seeking out social connections that were understanding of their MS and ceasing contact with people who were not empathetic or understanding of their MS. For example, being understanding of fatigue levels or considering physical accessibility needs that did not include assumptions about their level of disability. These findings suggest that having empathetic and understanding social support networks may support social well-being and possibly benefit the health of women with MS. Conversely, not having adequate or empathetic social support may lead to feelings of isolation but may be mediated through engaging with new supportive social connections to regain feelings of social well-being.

Some participants noted that their relationships improved and strengthened after being diagnosed with MS, thus enhancing feelings of social well-being. For example, one participant described the relationship with her second husband as "voluntary... because I already had the MS once we got married." One participant discussed having a large supportive social network of friends and family who helped by accommodating her

accessibility needs. This included her son who had newly renovated her home to accommodate her physical needs; she discussed how he added grab bars into her bathroom and redesigned her condominium to meet her accessibility needs. Furthermore, he ensured she had her physical accessibility needs met at his own home as well so she could comfortably visit and attend family events, as she described social outings as being challenging for her due to bladder symptoms related to her MS. Several participants noted that having others accommodate their accessibility needs from their own perspective allowed them to feel respected and promoted feelings of inclusion, which enhanced their social well-being. This was described by several participants while travelling with friends and family as well as having greater aspects of physical, mental and emotional well-being when social connections offered to accommodate their needs. Participants described valuing having the ability to enact personal agency for their accessibility needs to people in their social networks. Furthermore, social supports may help promote coping and mental well-being by actively encouraging and emotionally supporting women with MS while they adapt to living with MS and acquire new coping mechanisms. This was described by one participant whose parents encouraged her to participate in creative outlets and helped her accept her MS diagnosis. These findings suggest that participants who have empathetic social networks that promote the participants' agency in social situations were more likely to experience feelings of social well-being.

Having the ability to maintain employment was noted by participants as improving feelings of social well-being. Participants who felt that they could disclose their MS diagnosis and express medical needs such as accommodation requests at work to meet accessibility needs, flexible working hours and time off work for medical

appointments, described feelings of social well-being. Employers who accommodated participants' accessibility needs were viewed as being understanding and flexible.

Participants generally expressed gratitude for employers and coworkers who they felt supported their needs with MS, and this appeared to influence the participants mental well-being through decreasing work-related stressors and led to feelings of inclusion.

However, it is important to note that not all participants were able to remain employed with their MS.

Obtaining volunteer roles were described by participants who were unemployed or receiving disability funding as important and provided a sense of purpose and meaning, thus enhancing feelings of social well-being. For example, several participants indicated volunteer roles were more likely to offer accommodations for their MS symptoms, such as needing time off to conserve energy and manage fatigue. Volunteer roles included participants utilizing previous knowledge and expertise gained through education and previous employment in areas such as counselling people with MS, engaging in MS peer to peer support, volunteering as an assistant for sexual assault victims, and as board members for condominiums, long-term care centres and municipal committees; the latter was often demonstrated as being political in nature to advocate for people with disability and enact changes to structures such as institutions or enhance public accessibility. For example, one participant described volunteering with a city planning committee to promote social inclusion for people with disabilities. She described that this work made her "feel great" and discussed the impact this work had in relation to law and politics in Ontario:

...According to the Ontario government, any municipality over so many people have to have that accessibility committee. So, we look through the different plans that are coming through. Buildings like, Walmart or Superstore

when they're building a new park, we look for the parking spots... if they're wide enough, we look for lighting, path of travel and any county owned building, we are allowed to look what's on the inside. Most of it's on the outside for like private businesses or any county owned facilities; we have to look at the insides to say for like accessible bathrooms and you know, make sure the turning radius is right and the level of the sink and the paper towel and you know, stuff like that. It's fun. It's a great, it's a great committee. We advise the [Name of county] on some of the things like their websites and stuff like that. - Geneva

She demonstrated an ability to exercise agency to enhance structures politically through her knowledge of disability laws and advocating for more accessible public spaces. This was further described by two other participants who described being involved with their condominium boards. Participants who were able to express agency and influence social structures were noted as advocating for more accommodating environments that benefitted the social well-being of others with disabilities.

Participants who engaged in roles such as MS peer-to-peer support described being partnered through the MS Society to share their personal knowledge and expertise with others newly diagnosed with MS. Several participants described that engaging in this role provided a sense of validation for their experience with MS, as well as provided an opportunity to help others newly diagnosed with MS. One participant described receiving MS peer support from other individuals when she was newly diagnosed and described that she now wants to be “that positive person” for someone else. She described her experience with MS peer-to-peer support after being diagnosed:

I was in a fragile kind of state and I just remember how much that helped... there's no way to really pay somebody back for that, right? But I remember thinking, if I could do that for somebody else, you know, just to sort of take the edge off it... and the first person that I was sort of matched with, if you will, when I was doing the peer support stuff with the MS Society was a woman who was newly diagnosed. And her situation was so similar to my own... she was about the same age and she had young kids and she was very afraid and all of this stuff... and we just happen to have personalities that meshed also. I could tell I was helping her to feel better, you know, like there were times where she would say to me like, you know, I hope I'm not calling you too much... But... she said,

honest to God, like getting off the phone with you makes me be able to sleep at night... And I remember thinking, I get it...I remember that. - Bridgette

Engaging in roles to educate others on their experience with MS appeared to validate participants' personal experiences with MS, including receiving and providing empathy and understanding of their experience of the disease and improving accessibility in public spaces.

Use of technology, such as social media to connect with friends, family and other MS community members were described as beneficial for promoting mental and social well-being by a majority of participants. One participant did highlight the limitations of technology with social well-being due to having visual disturbances from her MS and preferring in-person connections. Several participants, including older adults in the study described utilizing handheld devices such as cell phones or tablets to connect with their social network through emails, phone or video calls and social media. One participant discussed running an online social media page for people with MS and described this as, "it's so helpful because when you're first newly diagnosed, you don't really know what to do." She described feeling a sense of being part of an online community which benefitted members through having empathetic social connections as well as help in information seeking and stated, "even the first few months, not knowing what to expect, being able to ask questions to people who understand what you're going through and getting answers to questions." This participant discussed her use of social media to connect with others who had MS to learn and provide helpful information for managing various symptoms and overcoming challenges. Utilizing technology for social connection was also noted by several participants to connect with friends and family and to keep updated with social events. Various forms of technology allowed some participants to connect meaningfully

with others, including cell phones, emails, social media event invites, online games and videoconference calls. Using technology to connect with others may improve social well-being and mental well-being for this population but may have limitations for anyone experience optical symptoms with MS.

Theme 3: Obstacles for Women with MS

Several participants noted numerous barriers to experiencing optimal health and well-being. Experiencing challenges for health and well-being were demonstrated to impact participants' ability to manage their health needs. For example, structures such as public transportation were more difficult to access during extreme weather in the winter months for Southwestern Ontario. Agency was affected when experiencing barriers, as this may inhibit women with MS from making decisions freely while engaging with structures to manage their health and well-being. Having unsupportive family and institutions such as MS clinics, or economical factors like experiencing limited access to finances to manage medical, accessibility and housing needs for people with MS presented as barriers.

Although this dissertation's focus is with exploratory data from an interpretive lens, some aspects of power imbalances between participants who experienced barriers with various structures were interpreted as a hinderance to physical, mental and social well-being. This aligns with the literature about women with disabilities being noted as a disadvantaged group. In this study, several participants openly discussed their experience with intimate partner violence (IPV) or experiencing discrimination as a result of a disability when discussing social well-being. Additionally, aspects of poverty such as housing insecurity and challenges with affording MS medication were also noted by participants. Therefore, as these narratives were graciously and openly provided by

participants as key aspects preventing them from experiencing health and well-being more fully and will be included in this section.

Barriers to Maintaining Physical Well-Being

Limitations to physical well-being include experiencing barriers to medication, treatment and accessibility needs. The study revealed a lack of accommodation across various locations, which often impeded agency and impacted physical well-being for participants, such as accessing structures like public spaces, hotels and hospitals that lacked adequate accessible washrooms. For example, one participant discussed accessing public washrooms in general caused feelings of distress

I'm obsessed with washrooms... it's been a real big problem... I'm going to [name of Canadian city] next week for surgery... when we went through for the initial appointment, we had booked a hotel in [name of Canadian city], wheelchair accessible room. I went into it, and there was no bars, there was nothing... and there was a bathtub. So we went down and she says, 'well it's partially accessible.' Which meant there was probably room for the wheelchair to turn and that was it. So she gave us another room with one bar, still had a bathtub. I mean, how is that wheelchair accessible? ... booking a hotel this time my husband was six hotels before we got a proper wheelchair accessible room. I mean, this is... the hard part. If you want to do anything, you've got to make sure to ask all the right questions to get there. I need a roll in shower and everything else. - Sharisse

This participant was required to travel out of province for surgery, and when describing seeking accommodations that were accessible, she indicated that when the physical accessibilities are inadequate it is “terrifying” for her, but when she has adequate accessibility while travelling, she can “relax.” She expressed that places in Ontario that are labelled as accessible, are often not. Which was a sentiment shared by other participants. Further, participants expressed that there is a lack of accessible spaces in public designed from the perspective of people living with disabilities. Several other participants alluded to inadequate travelling accommodations throughout Southwestern Ontario, which included complaints about accessibility issues in hotels, hospitals and

public areas, and were generally described as lacking adequate accessible structures like elevators and bathrooms. For example, one participant indicated that she did not have adequate travel accommodations while volunteering for the government in a role that required her to stay overnight in various hotels. These findings may suggest that further accessibility evaluations for both public and private sectors may be needed from the perspective of people living with disabilities, as this is not currently adequate for people living with disabilities.

Housing security was noted in the findings as a social structure that caused anxiety, stress and fear for participants for projected needs with MS and their physical well-being. One participant who was told to sell her home to cover her accessibility needs after being denied for government support by narrowly missing the financial threshold for approval. Five participants also discussed stressors over their housing and how MS might impact their ability to remain safely in their homes. One participant noted she was worried that she would lose her home due to the financial strain MS has had for her finances. She described her housing situation:

I'm in a city where there's very limited places to rent. We're in a rental crisis here. And a one-level home is not obtainable for me. I couldn't afford that. With the stress test that they introduced two years ago. When my mortgage comes up for renewal... I may not meet that stress test, so I may have to sell and rent. - Ilana

One participant did discuss losing her home and going bankrupt because of having to medically retire from work due to her MS progressing. As a result of this, she moved into a long-term care facility in her early forties, while her children had to go live with other members in her family.

Several participants described experiencing various invisible physical symptoms associated with MS such as pain, numbness, and fatigue and discussed the impact this

had with their health and impacted various aspects of physical, mental and social well-being. Fatigue was described by several participants as being physically and emotionally draining, greatly impacting their energy levels and ability to engage in social and physical activities. This was described by one participant, who is a middle-aged adult working full-time to support her family as the only income earner in her home and responsible for caring for her sick spouse and disabled mother. She described her fatigue as “terrible” and denied feeling well when being asked if she experienced feelings of well-being. She stated she was “... exhausted all the time in a lot of pain.” Fatigue was attributed by a participant as a challenging symptom that prevented her from doing activities that she enjoyed, such as gardening, and created a factor that impacted participants’ agency by creating a barrier from engaging in self-care activities such as attending therapy.

Problematic invisible symptoms of MS may affect agency, as participants who experienced invisible symptoms indicated they created barriers for utilizing accessibility devices. Having invisible MS symptoms such as pain and fatigue that are experienced physically and mentally but are invisible, in that they are not necessarily apparent to others, consequently impacted how study participants utilized assisted devices and services. For example, one participant with severe pain related to MS described utilizing accessible parking spaces with an invisible disability while in public as,

... I do get like the eyes cause of the me using the um, handicap thing... I got one really dirty look the other day when I took the last handicap spot, which I very rarely do, but I was having a really bad day... this woman like looked at me like crazy... So people see it cause I think they're gonna run after me and tell me like get the fuck out of that spot... - Reena

Participants discussed needing greater social acceptance towards using assisted devices for both invisible and visible MS symptoms.

The ability to enact agency when selecting treatment options to manage participants physical well-being was not evident for a number of participants. For example, those who had barriers to expressing agency when selecting treatment options were impacted by structures such as institutions like MS clinics. Unemployment and a loss of private insurance benefits, or experiencing financial difficulties were cited as barriers to managing the health and well-being of participants; this included limitations for disability funding. Several participants noted receiving limited government funding that did not cover additional medical needs, such as cannabidiol oil to help treat muscle spasticity caused by MS, which participants noted would otherwise be helpful in managing their health. Additionally, some participants described having to rely upon limited spousal income or described constrained financial means through their own employment that prevented them from receiving preferred medical treatments.

Other barriers included a lack of time due to personal responsibilities (i.e. parental responsibilities, caregiver role), limited access to finances, exacerbations of MS symptoms with extreme weather, limited public funding to support PA for women with MS and restricted availability for modified exercise classes that provide accommodations for people with disabilities. It is important to note that not all participants could afford attending physical exercise classes, but a majority of participants expressed an interest and desire to engage in PA and modified exercise programs. These findings demonstrate that personal financial situations heavily influence agency and what structures this population may freely access. Other barriers for engaging in PA noted by participants included fear of disclosing MS and limited class sizes. One participant noted that she regularly attended yoga class but stopped attending due to the yoga instructors changing regularly. This caused her to repeatedly explain her accessibility needs and resulted in her

feeling uncomfortable. Some participants who described experiencing barriers to PA noted that this resulted in unwanted weight gain and resulted in issues for body image.

Barriers to Mental Well-Being

Participants' reports of mental well-being were varied. Some participants disclosed having a history of mental illness, such as being previously diagnosed with anxiety or depressive disorders; this may lead to greater challenges to cope with MS and impact agency by creating barriers to managing health and well-being. For example, having MS was noted by several participants with a history of mental illness as making it more challenging to manage their mental health. Many participants discussed feeling emotions such as worry, stress or fear related to their MS, which impacted mental well-being and several participants indicated this worsened their MS symptoms. MS may impact mental well-being by negatively influencing self-identity; this may be further impacted by structures such as loss of employment.

One participant noted that she had bulimia nervosa and disclosed that her eating disorder may have caused her MS. Another participant disclosed being diagnosed with depression and MS and noted that she was suppressing her emotions and, as a result, described having a harder time coping with MS. Three participants noted that they were previously diagnosed with mental health disorders such as anxiety and depression while another participant had a panic disorder prior to becoming diagnosed with MS. A participant with a mental health history prior to her MS discussed how this was attributed for her presenting MS symptoms being dismissed when seeking emergency care and caused a delay in receiving a diagnosis. She discussed working in mental health and was a strong advocate for utilizing mental health services. This participant's experience in the medical field indicates that health care institutions may create a barrier to access

necessary care if dismissing invisible symptoms associated with MS and falsely attributing these to mental health concerns.

Other feelings which were noted to have impacted participants mental well-being were feelings of fear and anxiety. For example, participants discussed having fears related to the uncertainty of their future with MS. Some of these fears and worries were related to a fear of disease progression and potentially needing care. One participant felt isolated and began sympathizing with her friend who committed suicide because of her advanced MS. Fear and anxiety were also noted with the cost of medication to treat MS and the need to potentially receive funding for disability. This may indicate that fear of inadequate finances may create challenges for this population to manage their health and well-being. For example, this was experienced by one participant who described that her fears were alleviated after learning her employment benefits would cover the cost of her medication.

So when I first got diagnosed I kind of was in shock of how much these drugs cost and I was scared. I was super, super scared that none of my benefits would cover this. And I was super, super scared that I'd have to go on like disability or something like that, like a government funded program so I could get my medications. But then at the same time... I know a lot of people say I was very fortunate that I worked for the company I do and I have the benefits that I have because I haven't had to pay for them. I haven't had to pay anything for any of my drugs. And that seeing as like my drugs cost \$80,000 a year and all I've had to pay is \$9, it's pretty fortunate. So now, I'm good. If anything changes, I'm okay with it cause I know I can most likely pay for it. - Clara

Stress and fear related to covering the cost of medications used to treat MS was shared by several participants.

Other feelings that were expressed that impacted mental well-being included fearing for family, for example participants expressed fearing for their children, this included several participants who were dating and do not yet have children. This was

generally expressed as a fear for their children inheriting MS. Experiencing fear may be further exacerbated for women who have witnessed their family members with MS deteriorate, or have professional experience in a caregiving role for end-of-life care for people with MS, such as working in palliative care. For example, one participant discussed how her mother had MS and progressed rapidly. When this participant was later diagnosed with MS she did not disclose it to her family until after her father had passed away to avoid worrying him. This finding may suggest that fear and stress surrounding MS may impact family as a social structure.

Embarrassment was also discussed as increasing stress and impacted participants' mental well-being, this further influenced a decreased in physical well-being such as worsening for MS symptoms and subsequently decrease social activity and social well-being. Stress, such as emotional distress caused by experiencing the loss of a loved one, a loved one having an illness or serious incident, financial burden, relationship strain, caregiver burden for children or adult parents, or complications from treatments for MS were all noted as potentially aggravating and worsening MS symptoms. Feelings of embarrassment were described by participants experiencing cognitive symptoms with their MS. Cognitive symptoms noted by participants included difficulty with word selection and forgetfulness that made one participant feel "a little stupid," and led to feelings of embarrassment and stress. Stress and anxiety surrounding cognitive issues also made several participants worry about their employment security and how they were being perceived. For example, one participant who works as an emergency room nurse described experiencing cognitive impairments with MS and how this impacted how she may be perceived at work:

... do they think that I'm not a good nurse, or that I don't know what I'm talking about? Um, yeah there's lots of stress and again anxiety about... there's a balance between if people know then maybe there'd be more of an understanding or if people know then maybe they'll think you shouldn't be doing this, maybe you shouldn't be working. - Arleli

The findings suggest that embarrassment about cognitive symptoms is something that participants struggled with in silence. As cognitive symptoms are an invisible aspect of MS, and it may not always be apparent to others, participants noted this lessened feelings of mental well-being.

Participants described being labelled as “disabled” or having a “disability” or that of a “sick person” as mostly impeding their self-identity and impacting their mental well-being. For example, one participant shared having negative views of herself related to her MS and disability and noted she felt like she ‘became’ her chair and another participant described MS as “it’s a label.” Self-image was noted as impacting personal views of MS and was discussed by some participants as a lack of feeling desirable in both marriage and dating and participants noted this related to having issues with their body image. For example, binge eating and eating disorders, as well as reports of dissatisfaction with body image were expressed by several women in the study. One participant discussed her bulimia nervosa as a potential factor that contributed to being nutrient deficient and possibly causing her MS. Two participants described their means of coping with MS and generalized stress as binge or overeating which they attributed to unwanted weight gain and their experience with body issues. One participant described in detail her issues with body image and the impact this had not only with her self-identity, but also resulted in a near death experience as a result of receiving an elected gastric bypass surgery and discrimination from her neurologist for being overweight. These findings suggest that women with MS may experience complicated perceptions of body image and self-

identity when experiencing disability that impact their mental well-being and may require further support in this area.

Barriers to Social Well-Being

Social well-being was hindered for participants when experiencing a perceived lack of support from structures like family, friends and institutions such as MS clinics and hospitals providing their care. Participants noted that a lack of understanding and empathy from others for invisible MS symptoms was impacting their social well-being and decreased their sense of emotional support. There appears to be a complex relationship between physical and mental well-being in relation to social well-being. A decrease in physical and mental well-being may decrease participants' agency to engage in social activities. Experiencing less social well-being was noted to result in participants feeling depressed and isolated. Loss of meaningful relationships and employment were also described by some participants as lessening feelings for social well-being.

Not all participants described having adequate social support or experiencing social well-being. Some participants described having some supportive connections, strained or estranged relationships or little to no social support, which all contributed to decreased feelings for social well-being. Participants who described less social well-being generally discussed having higher levels of stress, for example, experiencing challenges with limited child support or while also acting as a caregiver for their adult parents. One participant who was involved with caregiving duties with limited social support described this as

... and then at home... as I said, I'm married, and I have both my mom and my dad living with us. My husband doesn't work. He hasn't worked in years due to depression and anxiety. So there's a lot of pressure on me from... I'm the sole provider in the household and being chronically ill is... it's a lot of pressure. - Audrey

Several participants discussed how being diagnosed with MS changed their social networks. For example, social connections with people who did not display empathy or understanding were noted as ceasing contact with participants. This was discussed by two younger participants who disclosed being in high school and post-secondary studies at the time of their MS diagnosis. Both participants noted that a lack of empathy and understanding for their MS symptoms led to a loss of social connections, including established friendships. Participants who reported having empathetic social support was viewed as an important aspect for maintaining social well-being. Several participants who discussed having meaningful social connections with others in their social network described people who understood invisible symptoms associated with MS such as fatigue and the need for energy conservation.

Several participants discussed how friends and family that did not ‘understand’ their MS diagnosis and the variability of symptoms they experienced, as well as decreased social networks and feeling fatigued, were noted as resulting in feelings of isolation. Isolation was observed to be challenging for participants, particularly those who described being lone parents, in same-sex relationships, dating, married and divorced. Having a lack of empathy and feeling misunderstood were noted as possible reasons that contributed to feelings of isolation. Isolation may further negatively impact mental well-being, as participants noted feelings of sadness and depression when experiencing isolation. Additionally, participants who were at home full-time due to having a disability from their MS were noted as being more prone to feelings of isolation, particularly participants who became medically retired due to having MS. The use of

technology helped some participants who were experiencing isolation. For example, one participant is a stay-at-home mother who described feeling isolated stated,

Being in isolating in my room, having a dumb little phone and talking to my friends, they don't know I'm in bed. It's awesome. They don't know that I have like, I've had the shittiest day ever just like talking to them. It's really nice. -
Reena

Maintaining social relationships with others takes time and energy and may be a challenge for women experiencing fatigue related to their MS. Several women discussed how fatigue impacted their social well-being as a barrier, and the need for the people and structures in their social network, such as family and friends to be understanding and supportive for their need of energy conservation. Fatigue was described by participants as impacting social well-being by needing to be selective or limiting social interactions and may contribute to less social activity. For example, one participant who had to cease her disease modifying MS medication due to financial restrictions noted she stopped attending events for a social group entitled the 'red hat ladies' since discontinuing her medication; this may suggest that structures such as challenges with personal finances may impede social well-being.

The study's findings revealed that three participants experienced intimate partner violence. The initial onset of MS was noted by one participant as a crucial time that women may experience abuse. The participant disclosed being abused by her former spouse after he became aware of her diagnosis. This may be further concerning for women with MS who have the presence of disability, and/or depend financially on their partners for assistance with managing their health and well-being, such as obtaining costly treatments, disease modifying medications and acquiring necessary assisted devices. Intimate partner violence, including emotional abuse was described by three

participants in this study. All participants in this study who reported any type of intimate partner violence or emotional abuse reported that they were presently separated from their abuser. Abuse was noted as impacting mental well-being and was described by one participant who had been married to her abuser for several years: “I was with my husband thirty years and it was an abusive relationship, so I tried to get out several times.” She described receiving an elective surgery and experiencing a post-surgical complication that required her to be admitted to the intensive care unit, where her husband elected to end her life and described this as:

...I was in ICU (intensive care unit), 50 years old and needed to go on a ventilator, he had told the doctor that, “no she’s 50 years old, she’s had a good life, she has MS, she doesn’t need to be on a vent.” I had given the consent, medical consent to my eldest daughter who’s an RN and she was working... I had given the consent to her and she consented to the... ventilator... after I came out of it and I came home from the hospital, he had taken everything, my bank card, my credit card, I had no access to my drugs that I needed when I had come home from the hospital... I had come home with a social worker because when I was in distress apparently, in the ICU, I disclosed everything about my abusive relationship... I didn’t find any of this out until long after... it hurt, it was like wow, you were going to let me die? Thank goodness my eldest daughter had the capacity and the knowledge and ya... he was willing to let me die, when I confronted him with that when I came home from the hospital he flat out said that I wasn’t supposed to come home. That he had plans for my life insurance... that’s... a tough realization... he wanted me to die so that he could collect my life insurance, this was the man that I thought loved me. And I don’t think he ever did. - Ilana

This participant described having a close relationship with her daughter, which she felt saved her life. Additionally, she was able to have a Registered Social Worker assist her to separate from her abusive spouse. These findings suggest that women with MS may be experiencing IPV but structures accessed by participants to manage their health are not routinely assessing this phenomenon.

Theme 4: Caring to Enhance Wholeness for Women with MS

Active listening and displaying empathy were noted by participants as important aspects for therapeutic relationships in addition to competency for practice. Feeling heard and cared for in an empathetic manner by health care professionals, such as their neurologists, was valued by participants for their health and well-being. Participants discussed that interdisciplinary health care teams, in addition to their MS specialists, may engage in therapeutic care practices involving empathy to support the emotional needs of participants. For example, several participants described not being able to disclose additional information or engage in dialogue about their health with their neurologists due to time restrictions during medical appointments. The importance of empathy was noted by one participant who stated her neurologist and MS clinic staff were, "...great support because I really trust these doctors... they are very knowledgeable... thorough. They give you time and they don't make you feel like, okay, get out." While another patient discussed the importance of understanding, listening and being empathetic towards her. She noted if empathy was absent within a therapeutic relationship, she sought care elsewhere and stated she doesn't ... "go to them anymore and I go find somebody else." One participant who is a Registered Nurse noted she believed MS patients, "just want to feel supported and heard," by their neurologist and health professionals.

The presence of empathy and active listening within the therapeutic relationship with neurologists were generally viewed as an additional bonus to receiving care for their MS. Several participants discussed the most important aspect for their health professionals caring for persons living with MS was having an up-to-date knowledge base and being competent. One participant, who was in an abusive relationship and

needing dietary and financial support to help her manage her health and well-being, noted that her neurologist did not display empathy within their therapeutic relationship. The participant felt the neurologist did not conduct further assessments, such as psychosocial assessments or screen for IPV. She discussed this practitioner as placing an emphasis on her being overweight during each medical appointment for her MS. She noted that the therapeutic relationship between her and her neurologist lacked empathy, as she felt she experienced discrimination for being overweight and was discharged from his care. Additionally, she discussed being refused a referral to another neurologist after no longer being able to afford her medication to treat MS. She described this as:

I think whether it's a neurologist or just a family physician, I think that empathy goes a long way. I don't think that my neurologist is capable of empathizing. I don't think that's something that's taught, I don't think you learn how to empathize, you either have it or you don't and he obviously doesn't. Because I'm not the first patient of his that has felt that way. And not all of his patients have a weight problem. So, for me, he made me feel like I would be in a better place physically if I was thin and maybe he is right. But the way he approached that, wasn't very professional, wasn't empathetic. - Ilana

This finding may suggest that health professionals, including neurologists who practice and approach therapeutic client relationships with empathy may be better able to meet psychosocial needs that are important to their patients. These findings may further suggest that active listening and empathy within professional therapeutic relationships which display a high level of competency may help improve the health and well-being for this population. Lacking empathy may have cultural implications, as noted by one participant who began practicing a traditional medical approach known as Ayurveda and engaged in spiritual practices from her culture and 'health tourism,' where she travelled to India to receive a treatment option that was not provided in Canada. These practices were not embraced by her neurologist. That is not to suggest that all specialists were

viewed as practicing without empathy, and many participants described having limited time in their appointments to address concerns with their health. Furthermore, when participants were noted as having empathetic and caring therapeutic relationships with their health professionals, there was an increase in agency for making informed decisions to manage their health.

Participants who described feeling unheard while engaging in therapeutic relationships with members of their health care team were more likely to experience barriers to managing their health and well-being. This may suggest that health care professionals working in institutions providing care for women with MS, such as MS clinics and MS specialists, may impede participants' agency for managing their health and well-being by dismissing their health needs. This included participants not feeling heard, being dismissed, insulted, receiving incompetent care, as well as reports of gender-based discrimination while engaging with health professionals. Albeit some patients who described feeling rushed at their medical appointments also described limited resources for their MS clinics. For example, several participants noted that they felt rushed and unsupported by members of their health teams. One participant noted that health professionals involved in her MS care have not always been 'patient centred.' She provided an example where her initial neurologist was not aware of newer medication used to treat MS and unwilling to listen to her. As a result, she received a referral to another practitioner. One participant, who was also a Registered Nurse and was previously employed in an upper administrative position in a teaching hospital noted that she felt rushed when seeing neurologists and described this as:

... initially I was quite shocked because... I wasn't used to being dismissed that quickly. I'm used to it now. So I know I go in and if I have anything in particular... it's right there up front cause otherwise I'm not going to have time to

get it said. But it made me angry at first because I wasn't used to that with a family doctor. - Keena

Interestingly, four of the study's participants who described the importance of empathy within the therapeutic relationship were also employed as health care professionals. A few participants described the benefits for seeing a Nurse Practitioner and noted that they were able to spend more time discussing their concerns. Several participants expressed either seeing a Nurse Practitioner or wanting to see a Nurse Practitioner in their MS clinic to allow them to have more dialogue and active roles in their MS care plans to help them manage their health and well-being, and allow for more time to ask questions about their MS symptoms.

Participants discussed challenges of having to act as their own advocate to navigate the health care system. This was described by one participant who, after her initial MS symptom onset, was unable to care for herself or her son she was raising as a single parent. She was actively working as a health care professional with a high level of competency and personal agency for navigating health systems, and described having difficulty acting as her own advocate and experienced numerous barriers to receiving adequate care. This resulted in a lack of continuity of care, confusion, feeling alienated, which impacted her health and well-being. She described this situation in detail:

I was paralyzed. That paralysis stayed with me for about four months actually. So it was visible. I also had... a lot of contract nurses, I also was told there was no shower for me to have, people were so transient in their job assignments. They didn't know the facility that they were working in. So therefore... I couldn't shower. So when I'm bringing this up to say I'd go to the washroom and I couldn't open the door and I know you could see me, but because there were old people, and you know, in my culture... I'm very respectful of the elderly... I get it that there are older people here, but I can't get up off the toilet because... at that time one of my symptoms... was when I would urinate, I would go into a very violent spasm because just the function of urinating was stressful and almost fell off the toilet... I didn't know what was happening and I thought, Oh, maybe I'm just overreacting because these are all health care practitioners and

they're not even responding. So they must think, you know, you'll be able to cope...was very... alienating and confusing. - Cari

These findings suggest that women with MS are not currently having their unique health needs met equally. MS clinics where neurologists are able to actively listen to the participants in an empathetic manner or provide access to patients to see NPs were generally viewed as more favourable for participants' health and well-being, and may have access to greater resources. The findings further suggest that having supportive health teams may enable patients to enact their agency through making informed decisions for their health and well-being, but that this may not be the reality for all participants.

Proposed Figure of the Health and Well-Being for Women with MS

This figure represents the overlap and complex nature that exists with each aspect of well-being that contributes to health, including the continuous and complex nature of agency and structure influencing health and well-being. Additionally, the figure represents the fluidity of how health and episodic disability are experienced by women with MS. Figure 1 illustrates how women with MS experience physical, mental and social well-being and health. This figure utilizes a cyclical pattern to visually demonstrate how women with MS may experience health with some form of diminished physical, mental or social well-being; for example, feeling healthy despite the presence of a disease such as MS or co-morbidities. This is conceptualized with the interconnected circles that represent health and well-being for women with MS, and are depicted with a dashed line to represent the porousness and fluidity of MS as an episodic disability. Factors that were described by participants as promoting physical, mental and social well-being are represented within each respective circle and overlap to demonstrate the relationship that

exists between various forms of well-being i.e., mental and social well-being.

Furthermore, items listed outside of these circles are a representation of the barriers that were described as hindering physical, mental and social well-being. It is important to note that participants described some aspects of well-being while also experiencing barriers to their health. For example, indicating they were healthy despite having MS and co-morbidities such as a cancer or a mental health diagnosis. As the study explored the impact of gender and the lived experience of MS, gender is presented as an overarching construct that may influence all aspects of health and well-being, including what promotes and hinders well-being, as well as the ability to autonomously maintain health and the complex influence of structure and agency and health and well-being. Lastly, although barriers are depicted as being outside the circles representing physical, mental and social well-being and influenced by gender, there may be factors that impede well-being in one, two or all three domains. For example, isolation may negatively impact both mental and social well-being, and may additionally be affected through physical well-being; for example, factors such as physical MS symptoms like pain and fatigue.

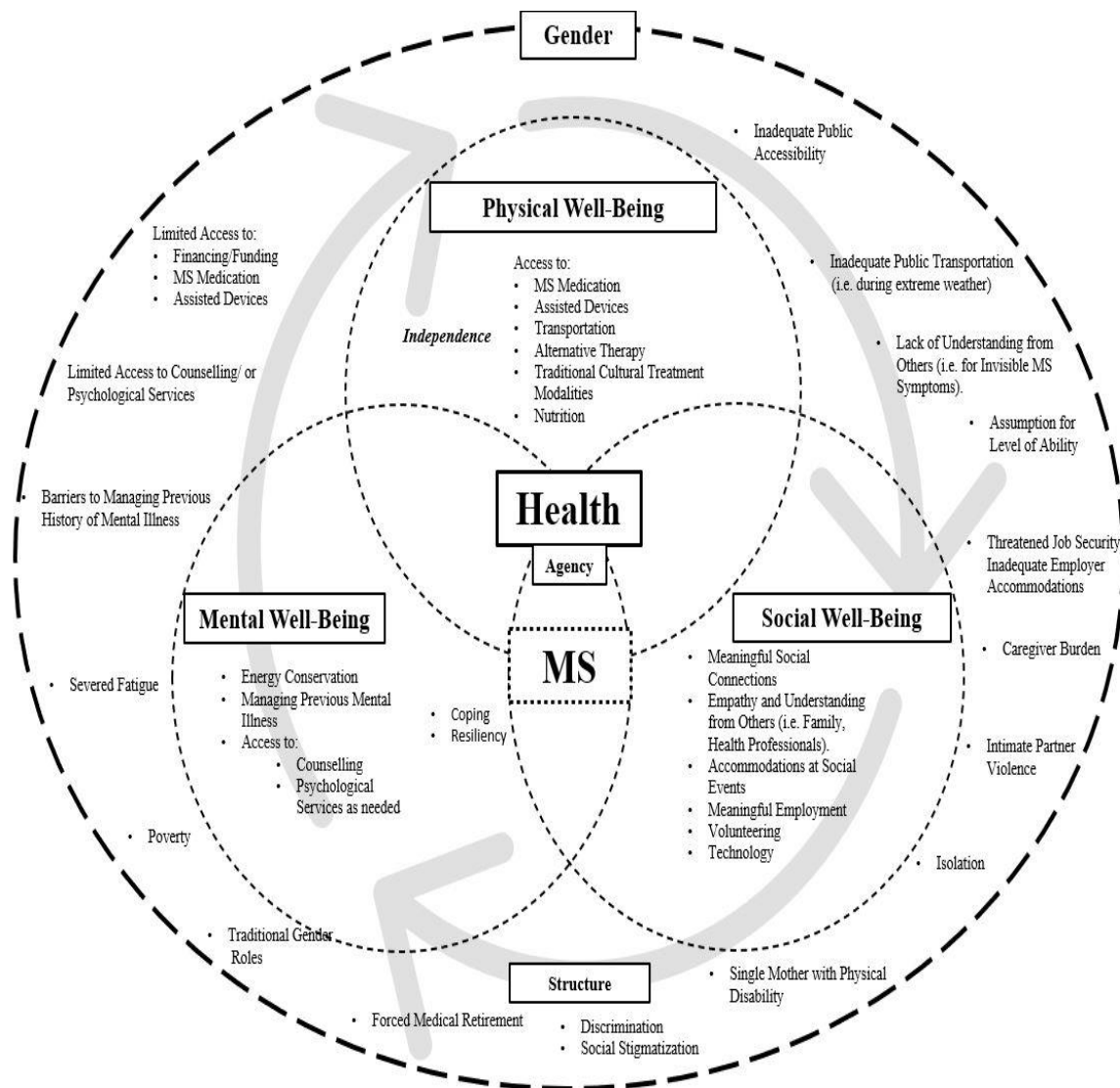


Figure 1: Health and Well-Being for Women with MS

Discussion of Findings

In this analysis, the exploration of the lived experience of health and well-being for women with MS was explored and revealed aspects for how gender influences the health of this population. These findings expand on the knowledge in existing literature that women with MS may experience social challenges such as changes to roles at home and work (De Villiers, 2004; Fraser et al., 2002; Strober & Arnett, 2016). Care plans should be individualized for people with MS and include preferred treatment modalities,

such as holistic therapies evaluated for their effectiveness like cannabidiol oil for muscle spasms, cognitive function and improved sexual function (Patel & Feinstein, 2017), modified exercise programs (Burscka et al., 2014; Fasczewski et al., 2018; Florindo, 2014; Guilamo et al, 2018; Hunt et al., 2014; Kalron et al., 2018; Motl et al., 2018; VanRuymbeke & Schneider, 2013; White & Costellano, 2008), and mindfulness or meditation (Kolahkai & Zargar, 2015; Pagnini et al., 2019; Senders et al., 2014; Spitzer & Pakenham, 2018). Similar findings were reported by Farra (1997) who reported women with MS want to make decisions for multi-optioned treatment plans that includes alternative treatments for their MS. Some foundational knowledge exists pertaining to how women with MS adjust, cope and develop resiliency with an MS diagnosis (Alford, 2017), but the literature does not specifically explore how this population experiences health and well-being as defined by the WHO (2014) while living with MS.

Findings from this study offer insight as to how having the ability to express agency when accessing structures promotes health and well-being for women with MS, and highlights barriers to health and well-being for this population within a Canadian context. Agency may intersect with various structures, such as social class and gender, with women experiencing disability reportedly experiencing less agency, especially with regards to mental well-being (Cockerham, 2005; Cockerham, 2013; Tony & Erna, 2006; Tutty et al., 2017). Participants who expressed having the ability to enact agency for preferred treatment options, including access to expensive MS medications, and having adequate personal finances to purchase accessibility devices such as handheld motor vehicle controls or renovate owner-occupied housing to accommodate any physical limitations, were noted as being more likely to experience feelings of health and well-being. Participants who described experiencing health and well-being were generally

highly educated, employed full-time or medically retired from high-paying positions and/or had adequate financial support from their families. Similarly, well-being has been previously explored by Olsson (2010; Olsson et al., 2010) who found that women with MS who were employed and had adequate resources were more likely to find meaning in their lives and experience well-being.

Conversely, the present study's findings demonstrated that women with MS who are unable to employ agency for preferences when access structures to manage their health subsequently experienced barriers to various aspects of well-being and health. For example, some participants noted aspects of physical, mental or social well-being while also experiencing barriers within one or more domains still indicated they were "healthy." This aligns with findings from Huber et al (2011) who suggest that some aspects for well-being, such as social and mental well-being, may be interconnected. Social and mental well-being were largely focused on access to finances which resulted in limitations for accessing preferred and medically necessary treatment options, lifestyle factors such as access to healthy food options and modified exercise classes for women with MS or disabilities. Women with disabilities in Canada may be more likely to live below the low-income cut-off (LICO) level as recent statistical measurements in Canada do not account for medications such as those used by this population to treat MS, and non-insured disability devices such as canes, walkers or wheelchairs (Council of Canadians with Disabilities, 2013; Statistics Canada, 2009). This is especially problematic due to MS being an episodic disability that may pose barriers to receiving supportive funding through the Ontario Disability Support Program (ODSP). This aligns with research conducted about women with episodic disabilities as there is a noted disparity for meeting eligibility criteria to receive disability funding as some women may

be viewed as “not being disabled enough” (Lightman, et al., 2009; Smith-Carrier et al., 2020; Vick, 2007; Vick, 2011; Vick 2014). Women with episodic disabilities fall between categories of either being disabled and “unemployable” and abled or “employable,” and as a result are at a heightened risk for experiencing poverty and therefore barriers to health (Chouinard & Crooks, 2005). Experiencing inequities such as poverty were noted in the findings as being further compounded when experiencing barriers to expensive disease modifying therapies for participants who had expensive co-pays for insurance or were forced to pay out-of-pockets expenses due to a lack of funding. Although in Ontario there are the Ontario Health Insurance Plan and the Trillium Drug Program, but the former does not cover medications used to treat MS and the later was noted by participants as having a challenging application process and restricted eligibility criteria. However, the Trillium Drug Program, as noted in the literature, is expected to continue to expand expenditures for catastrophic drug coverage for expensive drugs; which is the category that medications used to treat MS fall (Tadrous, M., et al, 2018; MS Society of Canada, 2021).

Access to disability funding and having inadequate provincial government funding were noted as a major barrier for participants to adequately manage health and well-being. The lack of adequate government funding impaired several participants’ access to medically necessary medication to slow the progress of their illness, as well as created financial strain when needing to pay for necessary assisted devices with limited personal finances. This is congruent with research conducted for women living with episodic disabilities that demonstrate this population faces challenges with barriers to employment, and are often discriminated against for funding eligibility which subsequently results in disparities and inequities, such as poverty and decreased agency

(Lightman et al., 2009; Smith-Carrier, 2020; Vick, 2007; Vick 2013; Vick, 2014).

Current provincial leadership has released a new vision for social assistance that is targeting people with disabilities and receiving funding through the ODSP to ultimately work towards employment and independence (Ontario, 2021b). This includes a proposed merger of the Ontario Works and the ODSP programs into one streamlined new program, Employment Ontario (Ontario, 2021a). The erosion of these programs creates a disparaging and bleak future for people with episodic disabilities in Ontario, as this further promotes systemic discrimination towards this population and this proposed change violates international human rights laws (Smith-Carrier et al., 2017; Smith-Carrier et al., 2020).

The study's findings revealed that some participants' mental well-being was impacted over the access to homes in Ontario that inadequately meet accessibility needs for people with disabilities, such as limited availability to purchase or rent one floor homes that may have adequate room for wheelchairs. Affordable housing in Ontario has been a documented problem that has led to a reported housing crisis (Centre for Equality Rights in Accommodation, 2020; Homeless Hub, 2018). This may further impact women with disabilities as they may be more likely to live alone, be lone parents, as well as act caregivers for elderly parents (Burlock, 2017). Even participants who were currently stable in relation to MS symptoms and reported high level of present function and ability, noted future fears for their trajectory with MS and how this relates to future housing markets in Ontario. In addition to a housing crisis in Ontario, the spatial time context for this study was during the winter months, and this geographical region experiences extreme weather in both the summer and winter months. This was reported in Canada for people with physical disabilities as experiencing challenges with mobility and an increase

in social isolation during the winter months (Lindsay & Yantzi, 2014). This may further complicate the health and mobility needs of women with MS through limited access to clear public sidewalks and public transportation, which can further exacerbate feelings of social isolation during the winter in Southwestern Ontario.

Current literature suggests that women with disabilities are more likely than women without disabilities to experience IPV (Ballan & Freyer, 2019; Ballan & Freyer, 2020). This may be further complicated for women with MS who are physically dependent on their spouse or partner for care, financially dependent on spousal income, and private health benefits for accessibility or medication needs as noted in the analysis for this study. This may be especially true for women who are receiving disease modifying therapies that may cost upwards to 55K per annum that are not covered through OHIP who do not have financial independence from their abusive partners (Ministry of Health and Long Term Care [MOHLTC], 2020a, 2020b; MSSC, 2020, Ontario, 2020). As per the author's understanding, this study is the first of its kind to identify how IPV may be experienced for women within MS, further investigation is needed specifically pertaining to this to better understand how this population experiences IPV.

Women with MS experiencing a decrease in mental well-being also described feelings of isolation and decreased social well-being. Mental well-being and social well-being were noted as being interrelated in the literature by Bassi et al. (2019) and Wojcicki et al. (2014). Isolation with this population may be a silent epidemic, including participants who appeared to have robust social supportive connections, such as large numbers of friends and family but may not be feeling understood for invisible MS symptoms and further impacts mental well-being (Davis et al., 2021). Invisible symptoms

are a common experience for women with episodic disabilities and may cause distress as invisible symptoms may not be viewed as valid by others (Vick, 2013; Solomon et al. 2018). Participants described at times not having empathetic support or understanding for emotional needs with MS which resulted in feeling isolated and impacted mental well-being. This was further complicated when participants were experiencing financial strain, engaged in single-parenting or caregiving for their older adult parents with the presence of physical disability. Graziano et al. (2020) examined women who are mothers with RRMS and have a mild to moderate disability and found that women who were newly diagnosed with MS who had children under the age of three were more likely to experience depressive symptoms and report less satisfaction with their self-identity. Similarly, Fong Sit et al. (2020) found that people with disability acting as informal caregivers may be prone to caregiving burden and experience feelings of depression, anxiety and stress. Although there is no direct treatment for isolation, utilizing MS services such as peer-to-peer support may help alleviate feelings of isolation through the creation of empathetic linkages for the unique challenges and experiences faced by women with MS as revealed in the study's findings. Participants in the study were noted to find meaning in sharing their experience with MS to others with this illness, which created a sense of belonging, validation for individual experiences with this disease and having someone to empathize with, and thus lessened feelings of isolation and increased feelings of social well-being. Invisible symptoms with MS should be assessed and validated by health care professionals to help support mental well-being for people with MS (Rieckmann et al., 2018). Additionally, having empathetic interprofessional care that validates invisible symptoms associated with MS may increase patient's confidence and improve therapeutic relationships (Rieckmann et al., 2018)

The study revealed how having MS may make it challenging for women to stay in the workforce, despite most participants reporting that they desired to remain employed. Interestingly, several participants noted how this impacted their mental well-being during situations such as changes in health status and the impact this had with their employment, i.e., progressing with MS symptoms or becoming medically retired and experiencing issues with self-identity. The latter may possibly be influenced by gender, as women in this study who were medically retired largely described working in services fields that required physical labour such as nursing, social work, personal support work, food and retail services which Diekman et al. 2010 describe as traditional occupational roles for women compared to male dominated fields such as science, technology, engineering and mathematics (STEM) (Diekman et al., 2010). This finding may suggest that traditional employment for women, such as care-oriented careers are devalued (Block et al., 2018) and lack accommodations for women with MS who are experiencing physical disability. Leaving the workforce due to becoming medically retired from MS was noted as detrimentally impacting the mental well-being for this population, such as feelings of depression, isolation, loss of self-identity and substance abuse. This was similarly reported by Strober and Arnett (2016) who found that women with MS leaving the workforce for medical reasons may be prone to utilizing maladaptive coping mechanisms, such as problematic substance use. This may further highlight systemic issues in policy and government through a lack of consideration for how women with disability may require accessibility needs in the workplace to maintain meaningful employment as employers may not be adequately accommodating for episodic disability (Lightman et al., 2009; Vick, 2013; Vick, 2014). Engaging in volunteer roles that utilized previous knowledge and expertise, such as peer to peer support through the MS Society

was demonstrated in the findings to provide a sense of meaning and purpose, therefore improving mental well-being for this population. This was similarly reported in findings from Kulik (2019), who evaluated people living with disabilities who volunteered in Israel and found that participants subjective well-being was enhanced through a reported increase in self-esteem and meaning in life.

Perceived discrimination from health professionals towards women with MS who are experiencing obesity and issues pertaining to their body image was noted in the findings. This aligns with a study that examined weight bias and discrimination towards patients with obesity in 400 physicians throughout Canada, including how the physicians viewed obesity in their patients (Alberga et al., 2019). The authors found that 18% of respondents discriminated against patients who were obese and noted their feelings towards this population as 'disgusted'. Furthermore Dietz et al. (2015) noted that physicians were more likely to spend less time with obese patients. The findings in this study indicate that neurologists and health care providers treating MS patients may be better able to meet the health needs for women with MS who are obese through careful consideration of any personal prejudice towards obesity. Ward et al. (2013) reported that people with MS who have the presence of disability may lose control for some aspects of bodily function and therefore experience weight gain.

Health professionals may better serve this population through engagement with empathetic therapeutic relationships that promote interdisciplinary care and respecting the autonomy of the person receiving care through careful examination and consideration for their personal health goals (CNO, 2006; RNO, 2002). For example, women with MS affected by medical retirement may benefit from support groups or individual counselling to help lessen the impact of potentially losing their self-identity and potential

decrease in mental well-being. The role of health professionals as an advocate may help ameliorate the living standards for this population with issues such as poverty, isolation or IPV that may uniquely effect women with MS (Annan & Bates-Jefferys, 2019; IPV Health, 2020, O’Doherty et al., 2014). Universal screening for IPV is currently recommended for all health care professionals to identify potential abuse and provide support and resources to women experiencing IPV (Registered Nursing Association of Ontario [RNAO], 2005; Todahl & Walters, 2009; United Nations, 2021; WHO, 2002). Promoting interdisciplinary care, such as Nurse Practitioners, psychotherapy for addressing psychological components of eating and developing healthier coping mechanisms as well as dietary referrals to help support healthy nutrition for women with MS, may enhance feelings of health and well-being. Additionally, it was noted in the findings that neurologists may be ‘rushed’ to get through patient interactions and the role of Nurse Practitioners (NPs) working within MS care teams were found to have the time to actively listen and engage with participants needs and may be well situated to assist in this area. Nurse Practitioners are noted in the literature as providing high standards of care and can provide significantly longer consultations for their patients when utilized within health care teams (Smits, 2020; Venning et al., 2000). Thotam and Buhse (2020) support that the use of NPs in MS clinics result in positive health care outcomes for people with MS such as a higher level of patient satisfaction.

Limitations

Findings from this study reflect a small sample of women effected by MS who were well-educated, mainly lived in city centres and accessed MS organizations resources both in-person and online; the latter suggesting a high level of literacy and access to finances to cover private internet costs. This may suggest that findings are limited and

may not apply to women affected by MS with low levels of literacy or education and their experience for health and well-being. Additionally, the sample consisted of 23 women with MS, each with unique experiences of their health and well-being with MS; the findings would possibly be different with a different pool of participants. Data was collected over a relatively condensed geographical area in southwestern Ontario over a short duration of time during the winter months just prior to the first COVID-19 pandemic lockdown. As collecting data for any phenomena is influenced by time and space (van Manen, 1990, 1997), further examination of this phenomenon during various time points throughout the calendar year and warm weather may further illuminate more in-depth understanding for current trends for health and well-being with this population. Several participants noted that extreme cold weather impacted their MS symptoms, therefore it may be possible that other women who may have been interested in this study at the time of recruitment may have felt physically unable to do so.

Additionally, the study sample included representation primarily from woman of European-Canadian ancestry. Two participants who were women of colour and identified as being bi-racial- being 'black' and 'white,' and 'Guyanese' and 'East-Indian.' Therefore, this study was unable to represent members of other ethnic groups, such as women who self-identify as Indigenous or women who are newly immigrated to Canada who are affected by MS. Due to the limitations with ethnic and racial diversity, inferences cannot be drawn in a more fulsome manner from this data as to how culture from an ethnic and racial perspective intersects with health and well-being for this group of participants or the broader population of women living with MS.

Conclusion

Experiencing health and physical, mental and social well-being without barriers to one's ability to exercise personal agency while engaging with social structures. The health of women with MS was noted as being impacted by agency and structures within society, such as level of education, employment status, finances and provincial laws and restrictions to disability funding in Ontario; how this fully intersects with the health and well-being for women with MS requires further research to better understand these relationships. The conceptualization of health and well-being for women with MS is noted in Figure 1 and begins to illuminate how gender and structures impacting people with MS intersect with the experience of health. Future research with mixed methods approaches that utilize critical methodologies, such as critical feminism or critical disability approaches to further understand these complex relationships, will help build upon the findings presented throughout this dissertation. Furthermore, how government policy and laws pertain to women with MS and episodic disability may require further exploration of issues such as the impact of poverty, discrimination, employment, accessible housing and access to funding for MS medications and assisted devices. Health care professionals caring for women with MS should reflect upon any biases towards women with MS, such as personal feelings towards obesity and therapeutic communication techniques that convey empathy. For example, practitioners should consider asking themselves reflective questions with their current practices, such as: am I providing the time, empathy and attention for this population to adequately address their health concerns from their perspective? And: Am I routinely advocating for patients to receive funding or screening universally for IPV for my female MS patients? Additionally, health care providers should consider advocating for equitable treatments,

medication and accessibility needs for women with MS; this includes advocacy to expand programs such as the ODSP to be more inclusive for episodic disabilities and for a more humane system of income distribution to help provide adequate funding for secure accessible housing.

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CHAPTER 6

FUTURE DIRECTIONS

This chapter will provide a summary of the study's findings and explore implications and recommendations to further support the health and well-being of women with MS. Secondly, implications and recommendations will be advanced for policy, practice, education, and research.

Summary of the Findings

The findings reflect that women in this study who are living with MS in Southwestern Ontario experience optimal health and well-being when they are able to enact personal agency when engaging with social structures that influence their health and well-being. This includes the ability to enact agency when engaging with economic structures such as securing adequate personal finances through employment or government support; securing physically accessible housing; adequate accessibility in public spaces, such as when accessing public bathrooms or transportation; and health care institutions, such as MS Clinics, Neurology departments in hospitals, and MS Societies. It is important to note that not all participants experienced personal agency when engaging with each social structure; conversely no participants experienced a complete lack of agency, but rather had a complex and possibly changing dynamic with multiple social structures at any given time. Meaning that some participants reported having agency when engaging with social structures such as family or marriage, but often reported inadequate accessible housing, access to finances for costly medications to treat MS and accessibility devices not covered by the provincial government. Such intersecting and potentially compounding nature of issues with social structures ultimately influenced

participants' agency and decision making surrounding personal preferences for managing their life situations while living with a complicated disease process.

As MS is a potentially progressive illness, an increase in financial burden was noted by numerous participants who were experiencing problematic physical symptoms as the illness worsened over time. This was further complicated through the presence of disability which was noted as impacting engagement in paid employment. This included having to take time off work due to exacerbations of MS symptoms or receive medical treatment for MS, having perceived threats to job security if disclosing their diagnosis and being forced into an early medical retirement against participants' own choosing. Employment was further influenced by gender. For example, a majority of participants who were employed currently or prior to having progressive MS symptoms, reported working in areas that are considered 'traditional' or conventional work for women like nursing, social work, personal support work and jobs within service industries. Furthermore, participants noted that MS impacted their social well-being and overall health if engaged in traditional gender roles such as motherhood or caregiving for older adult parents. MS was viewed as potentially adding another layer of complexity to these roles if one was experiencing physical or cognitive symptoms, and created more barriers for participants in the management of their health and well-being.

Major themes included "foundations of vitality for women with MS", "enhancing wholeness for with women MS", "obstacles for women with MS", and "caring to enhance wholeness for women with MS". The study's findings suggest that enhancing this population's personal agency, when engaging with social structures, may better serve the health needs of women with MS. The aspects of physical well-being, mental well-being and social well-being contributed to participants' overall feelings on a dynamic

continuum of being healthy or unwell. For example, participants who reported having less mental well-being, such as having an exacerbation of mental illness, were less likely to report feelings of social well-being. There was a connection noted between participants who reported experiencing physical well-being, including having access to medically necessary medications to treat MS or accessibility devices and experiencing feelings of social well-being. For example, having the ability to engage in secure paid employment and social gatherings with friends and family. The intersecting nature of gender, agency, social structures, and aspects of well-being has important implication for nursing policy, practice, research, and education.

Implications and Recommendations

This study revealed a complexity of issues related to women's experience of living with MS which have implications for nursing and allied health care professionals. More consideration and action needs to be given to how women with MS can further enact personal agency within the context of social structures that impact their lives, and health in particular. An increase in attention from public sectors that oversee policy on adequate housing, access to finances, medication and social supports for women living with MS and experiencing disability for this population was demonstrated as necessary through the experiences shared by participants. The optimization of health may occur for women with MS if they receive holistic, individualized care that validates their lived experiences and recognizes the ways in which gender, as a determinant of health, and social structures influence health and well-being.

Policy

The findings highlight that policies impacting women with MS may not always substantively consider the dynamic relationship between womanhood, disability, and

social structures, such as the financial burden of having MS. This study therefore holds important information for decision makers who can influence policies. For example, two participants disclosed narrowly missing the cut-off point for disability insurance and were disqualified for receiving adequate financial assistance from the provincial government. There was no consideration for the large sum of money they would have to spend annually to manage having MS with regards to both the cost for medication that is not covered by the Ontario Health Insurance Plan (OHIP), as well as high costs to renovating their homes to accommodate accessibility needs. The World Health Organization [WHO] (2019) indicates that adequate access to finances is an integral aspect for managing health. However, Ontario's current strategy of financial support for people with disability through the Ontario Disability Support Program (ODSP) should consider that the further erosion of this program could be detrimental to the health and well-being for this population by even further decreasing access to medically necessary financial support (Ontario, 2020; Ontario, 2021a; Ontario, 2021b; Smith-Carrier et al., 2017; Smith-Carrier et al., 2020). In addition, provincial government employees and health care professionals working with women living with MS should advocate for stronger and more comprehensive financial support to provide equitable access to health care for this population, as remaining in paid employment was demonstrated as challenging for participants with more advanced illness and disability. Furthermore, based on the study findings, more consideration needs to be given for financial support and access to accessible transportation, childcare needs, housing and expensive medications medically necessary to treat MS symptoms. Issues pertaining to economic social structures for people living with episodic illness and disability in Ontario, such as women with MS, may have these issues ameliorated through the reintroduction and evaluation of the

Ontario Basic Income Pilot (OBIP) program (McDowell & Ferdosi, 2020). According to McDowell and Ferdosi (2020) having access to a basic income support program was beginning to demonstrate promise for people with disabilities in Ontario to gain access to secure accessible housing, promote adequate nutrition and reduce access to emergency care services and may provide a prove to be a more equitable approach for income distribution in comparison to the current ODSP program.

Further implications for policy related to the participants' experiences is that accessibility is not universal throughout Southwestern Ontario and often inadequate for this population, including the need for improved accessibility in public areas such as public transit, bathrooms, hotels, and hospitals. The findings highlight that municipal policy changes can result in designing accessible public spaces. Decisions on such changes should be informed by inclusion of the expertise of people with disabilities as municipal policy committee members. In this study, a participant had volunteered on a municipal committee that had a mandate of 80% of the volunteer members on the committee must have the presence of a disability. The purpose of this committee was to amplify the voices of people with disabilities with an aim to ultimately meet accessibility needs in public spaces that may have otherwise gone unnoticed. If more municipalities instituted such key committee membership, such inclusionary practices might serve to advance public policy changes even further.

Nursing and Allied Health Care Professionals

Findings from the study revealed that women with MS may not be receiving adequate health care to manage their health and well-being, with many participants reporting a lack of consideration by health care professionals as to how their unique needs impact their overall health. For example, the needs of women engaging in

traditional gender roles (such as caring for children and older adult parents and experiencing exacerbations of MS related fatigue), who experience problematic MS symptoms (such as fatigue and chronic pain), might not be adequately addressed by the current health care system, such as not assessing barriers to social structures like financial constraints or secure housing. Nurses and health care professionals should help support women with MS by advocating for greater personal agency to enable women to make decisions for their health and well-being. In doing so, this may enhance their ability to gain and/or maintain control of the management of their illness. Participants who discussed experiencing adequate support for their health spoke strongly about being involved with health professionals in ways that enabled them to make autonomous decisions for their own well-being without being impeded by barriers to personal agency. They also experienced empathy within their professional therapeutic relationships with their MS care teams.

The role of health care professionals is to support patients to obtain optimal levels of health. However, it was noted in the study's findings that this population is currently being underserved by their health care teams. Health care professionals, including nurses, should advocate for patients to alleviate barriers that prevent patients from experiencing situations that prevent health and well-being, including the assessment of any potential threats to safety. For example, the findings suggest intimate partner violence (IPV) is not readily assessed by their MS specialized health care teams, although several participants noted seeking regular MS care exclusively. Furthermore, the study revealed that the financial burden of MS may further complicate the lives of women with MS who experience IPV to stay in, or prolong unhealthy relationships, to maintain medically necessary treatment. This may be particularly concerning for women who require

physical support from their partners, however, more research is needed in this area. Health care professionals working with this population must consider the intricate and often complicated role MS has on the individual's physical, mental and social well-being, including universal screening for IPV. Women with MS should be included as a partner in their care with their MS care teams regularly following universal practices for assessing IPV, as well as assess for any barriers to social or financial disparities (RNAO, 2012). Through the careful assessment of barriers to health and well-being such as assessing for IPV, health care professionals may provide crucial information on available community supports to alleviate the risks of potentially harmful situations and promote safe alternatives. Using these supports, women with MS experiencing IPV may enact their personal agency to manage their own health and well-being.

Additionally, in this study, women with MS may have varied access to health care professionals and require interprofessional teams to best support their health needs. If patients' needs are not attended to from a holistic and interprofessional perspective some women with MS may not get the time and attention to adequately or equitably manage their health and well-being. For example, MS clinics that are restricted to providing care exclusively from a neurologist with a high patient ratio may not have the time to assess for structural barriers to health and well-being. Interprofessional care teams that have the ability to refer to physiotherapy, registered massage therapists, registered dietitians, registered social workers, Registered Nurses and Nurse Practitioners who can work alongside neurologists, may be able to spend more time listening to patients' needs. This may include assessing for structural barriers such as disparities with social supports or financial constraints that may require assistance to complete troublesome funding applications that were identified in the study as both challenging and time consuming for

participants. Interprofessional teams that support women with MS may have the ability to enable this population to further enact personal agency when accessing social structures and improve their health and well-being. For example, Nurse Practitioners were noted as being highly beneficial to answering participants questions for their health in addition to neurologist's specialized knowledge, as participants felt Nurse Practitioners spend more time with them listening to and attending to their health needs. Health care professionals caring for women living with MS should be aware that they may be the only service provider that is regularly accessed and that the impact of MS is complicated and multifaceted for each individual. As such, the quality of care provided by health professionals could be transformative in nature instead of insufficient or ineffective.

Education

The study's findings indicate that health care professionals engaging in empathy with women living with MS are able to establish trusting and meaningful therapeutic relationships that provide holistic and thorough care that supports women's health and well-being. Through having empathetic therapeutic relationships, women with MS have the ability to express personal concerns, for example barriers to personal agency and issues with social structures. When receiving care that is not empathetic, this population may feel rushed and dismissed with their care, with crucial aspects for the health and well-being going unnoticed by their health care teams, such as incidents of IPV. Educators who are engaged in the professional development of future health care professionals, such as nursing, social work, or medical students, to care for this population should emphasize the importance of empathy to build trust in therapeutic relationships. Additionally, the study's findings suggest MS clinics may not be fully utilizing interprofessional care. This may be interpreted as a lack of understanding for

roles within the health care team that may benefit this population's ability to manage their health and well-being. Educators, including those in clinical practice settings, should emphasize interprofessional education that uses a trauma and violence-informed approach to care to ensure that there is an understanding of professional roles and how they provide supportive care for patients experiencing disparities (iHeal, 2021; Stokes et al., 2017). Interprofessional education and practice has been demonstrated to improve patient outcomes through the inclusion of competencies for enhanced communication and patient-centered care (Bainbridge et al., 2010; Khalili et al., 2013; Metersky et al., 2021, Mink et al., 2021). Learning how to support women with MS who are experiencing IPV will provide the necessary understanding for health care professionals to provide evidence-informed support to remove women from potentially dangerous situations and improve their health and well-being.

Lastly, the findings demonstrate that educators should refrain from teaching about episodic disabilities, like MS, from an exclusive bio-medical approach that gives primacy to pathophysiology of this disease. Although it is crucial that learners develop a robust understanding of physiological aspects of MS, that is only one aspect of the woman's life with MS. The findings indicate that further understanding is necessary about the ways in which gender and other determinants of health, disability, and social structures intersect to influence health and well-being of this population. It is proposed that when educators teach from this perspective, then students in health-related professional practice programs may better understand and practice the role of advocacy and assess for issues pertaining to health equity and support the attainment of women's health care needs as they live with MS. Furthermore, the development of a trauma and violence-informed approach best practice guidelines for health care professionals working with people who have

episodic illnesses and disabilities would assist educators in having appropriate material to avail to support their own knowledge development, which in turn could be used with learners in both theory and practice-based courses.

Research

MS researchers need to consider the dynamic and individual nature of MS to create more robust evidence to inform holistic care. It became evident throughout the undertaking of this research that a bio-medical model dominates the discourse in MS research and care practices based on such research, which may not always take into account the lived experience of MS. This includes an over-emphasis on research that examines women with MS through key outcome measures that are bio-medically focused such as number of births or pregnancy and MS. Such research lacks in-depth and contextualized input from those living with this illness. Furthermore, having a dominate bio-medical approach to how MS research is funded and disseminated may limit the type of information available to health professionals and those living with MS. Further, it has been observed that many international conferences focused on MS give primacy to accepting abstracts based on research from a bio-medical research approach. This is not being noted to imply that bio-medical research is unimportant to the health of this population, but such a heavy focus in this type of research can serve to negate plurality in research approaches, and ultimately creates a vacuum in the literature beyond what is known around MS from a medical treatment and curative perspective. In maintaining this status quo people affected with MS may have less support from health care professionals, because they may potentially have less scholarly evidence available to inform and improve upon current understanding and health practices.

There is currently a gap in the literature about power imbalances women with MS experience and this requires further research from a critical lens about the nature of living with MS and how this intersects with being a woman and experiencing disability. For example, further investigation is needed about how issues related to financial burdens, employment, housing, and aspects of unpaid caregiver responsibilities for older adult parents and young children. A mixed methods approach utilizing critical feminist theories, critical disability theories and perspectives could be used to further explore how agency is employed by women living with MS while they are engaging with a multitude of social structures. Such research could provide a more robust foundation of scholarly evidence for this population. The study's findings warrant that further foundational research using qualitative approaches is necessary on a national level, while also considering women with MS who are racialized, newly immigrated to Canada or living in rural areas as these were gaps not found to be addressed in the known MS-based research literature. Lastly, future research that considers a trauma and violence-informed approach to care may help illuminate how concerning issues like IPV affect women with MS and provide a stronger foundation of evidence to further inform healthcare practices.

Conclusion

This was the first known study within a Canadian context that addressed the health and well-being for women with MS; this is despite the issue that women are being diagnosed with MS at a ratio of 3:1 as compared to men, and are living in a country with one of the highest incidences for MS globally (Multiple Sclerosis Society of Canada, 2019). Consideration for managing the health and well-being of this population needs to occur from a holistic perspective that promotes personal agency for women to make their own informed-decisions and such agency should be supported by their health teams.

In Canada, the primary objective of health care is to promote, protect and restore the mental and physical well-being of Canadians and to enable access to health services without barriers to finances (Government of Canada, 2021). However, this study found that women living with MS experience a multitude of barriers to achieving optimal health and well-being within the context of MS. This study revealed several concerning gaps with addressing the health and well-being for women with MS living in Southwestern Ontario that demonstrate this population is currently being underserved. Treatment grounded solely from a bio-medical approach may unintentionally promote hegemonic practices that may not consider the whole person. Those serving this population should view people with MS as having mastery over their illness to promote health and well-being. However, the findings indicate that some current medical practices may be hegemonic and may not currently be supporting this population holistically, but is rather focusing on medical aspects of MS. To amend this, a proposed model to support the health and well-being for women with MS is demonstrated below in Figure 2.

The figure represents a pyramid, where the top peak represents women with MS and is supported from all aspects beneath it. The circle surrounding the figure is representative of a person's agency, this is experienced at every level of the model and is enacted in various ways. The bottom row is comprised of people in professional supportive roles for MS and eliminates the current hegemony within existing bio-medical structures. These supportive roles act as a foundation, similar to a structure of an actual pyramid and directly influence the laws, policies, health practices, education, research and social structures to advocate and support personal agency to promote the overall health and well-being for this population. Through careful redirecting of power, health care professionals and those supporting women with MS can increase personal agency to

navigate necessary social structures and play a key role in making decisions to support their own health and well-being.

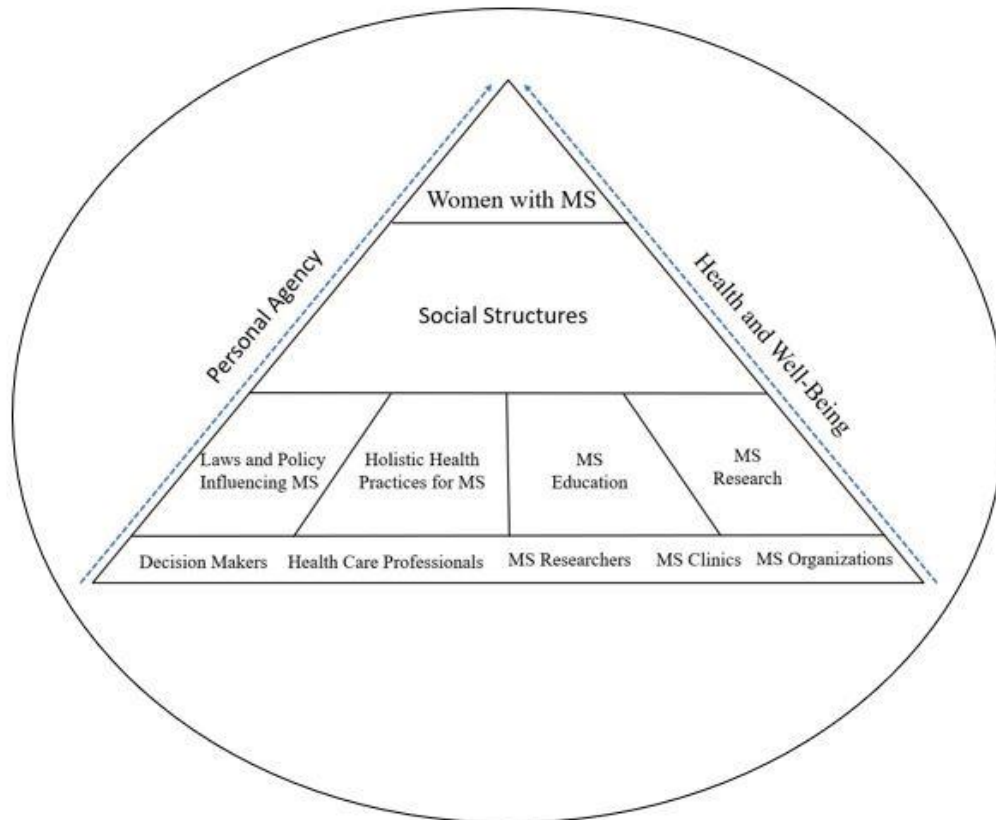


Figure 2. Model for Promoting the Health and Well-Being for Women with MS

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Appendix A: Letter of Information

Study Title: Understanding the Lived Experience of Health Through the Exploration of Well-being of Women with Multiple Sclerosis in Southwestern Ontario

Principal Investigator and Graduate Student's Dissertation Supervisor:

Yolanda Babenko-Mould, RN, BScN, MScN, PhD, Associate Professor and Associate Director, Graduate Programs, Arthur Labatt Family School of Nursing, Room 2311, FIMS & Nursing Building, Western University

Graduate Student Researcher (GSR): Jennifer Howard, RN, PhD Candidate, Arthur Labatt Family School of Nursing, Western University

Dear Potential Participant:

We are seeking to recruit women living with multiple sclerosis (MS) who are willing to partake in a research study exploring their health and well-being in regard to MS. Information regarding this study is listed below. Once you have reviewed this information, and if you would like to participate, please respond to the GSR, Jennifer Howard via email to [REDACTED] or by telephone to: [REDACTED] [REDACTED]. If you have any questions or concerns regarding this study, please do not hesitate to contact either of the study team members with the Arthur Labatt Family School of Nursing, Western University. This study will fulfill requirements for Jennifer Howard's PhD.

1. Invitation to Participate

You are being invited to take part in a research study because you are a woman who has been formally diagnosed with MS and may richly contribute to building upon what is known about a woman's experience of health and well-being when living with MS.

2. Purpose of the Letter

The purpose of this letter is to provide you with information required for you to make an informed decision regarding participation in this research.

3. Purpose of this Study

Although there has been a significant amount of research on the quality of life for people with MS, little research has been conducted about how women specifically experience health through the exploration of well-being in the presence of this illness. The purpose of this research is to provide a greater understanding of how women with MS may experience their health by better understanding their physical, social and mental well-being.

4. Inclusion Criteria

Inclusion criteria includes the ability to fluently speak and read the English language, the individual self-identifies as a woman, is over the age of 18, says that they have been diagnosed with MS, has the ability to make decisions independently- for example signed informed consent, resides in Southwestern Ontario, consents to being audio-recorded for the interview, and consents to use of de-identified data for future studies.

5. Exclusion Criteria

Exclusion/ineligibility criteria for the study includes: not-fluent in speaking or reading the English language, less than 18 years of age, has not informed the GSR about being diagnosed with MS, does not make decisions independently- for example has a substitute decision maker or legal guardian, does not reside in Southwestern Ontario, self-identifies as a gender other than a woman, does not consent to be audio-recorded for the study interview, and does not consent to use of de-identified data for future studies.

6. Study Procedures

You may contact the GSR by email or telephone and the GSR will verify if you meet the study's inclusion criteria. If you agree to participate, you will be asked to attend an interview in-person, by telephone, or via Zoom, depending on your preference. The interview will take approximately 60-90 minutes to complete. I will be asking you about how MS has influenced your overall health through understanding your experience of physical, social and mental well-being. The interview will be conducted by a method (i.e., phone or Zoom) or location (in-person), time and date convenient to you and the study investigator. Immediately prior to the beginning of the interview, this letter of information and consent form will be provided again to you for review and the GSR will answer all of your study related questions before starting the audio-recorded interview. If the interview is conducted by telephone or Zoom, the GSR will read the letter of information (LOI) and consent to you prior to starting the interview and will also address any of your study related questions. The LOI and consent form will be mailed to your preferred mailing address to sign and return to Dr. Yolanda Babenko-Mould at Western University by email or by mail in the stamped and self-addressed envelope. If the signed consent form is not returned, the interview data will not analyzed, and will be permanently deleted. After the initial interview, the GSR may need to contact you by telephone to share the findings and establish the extent to which you feel the findings are accurate in your opinion. This follow-up discussion will take approximately 15 minutes.

7. Possible Risks and Harms

There are no known or anticipated health risks or discomforts associated with participating in this study. However, during the interview a participant may feel discomfort (unease or anxiousness) about discussing their experience of living with MS. If that were to take place for you, the interview may be stopped and resumed when you feel ready again on that or another date, or the interview may be stopped and not resumed if that is your preference. There is a risk of privacy breach in every study which involves

the collection of personal identifiers. The study's investigators will safeguard all study related information by keeping information in a secured location at Western University as well as provide a unique identifier numerical code to each participant that is only recognizable by the study's investigators.

8. Possible Benefits

You might not directly benefit from participating in this study. This study may contribute to the literature by adding new knowledge about women's experiences of health and well-being while living with MS. Educators and health professionals may use the findings to better inform their practice, and to advocate for or create health policy regarding health care practices for women living with MS. Furthermore, as this is a qualitative and exploratory study there is potential to provide a foundation of knowledge that may lead to further qualitative, mixed-methods or post-positivist research in this topic area.

9. Compensation

You will be provided a \$10.00 (CAD) gift card to either Tim Horton's or Starbucks at the beginning of the interview as consideration of providing your time in the study. The \$10 gift card will be provided regardless of whether or not you choose to withdraw your participation in the study. If the interview is conducted by telephone or Zoom, the gift card will be mailed to your preferred mailing address along with this study LOI and consent form.

10. Voluntary Participation

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect. It is important to note that once you have completed your interview, that your responses will be pooled with other responses so it will not be possible to identify your responses. Thus, it will not be possible to withdraw study responses once the data has been pooled together and the data analysis process is underway. If you have chosen to participate in the interview by telephone or Zoom, data will not be used unless a signed consent form is returned. If the LOI-consent form is returned via email, it is important to be aware that email cannot be guaranteed as a secure form of communication. Once the consent form is returned, similar to those who completed an in-person interview, since your responses become pooled it will not be possible to withdraw your data at that point. Responses may be withdrawn prior to the data being pooled with other participants' responses. Although not anticipated to have to be undertaken for this study, the GSR and PI may choose to withdraw a participant if, during the interview, they are behaving in a manner that is deemed by the GSR and PI to be disorderly. The decision to participate will not impact the services you receive through the MS Society. Participation in this study will not impact any of your current medical care that you may be receiving. You may share study team members' contact information with others, but the study team members are unable to accept any identifying

information of others (i.e., names and contact information of potential participants) directly from you.

11. Confidentiality

All data collected will remain confidential and accessible only to the investigators of this study. If the results are published or presented, your name will never be used. A numerical code will be used in place of your real name. If you choose to withdraw from this study prior to initiation of the data analysis phase, your data will be removed and permanently destroyed. Identifiable information will be kept for seven years after study completion (i.e., signed consent form), and then permanently destroyed. Non-identifiable information (i.e., transcribed interview data) collected in this study will be kept for seven years after study completion, and then permanently destroyed. During the interview, you are asked to refrain from disclosing information that would identify you or others. Should any identifying information be disclosed during the audio-recorded interviews, it will not be included in the transcript of responses. Representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

12. Contact for Further Information

If you require any further information regarding this research study you may contact Dr. Yolanda Babenko-Mould, [REDACTED], [REDACTED], [REDACTED] or Jennifer Howard at [REDACTED]

If you have questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics (519) 661-3036, email: ethics@uwo.ca.

14. Publication

If the results of the study are published, your name will not be used and the name of the community or resource centre where you participated in any program related to MS will not be identified. If you would like to receive a summary of the study findings, please provide ensure that your email address or preferred mailing address is provided to the GSR either prior to or at the conclusion of the interview.

15. Consent

A consent form will be provided for you to sign on to the date of your interview, prior to commencing the actual interview. Participants do not waive their legal rights by signing the consent form. If you choose to have the interview by telephone or Zoom, this letter of information and consent form will be mailed to your preferred mailing address with a stamped and self-addressed envelope to enable you to sign and return the consent form by mail, or you may return the signed consent form via email, depending on your preference. Only data associated with participants who have returned signed consent forms will be

used in the study. If you do not return a signed consent form, your interview data will be permanently deleted from the study.

Thank you for taking the time to read this letter and for considering participation in this study.

This letter is yours to keep for future reference.

Consent Form

Study Title: Understanding the Lived Experience of Health Through the Exploration of Well-being of Women with Multiple Sclerosis in Southwestern Ontario

Principal Investigator and Graduate Student's Dissertation Supervisor:

Yolanda Babenko-Mould, RN, BScN, MScN, PhD, Associate Professor and Associate Director, Graduate Programs, Arthur Labatt Family School of Nursing, Room 2311, FIMS & Nursing Building, Western University

Graduate Student Researcher (GSR): Jennifer Howard, PhD Candidate, Arthur Labatt Family School of Nursing, Western University, London, Ontario, Canada

I have read the letter of information, have had the nature of the study explained to me and **I agree to participate**. All questions have been answered to my satisfaction.

Print name of Person
(DD/MM/YY)

Signature

Date

My signature means that I have explained the study to the participant named above. I have answered all questions

Print name of Person obtaining consent
(DD/MM/YY)

Signature

Date

I agree to have the interview audio-recorded.

Print name of Person
(DD/MM/YY)

Signature

Date

Print name of Person obtaining consent
(DD/MM/YY)

Signature

Date

I give permission for secondary data analysis of the transcript resulting from my interview to be used for future research by the study PI or future graduate students supervised by the study PI in order to gain a deeper understanding of the data through the perspective of a different research question or theoretical perspective.

Print name of Person
(DD/MM/YY)

Signature

Date

Print name of Person obtaining consent
(DD/MM/YY)

Signature

Date

Appendix B: Study Poster

Study Title: Understanding the Lived Experience of Health Through the Exploration of Well-being of Women with Multiple Sclerosis in Southwestern Ontario.

Principal Investigator and Graduate Student Dissertation Supervisor: Yolanda Babenko-Mould, RN, BScN, MScN, PhD, Associate Professor and Associate Director, Graduate Programs; Arthur Labatt Family School of Nursing, Room 2311, FIMS & Nursing Building, Western University

Graduate Student Researcher (GSR): Jennifer Howard, RN, PhD Candidate, Arthur Labatt Family School of Nursing, Western University

We are seeking to recruit women living with multiple sclerosis (MS) who are willing to partake in a research study exploring your health and well-being in regard to MS. You will be asked to participate in a 60-90 minute audio/recorded interview in person or via telephone or Zoom. Information regarding this study is available at the registration desk of this MS Society Chapter/Centre. Once you have reviewed this information, and if you would like to participate, please contact **Jennifer Howard** via email to [REDACTED] or by telephone to: [REDACTED]. If you have any questions or concerns regarding this study, please do not hesitate to contact either of the study team members with the Arthur Labatt Family School of Nursing, Western University. This study is being conducted as part of the Graduate Student Researcher's PhD in Nursing Program.

Purpose of this Study

Although there has been a significant amount of research on the quality of life for people with MS, little research has been conducted how women specifically experience health through the exploration of well-being in the presence of this illness. The purpose of this research is to provide a greater understanding of how women with MS may experience their health by better understanding their physical, social and mental well-being. We plan to recruit a total of 20 women with MS into this study.

Inclusion Criteria

Inclusion criteria includes the ability to fluently speak and read the English language, the individual self-identifies as a woman, is over the age of 18, says that they have been diagnosed with MS, has the ability to make decisions independently - for example provide signed informed consent, resides in Southwestern Ontario, consents to being audio-recorded for the interview, consents to use of de-identified data for future studies, and has not been in any relationships with study team members.

Exclusion Criteria

Exclusion/ineligibility criteria for the study includes: not-fluent in speaking or reading the English language, less than 18 years of age, has not informed the GSR about being diagnosed with MS, does not make decisions independently - for example has a substitute decision maker or legal guardian, does not reside in Southwestern Ontario, self-identifies as a gender other than a woman, does not consent to be audio-recorded for the study interview, does not consent to use of de-identified data for future studies, and has been in past relationships with study team members.

Thank you for considering participation in this study!

**Appendix C: MS Society Script for Study:
Understanding the Lived Experience of Health Through the Exploration of Well-being of Women with Multiple Sclerosis in Southwestern Ontario.**

Receptionist:

“Hello, we have received information on a study being conducted through Western University on the health and well-being of women with MS. This won’t impact your MS treatment or services. If you would like to learn more about this study, or if you have any questions please refer to the letter of information.”

Appendix D: Graduate Student Researcher's Study Screening Tool

Study Title: Understanding the Lived Experience of Health Through the Exploration of Well-being of Women with Multiple Sclerosis in Southwestern Ontario.

Pre-ambble: Thank you for being in touch about the study called Understanding the Lived Experience of Health Through the Exploration of Well-being of Women with Multiple Sclerosis in Southwestern Ontario. Before we discuss what is involved with the study, may I ask you a few questions about your diagnosis and background to see if you are eligible to participant in the study?

Pre-screening questions to be used by graduate student researcher when in contact with potential study participant to assess for study eligibility:

Are you able to fluently speak and read in English?

Do you self-identify as a woman?

Are you over the age of 18?

Have you been diagnosed with MS?

Do you have the ability to make decisions independently-for example sign an informed consent document?

Do you reside in Southwestern Ontario?

Appendix E: Semi-Structured Interview Guide

Study Title: Understanding the Lived Experience of Health Through the Exploration of Well-being of Women with Multiple Sclerosis in Southwestern Ontario

Points to state prior to beginning the audio-recording: During the audio-recorded interview you are asked to refrain from disclosing information that will identify you or others. Should any identifying information be disclosed during the interview, it will not be included in the transcript. You have the right to stop participating in the interview at any time and the right to withdraw from the study at any time. Would you prefer a gift card for Tim Horton's or Starbuck's?

- 1) Please tell me about yourself and your background? For example, your age, are you married or involved with a relationship? Do you have children? What level of education do you have?
- 2) Please share with me how you define health?
- 3) How do you define well-being?
- 4) What was it like for you to be diagnosed with MS?
- 5) Tell me please, what is it like for you to be living with MS?
- 6) How do you cope with living with MS? Probe: What sort of activities or ways of coping do you engage in to help you feel better in regards to living with MS?
- 7) What makes your life easier with having MS?
- 8) Conversely, what makes life more challenging with your MS?
- 8) How does having MS affect your personal relationships, for example your relationships with your family members or partner? Have they strengthened, deteriorated or stayed the same in any way?
- 9) How do you see your MS diagnosis impacting your family and friends? Probes: Has having MS impacted your social life? Have there been any changes to your social life since your diagnosis?
- 10) In what way, if any, does having MS impact your physical health?

- 11) Are there any stressors that impact your life from MS, and if so how does this make you feel?
- 12) Do you work or go to school? Has MS impacted this in any way for you?
- 13) In regards to your MS, what would you change about your current situation?
- 14) What helps you keep healthy and promote your own sense of well-being in regards to living with MS?
- 15) What challenges have you experienced with your MS that we have not already discussed? How have you dealt with these challenges?
- 16) Do you feel supported with your MS? If yes, how so? If not, why not?
- 17) What is your experience with nurses, pharmacists, physicians or other health care providers involved in your MS care?
- 18) How does the cost of medications and treatment for MS impact your decisions as to how you manage your MS?
- 19) Do you engage in any sort of holistic practices for your health? Probe: Such as meditation, spirituality or yoga?
- 20) How do these influence your life with MS?
- 21) Has MS impacted your emotional well-being? If so how?
- 22) What does having MS mean to you?
- 23) Is there anything else that you would like to say/share with me today that I have not asked you about?

Appendix F: Confidentiality Agreement: Transcribing

I understand confidential information will be made known to me as I have agreed to provide transcribing services for Jennifer Howard, a PhD in Nursing Student from the Arthur Labatt Family School of Nursing, Western University. I agree to keep all information collected during this study confidential, and will not reveal by speaking, communicating or transmitting this information in written, electronic (disks, tapes, transcripts, email) or any other manner to anyone outside the research team.

Name of Transcriptionist: _____ (please print)

Signature of Transcriptionist: _____

Date: _____

Name of Person Obtaining Consent: _____ (please print)

Signature of Person Obtaining Consent: _____

Date: _____

Appendix G: Research Ethics Board Approval



Date: 1 October 2019

To: Dr. Yolanda Babenko-Mould

Project ID: 113683

Study Title: Understanding the lived experience of health through the exploration of well-being of women with multiple sclerosis in Southwestern Ontario

Application Type: HSREB Initial Application

Review Type: Delegated

Full Board Reporting Date: 15October2019

Date Approval Issued: 01/Oct/2019 10:04

REB Approval Expiry Date: 01/Oct/2020

Dear Dr. Yolanda Babenko-Mould

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
LOI and Consent	Written Consent/Assent	29/Sep/2019	3
MS Society Script	Recruitment Materials		
Screening Tool	Other Data Collection Instruments	29/Sep/2019	3
Semi-Structured Interview Guide	Interview Guide	01/Aug/2019	1

No deviations from, or changes to, the protocol or WREM application should be initiated without prior written approval of an appropriate amendment from Western HSREB, except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Nicola Geoghegan-Morphet, Ethics Officer on behalf of Dr. Philip Jones, HSREB Vice-Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Appendix H: CURRICULUM VITAE

Jennifer Lynn Howard

(née Collins)

Education

- 2016-2021 **PhD Candidate**, Nursing, Western University
 Dissertation: Understanding the lived experience of health through the exploration of well-being of women with multiple sclerosis in Southwestern Ontario.
 Supervisor: Dr. Yolanda Babenko-Mould
- 2015-2016 **Master of Science in Nursing (MScN)**- Student, Western University
 Completed one year of studies and accelerated into PhD program
 Research project: Exploring the effect of music therapy on caregivers for people living with Alzheimer's disease (currently in proposal stage to be submitted to ethics).
 Supervisor: Dr. Yolanda Babenko-Mould
- 2007-2010 **Bachelor of Science in Nursing (BScN)**, Nursing, Western University

Academic Appointments

- 2021-Present **Assistant Professor**, Faculty of Nursing, Memorial University of Newfoundland

Research Grants

- Winter 2021 Memorial's Undergraduate Career Experience Program (MUCEP)
 Value \$1260
- Fall 2021 MUCEP-Value \$1260
- Spring 2021 MUCEP-Value \$630

- 2019 Nursing Research Interest Group- NRIIG Research Grant \$3000.00 awarded for doctoral research
- 2019 Sigma, IOTA Omicron Chapter- Health Initiative Funding Award on Behalf of The Arts Collective, \$1500.00 awarded

Scholarships, Awards, Bursaries and Recognitions

- 2021 Nursing Education Initiative (application eligible)- \$1500 value
- 2020 London West Community Recognition Award (by nomination)
- 2020 Ontario Graduate Scholarship- Waitlist
- 2020 Western Graduate Research Scholarship, \$ 8458.10 value
- 2019 Faculty of Health Science Travel Award (Fall 2019 Competition)
- 2019 Graduate Student Innovation Scholars (1st place), \$1500.00 awarded
- 2019 Helen Fasken Nursing Bursary- \$3200.00 awarded
- 2019 Letter of Recognition from the Dean of Health Science at Western University for Excellent Rating in Overall Effectiveness as a University Instructor
- 2019 Nursing Education Initiative, \$1500.00 value
- 2019 Ontario Graduate Scholarship - Restricted Waitlist
- 2019 Western Graduate Research Scholarship, \$13, 323.31 value
- 2018 Nursing Education Initiative, \$1500.00 value
- 2018 Ontario Graduate Scholarship - Restricted Waitlist
- 2018 Western Graduate Research Scholarship, \$13, 641.39 value
- 2017 Nursing Education Initiative, \$1500.00 value
- 2017 Nominated Twice for Teaching Assistance Award
- 2017 Western Graduate Research Scholarship, \$13, 590.70 value
- 2016 Nursing Education Initiative, \$1500.00 value
- 2016 Irene Nordwich Foundation Award- \$3000.00 awarded
- 2016 WISE Green Award- Finalist- \$500.00 awarded
- 2015 Nursing Education Initiative, \$1500.00 value
- 2016 Western Graduate Research Scholarship, \$8,730.46 value
- 2015 Western Graduate Research Scholarship, \$2104.33 value

2010

Dean's Honour List

Research and Teaching Interests

- Mixed-Methods in Nursing Research
- Statistical Analysis
- Research Methodologies
- Phenomenology and Qualitative Research in Nursing
- Art-Based Research, Teaching, Learning and Interventions
- Neurodegenerative Disorders (i.e. multiple sclerosis and dementia)
- Gerontological Health
- Community and Family Health

Teaching experience

Spring 2021

Supervisor, Faculty of Nursing, Memorial University of Newfoundland

Course title: 6660 Practicum 1

- Supervised three Master of Nursing students who were completing a practicum project.
- Developed more effective skills on critical appraisal of scholarly literature, including the use of the critical appraisal tool developed by the Public Health Agency of Canada.

Winter 2021:

Clinical Instructor, Faculty of Nursing, Memorial University of Newfoundland

Course title: 1520 Caring for the Older Adult: Practice

- Supervised several students in a long-term care setting to promote safe and dignified care for older adults.
- Promoted adherence to public health measures for COVID-19 restrictions.

Course Lead, Faculty of Nursing, Memorial University of Newfoundland

Course title: 1014 Health Assessment

- Delivered course primarily via remote delivery due to the COVID-19 restrictions.
- Promoted diversity and inclusion thoughtfully by developing case base scenarios with characters from a multitude of social and ethnic backgrounds. Included a guest speaker from a federal BIPOC non-profit group who offered to share her patient experience from the perspective of being a woman of colour.

- Fall 2019 **Teaching Assistant**, Arthur Labatt Family School of Nursing,
Western University
- Course title: Ways of Knowing-Data Analysis
- Evaluated term papers and final examinations.
 - Supported students learning application of research evidence to nursing practice.
- March 2019 **Co-Facilitator**- Interprofessional Education Day
- Facilitated discussions and activities for groups of allied-health students.
- Winter 2019 **Clinical Instructor**, Arthur Labatt Family School of Nursing,
Western University
- Course Title: Professional Practice: Supporting Health
- Evaluation and support of second year nursing students implementing nursing assessments, interventions, writing nursing care plans and documentation.
- Winter 2019 **Clinical Instructor**, Arthur Labatt Family School of Nursing,
Western University
- Course Title: Professional Practice: Families and Communities
- Supervise students at local agency placements that promote the health of families and community.
 - Act as liaison between school and agency to coordinate agency orientations.
 - Supervise praxis sessions to help foster reflective nursing practice
 - Grading assignments.
- Fall 2018 **Clinical Instructor**, Arthur Labatt Family School of Nursing,
Western University
- Course Title: Holistic Health Assessment I
- Evaluation and support of first year nursing students developing nursing assessments.
 - Grading assignments.
- Fall 2018 **Clinical Instructor**, Arthur Labatt Family School of Nursing,
Western University
- Course Title: Health Assessment
- Evaluation and support of first year nursing students developing nursing assessments.
- Fall 2018 **Teaching Assistant**, Arthur Labatt Family School of Nursing,
Western University
- Course title: Ways of Knowing-Data Analysis

- Proctor for examinations.
 - Evaluated term papers and final examinations.
 - Supported students learning application of research evidence to nursing practice.
- Winter 2018 **Teaching Assistant**, Arthur Labatt Family School of Nursing,
Western University
- Course title: Health Promotion and Caring: Family & Community
- Evaluated mid-term, final examinations and written assignments.
- Fall 2017 **Teaching Assistant**, Arthur Labatt Family School of Nursing,
Western University
- Course title: Ways of Knowing-Data Analysis
- Chief Proctor for examination.
 - Evaluated term papers and final examinations.
 - Supported students learning application of research evidence to nursing practice.
- Fall 2016 **Teaching Assistant**, Arthur Labatt Family School of Nursing,
Western University
- Course title: Ways of Knowing-Data Analysis
- Proctored examinations.
 - Evaluated term papers and final examinations.
 - Presented difficult topics such as phenomenology in nursing research, relevance of scholarship to nursing practice, and professionalism in nursing.
 - Posted helpful videos online and additional lecture materials to supplement learning needs.
- Winter 2016 **Teaching Assistant**, Arthur Labatt Family School of Nursing,
Western University
- Course title: Ways of Knowing- Research
- Evaluated term papers and final examinations.
 - Attended and observed classroom function.
- 2014-2015 **Clinical Instructor**, School of Nursing, Fanshawe College
- Instructed first and second year Registered Practical Nursing students in various clinical settings, including medicine, palliative care and orthopaedic surgical unit.

Research experience

- 2019-Present **Manuscript Reviewer**, Canadian Journal on Aging (3)

- 2019

 - Assisted in peer-review process for articles related to dementia and caring for older adult populations.

Independent Arts-Based Research Consultant, Arthur Labatt Family School of Nursing, Western University. Jackson, K.T., Mantler, T., & O’Keefe-McCarthy, S. (2019). The PATH to Knowledge Mobilization: Research Shared through Art and Poetry. Western University, Ontario.
- 2019

 - Acting as an arts-based research consultant for project investigating women who have experienced violence. Consultation on study design, research methodology and provided background research with an arts-based lens for data visualization.

Independent Arts-Based Research Consultant, for Big River Analytics, Terrace, British Columbia. Project on survey for Indigenous Art patrons based in Canada.

 - Providing consultation for recommendations based on current available research, including details surrounding cultural appreciation for Indigenous art in Canada.
 - Conducted literature review and provided relevant articles to project managers.
- Present

Visual Artist, Arthur Labatt Family School of Nursing, Western University with Dr. Kimberley Jackson.

 - Provided visual artistic interpretation from data that was inspired by poetry from women who have experienced violence.
- Present

Research Project, Arthur Labatt Family School of Nursing, Western University with Dr. Babenko-Mould.

 - Proposal accepted for candidacy examining committee on understanding the lived experience of women with Multiple Sclerosis in South Western Ontario.
 - Ethics approval received from Western University Research Ethics Board.
 - Currently in recruitment and data analysis phase of research.
 - First three chapters of dissertation complete.
- Present

Research Assistant (Volunteer), King’s School of Social Work, King’s University with Dr. Smith-Carrier and Dr. Béres.

 - Assisting in developing manuscripts and aiding in analysis for ongoing research project involving caregivers for people with dementia who participated in garden therapy.
- Present

Research Project, Arthur Labatt Family School of Nursing, Western University with Dr. Babenko-Mould.

- 2018

 - Proposal being submitted to ethics to study the effect of music therapy on caregivers for people living with Alzheimer's disease.

Abstract Reviewer, Canadian Nursing Education Conference
- 2017

 - Anonymously peer-reviewed abstracts for conference on nursing education.

Graduate Research Assistant- King's School of Social Work, King's University with Dr. Smith-Carrier and Dr. Béres
- 2013

 - Analyzing qualitative transcripts using phenomenological lens for people living with dementia who participated in a study on garden therapy.
 - Three articles awaiting publication; including one article as the primary author.

Research Project, Quality Improvement Council for the Operating Room Department, London Health Sciences

 - Pilot study utilizing mixed methods research to examine the needs and working relationship between the Operating Room Department and the Sterile Processing Department.

Administrative experience

- 2019-2020 **Independent Arts-Based Consultant**
- 2017-2020 **Creative Consultant**, Avalon Video Production Services
- 2015-2020 **Director and Co-Founder**, The Arts Collective, federally registered non-profit art group
- 2016-2019 **Chair**, The Arts Collective
- 2013-2014 **Art Director**, Lachie Music Festival
- 2011 **Committee Member**, Professional Development Steering Committee, London Health Sciences Centre
- 2007-2011 **Student Liaison and Representative** for Western-Fanshawe BScN Nursing, Elgin-Middlesex chapter for the Registered Nursing Association of Ontario

Peer Reviewed Publications

Present

- Howard, J. & Kerr, M.** Systematic review of the multiple sclerosis quality of life-54 (MSQOL-54) measurement Tool. In progress.

Howard, J. Silvaggi, A. & Booth, R. Effects of Electronic Wastage in Nursing Education. In progress.

Howard, J., Smith-Carrier, T., Béres, L., Johnson, K. & Blake, C. Interpretative phenomenology analysis and spirituality; using a spiritual lens to apply meaning. In progress.

Orchard, C.A, Morse, A., **Howard, J.**, ., Sonibare, O. & Al-Hamad, A. Defining nursing from an ontological and epistemological perspective. In progress.

Smith-Carrier, T., Béres, L., **Howard, J.**, Johnson, K. & Blake, C. spirituality and dementia. In progress.

Smith-Carrier, T., Béres, L., Johnson, K., Blake, C., & **Howard, J.** (2019). Digging into the experiences of therapeutic gardening for people with dementia: An interpretative phenomenological analysis. *Dementia*, 0(0), 1-18. Doi:10.1177/1471301219869121

Orchard, C.A., Sonibare, O., Morse, A., **Collins, J.**, & Al-Hamad, A. (2017). Collaborative leadership, Part 1: The nurse leader's role within interprofessional teams. *Canadian Journal of Nursing Leadership*, 30(2), 14-25. Doi: 10.12927/cjnl.2017.25258

Orchard, C.A., Sonibare, O., Morse, A., **Collins, J.**, & Al-Hamad, A. (2017). Collaborative leadership, Part 2: The role of the nurse leader in interprofessional team-based practice – Shifting from task- to collaborative patient-/family-focused care. *Canadian Journal of Nursing Leadership*, 30(2), 26-38. Doi: 10.12927/cjnl.2017.25257

Non-Peer reviewed publications

Howard, J. (2019). When Passions Collide. *Artist Blog*. Retrieved from: <https://www.jennifercollinsart.com/blog>

Howard, J. (2019). Research shared through art and poetry. *Artist Blog*. Retrieved from: <https://www.jennifercollinsart.com/blog>

Collins, J. (2019). Various Paintings. *Visual Fringe 2019 Program*.

Collins, J. (2018). Butterfly effect. *Visual Fringe 2018 Program*.

- Howard, J.** (2017). Website. *Artist Blog*. Retrieved from: <https://www.jennifercollinsart.com/blog>
- Collins, J.** (2017). Landscapes. *Visual Fringe 2017 Program*.
- Collins, J.** (2016). What nursing means to me... *In the Registered Nursing Journal*. November/December 2016. p. 30
- Collins, J.** (2016) The life and imagery of David Bowie. *Visual Fringe 2016 Program*
- Collins, J.** (2015) Landscapes. *Visual Fringe 2015 Program*.
- Collins, J.** (2013). Portraits. *First Friday Publication*
- Regional 2 Member. (2010, May/June). Resolution #2. *The Registered Nurse Journal*, 22(3): 23.
- Primary author for resolution submitted and accepted by the Registered Nursing Association of Ontario for the need to advocate against the centralization of pathological specimen laboratories.

Peer-Reviewed Presentations

- 2021 **Howard, J.,** Babenko-Mould, Y., Jackson, K., Smith-Carrier, T. (2021, July). *The Lived Experience of Women with Multiple Sclerosis in Southwestern Ontario*. The 20th Annual Thinking Qualitatively Virtual Conference: The World is Watching (Virtual).
- 2021 **Howard, J. &** Babenko-Mould, Y. (2021, May). *A Nurse's Experience of creating an Arts-Based Social Enterprise to Support Health: A Story of Empowering Marginalized Youth*. Legacy 2020 Research Conference: Honouring our Past, Creating our Future: Transforming Education, Services, Systems and Policies that Impact Health. London, ON.
- 2021 **Howard, J.,** Pike, A., Crane, D. & Babenko-Mould, Y. (2021, April). *Compassionate Approaches to Remote Delivery and Promoting Coping in Undergraduate Nursing Students: "5 Minutes of Kindness"*. Teaching and Learning Conference 2021 of Memorial University (Virtual).
- 2021 **Howard, J.,** Pike, A., Crane, D. & Babenko-Mould, Y. (2021, March). *Compassionate Approaches to Remote Delivery and Promoting Coping in Undergraduate Students: "5-Minutes of Kindness"*. The 2021 CASN Canadian Nursing virtual Education Conference (Virtual).

- 2021 **Howard, J.**, Babenko-Mould, Y., Jackson, K., Smith-Carrier, T. (2021, March). *Promoting the Health and Well-Being for Women with MS Through Interprofessional Care*. The 2021 CASN Canadian Nursing virtual Education Conference (Virtual).
- 2020 **Howard, J.**, Babenko-Mould, Y., Jackson, K., Smith-Carrier, T. (2020, May). *Understanding the Lived Experience of Health through the Exploration of Well-Being of Women with Multiple Sclerosis: Preliminary Findings*. The 2020 Annual Meeting of the Consortium of Multiple Sclerosis Centres. Orlando, FL. Poster Presentation.
- 2020 **Howard, J.**, Béres, L., Smith-Carrier, T., Blake, C. & Johnson, K. (2020, February). *Spirituality in Interpretive Phenomenological Analysis: Innovative Methods*. Health & Rehabilitation Sciences Graduate Research Conference 2020. Western University, London, ON.
- 2019 **Howard, J.**, Horan, B. & Dao Wang, T. (2019, November). *ID Biotech: Puracin: a novel solution against infection*. Graduate Innovation Scholars Competition, World Discoveries, Nov. 21, 2019. Western University, London, ON.
- 2019 **Howard, J.**, Béres, L. & Smith-Carrier, T. (2019, October). *Growing Stronger Relationships: Exploring Caregivers' Perspectives of a Therapeutic Gardening Program for People with Dementia*. Canadian Association of Gerontology 2019: Navigating the Tides of Aging Together 48th Annual Scientific And Educational Meeting. Moncton, NB.
- 2016 **Collins, J. & Silvaggi, A.** (2015, October). *Health Effects and E-Waste: a Reuse, Reduce and Recycle Program*. Sigma Theta Tau International, 29th Annual Research Conference, Nursing Research: The Path to Excellence. London, ON.
- 2016 **Collins, J. & Silvaggi, A.** (2015, March). *E-Waste: Reuse and Recycle Program*. A Quality Improvement Initiative for the Department of Sustainability at Western University- Finalist Competition. London, ON.

Non-Peer Reviewed Presentations

- 2014 Summary of findings for pilot study on exploring the relationship between the Operating Room and Sterile Processing Department, Quality Improvement Initiative for the Operating Room Department, Victoria Hospital, London Health Sciences. London, ON, Canada.

- Resulted in a follow up corporate funded study to further explore the intricate working relationship between both departments and how this influences patient outcomes. London, ON, Canada.
- 2012 Recommendations on Providing Nursing Reports to Physicians, Guided by the World Health Organizations SBAR model, London, ON, Canada.

Conferences Attended

- 2020 64th JBIC 2020 Conference of the Americas. (Virtual). Adelaide Australia.
- 2019 Canadian Association of Gerontology 2019: Navigating the Tides of Aging Together 48th Annual Scientific And Educational Meeting
- 2019 Practice Education Conference: Preceptor Well-Being: Working with Students in 2019
- 2019 Own Your Future: May Conference on Teaching
- 2017 Photovoice Research: Purpose, Philosophies, and Practices
- 2016 Nursing Research: The Path to Excellence. “Thriving Through Change.”
- 2016 Mixed Methods Research Points of Interface, by Dr. Sharon Docherty
- 2015 TATP, Western University
- 2015 TA Day, Western University
- 2014 Monitoring Wounds in the Community
- 2013 Difficult Airway Management and Rescue Airways with the Surgical Patient
- 2013 A “Vascular Affair,” Monitoring Vascular Disease and Wounds
- 2012 Get Sun Smart: Preventing and Detecting Melanoma
- 2012 Patient and Safety Summit, London Health Sciences
- 2012 Nursing Grand Rounds: Healthy Nurses, Happy Patients
- 2012 Geriatric Refresher Day: A Life Well Lived-Current Issues at the End of Life
- 2008 Women Abuse: Screening, Identification and Initial Response
- 2007 Pediatric Nursing Conference

Clinical Experience

2015-2021	Infusion Nurse Specialist , Bayshore Home Health <ul style="list-style-type: none"> Intravenous chemotherapy and biotherapy infusions in community setting for immune mediated illnesses
2012-2014	Operating Room- Staff Nurse , Victoria Hospital, London Health Sciences Centre
2011-2012	Sub-Acute Medicine- Staff Nurse , University Hospital, London Health Sciences Centre
2011	General Surgery- Float Nurse , University Hospital, London Health Sciences Centre
2011	Emergency Department- Float Nurse , University Hospital, London Health Sciences Centre

Relevant Professional Certificates:

2021	Heart and Stroke, BLS-Health Care Providers
2021	Canadian Professional Grant Development Workshop
2021	JBI Comprehensive Systematic Review Training Program (June 7-11, 2021).
2021	Bias in Peer Review, Canadian Research Chairs
2021	A Universal Course Designed for Learning Success, Canadian Nurse Educators Institute
2021	Keeping Up with Care: Evidence-Based Practice in a Virtual World, Canadian Nurse Educators Institute
2021	Implementing Interprofessional Education, Canadian Nurse Educators Institute
2020	Nurse Educator Certification Program, Canadian Nurse Educator Institute
2020	Teaching Certificate (partially completed requirements), Western University, ceased due to pandemic restrictions
2019	Graduate Student Innovation Scholars Certificate
2019	Ontario Core Indigenous Cultural Safety Training
2019	Desouza Institute: Chemotherapy Competency Maintenance Course
2019	Heart and Stroke, Advanced Cardiac Life Support

2016	Desouza Institute: Provincial Standardized Chemotherapy and Biotherapy Course
2012	AORN-Perioperative Nursing Certificate
2011	Initial Registration with the College of Nurses of Ontario

Webinars and Other Training:

2021	MUN NCO Introduction (Recorded): NCO Session 2
2021	MUN NCO Introduction (Recorded): NCO Session 1
2021	Open Book Assessment, Centre for Innovation in Teaching and Learning, Memorial University of Newfoundland
2021	Grade Tool in Brightspace, Centre for Innovation in Teaching and Learning, Memorial University of Newfoundland
2021	Online Rooms in Brightspace, Centre for Innovation in Teaching and Learning, Memorial University of Newfoundland
2020	Effective Online Discussions, Center for Innovation in Teaching and Learning, Memorial University of Newfoundland
2020	Embedded Principles of Universal Design in Remote Instruction, Center for Innovation in Teaching and Learning, Memorial University of Newfoundland
2020	Low Tech Solutions for Remote Teaching, Center for Innovation in Teaching and Learning, Memorial University of Newfoundland
2020	Do's and Don'ts of Audio Recording, Center for Innovation in Teaching and Learning, Memorial University of Newfoundland
2020	EDI in Research Grant Applications, Center for Innovation in Teaching and Learning, Memorial University of Newfoundland
2020	Getting Set-up in Brightspace, Center for Innovation in Teaching and Learning, Memorial University of Newfoundland
2020	Ethical Considerations in Mixed Methods Research. International Institute for Qualitative Methodology with Dr. Cain on Feb. 18, 2020
2020	Discovering Life-Changing Treatments for People with Progressive MS. International Progressive MS Alliance with Dr. Martino on Feb. 20, 2020

Committee Activities: Faculty of Nursing, Memorial University of Newfoundland

2020-Present Joint Curriculum Committee
 Search Committee

Academic Associations and Affiliations:

2020-Present **Member**, College of Registered Nurses of Newfoundland and
 Labrador
 2020-Present **Member**, Provincial Nurse Educators Interest Group
 2017-Present **Member**, Nursing Research Interest Group
 2016-Present **Member**, Sigma Theta Tau International, Iota Omicron Chapter
 2011-Present **Member**, College of Nurses of Ontario
 2007-Present **Member**, Registered Nursing Association of Ontario

Volunteer Experience:

2015-2020 The Arts Collective

- Co-founded and acted as volunteer curator, Director and Chairman of the Board.
- Experience gained in arts-based social enterprise development, grant writing, business plan development, policy writing, establishing community partners, managing volunteers and artists and marketing on social media platforms.

2012-2016 Big Brothers Big Sisters of London Ontario

- Mentor for a youth with behavioural and developmental needs.

2008-2011 Murry Park Sports Camp.

- Experience gained in event coordination, encouraging athletic and life skills development in at-risk youth.

2007-2010 Registered Nursing Association of Ontario

- Student liaison/ representative, increased student membership to RNAO by ~300%.
- Experience gained in organizing lunch and learns, coordinating social events, fundraising and organizing food drives for local charities.

Relevant Media Exposure:

Belanger, J. (2017, May, 30). London fringe: Art show offers break from on-stage action. *The London Free Press* Retrieved from:

<https://lfpres.com/2017/05/30/art-show-offers-break-fromon-stage-action/wcm/34eed341-478d-3abb-7444-e0fa85cc72c6>

Skinner, O. (2016, May, 31). Why the London fringe festival is an important stop on the Canadian circuit. *CBC Arts*. Retrieved from: <https://www.cbc.ca/arts/why-the-london-fringe-festival-is-an-important-stop-on-the-canadian-circuit-1.3609063>

Anonymous. (2010). Out & About. *In Registered Nurse Journal*, (May/June, 2010), 10. Retrieved from: https://rnao.ca/sites/rnao-ca/files/May-June_2010.pdf

Anonymous. (2008). Out & About. *In Registered Nurse Journal*, (February/ January, 2008), 9. Retrieved from: https://rnao.ca/sites/rnao-ca/files/Jan-Feb_0.pdf