The impact of MS on intimate relationships:
The role of identity

by

Melissa Pauline Bolton

A thesis submitted in conformity with the requirements for the degree of Doctorate of Philosophy
Applied Psychology & Human Development
Ontario Institute for Studies in Education
University of Toronto

© Copyright by Melissa Pauline Bolton 2014
THE IMPACT OF MS ON INTIMATE RELATIONSHIPS:

THE ROLE OF IDENTITY

Melissa Pauline Bolton

Doctorate of Philosophy

Applied Psychology and Human Development
University of Toronto

2014

Abstract

The present study explored the qualitative experience of women with multiple sclerosis to delineate the intrapersonal process, relational and broader social influences in the process of identity preservation/or/change. While there is a breadth of literature on the variables associated with relational satisfaction for those with MS, far less has been conducted on how identity is impacted or influences psychosocial adjustment following illness. The findings of this research were applied to broader principles asserted by identity theory and the identity negotiation theory (INT) in an effort to explore whether these theories could share added insight and value into the experience of these women. In-depth interviews were conducted with twenty-two women from across Canada.

Our findings suggest that women with MS undergo significant aspects of identity re-negotiation. Participants entered into a process of re-negotiation when they experienced a change in their social roles based upon physical disability. Within our findings was the emergence of three main groups of participants: Participants who did not experience physically disabling symptoms and thereby did not experience any identity disruption; Participants who
experienced identity disruption and experienced difficulty with these changes; and those who
d岛上well in their ability to adapt to physical changes and maintain continuity in aspects of their
identity. This was influenced by both intrapersonal variables such as ones ability to maintain
continuity in role-identities, find acceptance, positive reframe their situation and express
gratitude. Moreover, this was also largely influenced by interpersonal feedback and support
from their partner and peers.

Relational context played a significant role in identity preservation or alteration. An
intimate partner played a paramount role in whether women felt self-verified and nourished
while undergoing ambiguity associated with ever-changing physical limitations. The variables
that facilitated this process included: commitment to identity; relational clarity; continuity; self-
verification and an ability to preserve salient aspects of identity despite physical changes. This
study highlights the process of identity disruption for this population and provides valuable
insight into the process of preserving salient aspects of identity while navigating physical
disability both for the individual and the couple.
Acknowledgments

I would like to express my deep gratitude, respect and appreciation to my supervisor Dr. Margaret Schneider, whose instrumental guidance, mentorship and support has been invaluable throughout my graduate career and in my development as a clinician and researcher. I would also like to express my thanks to my doctoral dissertation committee members Dr. Stermac and Dr. Saunders for their guidance and feedback throughout this research venture. In addition, thank you to the MS society of Canada for their promotion of this study on their research portal and for all of their work and achievements to better the lives of individuals with this illness.

Like all achievements, it requires the support of a village (or in my case, large family) and I would also very much like to express my deep gratitude towards my parents and sister who have supported me in every way towards achieving my dream of attaining my PhD. Thank you to my husband for his unwavering support, patience and care all throughout the winding road of university & graduate studies. You have all been a source of constant encouragement, inspiration and support.

Finally, I want to express my deepest gratitude to my participants who shared their journey and lived experience openly and candidly. They revealed their stories of strength, humility, adversity and courage which has been treasured reassurance for the importance of this type of research and clearly illustrated the resiliency of the human spirit.
# Table of Contents

Abstract ..................................................................................................................... ii  
Acknowledgments ................................................................................................... iv  
Table of Contents ................................................................................................. v  
Chapter 1: ............................................................................................................. 1  

## Literature Review

1.1 Psycho-social implications of MS ................................................................. 3  
1.1.1 Relationship satisfaction ................................................................. 3  
1.1.2 Sexuality ......................................................................................... 4  
1.1.3 The well partner ........................................................................... 6  
1.1.4 Acceptance ..................................................................................... 7  
1.1.5 Relationship dynamics ................................................................. 8  
1.1.6 Research consideration ................................................................. 9  
1.2 Identity theory ......................................................................................... 9  
1.2.1 Inner Experience versus External Pressures .................................. 10  
1.2.2 Salience & Commitment ..................................................................... 10  
1.2.3 Role-Identity .................................................................................. 11  
1.2.4 Self-Verification ........................................................................... 13  
1.2.5 Research Consideration ................................................................. 14  
1.3 Identity Negotiation Theory ................................................................. 15  
1.3.1 Clarity ............................................................................................ 16  
1.3.2 Cooperation ................................................................................... 16  
1.3.3 Continuity ..................................................................................... 16  
1.3.4 Compatibility ................................................................................. 17  
1.3.5 Seven key mechanisms ................................................................... 17
<table>
<thead>
<tr>
<th>Chapter</th>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.7</td>
<td></td>
<td>Incongruence versus cooperation</td>
<td>63</td>
</tr>
<tr>
<td>3.8</td>
<td></td>
<td>Predictors of positive outcomes for couples</td>
<td>66</td>
</tr>
<tr>
<td></td>
<td>3.8.1</td>
<td>Cooperation &amp; Self-Verification</td>
<td>66</td>
</tr>
<tr>
<td></td>
<td>3.8.2</td>
<td>Communication and relational clarity</td>
<td>76</td>
</tr>
<tr>
<td>3.9</td>
<td></td>
<td>Identity is impacted by social context</td>
<td>80</td>
</tr>
<tr>
<td>3.10</td>
<td></td>
<td>Three emergent groups</td>
<td>83</td>
</tr>
<tr>
<td>3.11</td>
<td></td>
<td>Participants whose identity were not disrupted</td>
<td>84</td>
</tr>
<tr>
<td>3.12</td>
<td></td>
<td>Disruption in role-identity</td>
<td>90</td>
</tr>
<tr>
<td></td>
<td>3.12.1</td>
<td>Disrupted identity: Coping well</td>
<td>91</td>
</tr>
<tr>
<td></td>
<td>3.12.2</td>
<td>Disrupted identity: Struggling</td>
<td>97</td>
</tr>
<tr>
<td>4</td>
<td></td>
<td>Discussion Section</td>
<td>102</td>
</tr>
<tr>
<td></td>
<td>4.1</td>
<td>The internal processes of identity preservation or change</td>
<td>102</td>
</tr>
<tr>
<td></td>
<td>4.2</td>
<td>Relational influences on identity</td>
<td>104</td>
</tr>
<tr>
<td></td>
<td>4.3</td>
<td>The applicability of identity negotiation theory</td>
<td>106</td>
</tr>
<tr>
<td></td>
<td>4.4</td>
<td>Applicability of broader identity theory</td>
<td>107</td>
</tr>
<tr>
<td></td>
<td>4.5</td>
<td>Implications for clinical treatment</td>
<td>109</td>
</tr>
<tr>
<td></td>
<td>4.5.1</td>
<td>Individual Therapy</td>
<td>109</td>
</tr>
<tr>
<td></td>
<td>4.5.2</td>
<td>Couples Therapy</td>
<td>111</td>
</tr>
<tr>
<td></td>
<td>4.6</td>
<td>Research limitations</td>
<td>112</td>
</tr>
<tr>
<td></td>
<td>4.7</td>
<td>Considerations for future research</td>
<td>113</td>
</tr>
<tr>
<td>5</td>
<td></td>
<td>References</td>
<td>115</td>
</tr>
<tr>
<td>6</td>
<td></td>
<td>Appendix A:</td>
<td>123</td>
</tr>
<tr>
<td>7</td>
<td></td>
<td>Appendix B: Recruitment Flyer</td>
<td>125</td>
</tr>
<tr>
<td>8</td>
<td></td>
<td>Appendix C: Organizational consent</td>
<td>126</td>
</tr>
<tr>
<td>9</td>
<td></td>
<td>Appendix D: Information page &amp; consent form</td>
<td>127</td>
</tr>
<tr>
<td>10</td>
<td></td>
<td>Appendix E: Telephone Script</td>
<td>129</td>
</tr>
</tbody>
</table>
11 Appendix F: Post-interview information & resource page ..................................................131
12 Appendix G: Interview guide ..........................................................................................132
Chapter 1: Literature Review

Multiple sclerosis (also known as MS) is a permanent and chronic neurological disorder caused by focal demyelination and atrophy of nerves within the central nervous system (Bronner, Elran, Golomb & Korczyn, 2010). The resulting symptoms are expansive and can impact multiple systems within the body; causing impairments in hearing, vision, mobility, fatigue, incontinence and cognitive functioning (Britell, Burks & Schapiro, 2000; Harrison, Stuifbergen, Adachi & Becker, 2004).

MS is individual in its trajectory and is often characterized by unpredictability of symptoms and degree of severity. The majority of individuals experience a “re-lapsing-remitting course” marked by inflammation of symptoms with periods of remittance sporadically between relapses (Bronner et al., 2010). Regardless of the course of impact, MS is a debilitating and chronic illness with no present cure.

The MS society of Canada recognizes four different disease trajectories. The first, relapsing-remitting MS (also known as RRMS) describes an incremental stage course of the disease. Although the symptoms may be unpredictable at times, they typically are distinguished into separate stages in which additional symptoms emerge or the overall cluster of original symptoms become exaggerated. The duration of these episodes vary between two days to months. Between episodes there are periods of remission from symptoms and individuals usually function at their ability pre-episode. This time period is variable and unpredictable, averaging between months or years before experiencing the next attack of symptoms. At the point of diagnosis, the majority of individuals are characterized by this type of MS.
Relapsing remitting MS is often divided into two subgroups: benign MS and clinically isolated syndrome. Benign refers to a lengthy period of remission between attacks. In these cases there are few symptoms and typically no markers of physical disability. The primary symptoms are limited to sensory impairments to vision and touch. This course is relatively rare compared to the other types of MS. Clinically isolated syndrome (also referred to as CIS or Probable MS) is characterized by a single incident of symptoms (neurological symptoms). This is evidenced early in the diagnosis and a re-evaluation follows a few months later to look for any indication of secondary attacks (which would then indicate RRMS).

The second type is known as primary progressive MS (also known as PPMS). This trajectory is marked by a progressive, stable worsening of symptoms over time without the presence of relapses. Although individuals may experience periods of mild symptom stability they do not experience remission from symptoms (indicative of pre-symptom functioning). This type of MS is more common for those diagnosed in their forties and impacts 10% of those diagnosed.

The third type is referred to as secondary progressive MS (also known as SPMS). This trajectory usually begins with RRMS, which then deteriorates into SPMS. Through time, symptom relapses and remissions become less frequent. In turn, there is a progressive stability of symptoms and disabling conditions. This course typically occurs one decade after diagnosis and affects half of those diagnosed.

The fourth type is referred to as progressive relapsing MS (also known as PRMS). This course is marked by a continuous exacerbation of symptoms from the onset of diagnosis. Patients are originally diagnosed with PPMS, but after experiencing an acute attack of symptoms
the diagnosis is re-established as PRMS. This presents as the rarest course of multiple sclerosis, impacting only 5% of those diagnosed (Bronner et al., 2010).

1.1 Psycho-social implications of MS

Each subtype of MS is varied, unpredictable and results in physically disabling symptoms. Moreover, this disease is uniquely expressed and individualized. Women with the same type of disease trajectory can experience very different onsets, flare-ups and degree of disability. For many women, this onset can be incredibly disruptive and require them to accommodate for these changes in many facets of their everyday living. The ever-changing and uncertainty associated with MS as a disease causes continuous changes and hurdles.

Due to the unpredictable and disabling symptoms associated with MS, researchers have identified many psycho-social implications and personal costs of dealing with this chronic illness. Research has suggested that MS impedes upon social norms and previously established roles. The main variables that have been explored to date have been: social support, intimate relationships, acceptance and synchronicity; which have all been deemed important variables in coping with this illness. This section will explore each of these identified variables in greater detail.

1.1.1 Relationship satisfaction

Social support is believed to play a vital role in adapting and positively coping with chronic illness. Women with MS spend significant time and personal resources to ensure that their intimate relationship is secure as they navigate through this unpredictable disease (McCabe et al., 1996). There remains some tension in the literature as to the effects of relational strain
and/or satisfaction in coping with this particular chronic illness. Secondary physical effects (such as bladder dysfunction) can cause sexual dysfunction which some have asserted cause increased relational dissatisfaction (Schmidt, Hofmann, Niederwieser, Kapfhammer & Bonelli, 2005). However, overall this does not necessarily lead to higher levels of marital separation or divorce compared to the overall population (Hakim et al., 2000; McCabe & McDonald, 2007).

On the contrary, emerging research has illustrated that relationships are often enriched as a result of going through the process of illness. Partners are often re-appraised as being closer and more intimate, and husbands may develop greater respect for her strength and resiliency (Hefferon, Grealy & Mutrie, 2009). Moreover, some have suggested that undergoing an adjustment process together strengthens the bond between spouses as they uncover different facets to their relationship (Baraskova & Oesterreich, 2009).

McCabe et al. (1996) suggest that the quality of one’s intimate relationship becomes amplified in the face of adversity. In her research she discovered that: one-third of her respondents reported negative implications causing emotional distance or complete dissolution of the relationship; one-third reported that in spite of sexual dysfunction there were no changes in the relationship; and one-third reported experiencing positive changes in their intimate relationship (McCabe et al., 1996). McCabe postulates that ‘cracks’ within relationships become magnified upon diagnosis. Therefore, healthy relationships become stronger and those relationships that were flawed at the onset of diagnosis gradually dissolve (McCabe et al, 1996).

1.1.2 Sexuality

Sexuality and sexual expression are important features of intimate relationships. There is emerging literature on the impact of MS on sexuality for couples with this illness. For women
the physicality of sexual dysfunction can significantly impinge upon overall quality of life (Demirkiran, Sarica, Uguz, Yerdelen & Aslan, 2006). Symptoms of sexual dysfunction are multi-dimensional and impact individuals at the physical, emotional and psychological realms and is often exacerbated or mediated by social and interpersonal resources (Bronner et al., 2010).

The onset of MS typically occurs during young adulthood, a time when sexual identity and sexual scripts have been established and intimate relationships are emphasized as having great social value (Esmail, Huang, Lee & Maruksa, 2010). This disease strikes at a time of life where sexuality has been shaped and acts to contrast previous sexual normative and expectations established prior to diagnosis (Jonsson, 2003; Kralik, Koch & Eastwood, 2003; Schmidt et al., 2005). Women are forced to continuously re-define their sexual norms to adjust for unpredictable changes in their body. The impact of the physical limitations can alter her sense of sexual identity and her perception of self in this context both as a woman and as a partner. This can greatly impede upon how she views and understands herself and her body (Hordern, 2000; Schmidt et al., 2005).

This is further influenced by western social conventions regarding sexuality which include ideals of beauty, body image, self-esteem, communication within relationships, affirmation and acceptance from self and partner and the idea of ‘able-ness’ (Koch, Kralik & Eastwood, 2002; Schmidt et al., 2005). Women are faced with having to de-construct themselves as a sexual being and reconfigure their self-view to fit a disabling condition. Researchers have asserted that the impact upon sexuality and this particular facet of identity acts to then influence how this chronic illness becomes incorporated or accepted into one’s life and overall psychosocial adjustment (Kralik et al., 2003).
1.1.3 The well partner

As MS progresses, individuals can require greater support and dependence to fulfill functions of daily living. The increased level of reliance places pressure on the partner and can cause significant tension within the relationship (De Loach & Greer, 1981; Irving, Davidson, Hoy & Lowe-Strong, 2009; McCabe & McDonald, 2007; Schmidt et al., 2005). In a study conducted by McCabe & McDonald (2007) the partners of individuals impacted by MS were included. Researchers found that the partners were more likely to report negative repercussions for the relationship since the diagnosis. The partner may feel as though their emotions and needs are neglected in favor of caring for their partner’s chronic illness, which often poses a strain on the relationship (McCabe & McDonald, 2007).

MS is often associated with increasing physical dependency (Schmidt et al., 2005). Researchers have suggested that this shift in role within the relationship can be difficult, as women are traditionally considered the ‘nurtureurs’ by westernized gender norms (Morris, Woods, Davies & Morris, 1991). The fluidity in this role shift is based upon a multitude of influences including one’s level of flexibility and openness, notions of gender equality, understanding of illness, willingness to reach out to family and outside help, and level of vulnerability towards depression and anxiety disorders (Harrison et al., 2004). How their partner perceives and receives this new role within the relationship will also greatly influence the relationship. If the ill partner perceives dissatisfaction and frustration, it will often cause feelings of guilt and a lessened self-esteem (Esmail et al., 2010). This transition further impacts the quality of the relationship (McCabe & McDonald, 2007).

However, others have suggested that the dynamic between caregiver/romantic partner and the ill individual is multifaceted and there is often a fluid interpersonal process that
accompanies this transition in roles. In a qualitative study conducted by Irving et al. (2009) researchers found that many women with MS are conflicted by the changing dynamics. In becoming more dependent on their loved one many individuals become frustrated when others attempt to help them do things that they are capable of doing. They felt that others were undermining their abilities and capacities. Thus, these transitions are marked by the need to find an interpersonal balance.

1.1.4 Acceptance

Research has illustrated that acceptance of MS plays a key role in relationship and marital satisfaction. Harrison et al. (2004) discovered that couples who remained married while coping with chronic illness all cited acceptance of disability as a major influence on their marital satisfaction. Acceptance often correlated with flexibility and adjustment towards disability and resulted in greater health outcomes (Burton, 1995; Harrison et al., 2004). Whereas negative reactions from a loved one can strain the relationship, acceptance of the illness facilitates self-acceptance and relationship satisfaction (Harrison et al., 2004). The acceptance of one’s partner can greatly influence one’s self-acceptance of MS.

Acceptance of illness is associated with a better prognosis for individuals suffering from MS (Harrison et al., 2004; Stuifbergen, Seraphine & Roberts, 2000). Research has demonstrated that acceptance facilitates healthy psychological adjustment and correlates with greater life satisfaction (Burton, 1995; Harrison et al., 2004; Stuifbergen et al., 2000). Acceptance also correlates with higher health promoting behaviors which indirectly aid in decreasing the severity of symptoms and sexual dysfunctions (Harrison et al., 2004; Stuifbergen et al., 2000).
Relationships which are established after diagnosis of MS typically have a positive impact on the psychological and emotional wellbeing of partners, and those who date and marry after the female partner has received the diagnosis of MS report higher rates of marital and relationship satisfaction (Crewe, Athelstan & Krumberger, 1979; Crewe & Krause, 1988; Harrison et al., 2004). It is postulated that since the relationship was formed with knowledge of the disability and its potential demands, acceptance is higher than if the diagnosis had occurred midway through the relationship (Harrison et al., 2004).

1.1.5 Relationship dynamics

Studies have also focused on coping strategies, care burden, sexual dysfunction and the effects of MS on relationships (Blank & Finlayson, 2007; Boeije, Duijnstee, & Gypdonck, 2003; Boeije & vanDoorne-Huiskes, 2004; Cheung & Hocking, 2004; Courts, Buchanan & Werstlein, 2004; Good, Bower, & Einsporn, 1995; McKeown, Porter-Armstrong, Baxter, 2003; O’Brien, 1993). However, less research has been done to evaluate the dyadic exchange between intimate partners as they navigate this unpredictable disease (Starks, Morris, Yorkston, Gray & Johnson, 2010).

In a qualitative study conducted by Starks et al. (2010) researchers evaluated potential risk factors associated with relational strain. The results indicated that the degree of relational strain was categorized by synchrony, with couples who are ‘in sync’ faring better than those ‘out of sync’ with their partner. Synchrony was related to which course of MS an individual experienced. Those with relapsing-remitting MS, synchronicity between partners and a collaborative problem solving style fared better than those ‘out of sync’. Although ‘identity’ was recognized as a variable associated with the degree of relational strain, researchers failed to
elaborate on the unique contributing factors associated with identity within the relationship and whether that influenced said process.

1.1.6 Research consideration

The onset of MS interrupts the social norms and scripts of the individual and her intimate relationship. In particular, it has an impact on relational satisfaction, sexuality, synchronicity, acceptance and social roles. Researchers believe that identity is an important factor in determining how women navigate this interruption and the consequent changes in their lives.

In addition, identity and intimate relationships are interactive. Thus, identity may mediate the impact of a debilitating illness on the individual and on her intimate relationship, while the relationship itself may affect identity as it changes due to the impact of the illness. Therefore, the purpose of this study is to investigate the impact of MS on identity and to investigate the interaction between intimate relationship and identity and how these factors combine to affect the ability to cope with the disabling symptoms of MS.

1.2 Identity theory

In accordance with identity theory, identity is conceptualized as the “set of meanings that are tied to sustain the self as the individual.” (Stets & Burke, 2000, p. 229). The associated values and meaning are consistent and function across different situations and roles (Stets, 1995; Stets & Burke 1996). Generally speaking, identities are created from self-views which result from their beliefs about their self. They are also created from role-identities and group memberships, and from the interpersonal verification from others that solidify individual’s perception of their identity (Stets & Burke, 2000).
1.2.1 Inner Experience versus External Pressures

To date, there has been discussion regarding whether the internal processes or external environmental pressures are more influential over the shaping of identity (refer to the work by work of Stryker & Burke, 2000). Regardless, it is well recognized that social environment has an impact. The interaction and feedback from environment influences appraisals and behaviour. According to identity theory, individuals aspire to act in a manner that is congruent with their identity (Stryker & Serpe 1994) because behavior is an expression of identity. Furthermore, that expression is embedded within the interaction of interpersonal exchanges and social environment. There is a drive to create meaning and have one’s sense of identity confirmed by others.

1.2.2 Salience & Commitment

Salient (or valued) aspects of identity are those that are stabile across a variety of contexts and situations. Social identity theorists assert that a salient aspect of identity is that which colors perceptions and influences an individual’s behavior; whereby that set of standards and meaning would become triggered in relevant situations (Oakes, 1987; Stryker 1980). For example, if an individual maintains the perception of him/herself as a competent person, then this perception would become activated in situations where he/she were called to perform a difficult task and success would be an important goal.

Identity salience is strengthened by commitment. One’s commitment to any given social role and interpersonal environment is an important factor in whether that aspect of one’s identity is prized. Basically, how much it would then personally impact or cost to lose that aspect of their identity should their social role change or be altered? Stryker & Serpe (1982; 1994) have
asserted this is based on two fundamental variables. One, commitment is based on the number of people who are linked to that aspect of your identity. They propose that the greater the individuals involved will increase the likelihood that aspect will become triggered within a situation. For example, if that competence was linked to being the manager of a company, then the level of commitment to that aspect of one’s identity would be solidified. In addition to sheer quantity it is also the quality of the relationships and the perceived importance of those relationships which also increases salience to one's identity. For example: being perceived as competent by your partner would be of greater value than that of an acquaintance. Identity theorists have asserted that the greater the commitment to valued aspects of oneself, the more salient that feature of their identity will be in influencing behaviors (Stryker 1980; Stryker & Serpe 1982).

As people have different valued aspects to their identity and many identity-roles, complimentary identities can act to further reinforce one another. However, discrepancy results in competition or conflict (Stryker et al., 2000). In this case, whichever aspect of identity has a higher level of stability and commitment will set the precedent. If the situation is less threatening, it will require low commitment and stability. Due to the discrepancy, the individual will likely lose motivation in this regard and it will be disregarded and inconsequential in influencing behaviour. Moreover, if the situation calls for equally high levels of commitment between competing aspects of identity, then it will result in distress and cause the individual to address action to resolve the discrepancy (Burke, 1991).

1.2.3 Role-Identity

According to Stets & Burke (2000), “The core of an identity is the categorization of the self as an occupant of a role, and the incorporation, into the self, of the meanings and
expectations associations associated with that role and its performance” (Stets & Burke, 2000, p. 225). Within roles there are perceived expectations, meanings and standards associated which in turn then act to guide performance (Burke 1991; Burke & Reitzes, 1991).

‘Role-Identity’ refers to which social roles an individual will adopt, endorse and is based on underlying personal beliefs. Some roles will have higher priority over others. For example: for some having a defined family-role may be more important than an occupational-role or vice versa. These role-identities, or roles that we adopt, are defined both by what we subscribe to as being important in our lives, paired with our larger social structure (McCall & Simmons 1978; Stryker, 1980). Our role-identities are believed to be a representation of ourselves as a whole (Stets & Burke, 2000).

Endorsing a particular ‘role identity’ requires individuals to then meet the expectations required of that position. This is fulfilled through interpersonal interactions and negotiations, while also navigating environmental resources to meet the demands of that role. For example, in a role you assume a list of internally defined expectations of self (i.e. perceptions of what is required to successfully meet the demands of that role) as well as the social demands that are required of that position (interpersonal demands, as well as external resources to meet same) (Stets & Burke, 2000). Therefore, individuals must strike a balance between core facets of their identity with that of the demands of their role-identities (Stets 1995). For example: the belief of being a competent person is therefore verified by role-identities as an effective employer; which would be solidified by positive feedback from colleagues.

Identity theorists have asserted that negotiation is required to match up the individual’s expectations and perceptions of what it takes to fulfill a certain role, with that of their behaviors in interacting with others to negotiate that role as it relates to others (Burke, 1980; Burke &
Reitzes, 1981). Individuals internalize a series of expectations, meanings and appraisals of the demands of the role and how it relates to the expectation of others. Ultimately, role-identities are a dyadic experience based upon feedback (Thoits & Virshup, 1997).

As mentioned, these roles are not all created equal and we are more highly committed to ones that represent valued aspects of identity. Therefore, we will act to preserve and maintain the meaning associated with fulfilling the internalized expectations of that role, as well as the appraisals and feedback received from others about our performance in that role. Role-identity is a representation of our valued aspects of core features of our identity (Stets & Burke, 2000).

Our roles are interconnected, interactive and function based upon interpersonal exchange and feedback from others (McCall & Simmons 1978). When different people bring their own perspectives and beliefs regarding role it creates a microcosm of group norms and expectations (for example: assigned expectations and hierarchies within employment settings) (Riley & Burke 1995; Stets 1997; Stets & Burke, 1996). If and when interests are at odds, role performance can only be accomplished through negotiation. Researchers have discovered that when negotiation regarding roles cannot be met then individuals in those respective positions become less satisfied and/or will leave that role (Riley & Burke, 1995). Conversely, when roles are negotiated successfully (and verified by others) then it enhances an individual’s attachment to that role (Burke & Stets, 1999).

1.2.4 Self-Verification

When parts of one’s identity are not socially reciprocated or validated, then a discrepancy occurs which breeds a level of psychological distress. Conversely, when one experiences self-verification in their exchange the resulting emotions are positive thereby further reinforcing the
commitment of same (Burke & Stets 1999; Ellestad & Stets 1998; Smith-Lovin & Heise, 1988; Stets & Tsushima 1999). A discrepancy thereby produces negative emotions and acts to then motivate and encourage alternative behaviour in an effort to then find congruence between aspects of identity and external feedback (Stets & Carter, 2011). Other researchers have asserted that the term self-verification is embedded within the term identity itself as it is believed to be comprised of both one’s personal sense of self paired with whether this is also mirrored and confirmed by others (Howard, 2006).

When an individual has a salient role-identity and receives positive feedback (self-verification) regarding their performance, this increases their self-esteem (Burke & Stets, 1999; Franks & Marolla, 1976; Hoelter, 1986; Stets & Burke, 2000; Stryker, 1980). Moreover, that same situation would also provoke a sense of control and mastery over one’s role and therefore also increase feelings of self-efficacy environment (Franks & Marolla 1976; Gecas & Schwalbe, 1983; Stets & Burke, 2000).

1.2.5 Research Consideration

The literature on identity theory suggests that one’s level of salience, commitment, role-identity and self-verification within a social context are all important variables in understanding how identity is maintained (reinforced) or altered (distinguished). It is hypothesized that these processes come into play during times of identity change, and may play a role in how individuals with MS preserve or change aspects of their identity.
1.3 Identity Negotiation Theory

As previously discussed, when aspects of one’s identity are challenged by incongruent external feedback, researchers have proposed that it can result in a re-negotiation process. The identity negotiation theory (INT) asserts that one’s identity is influenced by whether it is ‘nourished’ within social contexts (i.e. verified by others). Social feedback that is congruent with sense of self, identity is strengthened. When it is not, it creates anxiety and sets in motion re-negotiation.

Individuals are more satisfied with intimate partners who will confirm aspects of their identity rather than challenge it. Moreover, they will alter features of their identity in an effort to facilitate positive interpersonal relationships to understand themselves and where they fit in the world (Swann & Bosson, 2008). INT proposes that our social environment helps to facilitate identity; however; there is also a parallel process by which we attempt to seek out self-verifying environments where our identity remains unchallenged. This is particularly true for individuals within a romantic relationship. Individuals seek out environments which are self-verifying and congruent with internal representation of self.

The processes of INT are largely implicit and primarily occur at a subconscious level, with transition in and out of awareness of these negotiations. This process typically shifts into consciousness when identity is not confirmed through external feedback. ‘Incongruence’ causes individuals to then question their identity and therefore forces this negotiation into cognitive awareness. There are distinct principles of identity negotiation processes which occur automatically (Jones & Pittman, 1982).
1.3.1 Clarity

INT proposes that ambiguity creates a sense of discord. For example: partners who are ambiguous about their relationship goals experience imbalance, disappointment and incongruence. Therefore, identity negotiation is best when individuals provide in-depth and accurate information about their identity to their partners in a clearly communicated manner. Those who communicate their identity to their partner within the earlier stages of their relationship fare better as it diminishes the possibility of misunderstanding and conflict. However, this can only occur for those who have a clear sense of who they are. Some individuals may enter into romantic relationships by searching for clarity from their partner to provide them with cues regarding who they are expected to be (Synder & Klein, 2005; Snyder & Swann, 1978).

1.3.2 Cooperation

INT suggests that romantic partners often cooperate with one another by acting in an identity consistent manner. This avoids identity re-negotiation between partners, which can often be disruptive to the relationship. For example, this often involves one partner reciprocating acceptance of their identity if their partner has just extended them that same courtesy. Cooperation then acts to strengthen the negotiation and provide harmony in the relationship (Swann & Bosson, 2008).

1.3.3 Continuity

Within intimate relationships, individuals expect their partner’s personality and identity to be relatively consistent through time and across situations (Athy & Darley, 1981; Rempel,
Holmes, & Zanna, 1985). INT theorizes that this principle is challenged when there is an external event which acts to disrupt the previously established identity. For example, when a person becomes ill or loses a high status job. This transition is multi-layered as individuals attempt to create overlap between the previous and new identity. The change often results in power imbalance and the couple therefore struggles to re-define what is expected within the context of their relationship (Swann & Bosson, 2008).

1.3.4 Compatibility

Individuals assume multiple identities across different roles in their life. An intimate partner can also assume the role of spouse, parent and friend. This model asserts that couples fare better when these different roles are congruent and compatible with one another and their personality remains relatively stable across contexts. For example, inconsistency would be an individual who is responsible in their role as a parent but irresponsible as a spouse.

1.3.5 Seven key mechanisms

This model asserts that there is also a breadth of ‘intra-psychic’ mechanisms working that aid in retaining and protecting identity (similar to that of classic defense mechanisms). These act to facilitate continuity upon receiving discrepant feedback in an effort to reduce the discrepancy. The researchers identify seven key mechanisms: selective attention, discounting, biased interpretation, anxiety, biased recall, thematic coherence and compartmentalization.

1.3.6 Model of identity negotiation

INT proposes an interactive process between self-view, situations, appraisals, relationship goals and outcomes. The model begins with initial identity and relationship goals. Identity is
again defined by your perception, as well as the feedback provided by others which then become superimposed to strengthen same. Relationship goals are defined as the optimal desired outcome that individuals strive towards when they first enter into the social interaction. The authors assert that at the broadest definition this can include goals such as the need for acceptance, agency and communion (Swann & Bosson, 2008).

1.3.7 Negotiations between partners

Partners display their identities to one another in a variety of verbal and nonverbal ways. In addition to the overt behaviors, body language and verbal communication individuals also display their identity through their choices (for example: choice of clothing, how they design their space and personal media). Therefore, partners try to communicate their identity through as many avenues as possible.

1.3.8 The person’s & partner’s situated identity

A ‘situated identity’ is when an ‘active portion’ of the person’s identity is drawn out by a particular situation. This includes the person's own cognitive and affective contributions, combined with their partner's response. Discrepancy will always be present, however great between initial identity and the situational identities. Situational context that are powerful (such as emergencies) or those that provide objective information (such as failing a task) can cause great discrepancies between initial and situational identity (Swann & Bosson, 2008).

‘Situated appraisals’ is the belief that partners also develop in result of identity negotiation. The process operates in an optimal fashion when ones situated identity also matches that of their partners situated identity as they will be better able to predict negotiators reactions
and behaviors within the context of the situation (to maintain continuity). When partners situated appraisals differ or conflict, the interaction feels unresolved and dissatisfying.

After partners have then worked through this process they then have a ‘working consensus’ (Goffman, 1959). At this point in the model, partners will now have the opportunity to work towards the initial relationship goals that were brought into the social interaction. The authors identified multiple positive outcomes that may result from this exchange. Relationship quality depends on the degree to which the person believes that their partner is verifying and matches how they view themselves. This leads to greater marital satisfaction and lower rates of divorce (Swann, Chang-Schneider, Angulo & Wood, 2008). Self-verification by a romantic partner aids in predictability, continuity and promote the likelihood that relationship goals can be achieved. Consequently, discrepancy between situated appraisal and a partner's situated appraisal facilitates negative emotionality. Within romantic relationships, this leads to marital discord (Swann & Bosson, 2008).

1.3.9 Resulting identity and relationship goals

INT concludes and consists of both partner’s identities and relationship goals after the exchange has occurred. Typically, the resulting identities will resemble the initial identities but there is also opportunity for change and transformation during the process. Identity change or stability depends upon five conditions: 1. The part of the identity that is being negotiated is relatively uncertain or deemed less integral to the person. 2. Interpersonal feedback falls outside of the partner’s threshold for acceptance. 3. The feedback that is provided is from a reliable source and cannot be discounted. 4. Although there maintains a discrepancy between initial identity and the feedback, the overall outcome was favorable. 5. One social environment does
not contain the structures that are needed to sustain their initial identity (Swann & Bosson, 2008).

1.4 Identity negotiation and illness

Due to the ever-changing symptoms of MS based both in its type and variable disease course, one cannot predict the disabling effects of this chronic illness at any given time (Irving, Davidson, Hoy & Lowe-Strong, 2009). The physical impact can have a significant impact on an individual’s body, emotions and that the reactions elicited from others in response to their illness. It can cause one to re-evaluate their sense of self and their perceived personal worth (Irving et al., 2009). In turn, recent studies have suggested that there is a process whereby individuals must first undergo a period of ‘coming to terms’ and accepting MS into facets of their identity (Boeije, Dujinste, Grypdonck & Pool, 2002; Irving et al., 2009).

INT proposes that the development of illness greatly disrupts intimate relationships and acts to motivate the process of identity negotiation. When a chronic illness such as MS is diagnosed to one partner; the physical, psychological and emotional changes greatly impact identity negotiation. This acts as an impetus which forces couples into re-negotiating their identity as a couple. Illness causes disruption in the previously established continuity of the relationship and couples are faced with having to: assimilate the illness into their existing one; re-negotiating to evolve a new identity or leave the relationship entirely (Swann & Bosson, 2008).
1.5 The present study

Individuals in relationships expect their partner’s identity to be relatively consistent through time and across situations (Athay & Darley, 1981; Rempel, Holmes, & Zanna, 1985). The onset of chronic illness such as MS has the potential to disrupt the identity of the ill partner in a number of ways, leading to inconsistency and incongruence of the two partners’ perceptions because of the impact of the illness on her abilities.

In coping with these changes, both she and her partner may arrive at different conceptualizations of her identity, thus creating tension in the relationship (Swann & Bosson, 2008). Because the symptoms of MS may continue to change and become more severe, this process of identity disruption can be ongoing and lead to relationship difficulties. Therefore, the purpose of this study is to investigate the impact of MS on identity and to investigate the interaction between intimate relationship and identity and how these factors combine to affect the ability to cope with the disabling symptoms of MS.

This study will explore this process using the previously identified variables (relational satisfaction, acceptance, synchronicity, social roles), explore identity as a distinct variable and compare our findings to pre-dominant aspects of both INT and the pre-dominant features of identity theory (salience, commitment, congruency and self-verification) to see if utilizing these concepts aids in better understanding this process.

Specifically the research will ask:

1. Does multiple sclerosis impact one’s identity? If so, does that result in a process of identity preservation or change? If so, what are the most specific aspects of identity that were recognized in the re-negotiation process?
2. How does the onset of multiple sclerosis interrupt relationships?

3. Is this process mediated by one’s intimate relationship? If so, what relational variables have the largest influence on this process? What aspects of this process lend towards being satisfied with ones relationship?

4. As MS is unpredictable, what is the role of ambiguity and/or invalidating feedback in process of re-negotiating relationship goals? Does it lend to relationship cohesion or discontent? Ambiguity regarding the course of illness, future of the relationship, and impact upon the previously established expectations of the couple (for example: employment, children etc.).

2 Methodology

2.1 Participants

Semi-structured interviews were conducted with females who, a) had a diagnosis of MS, b) were 21 years of age or older. c) were with the same partner and relationship that they were in when diagnosed, or who were in a relationship at time of diagnosis but the relationship has since ended (within the past year).

This study focused only on the experiences of women for several reasons. The prevalence rates of MS are significantly higher for women than men (3:1 ratio), and Canadians have the highest incidence of MS per capita in the world (Orton et al., 2006). Secondly, research suggests potential influence of gender roles (e.g. female as caregiver) in discussing the experience within intimate relationships. Furthermore, this study focused on heterosexual women because research suggests that the dynamics in lesbian relationships are also different. Research suggests that
lesbian couples do not typically endorse traditional feminine-masculine social roles, as roles are based on individual’s skills or specialization within the household (Garnets & Kimmel, 1993).

The final sample size was comprised of 22 females who ranged in age from 30-63 (M=45). All participants were fluent in English. The majority of women (81%) were from Ontario (n=18); with the others residing in Western Canada (British Columbia and Saskatchewan). In terms of MS subtype, the majority of participants (72%) were diagnosed with relapse-remitting MS (n=16); and 27% (n=6) had a diagnosis of progressive (primary; secondary and remitting) subtypes. Age at diagnosis varied between 22 years old to 51 years old, with an average being 38 years at diagnosis.

2.1.1 Relationship Descriptors

The length of relationship at the point of diagnosis varied between 1 year- to 27 year relationships (M=11). The classification of relationship at the time of diagnosis also varied. One participant was in a dating relationship, two were engaged when diagnosed; four were common-law married (and also engaged); and 18 were already married to their husband when diagnosed. At the time of the interviews, all participants (n=22) had married their same partner. One participant had very recently divorced and was now in a dating relationship. Within her interview, both relationships were discussed at length. For more demographic information, please refer to Appendix A.

2.1.2 Employment Descriptors

Of note, the majority of participants (n=13) of participants had lost their job as a direct or indirect result of their illness. Many of the individuals were professionals and had careers within helping professions including: nursing; disability insurance providers; veterinary services; and
teachers. At the onset of our research, the impact on employment was unforeseen and we did not gather further demographic information regarding this variable.

2.2 Procedure

Participants were recruited for a study on the ‘Effects of MS on one’s intimate relationship’ through advertisement posted throughout the MS Society of Canada – Research Portal. Flyers were also distributed by MS clinics throughout Ontario, community resources, and health centers (with organizational consent). Upon contact with the researcher (via email), potential participants were sent the informed consent information. After having reviewed the informed consent and asking questions, participants indicated whether they wanted to participate and a meeting time was established via email or telephone.

Due to the physically disabling effects of MS, it was acknowledged that many would not be able to travel for the interview. As such, accessibility was provided through telephone interviews as a provided option. As it turned out, all interviews were conducted via telephone due to physical mobility and travel issues. As such, participants were sent a copy of the informed consent information to be reviewed and signed prior to our interview. We again verbally reviewed the informed consent at the time of our interview, and all participants provided both written and verbal consent to proceed.

It was initially estimated (and advertised) that interviews would last approximately one hour in length. For those who were continuing to discuss their experience at the one hour mark, they were provided with the option to stop the interview at that point (although they were also made aware at the beginning of our interview that they were free to withdraw or stop the interview at any point in time). However, many participants asked if they could continue with
the interview beyond the 1 hour mark and the average length of interview was between 1-2.5 hours.

Each interview was audio recorded; transcribed and filed in a locked cabinet in the primary researcher’s office. Upon completion of the interview, the participant was presented with the opportunity to ask questions about the study and was provided with contact information regarding different health and relationship resources for individuals with MS. Each participant was compensated $20 for their participation which was sent via e-money transfer to their email of correspondence.

2.3 Measures

Data was gathered using semi-structured interviews which explored the experience of women with MS. The interview guide was constructed based upon previous research which identified the following variables: internal impact of MS; process of coping with this illness (and degree of symptoms); impact on identity; relational satisfaction (pre- and post diagnosis); acceptance from partner; communication; synchronicity; changes in role-identities (and consequent experience of same).

Participants were asked whether having received a diagnosis of MS and consequent symptomatology had impacted their identity. Specifically, they were asked to describe how disruptive MS was to their identity for themselves and within their relationship. They were asked about salient features of their identity (pre- and post diagnosis), impact of ambiguity and unpredictability, and overall impact of MS upon their wellbeing (both individually and as a couple).

Overall, the interview guide was three pronged insofar that it explored the following:
1. The impact of MS on identity.

2. The impact of MS on relationships.

3. How the impact of MS on identity is mediated by relationships.

2.4 Data analysis

This qualitative study employed the use of semi-structured interviews to explore the subjective experience of identity preservation or change for women coping with MS. The transcripts were analyzed for their descriptive phenomenology using the constant comparison methodology (Giorgi, 1997).

The constant comparison method of analysis is a widely used form of qualitative analytical methodology (Glaser & Strauss, 1967). First, the transcripts (data) were reviewed numerous times by the primary researcher to become familiarized with the narratives. Next, broad categories of information were defined based on areas of interest (also referred to as open coding). This included categories such as: the impact of MS on identity, social influences and relational factors. The interview data were then scoured and separated by blocks of data based on similar content (ranging from a sentence to a paragraph). For example, all participants who discussed the invisibility of their symptoms would be grouped together. Themes were evaluated both within and across transcripts and were established based upon how many participants endorsed that particular sentiment. For purposes of this study, responses by three or more participants constituted a theme.

Upon establishment of these categories, the data was then analyzed for interconnected and related themes. This is referred to as axial coding (Strauss & Corbin, 1990). For example,
all participants who noted employment as an important part of their identity would first be
grouped together as a broad category. Then this category would be further evaluated for sub-
themes. For example, a group of participants who lost their jobs found fulfillment in
volunteering. Through this process of data analysis, a network of overarching broad themes with
many encapsulated and interconnected themes emerged which represented the experience of
these women. In consultation with my doctoral supervisor, this process was undergone six times
to ensure that the categories and nodules of data were refined and grouped accurately.

To ensure the reliability of data analysis and emergent themes, the data was also
reviewed and analyzed by a second researcher who was provided with four randomly assigned
participant transcripts. In this capacity, inter-relater reliability was attained and deemed
adequate, as there was 96% agreement and consensus was attained on any areas of discrepancy.

2.4.1 Trustworthiness & Rigor

Analysis of findings was conducted using Guba’s ‘model of trustworthiness’ (1981) as a
measure to ensure the thoroughness and replicability of results. This model asserts that there are
four primary elements towards ensuring trustworthiness in qualitative research: truth value,
applicability, consistency and neutrality.

‘Truth value’ (also referred to as credibility) refers to whether there is confidence in the
findings, insofar that the informants’ responses were appropriately contextualized (Lincoln &
Guba, 1985). One key component being that there remains a measurable perceptible reality. In
the context of this study, our research explored the subjective reality of women’s experience in
coping with their chronic illness. This allowed a first-person account of participants’ narratives
and is believed to be an accurate representation of their reality.
As proposed in the model, credibility was also accomplished through the interview itself. The semi-structured and consistent approach to the data collection; as well as the structure of the followed open-ended questions (e.g. what was that like for you?) permitted consistency regardless of the scope and variability of the experiences shared in the interview (Krefting, 1991; Lincoln & Guba, 1985).

This model also proposes that qualitative analysis maintain a level of applicability across contexts and with other populations. This ensures an ability to generalize the results of the findings. However, qualitative research differs from quantitative methodology in this regard, as there remains greater focus on experiences rather than whether the results can be generalized or stratified across the population as a whole (Guba, 1981). One of the unique and positive contributions of qualitative study is that it allows for research to be conducted in a naturalistic manner without controlling for variables. Guba (1981) instead proposes that qualitative research aspire to be ‘transferable’ in that the findings can be applied to contexts outside of the scope of the study. Lincoln and Guba (1985) have proposed that if the researcher has provided in-depth descriptive data this would then permit other researchers to then make comparative analysis in future study, and applicability has been attained. The provided step-wise descriptive analysis satisfies this criterion. Moreover, as will be discussed later in this paper, were clear and consistent themes that mirrored that of both previous studies with individuals with MS, as well as those with other forms of chronic illness which demonstrates a transferability of the results from this research.

‘Consistency’ refers to the potential replicability of the findings. This again largely differs from quantitative methodology, as the key objective of qualitative study is to gain knowledge from the participants experience rather than provide a structured and variable
controlled setting of experimentation (Field & Morse, 1995; Krefting, 1991). Therefore, this model asserts that qualitative methodology aspires to be dependable, which Guba (1981) describes as a `trackable variability.` This refers to variability which can be explained by the researcher and explores the range of human experience shared by participants rather than the average alone.

The fourth principle is neutrality, which calls for researchers to maintain an unbiased approach to research collection, analysis and findings (Guba, 1981; Krefting, 1991). However, within qualitative research lengthy observation or interview is encouraged to decrease the distance between participants and researchers. Neutrality is thereby referred to as unbiased approach to the data (Lincoln & Guba, 1985). It is proposed that this is achieved through accomplishing both truth value and applicability in research.

3 Results

The results will be organized as followed: First, I will discuss the internal experience of those who were impacted by MS and the role of identity throughout the process of navigating this chronic illness. Secondly, I will discuss the impact of MS upon relationships and relational processes involved in facilitating identity preservation and positive outcomes (and conversely ambiguity and dissatisfaction). Third, I will discuss the overarching social context and the role of social environment upon identity. Finally, I will discuss the emergent groupings of participants.

Based upon the results of this study, there were significant differences between groups of women. The names of individuals and identifying information have been changed to preserve anonymity.
3.1 Internal experience

As previously discussed, the onset of MS can disrupt one’s life and impede upon physical ability. When this occurs, identity theory proposes that salient aspects of oneself get, "called out" in an effort to cope, and incorporate the disease course into one’s life to promote psychosocial wellbeing (regardless of whether one is adjusting positively or with difficulty).

For all participants (n=22; 100%) the prospect or onset of more physically disabling symptoms caused anxiety. This anxiety set in motion the changes in perspective, sense of self and the need to renegotiate their identity to fit these ever-changing symptoms. This was often a difficult process.

All participants (n=22; 100%) commented on the impact that physical episodes cost their sense of self.

Well I guess the big thing is not being able to do as much physical. I used to be extremely active so I’m very unhappy with that. (Kelly)

My body was betraying me…The change in my body is hard. It’s the physical aspect and the toll it takes. I don’t feel my body. I don’t feel having sex, I don’t feel it. I don’t feel the sensations in my lower body for quite a while now and sometimes it moves up to my neck. I was going through it not understanding. When my back acts up then the sensation in my body acts up. I noticed that I don’t feel my legs, or the tingling in my arms, or stuff like this. When I was distressed (before MS) I would go ride a bike, anything. I was always moving. I always felt like I was moving. It’s impacted me physically. (Megan)
Well I guess the big difference is how extremely active I was. Now, I’m hardly able to do anything. I just feel a lot less capable in terms of everything which is in fact true. (Kelly)

I used to compete in triathlons. I no longer do. I probably shouldn’t say that I can’t do it but I don’t feel that I can work out to the intensity that I used to do. I used to work out nine times a week. That’s not something that I feel would be good for me to keep doing. (Lauren)

There are things I can’t do anymore mainly because I have problems with my fingers, hands and my forearms. I have a lot of pain. Ninety percent of the time I have no feelings in my fingers. I have no strength in my arms. So there are things that I can’t do anymore and at the end of the day I’m on massive doses of Ritalin now which has helped me tremendously…Ritalin for the chronic fatigue. (Lindsay)

I used to walk to work every day which was 2 km each way and then I’d often go to the gym over lunch hour, or else go walking over lunch hour. Sometimes I would go for walks just to go for walks. Naturalist group hikes and they were always way ahead of me. Whenever that happens I guess I really get disheartened. I feel a combination of annoyed and just basically very unhappy because I mean I like to be very active. (Kelly)

Many participants (n=6; 27%) also noted that they had experienced noticeable cognitive changes, which they attributed to the effects of MS. Having to cope with changes in attention and memory were quite difficult. Many compared their present state to how they were prior to having MS which caused anxiety and discomfort.
One of the more challenging things from an identity perspective has been that from a cognitive perspective. That’s where I have noticed more of a challenge, remembering things. So from an identity perspective, I pay more attention and take more time because I know I am having more of a challenge cognitively. That’s been more challenging. I will sometimes ask the same questions over and over again; or I am like a slave to spell check now; so I find that including the numbness, a lot of my symptoms are cognitive. From an identity perspective, I don’t do as well as I could. Consciously, I am aware of that. (Sabrina)

Mostly everything has changed. One of the worst parts was that I had to leave my job, dealing with cognitive impairment and extreme exhaustion. (Wendy)

But I think at this point I’m more concerned with possible cognitive changes than I am of the mobility. Because I think that would be more upsetting. I can deal with mobility issues more easily, well not easily, but adaptively. I see some of the patient’s who have serious cognitive issues and that’s when I’m like, “oh, oh crap.” (Amanda)

Yes. Just my ability to filter things through my brain properly, normally, was turning around. For me it was scary. (Megan)

The problem with MS is that I now have a problem with words with the cognitive or my executive functioning. That’s probably the hardest part about it. My memory used to be my best gift and its awful now. I can’t find the words. (Sally)

My short term memory sucks because of the MS, and I can still drive because it’s in my long term memory. Everything that’s burned in there and if I do something new, or learn something new and do it often enough, I can get it to where I don’t have to have it written
down to do it. I have my brain I carry around that has a please return because I leave it all over the place. My memory was my best gift and I think that’s the thing that I miss the most. My files would be 2 feet off of my desk. (Sally)

So I would be brilliant...more brilliant now than the MS is, is what I’m trying to say. No this is...I know that there are neurological deficits because of the MS that bother me. And I would like to get back to...there are times when I can’t find the word that I want to express but I can’t say the thing that comes to mind. (Anna)

3.1.1 Invisibility of Symptoms

The majority of participants (n=12; 59%) noted that the invisibility of both physical and cognitive symptoms of MS had an impact on their identity and on how they were viewed by others in social situations. In turn, there was a process of disclosure and associated anxieties that many faced in their process of coping with multiple sclerosis.

Many participants commented on the general invisibility and having to disclose in order to have others understand their physical experience.

The effects of the damage are inside. So when we say that we’re too tired, that we have a headache, or we’re in pain, I find that 99% of people in our surroundings just minimize it or just don’t believe it. Or they just don’t care. Whereas if for some reason somebody sees me with a cast they are going to be cheerful and nice! (Lindsay)

It’s interesting because I take a long time walking. I can’t walk fast. You would think, based on if you looked at me, that I could walk fast. It just takes me time. I find that people pass me or get a little frustrated especially with rush hour. Everyone’s in a rush. That’s fine.
I try to get out of people’s way but I can’t walk fast enough so it depends…I think it would be (different if using a cane). Not that I need to. I think it would be clearer to people that ‘Hey, I can’t do it. I can’t do it as fast as people would see.’ (Sabrina)

That has sometimes been very difficult, the invisible nature of my symptoms, numbness and things that I feel. However, looking at me you would never know. It’s difficult because, my coworkers were very supportive when I was going through the diagnosis and when everything was numb and then it’s almost like people forget that it’s there. (Lauren)

It’s invisible so people are detached, but I can’t blame them. I mean before I had this I was like that. (Lindsay)

I think that the biggest part is physically to look at me you wouldn’t ever know that there was anything the matter with me. Probably the biggest thing that I deal with on a day-to-day basis is the fatigue. I don’t know if most people have talked about that a lot or not, but just this kind of fatigue that no matter how much you sleep, you are tired, right? So I mean it’s just like a very heavy kind of body fatigue, mental fatigue, right...so that I find for me it is burdening because there’s times where I don’t feel as though I can contribute as much as I want to. (Christine)

I just lose my focus. But people can’t see that. And they can’t see the pain. And they can’t see the fact that my arm doesn’t work. (Sally)

I don’t know if you have talked to other people but I feel like because MS is such an invisible disease sometimes I feel like I need to tell my husband what’s going on daily. How are my hands today, what do my legs feel like today and I don’t necessarily do that
prior to… but I didn’t need to. I now sort of feel like I need to say, hey look my hands are really hurting today or I am feeling really good today. (Lauren)

As the symptoms of MS are often invisible, at least superficially, there is a discrepancy between how the person looks and their internal experience. This often causes anxiety and/or frustration.

I feel a little more self conscious because I am young and I look reasonably healthy. I look healthy so no one can tell. I feel like people are staring at me. I feel a little more self conscious that people are judging me because I don’t have a cane. I don’t walk with a cane and there may be a day where I need to but right now I manage. I try to avoid stairs, I take the elevator. (Sabrina)

It was very frustrating because although finding out you have MS is a terrible thing… and it’s almost like people because they can’t see it either, you feel like people don’t believe what you’re saying…Like even now people don’t understand that you have an illness because although I’m still able to walk and function, my stamina is not as long. (Jessica)

Due to the invisible nature of symptoms, participants (n=10; 45%) often felt that others could not relate to their experience, which would create anxiety and incongruence between their experience and their interpersonal feedback.

My mother was hounding me just before Christmas saying, “What do you want for Christmas?” I was like, “Oh jeez I have grown out of wanting things for Christmas.” So I asked for earrings that I can put on, because my hands are so numb that I can’t do studs anymore. I can’t feel them. So I would really like some earrings that I can wear. That would be great. So what do I get for Christmas? I get these great silver earrings, but they have studs with little backings. And I just thought… She just doesn’t get it… It’s frustrating
because I don’t want to have to keep saying that my hands are numb but I thought I had to explain because people forget. (Lauren)

He claims to know how I am doing just by looking at me. Yet a couple of weeks ago he was surprised when I told him I am in what most people would classify as pain every waking moment. He said, “Well you don’t look it.” And I said, “Oh course not. Because it’s too much to get your mind around the fact that you live in constant pain.” So that’s what I mean when I say that it’s amazing what you can get used to when you have to. I don’t show it. Sometimes I limp when my legs and feet have really had enough. I limp. That surprises him because I present as so capable and efficient. I haven’t really changed a whole lot about our roles in the relationship and around our division of labor so much that he is surprised when he actually sees the evidence of me having some symptoms. (Elizabeth)

Conversely, some participants (n=6; 27%) felt stigmatized because they relied upon mobility aids. There maintained an internal struggle between coping with the invisibility of symptoms versus using mobility aids.

As my symptoms became more visible I had to use a cane. That was the first mobility that I had to use and I just felt like I was really hesitant in taking that step because then it was obvious to other people that I was different. Using a cane or any mobility devices, I thought that there was a stigma attached to that. I did eventually, you know, get over it because I needed to. But I felt that as I needed to use these devices, from a cane I moved to a walker, and then a walker to a scooter. Instead of walking proudly, because I could actually physically walk, you know, and I could wear high heels and I could wear attractive clothing and be noticed and be acknowledged by the general public. I kind of withdrew into myself. I think because I’m in a scooter, so it’s more so, people just look at me and they are trying
to figure out why is this young person using that mobility aid? Is she just lazy? Is there something wrong with her? Just that kind of thing and I get a lot of stares. (Shannon)

These results were unique and not encapsulated by overall identity theory or INT. The process of disclosure appeared to be an influential factor on identity, particularly when they were not already 'out-ed' by visible symptoms. This created a unique process of negotiating their illness within their social context.

3.2 Significant Aspects of Identity

The physical limitations and cognitive changes associated with multiple sclerosis adversely affected many different aspects of their lives that were related to their identity. This included: sexuality, physical appearance, emotional regulation, and perhaps most significant, job loss.

3.2.1 Impact on Sexuality

For the majority of participants (n=13; 59%), having to cope with the symptoms of MS impacted their sexual intimacy and expression with their partner.

Our intimacy was greater. We had more of a sex life prior to the symptoms creeping in…Because I want to have sex. But I can't. I want to be intimate but I can't. I can't feel anything and it actually hurts the next day. My whole spine right through to my neck, I am not necessarily hurt then but the next couple of days is really- oh my lord- I feel like steam rollers have gone over me. It's just some nights it's just not worth it for me. I am already in a lot of pain, if I go up one more threshold I am going to have to take more medication
which I don’t like doing. I mean, I got off all of the heavy duty drugs for that reason.

(Megan)

I lost feeling in my lower back area… I can remember going to physiotherapy and she was working on my back and I couldn’t feel it. I could feel pressure but I could not feel the touch. That impacted my relationship quite a bit…. when you can't feel anything in your pelvic area. (Megan)

For these participants, the physically disabling effect of MS impeded upon their ability to engage sexually as they had prior to diagnosis. This proved to be a source of distress, as they cognitively wanted to engage sexually but physically could not without pain.

3.2.2 Physical Appearance

For many participants (n=7; 32%), the impact upon physical abilities and the symptoms of MS also took a toll of their self-image and their perceptions of their physical appearance.

I used to be a dancer so it's harder for me because I don’t have the same body type. When I say I'm overweight, I am not talking 100 pounds, I am talking maybe 15-20 pounds but when I am that much overweight I feel it a lot, not just in my clothes but in my breathing a lot. Because I was always able to exercise and dance between 30-40 hours a week whenever I wanted to and now I can do it for so long and then I have a setback. (Chantal)

A lot of it (attributed to MS). I have gained weight in addition from the medications I have taken to increase body weight (i.e. pain killers)... There was so many that we tried and stopped and tried again. This caused me to gain weight. To put it this way, with my youngest I was 97 pounds and three months pregnant. My top weight, I ballooned because I
was retaining water with my eldest boy, I topped 140 something pounds. That’s the heaviest I was ever in my life, when I was pregnant. Now, I went to the doctor’s office a couple of months ago and I was just over 140. I have never been that and not pregnant. It impacts me. Clothes don’t fit so I am wearing one pair of jeans, a few tops, I don’t want to get rid of everything because I can’t afford to buy but I can’t – what if I start losing weight? The optimist in me is still in here somewhere. I might be able to fit into this stuff. That whole impacted my self-image. How I saw myself. It impacted my relationship and still does with my husband (prior to diagnosis and after) (Megan)

I mean even just physically, I was always slim and, maybe not in shape but I was always a good weight. Not that I am not now, but I struggle with that obviously as mobility is an issue. (Shannon)

Normally I would be up at 5 am and work out before work and that just has not been happening. On the other hand, since then I haven’t been following any form of diet and I haven’t been eating well. So there’s been weight gain, and I know that exercise and eating healthy affects your mental health. (Lauren)

The secondary effects to coping with MS included changes in physical appearance which was often a difficult transition. Therefore, this proved to be a valued aspect of identity for many of these women.

3.2.3 Impact on emotion regulation

Changes in physical and cognitive abilities also played a role in the impact of her emotional states. Many participants (n= 11; 50%) experienced both direct (caused by the lesions associated with multiple sclerosis) and secondary (caused by the indirect process of coping with
physical and cognitive changes) upon their emotional states. This too, required a process whereby they experienced distress and change due to these affective changes.

I think that’s had a negative effect. I don’t think it’s necessarily depression. I have felt down in the dumps a lot. Probably the last month and that’s compounded by the fact that I am ill- dealing with this nasty flu that won’t go away. Have also just started injections which is a daily reminder of what I have (MS). That’s something that I have been dealing with for the last month. I just started a new medication and it’s not going well and so I am sure that when you have talked to other MS patients, there is this emotional roller coaster of what this disease does to you. I think that’s where I struggle the most. (Lauren)

When the depression started we called the MS clinic and that’s when they recommended a psychiatrist- my psychiatrist specializes in depression for those with MS. He’s amazing. So I really have lucked out with my doctors as well. They have been phenomenal throughout the years. Dr. – is studying the lesions in the brain that causes the depression. I am depressed because I have a lesion in my brain that is causing the depression… It was hard because it took so long to find the right medication. There are side effects with everything. (Chantal)

You are used to being a certain way. If I wake up and my energy is good and I am in a good mood, I have no problem talking to people… or visiting with my mom and dad… or going to the mall and chatting with salespeople. If I wake up and I am in a bitchy mood I won’t go out… and I think it’s because I was always talkative with sales people. I used to work in sales so I know what it’s like to work with miserable people. So for me, if I can’t wake up and feel like I am in a good enough mood to go out and be social and be nice to people…then I don’t go out. And people say to me when I tell them that, “Well I have never
seen you in a bad mood or anything like that.” And I say, “That’s because when I am like that I don’t go out because I don’t want to.” There are certain people that I can be like that with. I can be that way with my mom and dad and they understand it. To me every second that I spend with them is so precious, I don’t want it to be me being bitchy or irritable or snappy or anything like that. (Erin)

Now I say what I mean...say what I have to say, maybe not always in the best therapeutic way, but I will say what I need to say and I let it go. Because if I keep going then it does have an impact on my MS because of the stress and all of the emotional stress of it all will make me feel unwell. So it definitely has changed in that respect. (Christine)

It can be and still can be very intense but even back then I was noticing these changes. I have a good relationship with my family doctor and I was constantly telling her- this is unreal, flip a dime and I can go. And it's all body encompassing it’s not just brains- it’s the whole body that gets into this. I feel my heart racing, my blood pressure rises, I get tense. Everything is involved and it can leave me physically draining. Yes I do (directly attribute this to MS). I had to go back and search discussions about the MS and went through what people were posting to see if all of this could be attributed. I was really concerned. And from what I read yeah a lot of people experience that type of anger. (Megan)

The symptoms associated with MS often resulted in changes either directly or secondarily associated with changes in emotion regulation. This was a cause for concern for this subgroup of participants, as it impeded upon their previously established personality and worldview, which was a valued feature to one's identity.
3.3 The role of employment

One of the most salient parts of identity for many women was the role of employment and their perception of self as a hard worker. The impact of MS upon their identity as an achiever, the significant decline in job performance or, for some, the loss of their job altogether, were prevailing themes.

The impact of MS was particularly acute for those who viewed themselves as high achievers or placed a great deal of value on achievement. Participants whose job was an important part of their identity had difficulty adapting to the limitations caused by multiple sclerosis (n=6; 27%).

I just made a conscious decision. But when you are embedded in that, it takes some time because you are used to that lifestyle or that more because my ambition of being a go getter or that kind of thing- I kind of let that –It didn’t become very important to me and stuff. (Sabrina)

You would notice that I was driven. I was driven to succeed in all areas of my life. I was working quite a bit, over and above what I needed to do at work to succeed. (Lauren)

I was raised in a household where there was high work ethic and standard, it’s important to work and contribute and do the best you can and to be consistent in what you do and produce high quality. (Elizabeth)

That’s one of the things that bothers me now. I am less perfect now. I always was but in my mind perfectionism was the goal. It’s (MS) impacted it all the way around. (Sally)
Many participants noted how their job performance suffered in result of coping with symptoms. As high achievers, this was discrepant from their self perception and was a struggle to renegotiate this into their sense of self (n=5; 22%).

The cognitive issues I knew were there because I knew that I was not doing my job the best that I could and that is why I was there longer every day. Because of the perfectionist in me I would stay until the job was done. (Sally)

It has [MS impacted identity]. The biggest thing I valued was my work ethic. I was going through physical problems without knowing what the underlying cause was. By the time I took leave, my reliability in the workplace was not there. I lost my ability to do my job which really impacted me quite a lot. (Megan)

One participant who was a registered nurse indicated, “It’s frustrating because there’s...like when I was working I was always afraid that I would get one of these vertigo spells and when one of my patients were in need of my care and it really frustrated me.” (Jessica)

I know I was really worried about my job. I have seriously given everything, every year when I have my review they are pleased that I am always willing to do what needs to be done. I take on other peoples work… that kind of thing. I have always operated and have a great relationship with my bosses, they are terrific people and we have a good relationship. Even with that, I was very afraid, feeling insecure when I started back at work because I could only work a few hours a day. Other people had to start taking on some of my work. That was probably one of the most difficult things as well. Letting other people do my work because I was always the one to do theirs. There is insecurity there. They started taking all of these responsibilities away from me. They were doing that to relieve me. So that I
wouldn’t have to feel that was going to be piled on. But I also felt that they were writing me off too soon. I have kind of worked through that. (Olivia)

Some lost their jobs which had a significant psychological impact. This was often a devastating event, as employment proved to be a valued part of their identity (n=13; 59%). This was clear, as many women invested a great deal of commitment into their jobs, and believed that it was a strong part of who they were.

It was pointing me to a different career path and I had thought of before and it was more in line with my thinking and just the way I was. So losing that was a pretty big loss. It’s such an important identity in our world, and I never realized it. I didn’t think I was that attached to it. But when you don’t have it… I was going somewhere and now people still look at you like… Everyone expects you to have a job; everyone expects you to have a career. Now I don’t. I mean, I am going to school but it’s kind of a waste of time because I don’t know if I will ever use it. (Jackie)

Mostly everything has changed. One of the worst parts was that I had to leave my job, dealing with cognitive impairment and extreme exhaustion. (Wendy)

I don’t work anymore. I lost my job. There are so many things. And that all basically has to do with your self-worth. It was my job. I was very much in my job and I felt self worth because of it – which is stupid. A lot of people do. So that was a big part of it… I didn’t feel very good. I really didn’t… I left voluntarily. I left because of my illness because I really couldn’t do it. (Louise)

I was a school teacher and I actually ended up being forced out of my career due to MS. It was pretty upsetting and stressful. It came out of the blue and I honestly thought that it
wasn’t going to go that way. I honestly thought that they were going to take me out of my regular classroom setting. Which, there were issues too because some of the parents were complaining because I was only there part time. And it was hard for the kids to have two different teachers coming and going and communication between the two. So some parents were asking to have their kids pulled from my class because I wasn’t there all of the time. I really thought that what would happen would be that they would give the full time work to the other person and instead have me half time working in the school working with special needs or something working one on one. And that’s the impression that I was given. My principal, she thought that was the direction it was going to go. Instead, they just pulled the plug and said, “You’re out of there.” (Shannon)

Absolutely (MS impacted identity). Your job often defines you and it certainly did for me. (Sally)

For a couple of participants, job loss also caused stress through financial hardship (n=4; 18%).

The strain it’s putting on my husband too because he knows that financially it’s tight and the added stress on him to get a position is difficult. It's not like he hasn’t been trying. He sends off resumes more than anyone I know. It's frustrating for him. (Megan)

We had just bought a house too at that time. So it was kind of a stressful period financially for us as well. And I took on more of the financial burden part than he did. He, kind of, never really handled that part of it. (Michelle)

We try to do it logically but I think that financially we can afford for me to work part time, what I try to reason with him I want to have a full time job for the benefits because if I can’t
work I can’t get paid. So that’s been the biggest thing from a relationship perspective, lifestyle and what will work. (Sabrina)

For many participants, successfully adjusting to this change involved re-defining this aspect of their identity in the form of volunteering and giving back to their community. This created a renewed sense of purpose and fulfillment (n=6; 27%).

For one participant who was forced out of her teaching career due to her MS she stated,

It was like I had a lot of self confidence, especially as a teacher, an educated professional, especially in my role I felt very proud of that. When my career was taken away from me that was pretty devastating and I felt it was the same way with having to use mobility aids. When I started having to use a cane it was just before I was put on disability with my teaching job and that was tough. I think it was approximately five years (after being diagnosed). After that was sort of ripped away from me it was like a part of my identity was gone. I had to find a new identity and like I’ve said, I have sort of re-created my new identity into a homemaker, a wife, a friend, you know, my relationships. But then, I felt like I needed more. So several years ago I started doing volunteer positions and I thought, maybe I can make a change and feel like I am doing some positive in the world instead of my immediate circle. I don’t feel that that was very far reaching. Whereas doing volunteer work, I feel that the ripple effects go out further. (Shannon)

I would regularly give speeches to the chapter of the MS Society talking about the significance of how I can get insurance with MS. Because as a person with MS, there’s no way they can buy standard life insurance. So that I say, “Okay these are the things that you can do,” and the insurance companies, I don’t know whether they misinterpret what is being
said to them or that they choose to misinterpret for their own benefit and terminate coverage’s on people with MS and don’t give them benefits and stuff. And I’ve done that voluntarily for the last 20, 30 plus years simply...just simply because I know these people can’t afford to pay me. I know that they...it allows me to give back to them because it’s one of the unfairness of our system. It gives me great joy to help somebody and I’ve become friends with most of the people that I’ve assisted with their insurance. I would say that over the 37 years that I’ve had...no, it’s 27 years since I’ve know what I had...that I have probably counseled over 200 people with MS. (Anna)

For many, the process of losing their job forced them to re-evaluate their priorities and how they want to spend their time. In retrospect, participants indicated that the results were favorable as they had gained a better balance in their life, and redefined their priorities (n=4; 18%).

They have some different groups there that we’re both interested in joining. I think it’s the Kiwanis Club that they have. They do a lot of fundraising and stuff like that. That’s the type of thing we like...I know they do like fundraising for the food bank. They do fundraising for families in need at Christmas. I think it’s always been a part of my life. Quite a few years ago we helped provide a Christmas for a young mother and her four children. It was funny because I didn’t want her to know who did it, but she found out that I was one of the head people that did it and she was very thankful. I said to her, “We got more out of it than they got out of it.” (Jessica)

I think if it wasn’t for the MS I would probably still be doing the workaholic rat race type of career ambition doing whatever to get ahead. To tell you the truth I think it’s been positive. I didn’t realize how much I was doing. So I think that regardless of the MS, because it was a bit much for anyone to tell you the truth. (Sabrina)
Now this may or may not have changed if I didn’t have MS, I’m not... I mean, who knows right? But I’ve always been that type A personality and being driven and having a lot of follow-through. I was happy and content all the time to just kind of go through the work, do my 12 hours, come home, and then leave work at work. Whereas now, I’m much more involved in committees and educational, like initiating education for staff and actually teaching the education courses that are being you know implemented at work. I’ve gone to international conferences and done presentations on like the work we’re doing on the unit so yeah... It’s kind of like I’m tapping into you know the things that I’ve always wanted to do but never really took the initiative to. (Christine)

Our findings suggest that coping with the physical, cognitive and emotional changes brought on by symptoms of MS impacted valued features of identity. For participants, the emergent aspects included impact to physical appearance, sexuality and employment. Of these, employment appeared to play the most dominant role in identity and sense of self and purpose. For those who suffered loss in this regard, there was a period of adjustment and re-negotiating this aspect of their identity. This loss provided an opportunity for them to find balance and redirect their focus through shifting their priorities.

3.4 The role of ambiguity

Ambiguity was evident from the onset, when individuals were initially diagnosed with MS. It pervaded the diagnostic process and generated fears regarding the variance and uncertainty of worsening symptoms. The majority of participants (n=17; 77%) found the process of acquiring an accurate diagnosis to be vague and laborious.
It took several years as I have been having symptoms unknowingly for awhile. I was even admitted to hospital in the winter of 2008/2009 and had a battery of tests run. Nobody even mentioned MS. It was extremely frustrating to know you are feeling these things and being told that they can’t find anything wrong with you. (Wendy)

That was very compelling to have that discussion and think this is me now. I had that discussion with myself when I was looking on the internet; my permanent symptoms came on very suddenly in a matter of overnight. In that my ankles, feet, soles and legs came on overnight. I thought what the heck is this? This is bizarre. What is going on with me? (Elizabeth)

My own general practitioner was extremely good, but it was hard to see the proper specialist. Once I got to see them, the diagnosis came within two weeks. That whole eleven months was extremely trying because I did not know what was wrong with me. So that was very stressful. (Louise)

My husband had just left the room moments before he had come in. So the doctor left me there, and saw my husband come back. So he explained it to him, and he said I was going to be passed to the care of the MS clinic. MS was not his specialty. They began their testing process to rule out everything else. It was pretty awful. It was pretty scary. (Olivia)

The diagnosis of MS at that point in time, what they did was they looked at all the neurological, horrible things it could be and ruled them out. Then they said; “Well, you’ve probably got MS,” or they didn’t say anything, which they didn’t say to me. So...I know because I had what I now know with the foreknowledge of a medical person and MS, I had probably four or five MS flare-up attacks in that intervening nine years. And I know that
my medical files said ‘suspected MS’ but nobody bothered to tell me about it. Which pisses me off royally now but... (Anna)

Ambiguity was particularly evident during the early phases of coping with this chronic illness, particularly regarding uncertainty due to disease trajectory and the possible worsening of symptoms which often caused anxiety and fear. This was true for the majority of participants (n=16; 72%).

Oh I think everyone has the same initial fear of, “I’m not going to be able to walk,” and “I’m going to die early.” I think that that’s kind of a normal reaction, right? (Amanda)

There are some fears about the future for sure. If I have a second attack that impacts my vision. If I have vision damage, I don’t see how I would be able to do my job. And I love it so much that it's hard for me to think about now doing that. But I just keep telling myself, it may never be your vision again. (Olivia)

It was for my son [had fear]. Because my son was two and a half years old, so I just started thinking, “I’m not going to be able to play soccer with him. I’m not going to be able to do anything because I am going to be in a wheelchair.” That’s automatically what my head thought. (Michelle)

I totally zoned out. It was a total shock and disbelief. You just spiral out and you think oh my god what’s going to happen? Fear of the unknown I guess…Yes. I guess, because you honestly don’t know. You don’t know what’s going to happen next. (Louise)

Frustration I guess. It frustrates me a little bit because it’s like, “Well now I have to consider things that I wouldn’t have had to consider before.” Like the ‘what if’, the unknowing ‘what if’? (Amanda)
The majority of participants (n=18; 81%) contended that the unpredictable and disabling physical conditions associated with MS had an impact on their identity. It was difficult for most to cope with the ever changing symptoms and constantly re-create their identity.

My friend said, “Many people find it’s easier to cope with a diagnosis of cancer because it’s cancer. You either beat it or you don’t. And that’s it. With something like your disease you constantly have to come to grips with the changes. You are never at a constant place.” Once we hit upon that it opened up everything for me. And I really saw, yeah now I can deal with this. Because you’re absolutely right. Because you get to a place and you think, okay I am doing really well here. This is great. This is how we are. And then WHAMO you’d have two or three weeks where the symptoms are just sky rocketing and then you are at a different place and you have to come to grips with it again. And I didn’t quite understand that I had to do that, and so I had difficulty after I would have an episode. (Louise)

So I think that from an identity perspective I think that because it is unpredictable-- I think that’s the other part from an identity perspective. I think that because MS is so unpredictable and people have such varying symptoms and um I didn’t know what was going to happen… we are expecting that things will change. We don’t know how or when. (Sabrina)

Until I was given all of the literature to read, I had probably done more reading than most but as someone who has an invested interest in learning so I wasn’t appreciative of all of the different types and subtypes of MS. So it’s not a cookie cutter. You say Jane Doe has breast cancer, and you all kind of know what that means and where she is headed. This is not the case. It’s not cookie cutter, but this wise neurologist of mine said, “How good are you at living with unpredictability?” I said to him, “Do you know that you are going to get
home when you leave here?” And he said, “Touché.” None of us knows if we are getting home tonight or to work tomorrow. We all live with unpredictability but we just don’t label it as that. We take it for granted. (Elizabeth)

With MS you just don’t know what's coming next. Nobody ever knows what's coming next but it's like all of a sudden the chances of something happening are greater. (Olivia)

I don’t know what rhythm it could go. That’s the beauty of MS. Anything can happen at any time without any warning. (Lindsay)

Three participants in particular experienced marked frustration (n=3; 14%) having to RSVP to social gatherings, ‘health-pending.’ They indicated that due to the uncertainty of their symptoms and physical abilities, they were unable to confirm social events. In result, they had to cope with the uncertainty in their schedule in this manner, which proved to be at times, a disheartening experience.

In fact this morning, I got an email from my brother for a pool party Saturday or Sunday. But he wanted us to keep it open. And he knows that my reply is going to be ‘health pending’ we’ll be there. I missed so many family functions, so many work functions because I couldn’t physically do the walking. Handle the conversations. Pretend that you're normal, that you can swim. I can do the swimming, but I pay for it. But I enjoy being in the water because I am weightless and my leg does not hurt as much. Taking a hot shower hurts. I haven’t had a hot shower in years because the cooler the water the less pain I have. It's annoying. I get angry with it. I can wake up all excited and take one step and it all goes down the drain…because I have taken that step and the pain shoots through me. (Megan)
Day to day means that no matter what my intentions are for that day can be side tracked really easily. It's very disappointing and I get angry. I have to direct my anger at something. I can't sit at the kitchen table and work at my computer for any length of time without being in pain. I ignored it for as long as I can. Then I will sit and watch TV. But I can’t sit and watch TV for any length of time. And I have a recliner I can switch my positions. It satisfies it for a little while but not a long time. The physical impacts me so much. I can say, “Let’s go to Costco today.” I will take a shower and then I will get a kink in my neck that hurts just to move side to side and its like, “You go to Costco I can’t do it right now.” There are so many things that I have backed out of and said you go ahead, I can't do this.

Ambiguity and uncertainty of symptoms and disease course played a role in identity change. Participants were required to cope with ever changing and unpredictable symptoms, which was often a source of anxiety and distress.

3.5 The impact of MS on relationships

From the moment the women received the diagnosis they became surrounded by change. For example, a significant number of participants feared that their partner would leave them (n=7; 32%).

There was definitely a while there like, right after I was diagnosed that I was like, “You’re going to leave me! Oh my god!” He was like, “No.” (Amanda)

At the time, we were planning our wedding. So after I was diagnosed, and my husband and I got another car. Before my appointment, we had ordered our invitations, and then after my appointment we were going to go and order our wedding cake. In between, when I was diagnosed and I got into the car, the first thing I did was ask him if he still wanted to marry
me. He said to me, “Why would I not still want to marry you? You're not a different person. We have always been there for each other why would we not continue on with our plans? Why would I not want to be with you?” This was after hearing that I was definitely going to be in a wheelchair and most likely going to die from it. And I was thinking that he is not going to want to be with someone like that. But he was the total opposite. (Chantal)

Yep. I told my husband, “Don’t have the fear, you didn’t sign up for this,” and I’m crying all the time. I’m like, “Just leave; you didn’t sign up for this, just go.”…I didn’t think he deserved to have a broken woman. You know, I thought, “Go out, find a real woman, a real wife, a real life and just go.” (Stacy)

So after I talked to that doctor, he said just forget about it. I sat down with my fiancée and I said, “I don’t know where this journey is going to take me.” Because I kind of had this hope in my head of where my life was going to go and what was going to happen. This just sort of threw a curveball at me and was this whole other road that might—that my life might be going down. And I said, “I don’t know what’s going to happen and I don’t want you to have to deal with any of this. This is not what you signed up for when you asked me to marry you. There is still time to back out.” This was only January and our wedding wasn’t until July. It’s not like the invitations had gone out yet or anything. And he just looked at me and said, “No. I love you. And I want to marry you. We will deal with whatever we need to deal with together.” I actually repeated that question to him, or offer of backing out, two more times because I wanted to make sure. I didn’t want him to have any regrets or say, “Oh why did I go ahead?” I gave him two more opportunities and all three times he said the same thing, “No. Why do you keep saying that? I love you.” (Shannon)
I think part of my fear was who wants to live with someone who has this diagnosis? We weren’t married at the time…One of the things, Brad was married prior. I was in a long term relationship prior, so we didn’t feel like getting married. After my diagnosis, everything sort of changed for me. Now I want the security. Now I want the need to be married, the want to be married. And he still wasn’t there. So there was a little bit of stress in our relationship. I knew he wasn’t going anywhere. In the back of my head, I knew that he wasn’t going anywhere but for me, my view around marriage sort of changed. I think it was – a lot of it was around the fear of being alone. Being scared that there wasn’t that commitment on his level. That if this disease got to the point of where I couldn’t walk, would he stick around. I think that was part of it. (Lauren)

At that point, I presented with the problem and I said, “Okay, I’ve got to get myself to an ophthalmologist, there’s something wrong with my eye.” So I put my kids together and we jumped on the subway and went to an ophthalmologist. He immediately said, “I would like to hospitalize you. I want to do a brain scan,” etc. etc. etc. And I’m going “This man has agreed to marry me – I cannot saddle him with the cost of that.” And this doctor was pursuing, absolutely certainly, MS. (Anna)

In addition, there were many lifestyle changes. The disabling physical effects of MS limited their ability to enjoy activities they had shared with their partners as a couple. This was anxiety provoking and frustrating (n=10; 45%).

One of the things that we like to do is vacation and MS impacted our wedding a bit. We had thought about a destination wedding… but heat exacerbates symptoms and because I had a relapse I said maybe we shouldn’t be going. It may not be a good thing for me to do. That had a bit of a negative impact because I now always second guess whether I should be
traveling that far away? Is there going to be medical care? Should I be going to hot climates? That has sort of impacted some of our vision now. And I think that’s something he finds difficult. We had gone south for the winter often and would lie on the beach for seven days. That’s not something I foresee in my future because of the heat. That’s something that he enjoys doing. So that’s a bit upsetting. (Lauren)

We don’t travel as much as we used to. Like, driving two to three hours across Montreal to see my family I find exhausting. To me something that is exhausting is unpleasant and I try to avoid it, and that he finds excessively frustrating. (Lindsay)

It’s impacted going out and having a drink, having get-togethers. My migraines are triggered by heat and noise. I’ve always, always had problems with noise. Now the only difference is in the past year, noise, whether it’s my son screaming, my little dog barking, kids talking too much in my classroom, I’ve developed migraines in the last year and they are horribly painful. So get-togethers are things that I try to avoid at all costs and my husband is a person who likes to be around people. He needs that and that is very difficult for him. That’s very difficult. If I’m not feeling well I will avoid those at all costs. The only ones that I attend and force myself to attend are family events. (Lindsay)

He wanted to go up to a cottage and have a bonfire and play some music, and I say go ahead but not for me. Because I would be stuck there, in pain, and it’s not like I can just lie down or stay to myself. Not be involved in music or playing horseshoes. I can’t do that. So his ability to enjoy life as well, its impacted him. (Megan)
The physically disabling symptoms impeded previously established norms and activities shared by the couple. This had an impact on the couple’s compatibility and resulted in shifts in the power dynamics. These changes can be best understood in terms of role changes.

3.6 Losing and adopting new roles

One of the most difficult elements to rectify for couples was changes in power dynamics and changes in roles. The symptoms of MS affected many aspects of functioning and resulted in many types of loss. Loss often resulted in role-transitions. Changing roles and adopting new roles inherently resulted in changes in sense of self and role-identity. Ten participants (45%), reported transitions from independence to dependence and from nurturer to the one being nurtured. They felt powerless and experienced decreased self-esteem as a result. Many women overall (and all in this category) (n=13; 59%) struggled with competing views of prior self as independent, with an increase reliance on others for physical support. This often caused cognitive incongruence, and led towards a bereavement period of sadness, anger and loss.

Well yeah basically because I’m not able to do things so I guess it makes me feel more or less incompetent. I just feel a lot less capable in terms of everything which is in fact true. (Kelly)

It makes a big difference. It’s also scary when you have a disease like this and it’s not something that I would have thought of before. I was independent. But now, when my kids are gone and it will be just my husband and I; I will be alone all day. I won’t have someone to get something for me if I need it. I won’t have someone to take the dog out. So it’s kind of a scary thing now. It’s different that just having your kids leaving. (Jackie)

Participants reported feeling guilty because of their dependence (n=12; 54%).
I am still feeling the guilt and I say that- I say that I get what you're saying, so if my husband says to me, “You have no reason to feel guilty. You're sick. It's not because of you as a person, it’s because you’re not able to do it because you have MS.” I put the guilt on myself because I guess it goes back to me being able to do everything. I am unsure about. And I wonder maybe because I feel so strongly about feeling guilty about not being able to do those things. Have I not accepted that I have MS at this point? I think I have but it’s that when the symptoms come that’s when I start feeling… I know I have MS… I think I put more pressure on myself and more guilt on myself. (Chantal)

Well more of physical things like I took care of the cooking, cleaning things and those are the ones he hasn’t stepped up for, which is what I would have liked. And then the stuff that’s more for me, I would rather still have my own independence. (Jackie)

Well yeah. I hardly do anything anymore...I’m not happy with it... (Kelly)

That’s the worst part. I don’t do anything for myself. I don’t work because even if I did have enough energy in a day, I could not get to a job because I can’t drive. It’s so impacted everything. I can manage in my house but that’s the limits of my world unless someone takes me somewhere. (Jackie)

So that’s another part of your identity, to be dependent. Really frightens me. The idea of being dependent and relying on people to do things for you, I prefer death. It’s very significant to me. The whole notion of having been a caregiver my whole life, I don’t want to be the source of someone having to care for me. (Allison)

The combination of physical uncertainty and vulnerability led to a period of decreased self worth for half of the women (n=11).
I think it (MS) diminishes your value and your self-worth. I struggle with that. (Louise)

I am disabled, uncoordinated, and a lot slower mentally (and physically). I am kind of wasted space and do not feel that I am contributing anymore to this life. I know my boys still need me and my husband still wants me around so I really try even though the pain and struggle becomes unbearable by times. (Wendy)

Communication, respect, for myself and for others- at times, I didn’t respect myself because I felt that I was less than I am. I think I still am a little bit (trying to reconcile). Again it’s more the physical things that I am not able to do. I think it’s just, I am very hard on myself and I have had MS for 15 years so even at 15 years I still find that when I am having an episode- it’s not that I don’t feel good enough that I deserve to have certain people in my life or anything like that. I am harder on myself because I can’t get up and empty the dish washer. Its small stupid things. In the big picture, it is small stupid things. (Chantal)

I have gone from being an efficient, smart, successful woman to being a disabled, helpless person. (Wendy)

The feelings of powerlessness and despair were especially evident for eight women (36%)

It’s just been a nightmare because you don’t know how to deal with it. And I think that the worst thing is, I have been in bad spots in my life, and gone through different phases, but you always knew that they were your choices or you could have made a different choice. You could have tried harder and made it better. There was always something you could do, and you always had that hope that okay maybe next year it will be a little bit better. But with this one it’s hard to have hope. It’s hard to even picture anything being different and I think that makes it the hardest to deal with... I have always felt that in my life that every
year has been better than the last. So I didn’t have to have the long term goals because there
would be something. Whatever it was that would come along. But now that I don’t see that,
then you realize that you can’t. At least before, I had the choice to make the goal if I wanted
to and now I feel like I don’t have the choice to make a goal. (Jackie)

For some participants the struggle involved losing their role as a nurturer and becoming
the one who required care. In turn, this caused disruption to their sense of self and their
perception of personal worth (n=6; 27%).

When I raised my family and I could do it. I was so focused on everyone else. And now that
I have to focus, I have to because not focusing on me could set me back...In some ways it’s
good. It gives me a lot of guilt. But in some ways it’s good that I know that I’m doing what
I need to do. And I am trying to tell people what that is. (Jackie)

Well actually before I was sick, I was the person who did everything and took care of
everyone. And so it was a complete role reversal. I don’t know. My whole life has been
about making everyone else happy. It is one of my core beliefs. I believe that you should
serve other people. So if I start taking steps for myself then I feel guilty. (Jackie)

It’s very significant to me. The whole notion of having been a caregiver my whole life, I
don’t want to be the source of having someone to have to care give for me. Not to be the
caretaker. I am not care taking anyone at this point. I am a nurse by profession. I don’t
want anybody dressing me, bathing me, cleaning my bottom. I have done that for years to
others. It’s part of me. But I don’t want others doing that to me. I don’t want that to me.
(Elizabeth)
3.6.1 Changes in roles and power dynamics

For many, the physical changes and inability to complete previous activities causes some imbalance and anxiety regarding the changes in roles which can be a contentious process. Many of the participants indicated some ambiguity and discord with the shifts in power dynamics within their relationship, as they were physically unable to fulfill all the tasks and roles they were otherwise able to prior to illness (n=9; 41%).

I felt good (in the relationship prior to diagnosis). I think then, and we still do, well no probably more so then… it was more of a partnership back then. Because I was very strong, to be honest, in the early years I was the bread winner. I was making more money than he was and that was actually the main reason he didn’t propose to me. He is very traditional and he said that until he was making more money and felt that he could take care of me he felt that he could take on that role of husband. And to me, that didn’t really matter but it really mattered to him. Back then, again, I was so confident. I was confident in my role as a teacher, role as a girlfriend, in my role as the bread winner, which he didn’t love. But so, we were really sort of partners back then and we would sit and look at finances and sorted – okay well I will pay for this and you pay for that. Can we afford to do this trip and can we afford this purchase? Everything was very partnership. Not… that it isn’t…now but he tends to take more of a leadership role now after the diagnosis…It makes me feel not as… I don’t know- not as much of an equal in the relationship because he has to do so much more for me than he had to previously. It makes me feel not quite the person that I was or that I should be. (Shannon)

I think I had a lot more say in the relationship back then whereas now I feel often that he has excessive amounts of say in the relationship. (Kelly)
For many, changes in the power dynamics and in the roles were quite difficult and there was a shift from being perceived as equals, to that of being a caretaker.

If I could still do that, it would be fine but now I have to rely upon him. He said he ‘accommodated’ me. And I got really upset and said, “Well you can stop.” And he said, “I don’t know why that word bothers you, we use it at the school all of the time.” And I said, “I am not one of your students, I am your wife.” (Sally)

He is very protective of me, sometimes I feel bad that he is my like my caretaker in some ways. He seems fine with it. And because of this, his eyes are open too… he cares for other people… strangers he sees struggling, who have a disability, people on the side of the road who are struggling with their scooter. He will pull over on the side of the road and jump out and go help them… (In terms of changes in the relationship) I would say that the romance part of it. Not that he has ever been particularly romantic, but I would say that has declined a bit only just because of the fact that we do have a different sort of caretaker–patient relationship on some level. (Shannon)

Helpful but, I know it’s almost become his new identity taking care of me instead of being with me. (Jackie)

The impact on previously established roles and norms set by the couple caused many participants concern. For many (which will be discussed) this led to incongruence between partners and discord.
3.7 Incongruence versus cooperation

Ten participants described sources of conflict that were directly related to the illness, and felt that their partner was not being cooperative in helping them cope. This discrepancy between want and what they were given from a romantic partner created relational discord. It left individuals feeling anxious, frustrated and misunderstood (n=10=45%).

Ohhh many times. You know, “Have a drink. Have a drink.” He doesn’t say that all the time but when we have family gatherings and stuff like that. Even my mother “Oh you know a drink won’t hurt you.” And then they find me kind of boring when I have to repeat all the prescription drugs I’m taking and what the negative effects could be if I take that. No I have no desire to… I have no problem, like the alcohol I mean I have no problem at all. To me it’s as if I missed stuff. It was fun but there are a lot more things now that I consider a lot more fun than that was. It’s just I find it really annoying having to explain or having to repeat myself as to why I’m not interested in doing that. You know people don’t understand me just like I don’t understand them and I think that is perfectly normal. It’s funny how the few people around me who have chronic diseases how they totally understand my point of view. (Lindsay)

Yeah and sometimes he still doesn’t let me...sometimes I still play the poor me card and he doesn’t let me which is probably good because it’s not really the best use of my time or energy...Oh I get pouty and I’m like “Wah!” Then I go pout by myself for the night and I realize how foolish I’m acting. (Amanda)
It’s been tough for him the past 4-6 weeks when I have not been feeling great. He is the most positive man I have ever met. His solution is to look on the bright side. Sometimes I don’t want to look on the bright side. You know. I want to wallow for a day. (Lauren)

I don’t know. He seems to think that I have a lot more anger. I don’t see it. In fact, I think that it’s just him projecting a little because he has been angry…I probably am. I mean of course there is going to be anger. I am just ticked off that I got stuck with this. I think he feels that now that I am angry, I am just not happy with any of life…So if I start talking about things, like my personal way to be in my world, if something upsets me…like something I read in the news. I like to talk about it. I like to tell people I am upset about it. I think anger keeps you on your toes *laughs*. He doesn’t like that. He doesn’t. He thinks we are supposed to go along like the world is dandy. (Jackie)

For many participants, the feedback they received left them feeling misunderstood (n= 7; 32%).

There’s been a few times where I’ve been like “You just don’t understand!” But I mean he’s actually done a lot of research…I mean I think there’s something you just always don’t understand because no matter what you’re talking about, like when he has a cold he’s probably like, “You don’t understand!” I’m like “Suck it up! You’re being a baby!” but I mean there’s definitely moments of frustration where I’m like “I’m tired. I hope it’s not my MS” and he’s been like, “Go to sleep. It’s not your MS. You’re tired.” I’ll be like, “Clearly I’ve been up too late. I need to go to sleep.” He was definitely frustrated when he wouldn’t let me play the poor me card, for sure. I was like, “You don’t get it!” and he’s like, “No, no. It’s been two months. Like I understand that you need to be upset and I understand that you need to cry, but let’s get over; let’s move on.” So there was definitely some frustration at
that point, but I mean, he was right. Like I definitely was playing the poor me card, but it was frustrating at the time, like “Why don’t you understand?” (Amanda)

I think at times it does (strain the relationship). Because at times when, you know, when it’s one of those days when it’s a bad day and I’m angry that I have this, and he’s not taking the initiative. I think to myself, I ended up with this disease. And I have someone who, I guess, doesn’t understand it, so it doesn’t help. It makes it tougher. So I think that some of the way that I am of not wanting to be huggy or kissy is because I might be a little resentful of the fact that he doesn’t understand that I have this and that some days is hard. It’s not his fault 100% because maybe I am not communicating that. (Michelle)

We are not fighting as much about that stuff. I feel like sometimes my husband doesn’t really understand the disease. He doesn’t understand that if I am tired that day. I mean, he is pretty good. He is a good guy and everything- but he doesn’t take the initiative to do things like bathe my son or with the thought in mind that I am probably tired. I usually am tired. So if I ask him he’ll do it, but he hasn’t really changed in any sense of thinking, ‘You know what? She’s got this disease let me help her.’ If I ask him he will do it, if I don’t then he won’t do it. (Michelle)

The following quotes describe a delicate balancing act between participants and their partner. On one hand, they wanted their partner to step up to the plate and help them when they were physically unable. However, on the other hand, they would also become frustrated when they perceived their partner to being too protective or that they were being prohibited from doing things that they were physically able to do (n=9; 41%).
It’s very hard. In some ways I wanted people to step up because they had to. Something’s he does not step up for which made me upset. But the things he did step up for... I am never really happy because the ones he does step up for I wish he wouldn’t. *laughs*

(Jackie)

He treats me like china and has become over-protective. (Wendy)

He considers me to be more fragile. He doesn’t commit to something because he explains my illness and the day to day. (Megan)

There are days where I can tell that he’s making an awesome effort and that he’s trying to compensate for the things that at the moment I’m not capable of doing. I would say up and down. (Lindsay)

Now I still try to do that but I can’t. So I guess, I do not know but he does it more because he thinks he should rather than because he thinks he has too (with husband)... Well there are some things that I just don’t need like he would be willing to get me a cup of coffee and I said, `no I wanted tea`` he would go back and get a cup of tea and I don’t need that kind of babying but he would do that. (Jackie)

3.8 Predictors of positive outcomes for couples

3.8.1 Cooperation & Self-Verification

Participants described higher personal and relational satisfaction when they perceived their partner to be mirroring back and confirming various aspects of their identity (n=14; 64%).
I have always been able to be myself. I think that’s one of the reasons why I am fortunate to be with my husband because he is one of the only people who I feel really gets me, understands me, and loves me unconditionally through everything and he just, he is absolutely my best friend. (Shannon)

Many described their relationship fondly and emphasized their gratitude for their partner (n=14; 64%).

Yeah! Yeah. We are there to support each other…No it’s been a great twenty six years. I would do it all over again. I still love him to bits. (Elizabeth)

It’s been great. We have been lucky in that we have had a good relationship and marriage. (Sabrina)

He is just an incredible person. It has opened his eyes up to persons with disabilities. He is extremely protective of me. He is very sensitive to how I am feeling and what’s going on with me. He is an incredible husband and I am so blessed. I just…our relationship is incredible. He is my rock, my confidant, my best friend. I am so blessed, especially knowing people with this disease. I don’t even know what the statistics are but I would say most relationships don’t survive it. (Shannon)

He’s a spectacular man. He cares about everybody and everything in his world. He...he loves his family. We had a...a sharing relationship that...that really had no problems. We were...we were very happily married or cohabitating as the first two years were. It didn’t matter. I know that I am blessed with a man who is the ultimate caregiver and who cares about everybody in the world. (Anna)

For many, verification came in the form of feeling supported by their partner (n=15; 68%).
He’s been amazing. He’s incredibly supportive, he’s my rock emotionally. He is just physically always there with his arm out or if he sees me struggling he is the first to turn to someone and ask, ‘Do you happen to have a chair that my wife can sit on?’ (Shannon)

He didn’t really say anything during the process, like when I was diagnosed, but he stood by me when I had to go for tests. It doesn’t matter if it takes 20 minutes or 20 hours, he never complains about anything. He’s very...I know he’s on my side. (Jessica)

He has been loving and supportive. He has been a great source of comfort and someone’s shoulder to cry on too. He has been present at appointments, taken over looking after a lot of household things, looking after our son as well. (Wendy)

Oh the same. Yeah, totally the same; very supportive, like you know, if I need him to pick up the slack with something around the house it’s not a problem. I mean I can tell if there are times that I ask him to do something, I’ll say “can you do me a favor?” and he just rolls his eyes because he’ll say “What is the favor?” And I can tell it has to do with the day that he’s having, and then I’ll say “you know what, I’m not asking you because I don’t want to; I’m asking you because I need your help.” You know...and yeah, he’ll be like “okay, yes, yes, yes, I’m sorry”. (Christine)

He had a lot of expectations of me to (pre-diagnosis) of things that he liked me to do with him. We would go out to the church, and I would go on visits with him. Stuff like that. He (now) just let all of that go and said- don’t worry about any of that stuff, let's just take care of you. Rest up. It was really good in that regard, and it continues to be like that. (Olivia)

There was so many times where even though physically I felt terrible. I felt really happy. I could get through it because of the support that I had. (Olivia)
I think he has been extremely supportive in a sense that he is also trying to cope with it too, so if you’re asking if he has been supportive to me, he has been very supportive. (Sabrina)

Having a husband act cooperative and accept their physical limitations was paramount for those who described relational satisfaction. Self-verification facilitated a smoother personal process when their husband was also adapting and accommodating in an accepting manner (n=14; 64%).

Because if I am having a bad bout of fatigue, my husband will come in and say what's wrong; and I am just kind of down because I can’t do what I want to do- and he's like it's like having a broken leg or like diabetes, it’s like having any other disease. And right now you just can't do anything. So he’s very supportive in that way. (Chantal)

And again, it’s silly piddle things, like I’ll say to him, “Would you like, mind going downstairs and bringing up the laundry for me so I can fold it?” Because going down the stairs I’m like “ugh.” Just the thought of it makes me tired right or on the...once every couple of months like if it’s in the afternoons I’ll have to go lie down and he’s like, “Go, go, go lie down,” where me I feel like I’m burdening him with more, but he's never. If anything he pushes me into going, you know like, “Lie down and rest more.” (Christine)

My husband helps me in that regard. He tells me to sit down. He calls me in from outside if I am in the garden and tells me to come in- that I have had enough; He does a lot of house work. (Elizabeth)

So if he saw that I was starting to do too much and that I was starting to crash he would say- okay, you know what, I know you made plans to go out today but I really think you should stay home. He doesn’t tell me, but we will discuss it. He will say, I really think that
you should stay home; you have been out for the past two days for more than you normally are and two days in a row is a lot for me. We sit and he rationalizes with me and it’s not that he wins but he just knows me better than I know myself. It's amazing to have someone in your life like that. I don’t know where I would be with the MS if I had of just kept pushing and pushing and pushing. It means the world of difference (i.e. having husband put things into perspective). But nobody knows what I go through every day except him. That’s because he sees me in good times and in bad. He sees me at all different hours of the day and night. If I am having a bad night and have to wake him up, he will stay up with me. (Chantal)

Since my diagnosis he talks about dividing responsibilities. When my hands hurt it was hard for me to…some textures really hurt my hands. Towels for some reason really hurt and folding towels and socks was hard. Putting my hands in hot water was hard. So he stepped up and did all of the dishes. Now he does all of the dishes, all of the laundry, all of the groceries every weekend. He lets me sleep in on the weekends and takes the dog out. And I don’t ever hear him moaning about it. I did this, I did that. (Lauren)

I think the division of household labor. He has picked up a lot in terms of housework. I love it. He picked up some of that before, because he was the retired one. I think he does it more willingly now because it is helping me. (Elizabeth)

Like I say, I am very dependent upon him. I don’t drive at all. I am dependent on him for obviously getting to different places. In the wintertime I can’t take my scooter. I live really close to shopping centre, groceries and stuff and in the winter when my scooter obviously can’t go in the snow. He has to grocery shop and even though I do most of the cooking I am dependent on him to do the groceries and pick out everything and that’s sometimes a
challenge. Oh he is fine with that. He doesn’t like doing the groceries, that’s pretty obvious. But he doesn’t complain. He will take the list and he never makes me feel guilty about it. Even about the fact that I need to depend on him. It’s just become part of our fact, our new way of life. (Shannon)

This acceptance was also modeled through the husbands’ own use of personal self-care. Many of the participants note that it was important for them to witness their partner practicing what they preached regarding good health and that this was modeled for them. This also facilitated a sense of team-work and cooperation regarding maintain good health as a unit, rather than being singled out by chronic illness (n=11; 50%).

And he's always been good with his own health. He will go to the doctor and if his blood pressure is high he will start exercising and take medication. His issues are genetic, so even though he tries the exercise and cutting out different things out of his diet, which we both did at the same time. (Chantal)

Those who described their relationship as maintaining a degree of satisfaction were apt to endorse their partner’s perspective and had empathy for their shared experience in coping with the effects of MS (n=10; 45%).

We’re talking more personal things as opposed to things that we can do together. I guess maybe just the whole like he feels like he has to be able to do so much for me and it’s probably hard for him sometimes. Well I know it’s hard for him sometimes. (Kelly)

The other part is that we have had a lot of discussion about how he has felt about MS. One of the times where I was dumping on him every day and he got frustrated with it, and he said, “Look you need to give me a break.” We had a bit of a fight that day. But he was like,
“Look I don’t know what I can do for you.” From his perspective he lost, because he wants to be the problem solver. He wants to fix things. He is the problem solver at work. But he can’t fix this away. I can’t do anything for you. I can’t feel what you feel. But what I can do is help. Help you out where you can. It really took me aback because I was so focused on my own helplessness and fear and I forgot that someone else is in this with me. So we have talked a lot about that as well. (Lauren)

You know, I think he has gotten better but he worries more than I do. So if I have numbness and stuff, it really bothers him. He is more worried about me. He tends to worry more about my MS than I do. I would too but I think he would be more because he has a hard time dealing with that kind of stuff. It bothers him more when I can’t move my legs and that kind of stuff. He worries about it more. He will ask me, “When will it go away already?” I think he would say that he worries more and worries about me more. So that impacts our relationship because he doesn’t know what’s going to happen to me. (Sabrina)

But then there is also his own coping with it, being diagnosed with my symptoms that I have had, that has been some things that he has had to deal with. And he tells me that he is being supportive *laughs*. He reminds me, which is good. (Sabrina)

But I still think he has. I think he struggles with that because he has said to me, you’re such a good person why did this have to happen to you. So it’s hurt him very much. It’s taken him awhile to really come to grips with it, probably longer than me. (Louise)

I was also really grateful for how he responded. I realize that I probably wasn’t giving him enough credit for how much he cared. I think it was harder on him than it was me. I kept thinking that, “Wow, he was really broken up about this.” Whereas, I felt that, when you
are the one that is sick you know how bad it is. But for people watching you… all of a sudden I was struggling to put my clothes on and it was harder for him. I think our relationship has changed. He probably realized how much he cared and did not want anything to happen to me. And for me, I realized that he would be there for me. (Olivia)

It was clear in the language used, how many participants viewed coping with MS as a team effort. They would frequent use the word ‘we’ in terms of the decision making process and accommodations made (n=7; 32%).

We made a good, sound decision. I did try some of the drugs that were available. I am not taking them now, but I did try them. He was wonderful, he really was. (Louise)

We make concessions to the disease when we have to but we try not to and accept the limitations. We’re facing the world as we are. (Anna)

Some participants indicated that their relationship was enriched as the result of undergoing this process together (n=9; 41%).

We have always been really close. We have had our challenges in our relationship for various reasons and that, but I am not sure. I think we are a little more conscious about the fact that I have MS but from a relationship perspective, to some degree I think it has brought us a bit closer together. It’s kind of hard to say that- I am not sure if that has or not because at different times when we had to deal with different things obviously we were not close at that time, or we were challenged in that. It’s kind of hard to say. (Sabrina)

I think...I don’t know. I think it has made us come closer. Now I realize I rely on him for certain things and it doesn’t seem to bother him in the least that I rely on him for certain things. (Jessica)
I think it has been enriched (since diagnosis). I have thought a great deal since responding to you and talking about relationships; I’ve been doing some thinking about it. I have thought over the years that any relationship that is a healthy relationship that does not have cracks, problems, that is...it is the partners are above board about whatever roadblock is being presented. They can deal with it if there are no problems beginning. I believe that our relationship has been enriched by the giving back. (Anna)

I don’t think that’s done it for us. I don’t think it’s strained it. It has brought us closer together. I think too that he knows that if god-forbid something should happen to him, I’m not going anywhere. (Jessica)

As unsettling as the whole experience has been, as far as our relationship goes, it has definitely brought us closer certainly at this point. It's been good. Which is why I was so willing to participate. I have had such a positive, the support I have received its way more than I would have ever thought. It's been good in that regard. (Olivia)

Part of that is why I fell in love with him. But I...I think there are other difficulties those chronic diseases bring up. We are...we assist each other in our lives. He and I...we...I’ve always felt that like two pieces on a jigsaw puzzle, where my personality goes out, his has an innie for my outie and so we can complement each other. (Anna)

If anything it has enriched our life (relationship since diagnosis) together simply because we know that everything...that what we’ve received, we’ve given. (Anna)

As proposed in the INT model, consistency in relational goals helps to maintain a sense of continuity within the relationship (n=9; 41%).
He’s actually from Prince Edward Island and so am I originally. We both have the same goals in mind and we both have the same future plans that we wanted. I didn’t actually expect to end up living with this gentleman or any aspects of getting married, nothing like that. I just thought he would be a nice companion as I grow older. I was sort of set in my own ways and that was it. I think that we have the same moral upbringing and we have the same goals in mind. I think that’s a huge thing for both of us. (Jessica)

I would say honestly, we are very fortunate in that – remember when I said our goals from prior to the diagnosis- we have pretty much accomplished those goals. There may be minor tweaks here and there because of my disability- you know we are financially comfortable, we travel, and we have a beautiful home which we had built. And all of those things had minor tweaks because of the disability but still the main goals have been accomplished. (Shannon)

No not really *laughs*. We were just talking about this the other day. I said to him the other day, it’s a good thing that your hobby is lying on the couch and watching TV *laughs*. It’s a good thing that he didn’t want to go dancing every night. In that regard, it’s been really good. (Lauren)

I think our goals were, well I know that his were when we were first engaged was, to start making more money than me. Which he did, two months before we got married, believe it or not. He was head hunted by the company that he is with now and he jumped way above the money that I was making. So I know that was sort of his goal, but I think our goals were always just sort of to live comfortably financially, to own a nice home, to be able to travel, at that point we were sort of back and worth- were we going to have kids, weren’t we? We
hadn’t completely finalized what we were going to do family-wise. But we were kind of on the same page about that and I mean, I would say those were sort of our goals. (Shannon)

3.8.2 Communication and relational clarity

As previously discussed, INT proposes that relational clarity facilitates better outcomes and identity continuity which then aids in a higher degree of relational satisfaction (as roles and expectations are maintained and not as disrupted). The results of this study suggest that this is influenced by the degree to which couple’s communicate. Those who communicated their experience and expectations with their partner, resulted in higher relational clarity (n=11; 50%).

Many participants indicated the importance of open and candid discussion and communication regarding MS and their fears, symptoms, and goals with their partners.

Yeah, we communicate more (since diagnosis). If I am feeling anything or if I have snapped at him for the smallest thing I always feel really bad or guilty right away. So he comes in and I apologize and he says, “I get it, you don’t have to apologize.” And I think that it says something about me as a person to not have something like that happen and not react right away because I know I am not like that as a person. I wasn’t before and I know I am not now, I think it's just everything I am dealing with. (Chantal)

I don’t know if it’s because of multiple sclerosis or if it’s because of my partner now because he’s very open to any fears that I have. So I’m slowly getting to the point where I can voice my fears with him. I don’t know that I do with anybody else, but I do it with him. I’m more open I think with David now than I was before. (Jessica)
But I think if it changed our relationship at all, it again…it kind of gives us more of a grounding if you will. So we...when we are thinking towards the future, you know that will get brought up in conversations right. So like, “well what if this were to happen? What if I don’t stay stable right? If I do end up having a relapse, how are we going to deal with it?” So if anything maybe it’s increased the communication. (Christine)

I think we communicate a lot better now. With the way we are feeling. The way I am feeling. The way he is feeling. I think that in the beginning when I was diagnosed, I think I was more so in denial. I never really wanted to talk about if I wasn’t feeling good that day, I just kind of avoided talking about it. I think we communicate a lot better now about things. (Michelle)

Talk. Talk to each other. Share how it makes you feel. With MS, how does it make me feel as a person with MS...You know how do you feel about having to take care of me all the time? Well you know, exercise that difficulty...talks about how it makes you feel and how you don’t like the way it makes you act. It’s special and I think that those with MS who are open about the problems in their lives to each other, they can make it. (Anna)

Conversely, participants who described a lack of communication within their relationship often described feeling anxious, isolated and/or distress. They often walked around their main issues associated with these changes, and missed the mark. This often created tension and disappointment.

We don’t talk about it. Ever. Ever. Ever. (MS). It’s a little challenging. He’s the only person that I would want to share it with. But he’s never once in four years asked me how I am. (Elizabeth)
Yeah, and I have tried to talk to them. But actually no one, not my husband or kids actually talk about MS…They won’t talk about the future. They won’t talk about how it affects me. That’s just something…I don’t know if there are not ready for it. They just don’t want to talk about those issues. It’s like everyone just skirts around it. (Jackie)

We don’t really argue that much. Maybe less communication might be one, or like not listening to each other, or not listening to the other person fully, not actually thinking about…I’m actually kind of guilty of not thinking about his feelings sometimes. Maybe being selfish, but yeah we don’t really argue a whole lot. But when we do, we definitely still have the same like…”okay we’ll talk later.” (Amanda)

For many participants, having already faced adversity within their relationship in various forms (illness, hardships etc.) prior to the diagnosis, helped heightened their ability to effectively communicate, and actually helped to neutralize the potential power dynamics caused by identity renegotiation (n=4; 18%). This was the case when the husband had prior medical issues that the couple had to cope with (i.e. cancer, heart attacks, male infertility).

I mean there have been times where we haven’t communicated. It’s been many years *laughs* but yeah I would say that I over communicate and he is less to communicate. We try to work it out. I think, you know, I think I always tried. He’s always been more closed and I tend to talk too much and over communicate. But I think that he and I have gotten better at that. I think the fact that prior to being diagnosed we had to deal with medical issues. So we had to get through that. It was pretty early on… So we had to deal with that pretty early on in our relationship. I think that kind of helped us work on our communication and dealing with issues. (Sabrina)
My husband was very good about it. I always said that it was the Ozzy and Harriet family, and I married into the Osborne’s – the dysfunctional. He would call me every day from work and ask me if I was up and had been out. And I would say no. And he would say- I want you to just go and walk up the street a couple of houses (she also had an anxiety disorder). And finally I did just kept doing that until I was walking around the block and walking further and I felt better. For someone who has never had any kind of relationship with people who have a mental health issue, I thought that he did very well. (Sally)

The findings suggest that those who have already faced adversity or hardship within their relationship prior to having to cope with MS, fared better in their ability to do so. This was also apparent for the one participant who had established her relationship well after having MS. She had recently undergone the dissolution of her marriage and was now within a new dating relationship. She discussed how it felt easier with her new partner, as he was aware and supportive of her having a chronic illness. He was aware of her symptoms and the expectations and norms of their relationship were established with these considerations in mind. As this finding was only endorsed by one participant and therefore preliminary, it does not constitute a theme. However, it would be interesting to explore whether this is a shared experience for those who establish an intimate relationship after diagnosis.

It’s easy because he said, “I didn’t walk into this blind. I know you have MS. I’ve known you almost 20 years. I’ve seen you your whole life and I know what I’m doing. And we’re going to do this together.”
3.9 Identity is impacted by social context

As proposed by identity theory and more specifically in INT, social context and external pressures and feedback influence and shape identity. The results of this study suggested that one’s identity is influenced and impacted by their social environment and their affirmation/or/incongruent information received from loved ones. The majority of participants (n=13; 59%) explicitly discussed the influence of their social circles on their identity. This was not limited to one’s romantic partner, as participants referenced the reactions from family, friends, co-workers, children, and partners as having impacted their sense of self in their incorporation of Multiple sclerosis into their person situated identity.

Many participants (n=10; 45%) believed that their illness singled them out, or caused others to view them differently. This was difficult for them, as they were struggling with discrepancy between how others treated them with their own self view and their own transition towards understanding how this illness fit into their life.

I have girl friends but I don’t want this to be… I don’t want this to be a topic of conversation every time I am with my girlfriends. Because then it starts to define me. In my mind, once and a while for a girlfriend to say, “How are you doing?” Is fine; but I have one friend who tries to… and maybe because she is a nurse, my best chum, she almost wants to treat me as disabled. Like she will go to help me down the stairs and I will think- what is she doing; don’t grab my arm in public. If I need help down the stairs, I will figure it out. It annoys me. It infuriates me. And I bite my tongue and I tell her in a softer way- I would really prefer if you don’t do that. (Elizabeth)
You know, and you just figure that people, especially important people in your family are just looking at you different. (Jackie)

I keep this diagnosis very secret. Nobody at work knows. There are over 2500 people at my employer but only a handful of close family and friends know because I don’t want this diagnosis to define me or how people see me or think about me when they interact with me. I fear that people will wonder if I have plaque in my brain and therefore I am losing my ability to make decisions at work or manage my responsibilities. So I prefer that they didn’t know. I also work with neurologists every day. That’s really challenging to pretend that – hide it. I live a life of secrecy. I fear pity. I fear being seen as less capable than I am. (Elizabeth)

There’s always risk when you disclose, which is why you have to gage how much, when and to who…Well you have to know your audience. And you have to get a sense of what the response might be. It’s a whole pile of trust. And for the right reasons, I don’t want any sob sisters, I don’t want anyone feeling sorry for me and presume that I can no longer stand to do the dishes, go down stairs- there’s that part as well. (Elizabeth)

Conversely, social support also acted as a buffer. It was evident from the interviews, that women coping with multiple sclerosis cited the importance of having quality relationships and friendships. Many participants (n=10; 45%) expressed how valuable having that support was to them throughout their process upon diagnosis- this is not to say that others do not believe that social support is important, however, they did not overtly discuss it in relation to having MS and subsequent changes.
I mean its (MS) certainly taught me how valuable my friends are. I was never a person- I am very picky about my friends- I was never a person who called every person my friend. I always said to people- I have few friends and many acquaintances. So I never used the term friend lightly. I have about seven friends. That’s it. I have one girl who I have known my whole life, she is six months older than me. So I mean, I am – when I have a friend, they are there forever *laughs*. In fact, some people I know are very envious of the friendships that I have because they are so long lasting. There is no one on my friend list that I haven’t known for under 15-20 years. They are amazing women. It goes both ways. (Louise)

He’s not as verbal as I would like (husband) but oh well. I wouldn’t say I have any girlfriends who have husbands that are as verbal as they would like them to be. So I think us girls just have to chat amongst ourselves. I have a couple of really good groups of girlfriends…We get together regularly and they are a source of strength. That’s great. I am very picky about my friends, I always have been. But I do have a couple of groups of girl friends who are tried and true. They are absolute rocks. And we are for each other. They have gone through cancer, diagnosis, divorce, death and we have been there for each other regardless of the challenge. (Elizabeth)

My friends have always been very supportive and continue to be. My mom doesn’t really know. She’s older, she’s 85. She doesn’t really understand MS and that. She knows that I have a problem but she doesn’t really understand it. My husband’s mother doesn’t know. Because it’s not apparent, we haven’t really… my mom kind of knows that something is wrong with my brain but she doesn’t have a good understanding of what MS is and stuff. I don’t because of their age. My brother doesn’t know because he has a mental health issue,
I don’t want to bother him. People have been supportive, but it’s kind of what works best for everybody. (Sabrina)

In terms of social support, satisfaction was again contingent upon whether the feedback from others was self-verifying and congruent with their identity or whether it was discrepant (which caused anxiety and dissatisfaction). Social support was enhanced when individuals felt that they were able to remain and continue within the social roles that had been previously established prior to the diagnosis, and not treated differently because of MS.

3.10 Three emergent groups

In reading the transcripts several times three distinct groups emerged each with shared experience. These groups consisted of: participants whose identity was not disrupted; participants whose identity was disrupted but fared well; and participants whose identity was disrupted and were struggling with these changes. These groups were demarcated by the thematic content of their narratives, as there were clear and salient themes which differentiated them into three discrete categories.

All participants indicated that both having received a diagnosis of MS and their consequent experience of physical symptoms impacted their sense of self on some level (as previously discussed). However, not everyone experienced a disruption in their identity.
3.11 Participants whose identity were not disrupted

The first group consisted of participants (n=9) who experienced changes in their life due to multiple sclerosis, but were able to maintain continuity in their roles (role-identities). These women did not experience a disruption in their lifestyle. Overall, their symptoms of MS did not significantly impede upon their ability to continue operating in the world as they have always had. Women in this category experienced little to no physical impairment (or had experienced more mild and transient episodes of symptoms that had resolved).

They expressed some fears regarding their diagnosis and the uncertainty of their symptoms. They also feared having to disclose the nature of their illness to others (as any
symptoms were largely undetectable by others) and were concerned that they would be treated differently in social situations or in the workplace.

For this group, relational satisfaction and relationship as a variable did not appear to be a mediating variable in terms of their identity and coping with multiple sclerosis, largely because their lifestyle remained unaltered. Therefore, regardless of whether their relationship was perceived as satisfying or not, did not appear to have an influence over their identity.

The following is a hypothetical composite of the shared traits and experiences of all women in this category:

**Allison**

Allison’s identity was not disrupted due to having multiple sclerosis. Although she has some fears associated with disclosure of her illness to others she fears that others treat her in a discrepant manner or assume that she was less than capable. She indicated that the primary reason for the continuity in this regard was that she does not experience any physically disabling symptoms at present. She is currently able to maintain her roles at work and at home.

Allison described her husband as always having been supportive towards her, and she admitted having gone through a brief period of adjustment following the diagnosis which he helped her to navigate. They had a good manner of communicating with each other, and there were no glaring areas of dissatisfaction in their relationship. She credits having MS as helping her to create a better balance in her life, as she has always perceived herself to be a Type A overachiever. As a couple, their perspective has changed in the sense that they live in the moment more, and engage in activities in the case that they won’t be able to accomplish them should the MS become worse.
For women in this category whose lifestyle was not disrupted by the onset of multiple sclerosis, there were clear themes. Overall, these participants indicated that although aspects of their life had changed, they were not greatly affected by the onset of MS.

So I would have to say that really everything has stayed the same, and if anything it’s gotten better. (Christine)

I don’t know if it impacted my identity so much as I hadn’t really become comfortable with the diagnosis or what it could possibly hold for me. (Amanda)

For all of these women, they indicated that their symptoms of MS were relatively benign and they did not suffer physical impairment in result.

I’m lucky because my MS is very stable so I would maybe have a different opinion if I was affected more on a routine daily basis with it. You know I may feel a little more strongly about how it has affected me, like with regards to my identity. But you know, overall I mean, yes. The way I like to think about my MS is that it’s definitely a part of me, kind of you know, it’s the same as when you say you’re a mom, you’re a daughter, you’re a wife, and you have MS because it definitely, you know, has the potential to affect your life in every spectrum basically. But yeah…I’ve been lucky, I mean, it’s a fraction of the pie but by no means is it who I am or does it, you know, steer who I am or what I choose to do with my life. (Christine)

So I think that it is difficult to answer because I think it will change, we are expecting that things will change. We don’t know how or when. That’s kind of a difficult question to answer, I don’t know. I think it’s been fortunate that I have had to change or cope has been
minimal compared to what other people have had to deal with. It hasn’t come to that point
where we have had to deal with more severe symptoms or ongoing. (Sabrina)

However, for some women (n=4) there was first a period of adjustment upon receiving
the diagnosis. For them, it was the having to cope with the uncertainty and the prospect that they
may someday have to cope with physically disabling symptoms.

When I first got diagnosed I took a bit of time to adjust… I wasn’t too sure about how
things were going to fall into place. I still don’t know. I think that it became a fear of the
unknown. So it took me a bit of time to know that a lot of times you don’t
know…regardless of whether you have MS, what’s going to happen. So I kind of took that
perspective. And that seems to have worked for now. (Sabrina)

Since these women were largely unaffected by physical disability, they did not
experience disruptions in their lifestyle or social roles. They were able to maintain their
employment and their major roles in their life. Megan was the only exception in this case; she
ended up having to quit her job due to the fatigue caused by MS. However, she noted that it was
not a significant loss. For her, employment did not appear to be a salient or important feature to
her identity, and therefore was not a significant loss in her life when she had to discontinue.

My whole life I wanted to grow up, get married, have a family, and own a home. And so I
had no big career ambitions. I just wanted to be a stay-at-home mom. (Megan)

Moreover, for women in this group having MS did not impede relational goals or ability
to carry out the previously defined roles and expectations set out as a couple.

Whether it be shared activities as a couple:
We were just talking about this the other day. I said to him the other day, it’s a good thing that your hobby is lying on the couch and watching TV *laughs*. It’s a good thing that he didn’t want to go dancing every night. In that regard, it’s been really good. (Lauren)

I think we still enjoy traveling and that. I must admit I think that what’s changed is that I think we take more initiative to do that. We travel almost four times a year now instead of once a year. And anything that requires a lot more activity or walking we will try to do that now- because we don’t know. So I think, we have always had the shared enjoyment of life, but I think we do it a lot more consciously now. Take advantage of doing things because we are not sure if I will be able to do it after. (Sabrina)

Of long term prospective plans:

The vision is basically the same, you know...like you know, watch the boys grow up, get married hopefully one day, have children if they wish, and yeah, still retire at 55 and do all of those things that we wanted to do still. (Christine)

The majority of women in this group (n=5; 64%) credited having a supportive husband in their ability to cope with MS. It appeared that having a supportive partner mediated the effects of the diagnosis itself.

One thing I guess I could say as far as my relationship with my husband goes, I was so pleased by how he handled it. We have been married for 22 years, almost 23 years. You always wonder, "Boy if I ever got something really serious, what would happen? How would that change things?" For me, just the way that he took it upon himself to find out information and comfort and be so supportive and loving was a real positive for me. As unsettling as the whole experience has been, as far as our relationship goes, it has definitely
brought us closer certainly at this point. It's been good. Which is why I was so willing to participate. I have had such a positive, the support I have received its way more than I would have ever thought. It's been good in that regard. (Olivia)

When I became sick, he became so supportive. It really drew us closer. All of those things that you get picky about or worry about dropped away. They really did. The important thing is getting through this and what would happen for my future. That was a change. Before, I was trying to do this all by myself and then I am much more open now. I guess I have changed in that regard…He had a lot of expectations of me regarding things that he liked me to do with him. We would go out to the church, and I would go on visits with him. Stuff like that. He just let all of that go and said, “Don’t worry about any of that stuff, let’s just take care of you. Rest up.” It was really good in that regard and it continues to be like that. He listened for hours while I talked about this stuff and tried to make decisions about my treatment. It's difficult for me to make decisions. He is very good. He will gather the facts and make a decision and move forward. I will go through all of my options over and over and over again and keep changing my mind. We have had to talk through this a lot. He doesn’t want to make the decision for me but help me sort through all of the information. So that’s been good. There has been a lot of communication. (Olivia)

I think that to some degree it has kind of brought us closer. I think that he is a little bit more supportive of things I want to do. For example, when I did the ‘MS climb’ he was completely against it because I was doing it by myself…He was really worried about it. But by the end he was really supportive and helped me do my webpage, and helped me get a lot of sponsorship. So I think that it has brought us closer together. I think that he kind of
respects the person I am, whether I have MS or not. I have always been like that. It’s just a different perspective now. (Sabrina)

Michelle noted that her relationship with her husband was not incredibly supportive prior to the diagnosis and that they experienced ebbs and flows. After the diagnosis, she noted that although her frustrations with him appeared to magnify (particularly as he was not stepping up to help out around the house more) due to the invisibility of her symptoms (i.e. fatigue) they started to communicate more effectively.

I think we communicate a lot better now. With the way we are feeling. The way I am feeling. The way he is feeling. I think that in the beginning when I was diagnosed, I think I was more so in denial. I never really wanted to talk about how I was feeling that day. I just kind of avoided talking about it. I think we communicate a lot better now about things.

(Michelle)

3.12 Disruption in role-identity

The majority of participants indicated that coping with multiple sclerosis did disrupt how they viewed their place in the world (n=13; 59%). They experienced a marked decline in their physical ability, which directly impacted their social roles, interpersonal dynamics with loved ones and their overall identity. They experienced discrepancy based upon what they were previously able to do versus what their symptoms would now permit. This often resulted in transition towards being more dependent upon others for aid, and changes to their identity-roles (both personally and professionally).

This group emerged consisted of two sub- groups: 1. Individuals who were positively coping; and 2. Individuals who were struggling (as evidenced by heighten psychological
distress). The next sections will explore the narratives and common themes amongst each of these groups.

Of note, it is recognized that coping is a fluid process and many underwent a process of adjustment and grief (which will be discussed). The following section is an observation of the differences between the groups, for clinical utility in helping individuals who are struggling with changes. However, less detailed responses will be provided as to preserve the anonymity of individuals who were undergoing struggle during the time of the interview.

3.12.1 Disrupted identity: Coping well

Within this group (n=7; 32%) of participants had undergone a decline in their physical functioning whereby they underwent a period of adjustment and grieved the loss of their abilities. However, through this process a transition occurred whereby they begun to find gratitude, positively reframed their experience and found acceptance in their situation. These participants tended to become more adaptive and accommodating to their symptoms, and were able to negotiate the transitions more smoothly. Many cited the importance of their social relationships in coping with these changes, and described their husband as being loving, supportive and self-verifying as a mediating variable in their ability to positively cope with the declining physical changes. These proved to be valuable coping strategies to temper the potentially negative effects of MS.

The following is a hypothetical composite of the shared traits and experiences of all women in this category:

Nancy
Nancy’s identity was disrupted due to the increasing physical disability caused by multiple sclerosis, and she was particularly impacted by how the visibility of her symptoms impacted her self confidence, her perception of herself as an able-bodied individual, and her overall independence. She reported that the biggest loss was her inability to continue with her career, which was a large part of how she defined herself, as she felt like she had lost her purpose in life. This was made worse by the fact that she was let go due to her physical limitations directly caused by the multiple sclerosis.

She recreated her identity by devoting her time to nourishing her interpersonal relationships as a homemaker, wife and friend. She started volunteering to help advocate for individuals with disabilities. She maintained that keeping positive is important for coping with this illness (and maintains that aspect of her pre and post diagnosis).

In terms of her relationship, Nancy indicated having a loving and supportive relationship with her husband. They communicated well, and she felt validated in her role in their relationship. The onset of MS occurred when they were engaged, and she said that it threw a curveball into their vision and relational goals as a couple. Overall she indicated that they have a highly communicative and respectful relationship and noted that the quality of their communication has enhanced having gone through this process together. She expressed a level of gratitude for this support in making these transitions easier.

Throughout the process of having to adjust to MS, the participants who experienced disruption but none the less fared relatively well were those who could adapt cognitively and emotionally. This included: acceptance of uncertainty; which than facilitated adaptation; positively reframing their situation; enhanced gratitude and compassion; and an overall perspective shift towards living in the moment.
As previously noted ambiguity and uncertainty can cause notable anxiety. What was realized through the interviews was that all of the women in this category underwent a period of adjustment which resulted in acceptance and overall increased emotional wellbeing. It appeared that those who found acceptance and were better able to preserve valued aspects of identity and maintain better continuity in their roles.

The sub theme of accepting uncertainty was clearly evident in the shift towards creating meaning and redefinition of one’s identity.

You can’t keep thinking about it (MS) every day; about the ‘what ifs?’ What might be? Sometimes you have to give it up and say, “What will be, will be?” (Elizabeth)

For all in this category, this required an acceptance, having to try different things and accommodate their changing symptoms, which facilitated adaptation.

Just to take it one day at a time. Don’t expect the worst, don’t expect the best. We’re all different so everybody’s perception is different and everybody’s symptoms are different. (Jessica)

Many participants indicated that throughout their process of adapting to their ever-changing physical limitations, the process itself made them more attuned to their body and their needs.

I have learned how to pay attention to my body. I have learned how to read my body. I have learned what my body is telling me. I think I am becoming one with myself. I kind of know now. I still push myself too far. I will still go somewhere and not take a portable or non-manual motorized wheelchair. I will walk with my cane and later think, “Oh crap, I shouldn’t have done that. I have to find a bench real soon.” (Louise)
Coinciding with acceptance, these participants noted that adopting a positive outlook facilitated their ability to incorporate the changes into their identity and their life with greater ease and promoted better overall wellbeing. This was true for all participants in this category.

I would say, my overall, and it could be because of my denial, but my positive outlook. I try to stay very positive and do everything and anything that I possibly can to stay healthy.

(Shannon)

Out of this experience, the only valuable thing has been the psychological work that has allowed me to come to terms with this… and to be happy no matter how disabled you are. In 2001, I would have said that I would never be happy with this disability and if I got worse and worse. I was already unhappy, I was depressed. What’s remarkable for me now, is that it is 2013 and I can fill out a survey- because I have respiratory issues and need a sleep apnea machine… (Katie)

One of the prevailing themes that emerged was the impact of how shifting priorities towards ‘living in the moment’ facilitated acceptance and overall wellbeing. For all in this category, they discussed how this allowed them to better cope with any changes in symptoms.

I think it’s been tremendously important. I love to travel. I took a lot of trips overseas when I was younger. I look back on those trips and I think- I am so happy that I did that. I have those amazing memories. And if I hadn’t of done that then, I would not be the same person that I am now. I probably would have many regrets but I don’t have them because I did those trips. I went to places that I always wanted to go to. So that’s crossed off the bucket list. That makes me so pleased. I mean, I don’t know, maybe I am stupid *laughs* people spend so much time being negative and worries and I can’t. My mother was a worrier, she
was a terrible worrier and maybe inside I kind of thought I don’t ever want to be that way. I
don’t want to be a worrier. And I am not. I am pretty laid back. (Louise)

I think a fairly good outlook. At times it scares me because I don’t want to get engrossed in
what could be or what could happen, but I think for the most part I just persevere and take
each step as it comes. (Jessica)

For all in this category, they noted that shifting their priorities towards small and simple things
helped put things into perspective.

I guess for awhile I wasn’t enjoying life as I had and I just learned to enjoy life again. And
to take pleasures out of the small things. There might be some big things that I can’t do
anymore but I take great pleasure out of the little things now. I find self worth in even the
little things. Whereas before, I needed the bigger things. And now, I don’t need those
anymore. (Louise)

Oh gosh, for me I take great pleasure out of being able to swiffer sweep my house.
*laughs*. Or do the laundry. For me, that’s a big thing and I am so happy when I can do
that. I take great pleasure in watching the birds at the feeder every day. I mean, little things
just make up a big picture. I see that now. Just the fact that I see the small picture in the big
picture and I can recognize that I am damn near perfect *laughs* and that I do have a huge
sense of self worth. I grasp each day and I love it and I live it and its very good… And I
actually thank MS for that. Because I was too caught up I think in the big picture and now I
see the little picture. (Louise)

All of these women indicated that having to cope with the adversity of disability caused them to
become more grateful and compassionate towards the plights of others.
This often acted to also enhance their ability to extend compassion towards others who struggle with hardship.

Just looking at people, we all have a cross to bear. Some people have it more visible than others. But we all have it. Some people it’s more obvious what their cross is to bear and you might see some people with obviously physically or developmental handicap or the loss of vision- that sort of thing. Even for people who don’t seemingly appear to have that challenge, everyone has got something. Just because you don’t see it doesn’t mean that it’s not there. So I think that I am a more compassionate person since this because you look at it. I went through a period where you can’t feel sorry for yourself; you can’t sit around and think why me; when really why not you. (Elizabeth)

Many in this group noted that having undergone this process of accommodation resulted in feeling resilient (n= 5; 83%).

I have never really gone there. It’s not my nature. It’s not my nature to feel sorry for myself. It’s not my nature to be anything but resilient. To suck it up buttercup! Constantly saying, “Oh my gosh!” Because I think to be that way would do a disservice to all of those brave people that I know who struggle with primary progressive MS. It’s a really horrific diagnosis. They would probably change places with me in a heart beat. So suck it up. I am walking. I am driving. I am working. So what if I don’t feel my feet and legs. So what if my hands get numb and I can’t put my earring on. Big hairy deal. You know really it’s the least I can do in support of those who do have such monumental challenges is to not whine about what God has given me to deal with. Since I was diagnosed I kind of view life like a big game of dodge ball. Tag- you’re it. There but for the grace of god, go on. (Elizabeth)
### Disrupted identity: Struggling

The second group of participants (n=6; 27%) experienced marked distress and overall struggle associated with physical limitations caused by MS. There was an apparent difference in their inner experience, as well as their social environment. These women indicated feeling as though they were in conflict with their illness and experienced guilt, anger and pessimism. This was paired with an invalidating environment, whereby they felt unsupported and misunderstood. They received feedback from others that was discrepant from their own perspective, which was a source of frustration and distress. The following is a hypothetical composite of the shared traits and experiences of all women in this category:

**Allison**

Allison experiences a number of significant physical disabling symptoms. She related that her identity has been disrupted due to these physical limitations and the ripple effects caused (losing her job; negatively affecting her relationships). This was a difficult transition for her, as she perceived herself to be a high achiever and perfectionist.

In terms of her relationship, she noted that she and her partner have never been good at communicating with one another and she has always experienced a level of dissatisfaction in their relationship. Allison said that she is now more dependent upon her husband to help her with symptoms related to her MS which is a continued source of frustration and anxiety. She believes that her identity has changed drastically, from being the type A individual who took care of everything and everyone to now requiring help from others. This is made worse by the feedback that she receives from her husband, as she does not feel emotionally supported by him.
For participants in this group, there was a process whereby they struggled with changes associated with MS. They underwent a process of dissatisfaction, struggle and psychological distress and it posed as a constant struggle.

For women in this group, having MS became the filter with which they viewed the world and became intertwined with identity in a global sense (i.e. perception of who they are as a whole rather than individual roles adopted).

Although you try not to, it kind of becomes your identity. And then everything that you look at is filtered through that. It affects everything like dealing with physical things, how you look, how you feel about that; how other people look at you; how they talk to you; how you respond. I don’t know… it's just everything. (Jackie)

There was an increased sense of hopelessness and pessimistic outlook from women in this category. Wendy described herself as now being, "Self-conscious and pessimistic."

Others indicated:

Well I don’t think the whole situation is anything but negative. (Kelly)

The women largely cited feelings of depression, guilt and anger in coping with this chronic illness.

For these women, they endorsed increased feelings of depression associated with having MS and the secondary symptoms caused.

And I mean, emotionally, I am depressed. (Chantal)
Yes, I experienced bouts of depression which were under supervision by my doctor. I was on medication for those. It didn’t help much other than weight gain which again affected my outlook on myself as it does now. It’s a negative outlook for me, because I have always been – I have what I have. (Erin)

Women in this group also endorsed increased feelings of guilt which caused emotional distress regarding not being able to fulfill their roles as they had prior, and which impacted their intimate relationship.

I have a lot of guilt. I feel really guilty about not being able to do what I used to do. It's all within myself. No one is putting it on me... So if I am really fatigued and I can't get up and do laundry that day, then I feel guilty. Whereas everyone else looks at is as I have a disease. It’s not that I am lazy so that’s the part that’s the worst for me. (Chantal)

It sounds like I am using it as an excuse to avoid it. But I am not avoiding it, it's just that I can't do it, and sometimes I think he feels that I am using it as an excuse. But it's not. It's very hard because it puts more pressure on me. (Erin)

As previously discussed, many participants noted the overall impact of MS on their emotions. For women in this group, they endorsed increased anger and described an ongoing struggle against their illness which bred psychological distress.

I would like to be able to not react in a negative way when my partner says little things to tick me off... I’m working at it. I have good days and bad days. I would like to be able to just let things slide off and by doing that ensuring that things don’t escalate in any negative fashion. (Lindsay)

I feel angry, fearful, depressed (Wendy)
I was a lot tolerant of the little things that used to annoy me prior. Afterwards, I wasn’t as tolerant. I would get angry and silent for days. (Erin)

In terms of relationships, 3 out of 5 of the women described being dissatisfied with their partner prior to the onset of multiple sclerosis. One woman described that having to cope with multiple sclerosis placed a significant strain on their relationship, which was once satisfactory.

We never had a terribly great relationship… We didn’t talk about anything. We didn’t argue and we didn’t talk. (Jackie)

I felt helpless, frustrated and angry when it came to making big decisions. Whenever I wanted to do something the answer was always NO. (Wendy)

This was true of communication as well. 4 out of 5 of the women in this category indicated that they had poor communication style within their relationship prior to the diagnosis.

Style of arguing: very unpleasant, yelling, cursing on his part. I know from my part, the frustration would grow, and grow, and grow, and grow, and I would feel like I would explode eventually. Sometimes what I would do was just...I had to leave to the room. (Lindsay)

Communication has never been our strong point. But when we needed to we did. Neither my husband nor I like confrontation. We avoid it like the plague. So even if something was bothering us we would hold it in and hold it in and then Boom we’d explode! Everything would come out and we would be good for another couple of months. (Erin)

One theme that emerged for women who experienced a more difficult time with these changes, was that they did not feel verified or validated by their partner.
One woman in this group stated that she felt really unsupported alone throughout this process,

It’s hard because I am pretty much alone. It’s really. I can’t talk to my husband. I don’t really have anyone that I can talk to about things. I have to deal with it all by myself.

(Jackie)

Individuals in this group noted receiving invalidating feedback from their partner, which caused anxiety and distress. There was greater conflict and frustration, feeling unsupported in their relationship.

My husband says that all I do now is bitch. It makes your core beliefs- It makes me think oh well, maybe it wasn’t that important to me. Maybe that wasn’t the purpose to life. Maybe I don’t need to make a difference *laughs*. Without having an outlet for some things like having a career then really I am just sitting in my house ranting and raving. But when my husband tells me that- then that really gets me kind of depressed because it’s like okay yeah your right, I am ranting and raving and it’s doing me absolutely no good. But yet I need to do that, because if I don’t do that then what do I have left. I have nothing if I don’t have that. I mean at least give me the right to rant and rave. (Jackie)

In turn, women in this group noted feeling more dependent and burdensome on their partner. This was often a role reversal which caused distress.

I have gone from being an efficient, smart, successful woman to being a disabled, helpless person. (Wendy)

Well yeah basically because I’m not able to do things so I guess it makes me feel more or less incompetent. (Kelly)
4 Discussion Section

The purpose of this research was to qualitatively investigate the impact of MS on women’s identity and explore the influence and impact on intimate relationships. In particular, we explored whether said impact is mediated by the women’s changing sense of identity, relational feedback and interactive changes with her partner while coping with illness. This included the internal process of individual coping, changes in relational dynamics directly caused by illness and the influence of one’s broader social landscape upon identity change.

4.1 The internal processes of identity preservation or change

For the participants in this study, the onset and diagnosis of MS itself did not necessarily result in a disruption in one’s identity. However, the prospect of increasingly disabling symptoms was a cause for worry and distress borne from the ambiguity of not knowing how the disease course or severity would later impact their physical ability. This process caused each participant to take a step back and reflect upon her identity, identity-roles and capabilities. Those whose symptoms were transient or less physically disabling were able to maintain continuity in their role-identities. Therefore, the diagnosis alone was not a strong enough catalyst to cause disruption.

The worsening of physical symptoms and increasing physical dependency acted as a direct catalyst for identity disruption. It was the direct changes to one’s physical and cognitive abilities that set in motion an increasing discrepancy between their view of themselves prior to illness and their current capacities. The result was a loss of previously defined roles-identities which was a cause of distress and anxiety. This was a fluid process which occurred whenever a disabling symptom emerged or they were no longer able to fulfill previously defined roles. The
primary physical limitations caused secondary identity changes to sexuality, physical appearance, emotion regulation etc. The findings were consistent with that of previous research which suggests that physical limitations cause a ripple effect to impede upon one’s view of their intimacy and beauty which causes distress and reconfiguration of their notion of sexuality (Hordern, 2000; Kralik et al., 2003; Schmidt et al., 2005).

The women who experienced identity disruption reported distress and anxiety during the transition period between losing and adopting new identity-roles. These emotions were triggered by the loss of independence, particularly as they moved from nurturer to being nurtured. This transition was difficult and caused a period of bereavement and loss, and many participants felt burdensome, powerless, guilty, angry and experienced decreased self esteem. This shift from nurturer to being nurtured was consistent with previous research (Morris, Woods, Davies & Morris, 1991). The implication of this finding would suggest that there is clinical utility in promoting continued independence for women undergoing these changes.

While all individuals in this grouping experienced identity changes due to physical symptoms, two groups emerged. One group of participants experienced markedly more distress and struggle compared to the other. These women felt as though they were in conflict with their illness and experienced guilt, anger and pessimism. They described being at odds with their symptoms and noted an ongoing struggle with changes in their physical ability. For this group of participants, MS became a large feature of how they viewed their worth rather than one of many aspects of themselves. This caused a sense of hopelessness and many women experienced increased depression, guilt and anger. This was often paired with an invalidating environment, whereby their felt unsupported and misunderstood. They received feedback from others that was discrepant from their own perspective, which was a source of frustration and distress.
The second group of participants also underwent a period of loss. However, they utilized a number of effective coping strategies. Those who were able to positively reframe their situation, find gratitude and accept their situation were more adaptive and accommodating towards their changing physical ability. Acceptance also permitted a sense of tolerance of the ambiguity caused by MS, as these women were better able to accept the uncertainty of their ever changing physical symptoms. In turn, these traits allowed participants to shift their perspective towards living in the moment, gratitude and enhanced compassion towards both themselves and others. Moreover, these participants cited the importance of also having a supportive and validating interpersonal environment and perceived their partner to be self-verifying. Those who found acceptance seemed better able to preserve salient aspects of their identity and maintain better continuity in their identity-roles (through adaptability and cognitive flexibility). These factors proved important in positively coping with the declining physical changes caused by MS.

4.2 Relational influences on identity

As previously discussed, this research sought to evaluate whether the dynamics within a relational context provided unique influence in terms of identity changes (or preservation) while coping with MS. It was proposed that the onset of chronic illness may disrupt the relational norms set by the couple which would require re-negotiation. To date, previous research has illustrated that perceived relational satisfaction and support plays a vital role in positive adaptation to chronic illness. McCabe et al. (1996) had suggested that the onset of illness would magnify the quality of one’s relationship pre-concern. Our findings also suggest this, as the majority of participants indicated that the onset of chronic illness enhanced either their satisfaction, or conversely dissatisfaction.
Our findings are consistent with McCabe & McDonald (2007) who suggested that how a person’s partner is perceived to react to changes in physical dependency will influence the partner with MS (and relational satisfaction). The results of this study suggested that women who perceived their partner to be supportive and self-verifying reported better communication and higher level of relational satisfaction compared to those who perceived their partner to be invalidating.

As previously mentioned, the shift in identity-roles within one’s romantic relationship was often a contentious issue which required re-definition and navigation by both partners. The impact of physical limitations often called for one’s romantic partner to take on different roles (i.e. care taker). For many participants, this caused a shift in power dynamics and they felt that they had shifted from an equal partner to that of a patient. This finding is similar to a study completed by Irving et al. (2009) who suggested that this is a fluid interpersonal dance that occurs between partners. Our findings indicated that participants felt best when they were provided some autonomy over activities that they were still able to accomplish independently, while their partners offered more assistance for activities that they were no longer able to carry out. In addition, couples who had already faced adversity (e.g. the male partner had health complications) the power dynamics appeared easier to navigate as the couple had already undergone a process of re-definition based upon alternative adversity. Our findings also supported that of Hefferon, Grealy & Mutrie (2009) who observed that the adversity caused by chronic illness can result in an adjustment process which acts to strengthen the bond for couples and result in an enriched relationship. Many participants noted that having undergone adversity increased their level of gratitude towards their partner, and they perceived their relationship to being more resilient in result.
4.3 The applicability of identity negotiation theory

The broader principles of INT apply to the psycho-social adjustment of women in their intimate relationship. In this study relational satisfaction was influenced by whether the woman felt nourished by her partner, and received feedback which was congruent with her own self-appraisal. ‘Clarity’ in this regard, facilitated better outcomes for couples, as she felt better understood and validated. Conversely, those who received incongruent feedback from their partner (for example: being perceived as less capable) experienced cognitive dissonance and ambiguity which caused dissatisfaction and frustration with their partner. This was also true of ‘cooperation’ and feeling accepted by one’s partner despite any fluidity or changes in identity. Moreover, for individuals who adopted new and dual identity-roles (for example: their husband also became their caretaker) those who were able to minimize the discrepancy between these roles and amalgamate them in a harmonious manner fared better in their relational satisfaction. Similarly, those who were able to adapt their roles to find continuity and consistency across different facets of their identity with their partner also boded well.

A couple’s level of communication played a role in the assessment of relational satisfaction and whether participants felt self-verified by their partner. Those who maintained a level of open dialogue and communicated with their partner appeared better able to maintain clarity and continuity of relational goals. Many participants indicated the importance of open and candid discussion and communication regarding their fears and concerns, aided in feeling validated. Conversely, participants who described a lack of communication within their relationship often described feeling anxious, isolated and/or distressed.
The INT theory proposes that the major processes of identity changes are caused by relational context over and above any internal processes. The results of this study do not affirm this as there was a clear interactive process between ones internalized process and their interaction with social environment in regards to identity preservation or change with neither aspect (individual or social) appearing to have greater bearing on the process of identity preservation or change. Therefore, it is concluded that the process is an interactive and dynamic process that operates at the intrapersonal; interpersonal and within a broader social environment (based in feedback from family, friends, colleagues). Moreover, the results of this study did not suggest the presence of any intra-psychic mechanisms in the process of retaining identity, which appears inconsistent with the INT model. However, it remains uncertain whether the research approach permitted for observation of this largely subconscious process. Overall, the major findings were consistent with the proponents shared by INT and key variables of identity theory literature which implicated: salience, commitment, self-verification, and the importance of continuity as paramount features of identity preservation.

4.4 Applicability of broader identity theory

As proposed by identity theory and more specifically in INT, social context and external pressures and feedback impact identity. Our findings affirm that one’s identity is influenced and impacted by their social environment and feedback from loved ones. This was not limited to one’s romantic partner, as participants referenced the reactions from family, friends, co-workers, children, and partners as having influenced their incorporation of multiple sclerosis into their identity.
The results of this study suggest that social support can be a protective factor in promoting optimal wellbeing of individuals coping with this chronic illness. Many participants explicitly expressed how instrumental having a support network was in their ability to navigate their illness. However, as was the case for relational satisfaction, the quality of social support was important. Our findings suggest that satisfaction in this regard is contingent upon whether they are receiving social feedback that is congruent with their identity and therefore self-verifying. Conversely, distress was borne when others attempted to treat participants in a discrepant manner due to their illness (for example: treating them as less capable). This was a cause of frustration and anxiety, which required re-negotiation. Social relationships were enhanced when there was a continuation in the roles as defined prior to the onset of illness.

One finding that was convergent from previous research was the impact of visibility of symptoms upon both individual and social perception. The results indicated that whether one’s symptoms were visible to others was influential in shaping identity and the impact of that visibility in a social context (for example: feeling self-conscious when walking in public). Visible symptoms allowed others to infer how the woman was managing physically. However, participants whose symptoms were not visible (for example: chronic pain; fatigue; numbness) accommodation required a disclosure process. The discrepancy between visibility and one’s internal experience often caused some anxiety or frustration. Conversely, there was also a level of internalized stigma regarding the reliance upon mobility aids. For those whose symptoms were visible, participants explicitly discussed the influence on visibility upon their social exchanges (and fears of being treated as less capable). There maintained an internal struggle regarding the process of disclosure and fears regarding invalidating social feedback. In turn, there was a process of disclosure and associated anxieties that many faced in their process of coping with multiple sclerosis.
Overarching social constructs also played a role in defining salient aspects of identity. Salience aspects of identity and commitment to identity appeared to be embedded within societal ideals. For example: employment was cited as a salient aspect of identity, largely based in its level of deemed importance at a societal level. The majority of participants terminated their jobs due to the direct symptoms of MS. This was cited as a major role loss, and many noted how individuals are largely defined by their level of motivation, work ethic and by virtue of their career. In turn, many struggled with this loss and how they perceived their value in society. It was more greatly complicated by the fact that many of these women were employed in helping professions. This loss deeply impacted their sense of self as a nurturer, which was difficult to rectify.

4.5 Implications for clinical treatment

The research findings have a breadth of clinical utility. There are numerous implications for clinical practice in working with individuals in both individual and couples therapy.

4.5.1 Individual Therapy

This study suggested that the degree of identity disruption was associated with the degree of physical disability, with some individuals coping better than others. The findings indicated that all who experienced physical decline underwent a period of bereavement, loss and many individuals cited resulting anger and depression. The identified protective variables that aided in re-negotiation and preservation were the following: positive reframing; gratitude; and acceptance. These psychological mechanisms could prove as effective treatment targets for those coping with MS to promote optimal wellbeing. Many of these skills are embedded within empirically validated treatment modalities, such as cognitive behavior therapy. CBT has been
proved effective in helping individuals with MS cope with major depression (Mohr, Boudewyn, Goodkin, Bostron, & Epstein, 2001) and the key mechanisms may be beneficial in aiding clients in this regard (e.g. cognitive restructuring and understanding the interconnectivity of affect, cognitions and behaviour). This is a suggested area of focus and intervention for this population.

As previously discussed, identity preservation and continuity are important in maintaining overall wellbeing. Therefore, helping clients nourish salient aspects of their identity despite physical changes and bridge continuing in their identity-roles would prove valuable. For example, re-creation of their purpose and meaning through volunteerism upon terminating employment was a means of continuing to function in that capacity regardless of the changes in roles. Clinicians can work with women to minimize the discrepancy between their previous ability and their current functioning, thus aiding in maintaining identity preservation through continuity. The results suggested that those who maintained continuity in their identity and identity-roles through adaptation and accommodation fared comparatively better. This would be an ideal treatment target in working with this population.

Moreover, the results suggest that the invisibility of symptoms is a unique contributing variable causing anxiety and ambiguity. There was a level of anxiety in being ‘outed’ by symptoms in the workplace and in public. There was an internal struggle with regards to disclosure. Clinicians can help in the process of exploring one’s internalized stigma and conceptualization of disability, negotiating their symptoms with the expectations of others, and when/how to disclose their illness to others. This may be particularly important with regards to the workplace, as many feared the responses of others and being perceived as less capable. Furthermore, individuals may also benefit from supportive counseling in the event that they end up terminating their employment.
Finally, MS is an unpredictable disease with physical symptoms which may ebb and flow through time. It may require continuous accommodation and adaptation. Our findings suggested that those who were able to cope with uncertainty fared better. In turn, this calls for a level of acceptance regarding the uncertainty regarding disease course and symptoms. Clinicians may help facilitate this transition through individual therapy, helping this population learn the necessary skills to tolerate distress and accept uncertainty. These treatment considerations are also embedded within empirically validated modalities such as mindfulness based cognitive therapy and mindfulness based stress reduction approaches (Kabat-Zin, 2003; Segel, 2010). This too may be a valuable treatment target in working with this population.

4.5.2 Couples Therapy

The results of this study may better inform couples therapists in their work with this population. Our findings suggest that the role of participants’ intimate partner was instrumental throughout the process of coping with MS. The results indicated that those who experienced their partner to be supportive, self-verifying and perceived the process as a team effort rather than being singled out as the ill partner, promoted relational satisfaction and overall wellbeing. As social support for women coping with this chronic illness has been identified as being paramount to coping, efforts directed at promoting ones preservation of salient aspects of identity and continuity in relationships would aid in optimal overall wellbeing. One main feature of this process was the role of communication. Clinicians can help couples navigate their changing relationship, roles and their experience of same. Helping couples approach chronic illness as a team effort may prove valuable in enhancing relational satisfaction. Moreover, helping individuals clearly communicate their anxieties and needs to their partner in the presence of an unbiased third party would act to aid in the negotiation between partners.
4.6 Research limitations

This study was not without some limitations. As previously mentioned, the recruitment materials advertised the research as the ‘effects of MS upon women’s intimate relationships’. There is a probability that the type of individuals drawn to this study may not be representative of the population as a whole. Moreover, as this study was largely advertised through the promotion of the internet, while researchers attempted to be as inclusive as possible (for example: by utilizing telephone interviews), those with more limiting physical impairment may not have had access to our advertisements.

One of the benefits of conducting qualitative research is embracing the experience of individuals within a naturalistic setting. However, in doing so, we cannot ascertain whether their experience would differ based upon different variables such as: type of multiple sclerosis; age at onset; or the length of time within one’s romantic relationship as discrete variables which may prove interesting for future study. Within the current study, there was wide variability in the lengths of time spent within one’s relationship and the length of time having been diagnosed with MS.

Additionally, the research is based upon self-report data. It is difficult to ascertain whether the statements made are an accurate representation of the events. For many participants these events occurred within the previous years (for example: the process of diagnosis). Thus, one’s accuracy of recalling these memories may be skewed by time.

This study only views the identity process through the female lens, rather than by both partners. Any account or knowledge of male opinions, reactions and influence is third party information. This is a limitation of the study, as it is difficult to ascertain the validity of these statements. Although it would prove interesting to include a male sample, it was outside of the scope of this research to do so.
4.7 Considerations for future research

To date, little research has been conducted to explore the ‘identity’ as a unique contributing variable to the wellbeing of individuals struggling with MS. The results of this research indicate that identity preservation is a protective factor which promotes optimal wellbeing for those who are navigating this chronic illness. Understanding identity within the parameters of one’s social environment is important in providing services and treatment to this population.

It is hoped that this qualitative research venture will better inform and direct more focused studies regarding the effects of MS upon identity. Based upon the results of this study the following areas of study should be considered:

1. The emergent data from the interviews were very rich in detail and aptly described the subjective experience of these women. As phenomenological research explores the creation of meaning from participants lived experience and their subjective reflection of same, it is proposed that continued research of this nature utilize a focused phenomenological type of data analysis to further deepen understanding regarding the process of those suffering from MS. For example, Smith’s Interpretative Phenomenological Analysis has garnered accolade in qualitative methodology as its approach explores the lived personal experience of participants while acknowledging the central role endorsed by the researcher and how these elements interact (Smith, 2007). Qualitative researchers have proposed that this type of approach to understanding the data is a means of better understanding the ‘essences’ of the human experience (Giorgi, 1997). It is suggested that future qualitative study of the process
for women with MS employ a phenomenological philosophy and approach to further deepen our understanding of the experiences of this population.

2. Further research evaluating the protective qualities associated with traits exhibited by the group of participants that fared well: positive reframing, adaptability and mindfulness (living in the moment) in the promotion of identity salience and overall wellbeing.

3. A dyadic research venture which evaluates the process of identity change for both partners in the relationship as they cope with the impact of MS.

4. As this study was qualitative in nature it is aspired that future research will take a more pointed look at possible unique contributing variables (which were unable to be controlled for in this present study). For example, future research could consider whether one’s type of multiple sclerosis is a predictive variable in their level of disability and identity change.

5. Future research which evaluates the unique process of disclosure for those who experience invisible symptoms, exploring whether the process is convergent in any way from those who are immediately identified in a social context due to visible aids.
5    References


## Appendix A:

*Table I. Demographic details of participants.*

<table>
<thead>
<tr>
<th>Participant Code</th>
<th>Age (yrs)</th>
<th>Years since diagnosis</th>
<th>MS Type:</th>
<th>Length of time (years) in Relationship (at diagnosis)</th>
<th>Length of time (years) in Relationship (in total)</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>62</td>
<td>37</td>
<td>RR</td>
<td>1</td>
<td>38</td>
</tr>
<tr>
<td>02</td>
<td>42</td>
<td>12</td>
<td>RR</td>
<td>4</td>
<td>16</td>
</tr>
<tr>
<td>03</td>
<td>33</td>
<td>8</td>
<td>RR</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>04</td>
<td>52</td>
<td>7</td>
<td>RR</td>
<td>22</td>
<td>29</td>
</tr>
<tr>
<td>05</td>
<td>53</td>
<td>4</td>
<td>RR</td>
<td>27</td>
<td>29</td>
</tr>
<tr>
<td>06</td>
<td>33</td>
<td>6</td>
<td>RR</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>07</td>
<td>42</td>
<td>1</td>
<td>RR</td>
<td>21</td>
<td>22</td>
</tr>
<tr>
<td>08</td>
<td>36</td>
<td>14</td>
<td>RR</td>
<td>4</td>
<td>18</td>
</tr>
<tr>
<td>09</td>
<td>45</td>
<td>2</td>
<td>RR</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>10</td>
<td>30</td>
<td>3</td>
<td>RR</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>11</td>
<td>42</td>
<td>4</td>
<td>PP</td>
<td>20</td>
<td>23</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>12</td>
<td>49</td>
<td>2</td>
<td>RR</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>13</td>
<td>49</td>
<td>16</td>
<td>RR</td>
<td>12</td>
<td>27</td>
</tr>
<tr>
<td>14</td>
<td>53</td>
<td>5</td>
<td>RR</td>
<td>22</td>
<td>26</td>
</tr>
<tr>
<td>15</td>
<td>57</td>
<td>10</td>
<td>SP</td>
<td>11</td>
<td>13</td>
</tr>
<tr>
<td>16</td>
<td>41</td>
<td>3</td>
<td>RR</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>17</td>
<td>42</td>
<td>2</td>
<td>SP</td>
<td>18</td>
<td>20</td>
</tr>
<tr>
<td>18</td>
<td>44</td>
<td>4</td>
<td>RR</td>
<td>17</td>
<td>21</td>
</tr>
<tr>
<td>19</td>
<td>63</td>
<td>12</td>
<td>RR</td>
<td>14</td>
<td>25</td>
</tr>
<tr>
<td>20</td>
<td>37</td>
<td>5</td>
<td>PP</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>21</td>
<td>51</td>
<td>27</td>
<td>SP</td>
<td>3</td>
<td>30</td>
</tr>
<tr>
<td>22</td>
<td>39</td>
<td>1</td>
<td>PP</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>
Appendix B: Recruitment Flyer

The impact of MS on women’s intimate relationships

Seeking Research Participants

One well documented side effect of Multiple sclerosis is the impact (both positive and negative) upon intimate relationships. That’s why this study is designed to look at this impact. You will be asked to participate in an interview lasting approximately one hour (via telephone or in person). You will receive $20 for your participation in this study.

Eligibility Criteria:

Heterosexual females (over the age of 21) who:

- Currently cohabitating with partner for at least 6 months, or were cohabitating within the past year.

- Have received a diagnosis of MS within the course of the Relationship

This study is being conducted under the supervision of Dr. Schneider at the University of Toronto. If you are interested in participating, or have any further questions regarding this study, please email me at:

melissa.bolton@utoronto.ca

MS & Relationships Study

melissa.bolton@utoronto.ca
8 Appendix C: Organizational consent

Dear (name of the director/chair of the organization)

I am conducting a doctoral research study on the effects of Multiple sclerosis (MS) upon identity within intimate relationships. One well documented side effect of MS is consequent relationship difficulties, which has been cited as the most distressing aspect of this chronic illness. Using semi-structured interviews, this research seeks to better understand the coping processes and identity renegotiation that occurs between individuals in romantic relationships as they navigate the debilitating effects of MS. To date, little research has been conducted on this topic. It is anticipated that greater understanding of this process would better equip couples counselors, health practitioners and those coping with MS a better understanding of how to promote greater satisfaction for couples.

I am writing you to ask whether your organization would be willing to help promote this study by including a link on your organizational website and/or by forwarding an announcement of the study to your email mailing list.

This doctoral dissertation is being conducted by Melissa Bolton, PhD student and is under the supervision of Dr. Margaret Schneider (OISE/UT). Please see attached for a copy of the information letter that will be provided to those interested in participating, as well as a recruitment flyer.

If you have any questions, concerns or further considerations please do not hesitate to contact me. I can be reached at melissa.bolton@utoronto.ca or by phone at (416) 925-2371.

Thank you for this consideration,

Sincerely,

Melissa Bolton, MA Counseling Psychology for Psychology Specialists University of Toronto.
9 Appendix D: Information page & consent form

You are invited to participate in a study about the impact of MS within intimate relationships. This research explores the positive and negative impact of MS on relationships and identity. This doctoral dissertation is being conducted by Melissa Bolton, a PhD student at OISE/University of Toronto under the supervision of Dr. M. Schneider.

You will be asked to participate in an interview that will take about an hour at a location that is convenient for you. During the interview you will be asked questions about the impact of MS, symptoms, your relationship (before and after diagnosis), perception of your partner, coping strategies and your sense of identity since diagnosis.

Sometimes people find it uncomfortable talking about their relationships, particularly when they are experiencing stress. During the interview if there are any topics that you don’t want to discuss, you can skip those questions. Additionally, if you wish to stop participating during the study, you are free to do so without any consequences. We can provide you with a resource list of information regarding, relationships and MS supports will be provided.

The interviews will be audiotaped and then transcribed. The audiotapes will be encrypted and transcribed. After transcription the tapes will be erased. No identifying information will be included in the transcripts. The transcripts will then be disposed of within seven years after publication. All information you supply during the research will be held in confidence.

Your name will not be associated with any part of the study. Your data will be safely stored in a locked facility and only I and my supervisor will have access to this information. The only limits to confidentiality are in instances where you indicate that there is a risk that you might harm yourself or someone else.

To thank you for your participation you will be compensated $20 for your time. If you have any further questions at any time about the study please feel free to contact the researchers.

M. Bolton, Researcher, Department of Counselling psychology, Ontario Institute for Studies in Education at the University of Toronto melissa.bolton@utoronto.ca

Dr. M. Schneider, Faculty Member, Department of Counselling psychology, Ontario Institute for Studies in Education at the University of Toronto Margaret.schneider@utoronto.ca
You can also contact the University of Toronto Office of Research Ethics at [416-946- 3273] or email at ethics.review@utoronto.ca if you have any questions about your rights as a research participant.

I have read the attached information sheet and agree to participate in the study regarding relationships as described.

Name and Date

If you would like a summary of the results of the study when it is complete, please provide an email or other mailing address below.

________________________________________________________________________
10 Appendix E: Telephone Script

*The participant emails and leaves a contact number.

*In the case that a potential participant emails and does not leave a phone number, they will be emailed the information letter.

If they leave a contact number:

“Hello [potential participant's name], my name is Melissa Bolton and I am a graduate student at the counseling psychology department at the University of Toronto. You emailed expressing your interest in our study regarding Multiple sclerosis and intimate relationships. Would you like to hear more about this study?”

(If No): “Thank you for your time, have a great day.”

(If Yes): “This study involves engaging in an interview which contains questions about MS symptoms, self views, identity and how you cope with this illness within the context of your relationship (supports etc.). For example, we may ask about “how/whether you have experienced changes in how you interact with partner since having to cope with the symptoms of MS.”

“Participation in this study will take approximately 1 hour of your time. To show our appreciation you will receive $20 compensation.”

“If you would like, I can sent you an information letter with more details about the study or I can provide more detailed information at the time of the interview. If you are unsure and would like some time to think about participating, you can contact me if you decide to participate and we can set up a time then. Or if you are interested in participating we could set up a time now.”

[IF they want more time to think about it]: “Take some time to look over the information letter. Respond back if you wish to participate. Thank you for your time”.

[IF YES; They want to participate]: “Thank you; we appreciate your interest in our research.“I have a session open on [day and date] at [time, a.m. or p.m.]. Will you be available then?

You will need to come in about 5 minutes early.”
[IF NO]: Offer another day and time until one is found that is mutually convenient.

[IF YES]: “This is great. Let me give you some important details about the study. Have you got a pen so that you can write this down and keep it with you?”

“My name is Melissa Bolton, with the University of Toronto. You should go to the [Xth] floor of the (place) [five minutes before the time scheduled] on [mention day and date again]. If you discover that you will be unable to make it, please call me at (416)925-2371 and leave a message if I am not available or email me at melissa.bolton@utoronto.ca. Please try to provide at least 24 hours notice if possible. I look forward to meeting you on (mention day, date, and time again). Thank you very much again for helping us with our research.”
11 Appendix F: Post-interview information & resource page

For more information on MS, relationship support and education contact the following:

Relationship Supports:

The Gottman Relationship Institute: http://www.gottman.com/

Crucible Marriage and Family Health Centre http://crucibletherapy.com/about/david-schnarch

Relationship Support Literature:

Hold me Tight: Seven conversations for a lifetime of love. By Dr. Sue Johnson (2009).


Seven Principles for Making Marriage Work. By Dr. John Gottman

MS Supports:

MS Society of Canada http://mssociety.ca/en/default.htm

MS Literature:


Multiple sclerosis: The Questions you have, the answers you need. By Rosalind Kalb (2008).
12 Appendix G: Interview guide

"The purpose of this study is to explore the impact of MS upon one's identity. Therefore, I am interested in exploring pre and post diagnosis your identity and prized aspects of yourself. In addition, I am interested in the impact of MS upon your relational identity and exchanges within your romantic relationship.

*After I get a general sense of you and your identity, I will then ask details about you, your relationship and the discourse of your multiple sclerosis.

GENERAL SENSE OF IDENTITY

-First, very broadly speaking- Can you talk about whether or how this diagnosis has impacted your sense of identity?

*Follow up questions will include the direct content obtained from this question.

PRE-DIAGNOSIS:

Relationship to Self:

Now I am going to ask you some questions regarding how you perceived yourself prior to having a diagnosis of Multiple sclerosis.

-If I met you prior to having MS- what would I notice about you?

-If you had to describe yourself in only a couple of words- what would those adjectives be?

-How did you see yourself and how you fit into the world?

-Prior to having MS what are the values and aspects of yourself that you prized? (If clarity is requires- such as your ambition etc.)

-Prior to having MS- what were the aspects of yourself that you wanted to change?

-We all take on many roles in our lives; can you tell me what were your roles (partner, caretaker, sister etc.)?
- What was your vision for the future?

**Relationship to Partner:**

- Tell me about your relationship with ______ prior to the diagnosis of MS?

- What initially drew you to ________?

- What do you think initially drew ________ to you?

- Couples generally get into a rhythm or routine - can you describe what your relationship was like with regards to your usual routine?

- If I were a fly on the wall at your home prior to diagnosis, how would I see you two interact?

- How well did you communicate?

- People have many types of strategies when it comes to disagreements or arguments. What was your argument style as a couple prior to the diagnosis? How did you feel afterwards?

- How did you feel about yourself and your role in the relationship?

- Some people tell me that they feel like they can be their true self with their partner, whereas others feel like they need to change to be desirable to their partner. What was it like in your relationship - prior to the diagnosis of MS?

- Were there aspects of the relationship that you prized?

- Were there aspects of the relationship that you would have liked to change?

- Generally speaking, what was the source of most arguments?

- What were your shared hopes for the future?

**Relationship to Illness:**

- When did you receive a diagnosis of MS?
-What was that process like? (How long did it take for them to accurately diagnose? What was she feeling during the interim?)

-What were the original physical symptoms that signaled something was wrong?

-What did you know about MS prior to the diagnosis?

-How did you react?

-Did you have any initial concerns, fears upon diagnosis?

**POST-DIAGNOSIS:**

**Relationship to Self:**

-How do you see yourself now?

-What about your identity? What parts of your sense of self have remained consistent throughout the process of coping with chronic illness? Which parts have changed?

-If you had to describe yourself in only a couple of words- what would those adjectives be?

-What are the values and aspects of yourself that you prize now?

-If you could, what aspects of yourself would you change?

-Since the diagnosis, has there been any changed to your different roles (list the ones that they stated)?

-How do you see yourself, and how you fit into the world?

-What is your vision for the future?

**Relationship to Partner:**

-Tell me about your relationship now. Has it changed since the diagnosis?

-Sometimes people tell me that coping with chronic illness can strain their relationship. What do you think?
Has your routine changed? If so, how?

In what ways are you different with your partner?

In what ways are you the same with your partner?

In what ways is he different with you?

In what ways is he the same with you?

If your partner were here, what would he say has been the biggest changes to your relationship?

If I were a fly on the wall of your house now, what would I notice about how you interact?

Has your role in the relationship altered or changed? If so, how has it changed?

Throughout this process, how has your partner been towards you?

How was he supported you?

Have there been points of frustration towards your partner?

How well do you communicate now?

Has your argument style changed?

Has MS impacted any of the things that you previously used to enjoy as a couple?

What are the aspects of your relationship that you continue to prize?

What aspects of your relationship would you like to change?

Generally speaking, what is the source of most arguments?

What were your shared hopes for the future? Have they changed?

Is there anything else that I haven't asked which you think would be important for me to know?

What's the one piece of advice that you would give someone who has just been diagnosed with Multiple sclerosis?
-Do you have any questions for me?

Thank you so much for your time, I really appreciate your participation.