The lived experience of mothering for women with multiple sclerosis

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The Lived Experience of Mothering for Women with Multiple Sclerosis

This thesis is presented in partial fulfilment of the degree of

Bachelor of Arts (Psychology) Honours

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Edith Cowan University
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Abstract

The lived experience of mothers with multiple sclerosis (MS) who have young children was explored. Using purposive sampling, 10 mothers with MS each participated in an in-depth semi-structured interview. The participants varied in demographics and had varying symptoms of MS. Interpretative phenomenological analysis identified four major themes. These themes are: changing life perspective; balancing life with MS; having children; and peer contact. The participants went through a period of avoidance before accepting life with MS and changing their life perspective. Adequately balancing life with MS, by conserving energy and having support networks, was essential to maintaining their well-being. The partners of the participants were the main support providers, although other people stepped in when the partner could not cope. The relationship between the participants and their partners either strengthened or weakened following the diagnosis of MS. Albeit having MS, the participants elected to have children. Having young children was physically taxing, yet very rewarding. Peer contact assisted the participants with a sense of belonging, which indicated the importance of having a wide variety of available peer support programs to assist mothers with MS. The current research provided insight into how such women can be assisted in their pursuit to live contently and mother despite MS. Insight into this experience can also provide increased understanding to the social network of such mothers, which could enhance the quality of interpersonal relationships and stimulate people to provide more support to such mothers. Future research directions are discussed.

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Supervisor: Dr. Eyal Gringart
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The Lived Experience of Mothering for Women with Multiple Sclerosis

Whilst people respond to living with a chronic illness in idiosyncratic ways, various aspects of the experience are shared across individuals. Insight into these experiences can provide valuable knowledge on the lives of people with chronic illnesses. Furthermore, it can facilitate increased public understanding, enhance the quality of interpersonal relationships, and assist people to live contently despite their chronic illness. The focus of the current research was on one type of chronic illness in particular: multiple sclerosis (MS). The lived experience of women with MS, who are mothers of young children, was explored. Previous research has focused on the experiences of mothers with MS; however, none of these studies aimed at specifically understanding the experience of women with MS, who have children in the early childhood years. Whilst having young children was physically taxing for mothers with MS, it was a positive mediator for well-being. First, background information as well as a discussion of previous studies on MS and motherhood are provided. This is followed by a description of the current research that has been carried out as well as its findings and interpretations. Finally, conclusions are provided along with propositions for future research.

Multiple Sclerosis

Worldwide, more than 2.5 million people live with MS (Steinman, 2014). Most people are diagnosed with MS between the ages of 20 and 40 years (Kneebone & Dunmore, 2004; Leary, Porter, & Thompson, 2005) and there are three to four times more women than men diagnosed (Kneebone & Dunmore, 2004). The average onset of MS is 30 years of age and the prevalence of MS is highest around 50 (Koch-Henriksen & Sorensen, 2010). Therefore, the number of people diagnosed with MS in a particular country depends on its population’s age distribution (Koch-Henriksen & Sorensen, 2010). In 2009 there were approximately 23,700 Australians formally diagnosed with MS, which was 0.1% of the
Australian population (Australian Bureau of Statistics [ABS], 2012). In Australia an estimated 1,000 people are diagnosed with MS each year (Taylor, et al., 2010, as cited in MS Australia, 2012). As MS typically does not affect longevity (Finlayson, 2004), the sheer number as well as relative proportion of people with MS in Australia is likely to increase. This is particularly the case due to the inevitable ageing of the population, which is predicted to see the proportion of people over 65 years of age increase from about 13% currently to about 27% by 2057 (ABS, 2014).

MS is a chronic illness that affects the Central Nervous System (CNS). The CNS consists of the brain, the spinal cord, and, the optic nerve (Monro, 1895). The CNS is responsible for the integration and processing of incoming sensory information and for determining appropriate activity by outgoing information to muscles and glands. The CNS consists of billions of neurons (Farley, McLafferty, Johnstone, & Hendry, 2014). These neurons are the basic units of the CNS and each consists of a cell body, axon and dendrites (Farley et al., 2014). The dendrites receive information and guide this information to the cell body (Farley et al., 2014). The axon is responsible for the propagation of nerve impulses, which guide the information from the cell body towards the synaptic cleft where neurotransmitters are released to facilitate communication between neurons (Farley et al., 2014). The transmission of information between the brain and the other parts of the body occurs through these nerve impulses (Farley et al., 2014). The nerve axons are encased in myelin sheaths, which act as insulation and facilitate efficient transmission (Kneebone & Dunmore, 2004). Oligodendrocytes are the cells that are responsible for the maintenance and production of myelin (Bradl & Lassmann, 2010). MS is classified as an autoimmune disease. It affects the myelin and the oligodendrocytes in the CNS (ABS, 2012).

The body’s immune system mistakenly attacks its own healthy myelin and oligodendrocytes, causing swelling and inflammation (Kneebone & Dunmore, 2004).
Demyelination occurs, whereby the myelin is broken down and lesions, also called sclerotic plaques, are formed along the myelin sheath of the nerve (ABS, 2012; Edwards, Barlow, & Turner, 2007; Pakenham, 2006). These typical MS lesions impair the conduction of the CNS’s nerve impulses (Edwards et al., 2007; Kneebone & Dunmore, 2004). As the immune system attacks the healthy myelin and oligodendrocytes at different sites of the CNS at irregular intervals, MS has an unpredictable prognosis and varied symptomatology (Edwards et al., 2007; Leary et al., 2005).

Most people with MS will eventually experience a relapse, caused by the inflammation of myelin. A relapse is the return of an old symptom or symptoms for 24 hours or more, or the emergence of a new symptom or symptoms (McDonald et al., 2001). These symptoms can come on rapidly and last for a number of weeks (Leary et al., 2005), and are not a pseudo relapse caused by an infection or by a change in body temperature (McDonald et al., 2001). In order to classify relapses as separate occurrences, there should be a minimum of 30 days between their onsets (McDonald et al., 2001). There are a number of types of MS, which are discussed next. An in-depth discussion on the psychological aspects of MS and motherhood with MS will follow later.

**Types of MS.** The level of recovery following a relapse determines a person’s type of MS. It is possible to differentiate between four types of MS. The most common type is relapse-remitting multiple sclerosis (RRMS) (Leary et al., 2005; Steinman, 2014). Approximately 85% of new cases are affected by this type of MS (Dennison, Yardley, Devereux, & Moss-Morris, 2010; Leary et al., 2005; Payne & McPherson, 2010). This type of MS is characterised by relapses, which are followed by a recovery to baseline or near baseline functioning. Any further relapses occur at irregular intervals (Leary et al., 2005; Steinman, 2014). In case a person does not return to baseline functioning, a residual neurological deficit and levels of disability are accrued. It has been found that 42% of people
suffering from RRMS increased their residual neurological deficit and levels of disability after a relapse (Lublin, Baier, & Cutter, 2003). There are pharmacological treatments available for people with RRMS, which aim to lessen the severity as well as frequency of relapses and thereby strive to limit the increase in neurological deficit and level of disability (Leary et al., 2005). However, these treatments can have potentially serious and limiting side effects and, therefore, not all people with RRMS follow a pharmacological treatment.

More than 80% of people suffering from RRMS will develop secondary progressive multiple sclerosis (SPMS) within 25 years from the onset of RRMS (Scalfari et al., 2010). SPMS is a type of MS with gradual progression. Contrary to RRMS, people with SPMS do not return to baseline or near baseline functioning; their neurological deficit and levels of disability progressively increase (Leary et al., 2005).

Primary progressive multiple sclerosis (PPMS) and progressive relapsing multiple sclerosis (PRMS) are both progressive from the onset of MS. These two types are considered similar as both cause a continuously increasing neurological deficit and levels of disability (Leary et al., 2005). However, PPMS has a gradual progression, without any relapses or remission periods, while PRMS has superimposed relapses (Leary et al., 2005). Of all people with MS, 10-15% have PPMS and 10-15% of all people with PPMS have PRMS (Leary et al., 2005; Miller & Leary, 2007). PPMS has a higher average age of onset than RRMS (i.e., approximately 40 years of age compared to 30) and the same number of male patients as female patients (Miller & Leary, 2007). A brief review of MS symptomatology is provided next.

**Symptoms.** Impaired sensory, motor and/or cognitive functions can be experienced by people with any of the four types of MS. These MS symptoms may or may not be visible. The severity and symptoms of MS depend on the size and the location of the lesions and the
activity of the disease. Therefore, the effects of MS are experienced differently across people and over time (Dennison et al., 2010; MS Australia, 2012; Pakenham, 2006; Vargas & Arnett, 2013).

The symptoms of MS are diverse and include, but are not limited to, fatigue, optic neuritis (i.e., visual disturbances), altered sensation (e.g., numbness, tingling, or pins and needles), motor issues (e.g., walking, balancing, or coordination problems), pain, thermo sensitivity, altered muscle tone (e.g., tremor, muscle weakness, stiffness, or spasms), vertigo, bladder and bowel changes, emotional and mood changes, slurring, sexual changes, and cognitive impairment (Dennison et al., 2010; Finlayson, 2004; Leary et al., 2005; MS Australia, 2012; Pakenham, 2006; Payne & McPherson, 2010).

Of all reported symptoms, fatigue is the most common, as it affects approximately 80% of people with MS (Fisk, Pontefract, Ritvo, Archibald, & Murray, 1994). Of these people, 55% described it as one of the most debilitating symptoms of MS (Fisk et al., 1994). MS-related fatigue, which is different to the fatigue experienced by healthy people after physical activity, can be a primary or a secondary symptom of MS (Bakshi, 2003). It can increase disability and decrease a person’s quality of life (Bakshi, 2003). From the discussion thus far, it is evident that MS symptomatology can exert significant effects, both physically and physiologically. Psychological aspects are reviewed next.

**Psychosocial issues.** As MS symptoms can have severe impact on people’s lives, being diagnosed with MS is life changing (Gordon, Feldman, & Crose, 1998). An MS diagnosis can bring with it many uncertainties due to its unpredictable course. It can lead to feelings of devastation, grief, fear, and depression (Edwards et al., 2007). A person diagnosed with MS needs to make changes in their life in order to adapt to life with a chronic illness. According to Charmaz (1995), a person goes through three stages during this
adaptation. First, the impairment/s related to MS need to be experienced and assessed by the person. Second, the person needs to acknowledge that their future will be affected by the illness and their self-image needs to change. Finally, the person should fully accept their illness and try to find balance in living with MS. As MS can affect a person’s life differently over time, people with MS could face the possibility of having to adapt to both their changing health status and related life events multiple times during their life (Dennison et al., 2010; Gordon et al., 1998; Reynolds & Prior, 2003).

However, not everyone with MS will admit to themselves that they have a disability and adjust life accordingly. Many people with MS have a slow progression of the disease. This may allow these people to slowly adjust to the changes in their life and prevents them from accepting their disability (Gordon et al., 1998). Especially, people at the early stages of MS have been found to not seek required assistance, nor disclosed their situation (Dennison et al., 2010; Gordon et al., 1998; Irvine, Davidson, Hoy, & Lowe-Strong, 2009; Lonardi, 2007). They did not seek contact with peers for fear of being viewed members of a stigmatised group, getting absorbed by their illness, or being classified as a fraud by more severely affected peers (Dennison et al., 2010). Additionally, people at the early stages of MS try to distance themselves from severely affected peers for fear of what the future might hold (Dennison et al., 2010; Irvine et al., 2009). Nevertheless, it has been suggested that people could benefit from contact with peers (Dennison et al., 2010; Gordon et al., 1998; Irvine et al., 2009). Having contact with peers could stimulate acceptance of MS, which stimulates positive psychological well-being (Pakenham, 2006).

Positive well-being is particularly important, because MS only rarely reduces life expectancy (Finlayson, 2004). As people with MS age, they have to cope with normative aging-related changes as well as those related to MS and its progression (Finlayson, 2004). One of the most predominant concerns for people with MS was found to be fear of the future.
This fear can be divided into three concerns: the fear of further mobility and independence losses, the fear of becoming a burden, and the fear of having to go to a nursing home (Finlayson, 2004). Interestingly, the psychological burden of having MS was rated lower than the fear of causing stress to others (Finlayson, 2004).

Still, there are high rates of depression among people with MS (Feinstein, 2011). According to the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5) a person with a major depressive disorder will either have an overall loss of interest or depressed mood for at least two weeks (American Psychiatric Association, 2013). They will also have five or more additional symptoms (e.g., feelings of uselessness, sleep issues, fatigue, suicidal thoughts, psychomotor agitation or retardation, weight loss or gain, and concentration issues) (American Psychiatric Association, 2013). These symptoms must not be related to a medical condition or substance abuse and should cause impaired functioning or significant distress nearly every day (American Psychiatric Association, 2013). Approximately 50% of people with MS will suffer from a major depressive disorder during their life (Feinstein, 2011). This is significantly greater than the 20% lifetime prevalence of depression among the general population (Kessler et al., 2005).

It remains a challenge to determine whether the depressive symptoms are related to MS and/or psychological factors (Feinstein, 2011). For instance, MS-related fatigue was found to be related to depression, as the level of depression was higher for fatigued people with MS compared to non-fatigued people with MS (Bakshi et al., 2000). Consequently, fatigue has a significant effect on the mental health and general well-being of people with MS. Fatigue did not depend on physical disability and it was, therefore, suggested that fatigue and depression are mediated by a common process, such as brain lesions or psychological factors (Bakshi, 2003).
Atrophy, due to hypointensity MS lesions (i.e., black holes), in the cortical regions of the bilateral frontal lobes of the brain, was found to be associated with depression (Gobbi et al., 2014). A distribution of grey matter atrophy contributed to the joint presence of depression and fatigue in people with MS (Gobbi et al., 2014). These findings indicated the possibility of brain lesions as a cause of depression in people with MS.

Depression in people with MS could also be related to psychological factors. The burden of the disease is not readily understood by other people (Gordon et al., 1998; Irvine et al., 2009; Lonardi, 2007) and it could lead to social exclusion, stigmatism, and discrimination (Reynolds & Prior, 2003). Additional factors that influence psychological well-being include the emotional burden of having a limiting chronic illness (Janssens et al., 2003), loss and grief (Sidell, 1997), coping style (Feinstein, 2011; Pakenham, 2006), attributional style (Kneebone & Dunmore, 2004), and social support (Dennison et al., 2010; Williams et al., 2004).

A person with MS has to incorporate the limitations that come with the disease into their life. These limitations, the unpredictable nature, the pervasiveness of MS, and the absence of a cure could create a substantial emotional burden (Janssens et al., 2003). Furthermore, it is likely that the quality of life and well-being are reduced due to the experience of loss (Janssens et al., 2003).

There are several types of loss that could be experienced by people with MS. For instance, there could be loss of control, loss of functioning, loss of health, loss of independence, loss of self-image, and a feeling of powerlessness (Sidell, 1997). After experiencing a loss, people with MS typically go through a period of grief, which is followed by adjustments to daily life in order to cope (Sidell, 1997). The presence of adequate social support was found to be crucial in periods of adjustment to loss (Dennison et al., 2010; Williams et al., 2004).
A person’s coping style also influences their adjustment to loss and life with MS (Feinstein, 2011; Pakenham, 2006). According to Feinstein (2011) problem-focused coping facilitates positive adjustment. When people used avoidant coping strategies, like denial, they were unable to move forward and adapt appropriately to life with MS (Pakenham, 2006). These people were found to have a higher risk of developing depression and anxiety (Feinstein, 2011; Pakenham, 2006).

This finding was contradicted by Boland, Levack, Hudson, and Bell (2012) and by Dennison and colleagues (2010). They found that avoidant coping strategies are not necessarily maladaptive for people with MS. As the progression of MS is unpredictable, people with MS do not like to be reminded of possible future disability (Boland et al., 2012; Dennison et al., 2010). They are often unable to tolerate thinking about what the future might bring and so use avoidance to sustain an acceptable quality of life (Dennison et al., 2010). Thereby, avoidant coping strategies can promote emotional well-being and be beneficial to a person’s self-image (Dennison et al., 2010).

Avoidance can be helpful to people with MS (Dennison et al., 2010). However, positive adjustment through avoidance is associated with having a low severity and symptomatology of MS. Avoidance can be maladaptive for people with severe and symptomatic MS, as high levels of disability can lead to a higher risk of developing depression and anxiety (Feinstein, 2011; Janssens et al., 2003). People with a high level of disability were advised to use problem-focused coping strategies (Feinstein, 2011; Janssens et al., 2003).

Finally, a positive attributional style, as opposed to a negative one, which is internal, stable and global, is important for a positive adjustment to loss associated with MS (Kneebone & Dunmore, 2004). However, according to Vargas and Arnett (2013), the
attributional style of a person with MS was not directly associated with depressive symptoms. It was found that attributional style was related to perceived stress and that this stress was related to depressive symptoms (Vargas & Arnett, 2013). Stressful events have been shown to increase the probability of an MS relapse, as the risk of a relapse is doubled after experiencing at least one stressful event during the preceding four-week period (Buljevac et al., 2003). This indicated the importance of a positive attributional style and a need to keep depressive symptoms to a minimum in order to keep the number of MS relapses to a minimum.

The quality of life of people with MS relies mainly on their mood (D’Alisa et al., 2006; Janssens et al., 2003). Depression often follows having been diagnosed with MS (Janssens et al., 2003). Additionally, during any stage of the disease, depressive symptoms are more prevalent among people with greater disability (Janssens et al., 2003). Only anxiety has higher prevalence than depression in people with MS (Garfield & Lincoln, 2012), especially after diagnosis (Janssens et al., 2003). In a study by Garfield and Lincoln (2012) 56.7% of the participants had clinically significant levels of anxiety. Those with higher levels of anxiety had lower levels of self-efficacy and higher levels of disability as well as perceived stress. Garfield and Lincoln also found a high comorbidity of anxiety and depression. This comorbidity led to an inability to engage therapy and more severe MS symptoms, mental health issues, and impairment in people with MS.

Suicidal ideation, preoccupation with suicide, was found to be common in people with MS, especially those with a comorbidity of anxiety and depression (Garfield & Lincoln, 2012; Turner, Williams, Bowen, Kivlahan, & Haselkorn, 2006). Testing people with MS for depression alone did not detect a third of the people who harboured suicidal ideations (Turner et al., 2006). As depression and anxiety in MS are treatable, a positive diagnosis and adequate treatment could reduce the suicide rate for people with MS.
It is beyond the scope of the current paper to provide an exhaustive account on MS. The interested reader can see Polman and colleagues (2011) for more information on the diagnosis of MS. For more information on the aetiology of MS, the interested reader can see for example, Kampman and Brustad (2008); Koch-Henriksen and Sorensen (2010); Milo and Kahana (2010); O’Gorman, Lin, Stankovich, and Broadley (2013); Ramagopalan and colleagues (2009); Rosati (2001); and Van der Mei and colleagues (2003).

Motherhood

Motherhood, which has been defined as the caring and nurturing of children to meet their physical and psychological needs (Francis-Connolly, 2000), is a common phenomenon, as it is a major life role for many adult women. Furthermore, it is commonly viewed as one of the most important roles these women perform in their life. Motherhood should be understood from a cultural perspective. The conceptualisation of motherhood has changed dramatically in Western culture over the past 30 years (Tummala-Narra, 2009). The changing cultural views on motherhood have been facilitated by the increase in geographic mobility, changing family structure, declining social support, an increase in available information, and economic pressures (Tummala-Narra, 2009). In Western culture, the ‘perfect mother’ was traditionally described as someone who is protective, considerate, supportive, and patient, whilst looking out for her children’s development and well-being (Barlow & Chapin, 2010). Many mothers believe that falling short of being a ‘perfect mother’ would have disastrous impact on their children (Francis-Connolly, 2000). This belief could result in stress and lead to a loss in the enjoyment of motherhood, in cases where mothers perceive a significant discrepancy between themselves and the prototypical ideal of motherhood (Tummala-Narra, 2009).

Motherhood has been found to be shaped by social interactions (Francis-Connolly, 2000) and individual perception (Dunbar & Roberts, 2006). Additionally, the life situation
of mothers influences their experience of motherhood. For instance, there are mothers who are married, single, lesbian, employed, mothers on welfare, and mothers with a chronic illness. All of these life situations could alter the practice and the experience of motherhood.

**Motherhood and young children.** The experience of motherhood also changes as children age (Barlow, Cullen, Foster, Harrison, & Wade, 1999; Evenson & Simon, 2005; Francis-Connolly, 2000; Horwitz, Briggs-Gowan, Storfer-Isser, & Carter, 2007; Umberson, Pudrovska & Reczek, 2010). The mothers of preschool-aged children are typically deeply involved with motherhood, given that they are particularly preoccupied with tasks related to their young children, due to high physical demands (Barlow et al., 1999; Francis-Connolly, 2000). However, as children age and become more independent, physical demands decrease, yet psychological demands increase (Barlow et al., 1999; Evenson & Simon, 2005; Francis-Connolly, 2000). Francis-Connolly (2000) found that most mothers of preschool-aged children had underestimated motherhood and the demands that come with it. They described motherhood as overwhelming, exhausting, and constant. The pressure to be the ‘perfect mother’ was exceptionally present among mothers of young children (Francis-Connolly, 2000).

Mothers of preschool-aged children were at greater risk of developing depression than were mothers of older children (Evenson & Simon, 2005; Umberson et al., 2010). Furthermore, the mental health of mothers was found to be most affected when mothers have children under the age of six (Horwitz et al., 2007; Umberson et al., 2010). The parenting stressors that increased the susceptibility to depression were difficulties regarding daily caretaking, child temperament, financial strain, maternal physical health, and the balance between work and family (Horwitz et al., 2007). Evenson and Simon (2005) concluded that the psychological demands of being a parent of young children outweigh the psychological benefits of having children. They also remarked that nonparents generally have less
depression prevalence than any type of parent (e.g., parents with older children). Thus, motherhood has been identified as taxing both physically and psychologically across contexts and personal circumstances. Mothering for women with MS is discussed next.

**Motherhood and multiple sclerosis.** The high rates of depression among people with MS (Feinstein, 2011), combined with Evenson and Simon’s (2005) finding that parents have a higher prevalence of depression compared to nonparents, suggest that parents with MS would have an increased risk of depression. Therefore, it is important to investigate the experience of motherhood with MS.

There are a large number of women with MS, who have young children, as women are often diagnosed with MS in the childbearing and rearing period. Historically, women with MS were advised not to have children and those pregnant were advised to terminate the pregnancy (Smeltzer, 2002). Nowadays, except under extreme circumstances, specialists do not provide such advice. It is up to these women to decide whether or not to have children.

Many women with MS were found to have difficulties with the decision to have a baby (Smeltzer, 2002). Especially as the unpredictability of MS produced uncertainty about the future (Smeltzer, 2002) and because in the three months following delivery there is an increased chance of a relapse (Vukusic et al., 2004). Nevertheless, despite such fears, most women did decide to become pregnant, although they adjusted the spacing between pregnancies as well as the number of children (Smeltzer, 2002).

MS symptoms, like fatigue, mood disturbance, mobility issues, and cognitive impairments, could impact the ability to be a mother. Especially fatigue affected many people with MS and can lead to coping difficulties, both physically and emotionally (Deatrick, Brennan, & Cameron, 1998). As mothers with MS recognised that energy was
limited and that looking after young children can be energetically taxing, they tried to regulate and limit their activities (Payne & McPherson, 2010).

Many mothers with MS had a support network in place to help them cope with daily chores and care for their children. Vital sources of support for these mothers included their partners, family, and friends (Irvine et al., 2009; Pakenham, Tilling, & Cretchley, 2012; Payne & McPherson, 2010). Family members, especially the partner, provide the main support. However, mothers who did not have a partner or family, or whereby the partner or family could not handle MS, did receive support from others (Pakenham et al., 2012; Payne & McPherson, 2010). Additionally, the support network, mostly consisting of family members, monitored the condition of these mothers and warned them when MS symptoms became more present (Payne & McPherson, 2010). Nevertheless, the support provided by a partner has been found to change relationships within the family (Arestedt, Persson, & Benzein, 2014; Irvine et al., 2009; Reynolds & Prior, 2003). Whilst some relationships became stronger, others weakened (Arestedt et al., 2014). Boland and colleagues (2012) found that relationships weakened when the couple had incongruent individual coping strategies.

The impact MS can have on children has shown to be a concern for mothers with MS. Previous research on the experience of children with a parent with MS found that parental MS could have a negative impact on children (Bogosian, Moss-Morris, & Hadwin, 2010), thereby confirming the validity of this concern. One study showed that during a relapse, mothers with MS reduced the amount of physical affection to their children, although they were not aware of doing so (Deatrick et al., 1998). However, another study indicated that mothers with MS increased the number of activities with their children during a relapse, yet promoted more mature behaviour from their children (White, Mendoza, White, & Bond, 2009). It is possible that these mothers went to great lengths to act according to the norms of
being a good mother, even when it was hard to provide physical affection, to prove that they were good mothers whilst trying to limit the negative impact MS can have on their children (Grue & Laerum, 2002; Reynolds & Prior, 2003). Thus, they can be considered adequate carers, even though occasionally being recipients of care (Grue & Laerum, 2002).

While parenting young children can be physically and emotionally challenging for mothers with MS, the rewards that come with motherhood should not be underestimated. It has been shown that these mothers had a higher quality of life, due to social activities, and they used more meaning-focused coping strategies compared to childless women with MS (Twork et al., 2007). This finding indicated that being a mother could be beneficial to these women’s health.

**Young children’s knowledge on illness.** Another reward that comes with motherhood is transferring knowledge to children. Knowledge is developed gradually as children age. Mothers are among the main contributors to a child’s learning, especially while children are young. Whilst four-year-olds have a basic conceptual appreciation of illness, it is not until nine years of age that they develop elaborate understanding of it (Myant & Williams, 2005). Initially, illness is understood through behaviour (e.g., wash your hands after using the toilet; White, Bellamy, Creech Powell, & Wittenauer, 2011). Communication and exposure to illness lead to an increase in the child’s knowledge of illness (McIntosh, Stephens, & Lyons, 2013; White et al., 2011). When teaching young children about illness, mothers refer to the child’s previous experience with illness (White et al., 2011). This social interaction assists young children to increase their understanding of illness (White et al., 2011).

Mothers with a chronic illness talked differently to their children about illness (White et al., 2011). As illness was a major part of their life and therefore more present, these
mothers talked to their children about illness more often than did healthy mothers and they tried to convey what it is like to live with a chronic illness (White et al., 2011). Children, who received more explanations about emotions by their mothers had a more thorough understanding of emotions and engaged more prosocial behaviours compared with children of healthy mothers (Garner, Dunsmore, & Southam-Gerrow, 2008). This finding suggested that young children of chronically ill mothers likely gain an emotional understanding of illness sooner than other children.

**Current Study**

Children in the early childhood years place a high physical demand on their mothers, as these mothers are predominantly preoccupied with tasks related to their young children (Barlow et al., 1999; Francis-Connolly, 2000). Most mothers with MS have limited physical and emotional capacity (Payne & McPherson, 2010) and this energy has to be maintained to be able to deal with stressful events, as these have been linked to MS relapses (Buljevac et al., 2003). During a relapse or MS-related fatigue a mother’s level of support and physical affection could be hindered, which could be difficult to understand by young children (Deatrick et al., 1998).

The current research objective was to explore the experiences of mothers with MS, who have young children. Previous studies have focused on the experience of mothers with MS; nevertheless, none of these studies were aimed specifically at understanding the experience of being a woman with MS, whilst mothering children in early childhood years. Payne and McPherson (2010) focused on the decision of people with MS to become mothers and the experience of motherhood during the postnatal period. Therefore, the focus in the current research was on women with MS who are mothers of children in the next
developmental stage, the early childhood years, which was suggested by Pakenham and colleagues (2012) to be addressed by future research.

Bearing in mind that being the mother of a child in the early childhood years is a physically demanding role; knowledge of the experience of having MS whilst mothering young children is important. Knowledge into these meaningful and significant experiences may inform institutions and practitioners in the MS area as well as women with MS considering motherhood and the social network of such mothers.

The current research, thus, followed on from the existing body of knowledge. The research question posed was: What is the lived experience of women with MS, who are mothers of young children?

**Research Design**

**Methodology**

The current research employed a qualitative research design and followed an interpretative phenomenological approach. Interpretative phenomenology has been informed by the epistemology of social constructionism through the theoretical perspectives of phenomenology, hermeneutics, and symbolic interactionism. Social constructionism acknowledges that a person’s understanding of reality is influenced by cultural and social aspects (Sloan & Bowe, 2013), thereby creating a unique experience exclusive to that person. All three theoretical perspectives are congruent with this philosophy.

Two methodologies, descriptive and interpretative phenomenology, have been shaped by the theoretical perspective of phenomenology (Sloan & Bowe, 2013). Contrary to descriptive phenomenology, which requires the researcher to transcend the research process, interpretative phenomenology considers that the researcher is part of the research process
(Sloan & Bowe, 2013). It aims to discover the meaning of participants’ experiences, which are influenced by the participants’ life world.

The theoretical perspective of symbolic interactionism focuses on participants’ experiences constructed through interaction with others (Shalin, 1986) and is thus applicable to social questions. On the other hand, hermeneutics, posits that language uncovers being (Sloan & Bowe, 2013) and is well suited to health related questions (Miles, Chapman, Francis, & Taylor, 2013). Therefore, these theoretical perspectives assisted in uncovering the meaning ascribed to living with MS, whilst being a mother of young children.

Individual semi-structured interviewing is well suited for this methodology, as interviewing facilitated in-depth exploration and understanding of the lived experience of such women. It provided them with an opportunity to talk freely about their experiences. It also allowed the participants and the researcher to co-create meanings of the experiences that were disclosed in the interviews (DiCicco-Bloom & Crabtree, 2006). The participants in the current research are discussed next.

Participants

Purposive sampling was used to recruit women with MS, who have young children, ensuring that each participant had at least one child under the age of eight years. The selection criteria did not include marital status or number of children. MS affects each person differently and the same person differently at different times and therefore affects the experience of maternal MS differently for each mother. With many variables possibly affecting these women’s experiences, it would have been difficult to set stricter selection criteria, especially with the limited time frame set for current research. For that reason the decision was made to look solely at the experience of mothers with MS who had at least one child in the early childhood years.
Initially, recruitment of participants was through research recruitment flyers (see Appendix A), which were posted on the notice board at the offices of The Multiple Sclerosis Society of Western Australia (MSWA) and at the office of one of Perth’s neurologists. As after one month only one participant was recruited through the use of the above recruitment methods, recruitment was extended to include the advertisement of the research in the winter edition of the ‘Bulletin’ magazine of the MSWA and in the Facebook group ‘Mums with MS’. It also included snowballing and the recruitment of Dutch women with MS, who have young children, through the researcher’s social network in The Netherlands. The decision to add the Dutch mothers was taken to enrich the research and enhance transferability of the findings.

With these recruitment methods, including the research recruitment flyers at the MSWA offices and an email to women with MS, who have young children and live in the Perth metro area, by Sue Shapland, the Member Services General Manager MSWA, a varied sample of 10 participants was recruited over a two and a half month period. The participants varied in demographics (see Table 1). All participants’ names have been replaced by pseudonyms.
Table 1

Demographics of the Participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age a</th>
<th>Marital status</th>
<th>Number</th>
<th>Age a</th>
<th>Diagnosis b</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ann</td>
<td>37</td>
<td>Married</td>
<td>2</td>
<td>7 and 16</td>
<td>1999</td>
</tr>
<tr>
<td>Bec</td>
<td>26</td>
<td>Single</td>
<td>1</td>
<td>1</td>
<td>2012</td>
</tr>
<tr>
<td>Cath</td>
<td>40</td>
<td>Married</td>
<td>1</td>
<td>3</td>
<td>1999</td>
</tr>
<tr>
<td>Dani</td>
<td>44</td>
<td>Married</td>
<td>2</td>
<td>6 and 6</td>
<td>1995</td>
</tr>
<tr>
<td>Ella</td>
<td>28</td>
<td>Married</td>
<td>3</td>
<td>0, 2 and 3</td>
<td>2010</td>
</tr>
<tr>
<td>Faye</td>
<td>31</td>
<td>Married</td>
<td>2</td>
<td>0 and 2</td>
<td>2013</td>
</tr>
<tr>
<td>Gail</td>
<td>41</td>
<td>Married</td>
<td>4</td>
<td>1, 4, 6 and 20</td>
<td>2010</td>
</tr>
<tr>
<td>Hana</td>
<td>38</td>
<td>Married</td>
<td>2</td>
<td>5 and 7</td>
<td>2014</td>
</tr>
<tr>
<td>Ina</td>
<td>33</td>
<td>Married</td>
<td>4</td>
<td>7, 12, 13 and 16</td>
<td>2010</td>
</tr>
<tr>
<td>June</td>
<td>30</td>
<td>Married</td>
<td>1</td>
<td>2</td>
<td>2014</td>
</tr>
</tbody>
</table>

*Note. a in years. b year.*

All research participants had RRMS with varying symptoms (see Table 2). Eight of the participants lived in Western Australia and two in The Netherlands. Only the participants in Australia were following pharmacological treatments. Of the Australian participants, two were recruited through a flyer at one of the MSWA offices, one through the ‘Mums with MS’ Facebook group, two through an email, which was sent to mothers with MS, and three through the research advertisement in MSWA’s magazine ‘Bulletin’.
Table 2

Main MS Symptoms of the Participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Main symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ann</td>
<td>Fatigue, motor issues, mood changes and optic neuritis</td>
</tr>
<tr>
<td>Bec</td>
<td>Fatigue, bladder problems, altered sensation and motor issues</td>
</tr>
<tr>
<td>Cath</td>
<td>Fatigue, altered sensation, motor issues, optic neuritis and vertigo</td>
</tr>
<tr>
<td>Dani</td>
<td>Fatigue, altered sensation and motor issues</td>
</tr>
<tr>
<td>Ella</td>
<td>Fatigue and optic neuritis</td>
</tr>
<tr>
<td>Faye</td>
<td>Fatigue and optic neuritis</td>
</tr>
<tr>
<td>Gail</td>
<td>Fatigue, cognitive issues, motor issues, optic neuritis and thermo sensitivity</td>
</tr>
<tr>
<td>Hana</td>
<td>Fatigue, altered sensation, motor issues and pain</td>
</tr>
<tr>
<td>Ina</td>
<td>Fatigue, motor issues, muscle spasms and vertigo</td>
</tr>
<tr>
<td>June</td>
<td>Fatigue, altered sensation and thermo sensitivity</td>
</tr>
</tbody>
</table>

Materials

Before an interview with a participant took place, the participants were provided with an information letter (see Appendix B) and an informed consent form (see Appendix C). A digital voice recorder was used to record each interview.

During the interview a semi-structured interview schedule, consisting of fourteen open-ended questions (see Appendix D) was used. The face validity and suitability of the questions was assessed by the research supervisor, the researcher’s aunt, who was diagnosed with MS when her children were young, and the researcher, who is part of the MS sub-population. There was agreement that the questions were clear and relevant to the scope of the research.

To provide an audit trail and reflexivity, the researcher kept a journal for the duration of the research. The researcher used this journal to reflect on the research and the interviews.
Any information that appeared significant to the research was included in the journal. The procedures of the current research are provided next.

**Procedures**

Ethics approval from the School of Psychology and Social Science Ethics Sub-committee was obtained before the current research commenced. The researcher also obtained a national police certificate, a requirement of the MSWA, before commencing this research.

Interested prospective participants were invited to contact the researcher. The contact details of prospective participants in The Netherlands were provided to the researcher through her social network. These prospective participants were contacted by the researcher. The prospective participants who had contacted the researcher by email were provided with the information letter and the informed consent form by return email. The prospective participants who had contacted the researcher by phone were provided with these documents in person before the start of the interview.

Four participants were met at a mutually convenient time at their place of residence. The other six participants, due to the large geographical distance between their places of residence and the researcher’s, were met at a mutually convenient time through Skype. After the participant had read the information letter and informed consent form, they were reminded that participation was voluntary and that they could withdraw from the study at any time. The researcher also answered any questions the participant had.

After the participant had signed the informed consent form, or given verbal consent through Skype, the interview commenced. The duration of the interviews ranged from 27 to
For the duration of the research, the data and voice recordings were kept in the researcher’s lockable office. Following completion of the research, the voice recordings were erased and the interview transcripts were stored in a secure filing cabinet by the research supervisor at Edith Cowan University for the duration of five years. After five years the interview transcripts will be destroyed. Participants’ names were replaced by pseudonyms so that transcripts are not identifiable.

**Data Analysis**

Interpretative phenomenological analysis (IPA), whereby meaning of the lived experience is believed to be co-created by the researcher and participants (Pringle, Drummond, McLafferty, & Hendry, 2011), was conducted during this research. According to IPA the data and the interaction between the participants and the researcher are simultaneously interpreted and results are ingrained in the words of the participants (Pringle et al., 2011).

After conducting an interview the researcher transcribed and analysed the transcript as soon as possible after its completion. In cases where this was possible, transcription and data analysis of an interview were conducted before the following interview. This assisted the researcher with uncovering emerging themes and adjusting interview questions to investigate these emerging themes further.

After transcribing an interview the researcher first got familiarised with the data by reading the transcript several times. During these readings the researcher made notes in the margins of the transcript, highlighted significant parts, considered journal entries, and
recorded ideas. Eventually, the researcher made an extract listing of all aspects of the data that were relevant to the research question. The readings, notes, and extracts assisted the researcher with coding the data. Initial codes were generated and sorted into potential themes. These themes were compared with the entire coded data.

When all interview transcripts were analysed, the themes were grouped into major themes. These themes told the overall story of the analysis. Compelling excerpts from each interview were also sorted into the major themes.

Analysis was guided by the data. Therefore, it was occasionally required, when new themes emerged during the analysis of an interview transcript, to analyse previous interview transcripts again. This assisted the researcher in establishing inter-relationships.

Triangulation was added to the current research by the verification of the findings. The findings were verified by member checking and cross analysis agreement. To allow for member checking, all participants received a copy of the transcript and a list of preliminary themes from their interview. Two days after the participant had received the transcript and the list of preliminary themes; they were contacted by the researcher by phone. The participants in The Netherlands were contacted by email. During this contact the participant was asked whether they agreed with the preliminary themes. All participants believed that the themes were reasonable reflections of their interviews.

Cross analysis agreement was also incorporated to verify the findings. Another researcher received two of the de-identified interview transcripts. The researchers compared their analyses during cross analysis agreement. Cross analysis was found to be congruent.

During the research the researcher kept a journal to provide an audit trail. This journal was used to reflect on the research and the interviews. The researcher recorded biases, emotions, and other information significant to the research. This journal assisted the
researcher to self-reflect. As the researcher is part of the MS sub-population it was important for her to be aware of her biases. Before the interviews commenced the researcher had also answered all the interview questions. The information in the journal and the reflection on the interview questions allowed the researcher to identify her position and to minimise its threat during data analysis. Yet being part of the MS sub-population the researcher believed that she was able to relate better to the experiences of the participants. As she knew personally what it was like for her to live with MS and be a mother of young children, she was able to establish unique rapport with these mothers who disclosed their experiences and provided valuable in-depth insight.

**Findings and Interpretations**

Data saturation was reached as no more new information was coming forth from the last two participants. Four major themes and eight subthemes emerged from the data (see Table 3). These themes are discussed in turn, along with illustrations from participants’ discourse.

Table 3

*Themes and Subthemes*

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changing life perspective</td>
<td>Avoidance</td>
</tr>
<tr>
<td></td>
<td>Seize the day</td>
</tr>
<tr>
<td>Balancing life with MS</td>
<td>Conserve energy</td>
</tr>
<tr>
<td></td>
<td>Support network</td>
</tr>
<tr>
<td>Having children</td>
<td>Pregnancy decision</td>
</tr>
<tr>
<td></td>
<td>Dealing with motherhood</td>
</tr>
<tr>
<td>Peer contact</td>
<td>Feeling judged</td>
</tr>
<tr>
<td></td>
<td>Sense of belonging</td>
</tr>
</tbody>
</table>
Changing Life Perspective

Being diagnosed with MS is life changing and requires significant life adjustments (Gordon et al., 1998). All of the participants talked about their changing life perspective after being diagnosed with MS. They talked about avoiding their MS diagnosis and the eventual acceptance of having to live with MS. After accepting the MS diagnosis they started to focus on seizing the day.

**Avoidance.** After being diagnosed with MS, participants initially could not accept their illness nor adjust their life perspective. The participants used avoidance as a way to cope with life with MS. Providing MS did not have a big influence on daily life, it was easier to ignore the diagnosis than to deal with it. The three stages, identified by Charmaz (1995), which a person goes through in order to adapt to life with a chronic illness, were put on hold and, consistent with previous research findings, the MS diagnosis was not disclosed to others (Dennison et al., 2010; Gordon et al., 1998; Irvine et al., 2009; Lonardi, 2007). According to Gail:

Well, especially the first couple of years I ignored the fact that I had MS. I didn’t do any research, apart from the medication, cause I had to choose one to go on. I didn’t really tell anyone, but I just ignored it, it didn’t really exist.

MS was still in the back of their minds, as they were not always able to avoid the fact that they have MS. Dani noted that “even though you hope it never comes back, it is not really denial, as you know that you have got MS and MS symptoms”.

The participants talked down the influence MS had on their lives. It was easier to get on with life and try to forget about MS, as long as MS symptoms did not interfere too much. According to Ann, going to work gave her a break from MS.
Yeah, you sort of pack up when you get to work. It is almost like you can leave your problems at home, because that’s where everyone knows you have got MS, so you are sick there, so you just go, ha!

June added:

Most of the time I ignore it and go on. A lot of the time there is not much I can really do about the symptoms. They are not noticeable to other people, so the only thing that I really do is taking it a little bit easier. Try not to spend too much time rushing around cause all that happens is I get really tired.

Even possible associations with more severe MS cases were avoided. The participants avoided MS information and going in to the MS society. For instance, Faye remarked that “I just don’t want to look into it too much”. By going into the MS society, especially MSWA’s Wilson office, the participants would encounter severe MS cases, which all participants found very confronting. Ann “found Wilson way too scary”. She continued:

It is huge. And it is full of worse case scenarios, and yeah. People, when you are newly diagnosed, they say come to Wilson and you are going these and you think, ho... I don’t want this anymore.... I refuse to go back to Wilson. Cause I can’t deal with it.

Just like the MSWA’s Wilson office, the MS society in The Netherlands was being avoided by Hana and Dani for the same reason. Dani explained:

You see so many people with a lot of misery over there and then I thought, oh, this is too much for me. I thought: if anything goes wrong and I become unwell, I will look for answers then. But before I go there again... I do not feel like going there at all. And I never have been there again. I do not want it.
The current findings that people in the early stages of MS used avoidant coping strategies, like denial, after their diagnosis are in accord with previous research (Boland et al., 2012; Dennison et al., 2010; Gordon et al., 1998; Irvine et al., 2009; Lonardi, 2007). These mothers did not want to accept their situation, as long as their MS symptomatology and severity were low. In addition to this, they avoided the possibility of meeting severely affected peers for fear of what the future might hold. This finding is congruent with the research by Dennison and colleagues (2010) and Irvine and colleagues (2009).

Similar to findings of previous research (Boland et al., 2012; Dennison et al., 2010), using avoidance as an initial coping strategy maintained these mothers’ emotional well-being. It provided them with an acceptable quality of life. This finding was contrary to Feinstein (2011) and Pakenham (2006). However, avoidance is helpful to people during the early stages of MS. In case MS has a severe and active progression leading to a considerable loss, avoidant coping strategies could result in a higher risk of developing depression and anxiety and should be avoided, as indicated by Feinstein (2011) and Janssens and colleagues (2003).

Therefore, avoidance of MS is not possible when experiencing a relapse. A relapse can lead to a loss of function, which is either permanent or temporary. Whenever there is a loss of function, life has to be adjusted to accommodate it. As previously uncovered by Gordon and colleagues (1998), the mothers who initially had mild MS symptoms were found to take a lot longer to work through the stages of adjustment and change their life perspective.

All of the participants have experienced loss of function. Of all the participants, Ann was most severely affected by MS. Ann has had to deal with severe MS symptoms and relapses every year. She was not able to avoid thinking about her MS diagnosis. Looking back at the symptoms she has experienced, Ann noted that acceptance of MS became easier.
With MS you become really quite good at dealing with things when they crop up. Because you do not know what is going to happen next anyway. So, when it comes, you sort of, you deal with it and move on.

**Seize the day.** Although avoiding the MS diagnosis at first, the participants did seem to have accepted life with MS and focused on the things that made their life worthwhile. MS changed their life’s perspective in a positive way. Dani said “I have been given a second chance”. “I do not want MS to stop me”, Bec added. “I have learned to do things for myself and that way it makes me a bit more happier to be around and for my child also”. Ella remarked that MS had sped up major life decisions and that she “might as well not waste time”. She continued:

> It definitely changed my life. For, in a sense, not that MS is something you want, that is kind of, makes you see life differently. Changes your perspective on everything. So it makes you live life differently. So you enjoy life now.

> Not only did the participants focus on seizing the day. Occasionally their family members had to remind them of the importance of it. Hana’s husband has reminded her often that “they have to enjoy the now”.

> By not dwelling on MS, by living consciously whilst making informed choices, and by doing things for themselves, these mothers showed the importance of seizing the day. Changing their life perspective assisted them to stay mentally strong and they hope that this will assist them in staying physically able as well.

**Balancing life with MS**

Staying physically strong is important for people with MS. Impaired physical functioning has a major impact on life and this impact needs to be dealt with appropriately.
Additionally, stressful events increase the probability of relapse (Buljevac et al., 2003) and therefore need to be kept to a minimum. Consequently, balancing is a vital part of life for people with MS. The participants talked about the importance of conserving their energy and having a support network available for balancing life with MS.

**Conserve energy.** Although conserving energy is important, it was difficult to manage by the participants. The participants noted that they just want to go and get things done. Nevertheless, when they did too much, the families of Ann, Cath, Faye, and Hana reminded them to take it easy and conserve their energy. Consistent with findings by Payne and McPherson (2010), their families could pick up the emergence of their old MS symptoms before they even noticed these themselves. Ann explained how her children responded when they felt she should take it easy, “And so, if I don’t go rest, there can be a huge argument. I don’t have time to rest, I have got stuff to do, you know”.

MS-related fatigue was experienced by all the participants and life had to be adjusted to deal with fatigue. Gail explained:

> Well, I find I do listen to my body a bit more now than I used to. I just used to keep going and going. Huh. And so now I do have down time days or you know I do have days where I don’t achieve very much at all which wasn’t really part of my personality before.

To cope with fatigue, most participants added rest time to their daily routines, as often their old MS symptoms returned when they became too fatigued. Hana mentioned, “When I am tired, I can’t walk well”. Ann and Bec also had issues with their walking when they became too fatigued, Cath had muscle weakness, Ina suffered vertigo and June had sensation difficulties.
The participants also managed their energy by trying to plan and limit the number of activities they engaged. Cath made sure that she spread out the jobs that needed doing so she did not need to do them all at the same time. Faye found that she had to reduce the number of activities. She remarked, “We have decided we need to cut down on a lot and next term we will be at home a lot more because I’m just not coping with it too much”. Finally, Ina explained that employment can be too strenuous as well:

Yes, very tired. Um, and even physically I don’t have the ability to do it and I tried working. I worked in a school for, because I am an education support. And I worked three days a week, a week. But that was really hard. Really hard, just like I said, oh my God, I can’t work like full time, five or six days a week. Then I would definitely end up with an attack.

Fatigue is the most common of all MS symptoms (Fisk et al., 1994). All mothers relayed their struggle with fatigue and tried to conserve their energy when possible. This finding is in accord with the finding by Payne and McPherson (2010), who also found that mothers tried to regulate and limit their activities in order to deal with energetically taxing motherhood.

**Support network.** Having a support network can help mothers conserve energy and balance life with MS as well. The participants in the current research had good support networks. The participants received support from their husband, older children, their parents, siblings, school parents, and the MS society. For all, except Bec, their husband was the main support provider. Their husband assisted them with daily tasks and by looking after the children. Cath remarked “I was relying a lot on my husband and he actually reduced his work hours to be able to help me more”.
Ella’s husband started helping out more as their family grew. She mentioned, “I noticed it is changing him as well. The more kids I had the more he’s changed, like what he does now is so much more then what he did when I just had one.” All, but one of the participants, had a partner. Previous research indicated that in cases where the mother with MS does not have a partner, or whereby the partner could not deal with MS, other people stepped in to provide required support (Pakenham et al., 2012; Payne & McPherson, 2010). The findings of the current research supported this assertion. Bec, the mother who did not have a partner, had a higher level of fear of the future, yet was adequately supported by her mother, which assisted her in coping with her fear as well. This showed that it does not matter who provided the support, as long as support was provided.

The relationship Bec had with her partner had changed after her MS diagnosis. Hana, another mother, also indicated that the relationship with her partner had changed. Before she was diagnosed with MS they were each other’s equal, as both of them had demanding jobs and contributed equally to the household. Nowadays she is only able to work two mornings per week. Their plans for the future had to be adjusted. Additionally, her husband “has an extra worry” with having a spouse with MS. Ann agreed with Hana that the husband has extra worries. She believed the MS diagnosis was harder on her husband, as “he is sort of thinking long term all the time”.

This finding supported the conclusion of the research conducted by Arestedt and colleagues (2014) and Irvine and colleagues (2009). After a family member was diagnosed with MS, not only the life perspective of the person diagnosed was affected, the whole family functioning was altered. Sharing the MS experience either strengthened the relationship between family members, or weakened it (Arestedt et al., 2014).
In Bec’s case, the relationship had weakened. Bec separated from her partner at the end of last year. Her partner could not deal with Bec’s MS diagnosis and did not provide her with any support. The results of the research by Bolland and colleagues (2012) suggest that this mother’s relationship would have weakened due to the couple’s incongruent individual coping techniques.

These findings demonstrated the importance of providing support to the whole family following a chronic illness diagnosis like MS. Assisting families in finding alternative ways to deal with everyday life could strengthen relationships, which would otherwise have weakened. It could also assist the partner and the family, especially those who were not able to handle the diagnosis, to cope with the diagnosis, and/or provide the required support to the person with MS. Nevertheless, none of the participants felt that they lacked support and were able to balance life with MS well.

**Having children**

“They are always first in my life”, mentioned Ina. “You can’t worry about yourself when you have got kids who need to be looked after and taken care of first”, added Ella. These are views most mothers of young children likely share with the participants; however, as Ann remarked “you are dealing with normal stuff as well, it is, it is sort of compounded with MS”.

MS symptoms can lead to physical and emotional coping difficulties (Deatrick et al., 1998), which impact on the motherhood experience. The participants shared their experiences of having children. They talked about the decision to become pregnant and how they experience dealing with motherhood.
**Pregnancy decision.** Not all the participants had to decide on pregnancy whilst living with MS. Hana and Ina already had their children and were not planning to increase their family further when they were diagnosed. The other participants gave varied reasons for becoming pregnant. Nevertheless, none of them let MS hold them back in their decision to become mothers.

However, Cath, Ella, and June had reduced the number of children they originally wanted. This change in childbearing plans has also been highlighted previously by Smeltzer (2002). The reasons they gave were lack of energy to look after additional children and the increased possibility of relapse. Ella explained, “We would have had four, but I choose not to be on treatment while pregnant and I can’t afford to have a relapse if I have got three other kids at home”.

Smeltzer (2002) found that the timing of childbearing had also changed following MS diagnosis. It was either delayed until the progression of MS was known, or it was sped up (Smeltzer, 2002). The findings of the current research concur. Bec and Ella both decided to become pregnant sooner than they had originally planned, due to MS. Ella pointed out:

> It made me wanna have kids sooner though. A 100 percent. Yeah, change, changed my life in a way I didn’t think it would. So if I didn’t have MS I wouldn’t have kids now. I would have waited.

Bec added:

> Well, I always wanted to become a mum and knew that if it was gonna happen, sooner the better in my disease to do it. Cause I didn’t know what the future holds and the longer I left it, it might limit my opportunities in becoming a mum.
Although being a mother of a young child is particularly challenging for someone with MS. Ann, Ella, Faye, Gail, and June did not let the MS diagnosis stop them from having more children. Faye would like to have a large family and has chosen her medication so she can have a natural family planning. Gail aligned her pregnancies with medication changes, an approach shared by June. Ella remarked, “When I have kids, I get a break from treatment”.

**Dealing with motherhood.** While many of the participants chose to become pregnant after their MS diagnosis, they found it hard to deal with MS and motherhood tasks, as MS affected their ability to mother. Planning was important to combat physical issues and fatigue. Activities had to be put in place to occupy the children when the mother did not feel well; however, it was not always achievable. Cath explained “as my child was getting bigger, it was hard, harder for me to lift my child and to look after my child. I had a lot of guilt with that.” Ann also felt guilty:

Very hard, because when you are tired and sick you still gotta look after the child.

You can’t stop.... You are exhausted, so that your child misses out in doing the normal things that other kids get to do and then you start feeling guilty!

The experience of motherhood was influenced more by the severity of MS than by the number of children. As previously indicated by Deatrick and colleagues (1998), mothers were not able to look after their children when they were experiencing new symptoms due to a relapse or when old symptoms briefly resurfaced. Fatigue also played a part in their ability to mother. During these times being a mother of young children was hard as children were not able to understand their mother’s illness and still required attention. Therefore, the mothers with one child, who had been severely affected by their illness, were found to struggle more compared to mildly affected mothers with a number of young children. This
finding is congruent with research by Deatrick and colleagues (1998), yet incongruent with research by White and colleagues (2009).

Unlike what was previously indicated by White and colleagues (2011), the participants did not talk to their children about illness, unless this was required after experiencing a relapse. All of them mentioned that their young children did not understand MS. Hana’s children were angry with their mum when they had to miss out on play dates. Dani wondered how other people viewed their family life as her children often told other people that their mother is sleeping a lot. The mothers with older children added that young children were more hands on than older children, as older children were able to help out and could look after themselves. However, the participants did not yet plan to tell their children about their illness, “It is a burden that they do not necessarily need to worry about”, said Gail, “It is a bit like sex education. I am not going to tell them until they are going to ask me.”

Nevertheless, being a mother enriched and provided purpose to the participants’ lives. Children kept mothers’ minds off MS; as they were too busy looking after their children. Dani looked back at the physical issues she has had in the past and added, “How big can this blessing be? To have two healthy children and to be able to raise them... That’s so special.” And as Bec added, “You can do it, just because you got MS does not mean you can’t be the perfect mum. Cause in your child’s eyes, you are so perfect”. By having children, these mothers were taxed physically, yet gained psychological well-being. It had a positive impact on their mental health.

Occasionally it was hard for them to look after their children due to physical complaints, yet the children kept their mind off MS and brought joy. Given that there are high rates of depression among people with MS (Feinstein, 2011), having a child could be beneficial to people with MS. As long as there is adequate support available during illness
complications and life with MS is properly balanced, the psychological benefits of being a parent of a young child could outweigh the psychological demands, which is contrary to the finding by Evenson and Simon (2005), yet in line with the finding by Twork and colleagues (2007).

**Peer contact**

Psychological benefits could also be gained by contact with peers, as indicated by previous research (Dennison et al., 2010; Gordon et al., 1998; Irvine et al., 2009). The participants considered contact with peers important as well. The participants relayed their feelings of being judged by the community and how peer contact provided a sense of belonging.

**Feeling judged.** Reynolds and Prior (2003) indicated that MS could lead to social exclusion, stigmatism, and discrimination. The participants of the current study concurred. As MS is mostly invisible, people do not realise the situation these mothers are in. They also have no idea what goes on inside or the impact their remarks can have on these mothers’ well-being. Often these mothers with MS have felt judged by the community. Bec stopped using her ACROD parking permit, due to the looks and remarks she got when she parked in an ACROD parking spot.

Even friends were not always understanding, when get-togethers were cancelled for health reasons, Ann and Dani recalled. Both have lost friends because of it. Therefore, it was important to talk to peers who could understand what life was like for them.

**Sense of belonging.** Gail did not want to talk to anyone about MS, although she was able to open up to a fellow MS patient in the hospital. Dani felt much supported by a friend who has rheumatoid arthritis, as this friend could understand the fatigue. Bec found that
talking to other people with MS at her Tysabri (i.e., pharmacological MS treatment) infusion day was comforting and June regularly met up with an MS coffee group. The participants felt lonely after their MS diagnosis and talking to other MS sufferers helped. It provided them with a sense of belonging. June explained

    Yeah, it is really nice just catching up with them and, you know, we are all just ordinary women. And the majority of them, there is, I think, one who uses a cane to get around but the rest, you wouldn’t have picked them out of the crowd as: oh, she has MS. So it is just a bit of a normalising experience... I find it just a bit, you know, a bit more of a, oh I am not the only one. There are other people out there that have normal lives too.

    The MSWA has a peer support program, which organises for people with MS to talk to peers. Although peer support was only provided for a limited time, Cath found it to be helpful and was sad when it ended. According to Cath and Ann there should be more of these programs, especially for mothers with MS.

    As indicated by previous research, people with a chronic illness can be assisted by having contact with peers (Dennison et al., 2010; Gordon et al., 1998; Irvine et al., 2009). The participants in the current research supported this finding. All participants disclosed that it was easier to relate to other people with MS. It gave them a sense of belonging and reduced their loneliness. Furthermore, it could prevent them from comparing themselves to the ideal of the ‘perfect mother’ and thereby reduce stress. By facilitating more contact between peers, people with MS may be able to better their mental health.
Conclusions

The lived experience of women with MS, who have young children, was explored in the current research. Previous research had focused on the experiences of mothers with MS; however, none of these studies aimed at specifically understanding the experience of women with MS, who have children in the early childhood years. It was important to look specifically at this experience, as motherhood during the early childhood years is physically demanding and mothers with MS have limited physical capacities (Payne & McPherson, 2010). This could impact their ability to be a mother and lead to, both physical and emotional, coping difficulties (Deatrick et al., 1998).

The current research findings indicated that a change in life perspective was initially difficult and, therefore, avoided by women with MS. Yet it was necessary for their psychological well-being. They had to be able to balance life with a debilitating chronic illness in order to stay physically and mentally strong. Mostly, they tried to conserve their energy when possible. Additionally, they required support from family members to assist them with this. Having children brought physical challenges; however, it assisted them in staying mentally strong. A reason also considered whilst making the decision to have children. To combat the feeling of loneliness, contact with peers was considered to be normalising and beneficial. Limitations of the current research are discussed next.

Rigour of the Method

A limitation of the current research may be seen in the selection criteria. The current research looked at the experience of maternal MS with at least one child under the age of eight years, without any further specification. Marital status, number of children, and MS severity were not included.
Additionally, the age of the participants at diagnosis and the time since diagnosis could have affected the experience of mothering with MS. The age of the participants at diagnosis varied from 21 to 37 years. The experience of the diagnosis could be different for someone in their early twenties, compared to someone in their late thirties. Furthermore, the time since diagnosis varied from one to 20 years. Someone who was diagnosed 20 years ago would have changed their life perspective and accepted life with MS, however someone who was diagnosed recently may still be in the process of changing their life perspective and accepting life with MS. Nevertheless, as the current research was exploratory, the broad recruitment strategy was appropriate. The implications of current research are provided next.

Implications

The findings of current research have a number of implications. The themes that have been identified by the current research show how MS affects the lives of mothers with young children. This knowledge can assist practitioners and institutions in the MS area, women with MS considering motherhood, the social network of mothers with MS, newly diagnosed women, the general public, and future research. It could enhance the quality of interpersonal relationships such mothers have with others and stimulate people to provide more support to such mothers as well. Additionally, it could assist newly diagnosed women with the acceptance of their MS diagnosis.

The current research findings reflected the importance of peer support. Peer support was considered a valuable resource by all the participants. With the benefits peer support can provide to such mothers, MS societies could consider offering a variety of peer support programs, which people can be part of for as long as they require. A peer support program for mothers with MS could provide such mothers opportunities to talk to other mothers who understand their situation. As the mothers compared themselves to healthy mothers who
were more energetic and physically able, it would hopefully facilitate a shift whereby mothers with MS compare themselves to other such mothers and not to an ideal of healthy ones.

However, mothers of young children have hectic lives; balancing their illness and their young energetic family. Furthermore, due to Australia’s vastness, it might be difficult for such mothers to meet peers in person. Therefore, peer support programs could be tailored to the lives such mothers lead. Members-only social media groups could be an option. Counsellors from an MS society could lead these groups and invite their members to join. These groups could facilitate contact with peers, provide support through the counsellors, and arrange get-togethers and online seminars.

**Future Directions**

Further research is encouraged to test and validate the current findings quantitatively with larger representative samples. This could be achieved by designing quantitative measures based on current findings. The knowledge acquired by the current research may also inform future research, which may focus on specific variables that influence the experiences of mothers with MS, such as marital status, the number of children, or a different developmental stage.

In addition, the experience of the partners of mothers with MS could be explored. Current research found that the partner provided the main support. The MS diagnosis had also changed these couples’ relationships. By having a spouse with MS, these men had extra worries, which could influence their mental health.

The mental health of the children of mothers with MS could be affected as well. Previous research has already indicated that parental MS has a negative effect on children
Young children were found to have a basic understanding of illness (Myant & Williams, 2005) and would not be able to understand their mother’s illness. The experiences of children of mothers with MS, between the age of four and eight years, would be valuable to explore in order to observe whether this age group is negatively impacted by their mother’s MS and how this may be addressed.

Insight into these experiences would inform institutions and practitioners in the MS area. Furthermore, it could assist in setting up support programs for these men and children, as there are currently limited support programs for the families of people with MS.

In conclusion, the current research provided an in-depth and meaningful insight into the lived experiences of women with MS, who have young children. Additionally, the current research also identified how such mothers can be assisted and provided a foundation for future research and practitioners in the MS area to build on. MS can have a significant influence on the lives of such mothers and, subsequently, their families. Nevertheless, despite facing many physical and psychological challenges and by changing their life perspective, balancing life with MS, having children, and peer contact, such mothers were able to live contently and mother despite MS. Especially as having young children can be regarded as a positive mediator for well-being.
References


Appendix A

‘Vitality’ Advertisement and Research Recruitment Flyer

Would you like to help?

- Are you a mother with Multiple Sclerosis?
- And, do you have child(ren) younger than 8 years of age?
- If so, then I seek your assistance!

There are a lot of challenges for mothers with MS, who have young children. Only due to the unpredictable nature of MS all of us experience this differently. My name is Astrid Plumb-Parlevliet and, just like you, I am a mother with MS, who has young children. Currently I am researching what it means to live with MS whilst being a mother of young children, approved by SPSS Ethics Subcommittee, as a requirement for the course of Bachelor of Arts (Psychology) Honours at Edith Cowan University.

You will be asked to share your stories. You will be asked questions on your feelings and views on this experience. This could be a great opportunity for you to talk about your experience, whilst contributing to research at the same time. Interviews will last approximately one hour and will be voice-recorded. In the research documentation you will remain anonymous and results will be confidential. Informed consent will be required.

I hope this research will help others understand what it is like to be a mother with MS and young children and provide insight into required services.

INTERESTED? PLEASE CONTACT BY PHONE OR EMAIL ON:

Astrid Plumb-Parlevliet
Phone number: (08) 9562 5963
Mobile number: 0423 936 231
Email: aplumbpa@our.ecu.edu.au

Supervisor: Dr. Eyal Gringart
Edith Cowan University
Faculty of Health, Engineering and Science
Joondalup, WA

If you wish to contact an independent person about this research, please contact Dr. Bronwyn Harman (Honours Coordinator) at b.harman@ecu.edu.au or on (08) 6304 5021.
Appendix B

Information letter

May 2015

Dear potential participant,

Subject: Maternal Multiple Sclerosis: Lived Experiences of Mothers of Young Children

Thank you for your interest in this research and for responding to the advertisement. My name is Astrid Plumb-Parlevliet and I am currently conducting this research as a requirement for the course of Bachelor of Arts (Psychology) Honours at the Faculty of Health, Engineering and Science of Edith Cowan University. This research has been approved by the Edith Cowan University School of Psychology and Social Science Ethics Sub-committee and Sue Shapland, the Member Services General Manager of the Multiple Sclerosis Society of Western Australia.

The aim of this research is to increase understanding and knowledge on what it means to live with Multiple Sclerosis (MS) for mothers of young children. As you are a mother with MS, who has young children, I would really like to hear about your experience. Participants will be asked to share their stories during one interview. They will be asked questions about their feelings and views on this experience. Interviews will last approximately one hour and will be voice-recorded. I will transcribe these interviews and provide you with a copy of the transcript and a preliminary list of themes. I will follow up by phone to discuss whether you consider these themes a reasonable reflection. The only people who will have access to the transcripts of your interview will be my supervisor and me. During the research project the data and recordings will be kept in my lockable office. After the completion of this research, the voice-recordings will be erased and transcripts will be stored in a secure filing cabinet by the research’s supervisor at Edith Cowan University for the duration of 5 years. After 5 years the transcripts will be destroyed. Participant’s names will be replaced by pseudonyms so that transcripts are not identifiable.

Participation in this research should not cause you any discomfort or distress. Nevertheless in case you would like to talk to someone following the interview about your experience, you may contact Lisa Papas, Manager Counselling at the MS Society of WA, on (08) 9365 4836. You could also contact the Crisis Care Helpline on (08) 9223 1111 or Lifeline WA on 13 11 14. Both of these services are available 24 hours a day, 7 days a week.
There are legal limits to confidentiality and therefore you will remain anonymous in the research documentation, through the use of a pseudonym, and results will be confidential. An informed consent form, which is attached to this letter, will need to be signed. Your involvement in this research is voluntary and you are able to withdraw from this research at any time. There are no financial benefits offered for participating in this research.

The results of this research will be presented at the fourth year poster presentation. Furthermore the results of this research will be published as a thesis and possibly in scientific journals or other media. Confidentiality and anonymity are assured for the poster presentation and for any publication.

In case you are interested in the results of this research, I will be happy to provide a summary of the findings to you. Completion has been scheduled for mid November 2015.

If you have any questions or require any further information regarding this research, please do not hesitate to contact me via the details found below, or my supervisor, Dr. Eyal Gringart, on (08) 6304 5631 or at e.gringart@ecu.edu.au. In case you have any concerns about this research or would like to talk to an independent person, you may contact Dr. Bronwyn Harman, who is the Honours Coordinator, on (08) 6304 5021 or at b.harman@ecu.edu.au.

Yours sincerely,

Astrid Plumb-Parlevliet, BA (Psych)

Phone number: (08) 9562 5963

Mobile number: 0423 936 231

Email: aplumbpa@our.ecu.edu.au
Appendix C

Informed Consent Form

May 2015

Research: Maternal Multiple Sclerosis: Lived Experiences of Mothers of Young Children

I, __________________________________, freely consent to participate in the research conducted by Astrid Plumb-Parlevliet as a requirement for the course Bachelor of Arts (Psychology) Honours at the Faculty of Health, Engineering and Science of Edith Cowan University. I consent that:

- I have read the information letter provided and I understand the purpose of the research.
- I have been provided with a copy of the information letter.
- I have been given opportunity to ask questions, which have been answered to my satisfaction.
- In case I have any additional questions, I may contact the researcher or the supervisor of this research.
- I understand that I will participate in one interview in which I will be asked about my experience as a mother with MS, who has young children.
- My interview will be voice-recorded and transcribed. After completion of this research this voice-recording will be erased.
- I understand that I will be provided with a copy of the interview transcript. In case I do not feel this transcript is accurate I will contact the researcher.
- I understand that all information provided will be kept confidential and that my identity will not be disclosed without my consent.
- I understand how the information collected will be used and that this will only be used for the purpose of this research and potential publication.
- I understand I am able to withdraw from this research at any time, without any penalty and explanation.
Participant’s signature  ________________________________  Date  ________________________________
Contact number  ________________________________
Researcher’s signature  ________________________________  Date  ________________________________

Researcher: Astrid Plumb-Parlevliet  ________________________________  Supervisor: Dr. Eyal Gringart
Phone number: (08) 9562 5963  Phone number: (08) 6304 5631
Mobile number: 0423 936 231
Email: aplumbpa@our.ecu.edu.au
Appendix D

Semi-Structured Interview Schedule

First of all I would like to thank you for participating in this research. I am very interested to hear about your experience of being a mother with MS, who has young children. Please know that anything you will be able to tell me about this experience is considered valuable.

1. Could you please tell me about yourself, your children and whether or not you have a partner?
2. Could you please tell me about your history with MS?
3. What do you consider the biggest issue you face due to MS?
4. How did you experience making the decision to become a mother?
   a. How did having MS influence this decision?
5. What does it mean for you to be a mother of a young child/young children whilst living with MS?
6. How do you experience balancing care for yourself, your child(ren) and daily duties?
7. Do you feel supported in your role as a mother?
   a. Can you give me an example of times when you did or did not feel supported?
   b. What was it like for you during this time?
   c. What sort of support would have made it easier for you to get through this time?
8. Have you ever been in contact with health care professionals and/or counsellors to discuss illness complications in relation to your family life?
   a. If so, how did this assist you?
9. What is your perception of the way your family experiences your illness?
10. In your experience, what do you think are the main issues faced by mothers with MS, who have young children?

11. Where do you find your strengths?

12. What do you think should be done to make life easier for mothers with MS, who have young children?

13. What would you recommend to other mothers with MS, who have young children?

14. Is there anything you would like to add that we have not discussed yet?

Thank you again for participating in this research!