The Relationship of Fatigue and Parental Disability in Mothers with Inflammatory Arthritic Conditions in Comparison to Mothers Without Chronic Diagnoses.

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THE RELATIONSHIP OF FATIGUE AND PARENTAL DISABILITY IN MOTHERS WITH INFLAMMATORY ARTHRITIC CONDITIONS

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ABSTRACT

Research suggests there is limited information surrounding how fatigue and parental disability impact the occupation of mothering. A woman’s dual role of mother and patient is rarely addressed, presenting unique parenting challenges and greater disability. The primary objective of this study was to explore the relationship between fatigue and mothers with inflammatory arthritic conditions comparatively to mothers without chronic conditions. Secondarily, the purpose of the study was to utilize the parental disability index and qualitative questions to examine further the impact of being a mother with an inflammatory rheumatological condition. Seventy-one mothers between the ages of 22-48 participated in the study in either the inflammatory group (n=38) or the non-inflammatory group (n=31). A mixed-methods analysis was used on the qualitative open-ended question responses to further understand statistically significant quantitative analyses. Two main findings emerged, mothers with inflammatory rheumatological conditions experienced greater fatigue than women without inflammatory arthritis ($z=4.765, p<0.0001$), and there was a relationship between fatigue and perceived parental disability in mothers with inflammatory rheumatological conditions ($r_s=0.460, p<0.0001$). Findings from this study highlighted the disproportionate impact of fatigue and parental disability for mothers with inflammatory arthritic conditions and the barriers they face to their everyday occupation of mothering.
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CHAPTER 1: INTRODUCTION

Inflammatory arthritis is an autoimmune disease affecting 1 in every 4 American adults making it a leading cause of disability (Park et al., 2018; Poudel, 2020). Arthritis affected 24.7% of the population between 1999-2014 and is projected to increase to 26% of adults by 2040 (Park et al., 2018; Poudel, 2020). Arthritis is characterized by persistent, painful inflammation of the synovial tissue in the body’s joints caused by an influx of inflammatory cells into the synovial membrane (Poudel, 2020). Common symptoms for arthritis include; joint swelling, tenderness, irritation, redness near or at the joint, reduced mobility, and loss of function (Heidari, 2011). Often these manifestations can be seen in the hands and weight-bearing joints, causing barriers to engagement in everyday activities. Arthritis is incurable; however, management through therapy, pharmaceuticals, and surgery affords many patients some relief.

The burden of disease for arthritic conditions is unequally distributed across genders. Though an estimated 92.1 million adults have either doctor-diagnosed arthritis or report symptoms congruent with an arthritis diagnosis (Jafarzadeh & Felson, 2017) inflammatory arthritis is two times more prevalent in females than males (Hunter et al., 2017). Furthermore, arthritis affects the female population at an earlier age than it does males (Helmick et al., 2008). Thus, many women are diagnosed with this chronic condition during a life stage when they may become mothers.

Past literature has cited that mothers with chronic pain experience more physical, psychological, and social difficulties, as well as more difficulty completing everyday parenting tasks than mothers without pain (Evans et al., 2005). In addition, mothers who experienced these limitations were less satisfied with their role as parents, consequently impacting many aspects of their lives (Katz et al., 2003). However, the needs of mothers with chronic pain or illness have not fully been defined or understood (Backman et al., 2007; Evans et al., 2005; Katz et al., 2003).
Thus, more research is needed to better compare impairment in this population to mothers without chronic conditions. Such understanding will help produce practical resources for mothers living with rheumatological conditions. (Backman et al., 2007; Del Fabro Smith et al., 2011; Katz et al., 2003).
Mothers with Inflammatory Arthritis

Women often occupy many roles throughout their lifetime, including wife, caretaker, professional, sibling, or daughter. However, women have consistently reported their most crucial role as being a mother (Backman et al., 2007; Del Fabro Smith et al., 2011; Mitton et al., 2007). Women describe motherhood as the primary aspect of their identity and the most significant life role they engage in (Backman et al., 2007; Del Fabro Smith et al., 2011). However, a woman may be restricted in her mothering occupations such as carrying her child or doing household chores due to the simultaneous management of a chronic condition (Backman et al., 2007; Del Fabro Smith, 2011). Mothers with inflammatory arthritic conditions face barriers throughout their day, including fatigue, physical disability, lack of support, and decreased energy, all contributing to an inability to balance their daily mothering commitments and tasks (Del Fabro Smith et al., 2011). There has been numerous studies regarding the impact that inflammatory arthritic illnesses can have on a women's role as a mother (Backman et al., 2007; Del Fabro Smith et al., 2011; Mitton et al., 2007; Vallido et al., 2010; Zelkowitz et al., 2013). However, this research area is limited as it does not compare mothers with inflammatory arthritis to mothers without chronic conditions. In addition, the majority of these studies have been limited to qualitative methods (Backman et al., 2007; Del Fabro Smith et al., 2011; Mitton et al., 2007; Vallido et al., 2010). There have also been a handful of quantitative studies that have used a comparison population however, they have been limited to mothers with various chronic pain conditions (Evans et al., 2005) or comparisons between two different types of inflammatory arthritic conditions (Poole et al., 2014). Furthermore, the relation of managing both a mother's diagnosis and role as a caretaker is one of the many barriers yet to be addressed through research. Providers usually only focus on one of these aspects, thereby leaving a mother to make self-
adaptions and develop her own coping skills (Backman et al., 2007; Vallido et al., 2010). The
duality of these women’s identity as a mother and a patient is rarely discussed (Del Fabro Smith
et al., 2011). One study found that avoiding breastfeeding while receiving treatment for their
illness was a universally accepted limitation for mothers with rheumatological conditions
(Mitton et al., 2007). Such restrictions impact women’s role as mothers, limit their parenting
choices, and force them to negotiate two aspects of their identity. Mothers reported that despite
their illness, they wished to remain in control and retain complete independent decision-making
regarding their children (Del Fabro Smith et al., 2011; Mitton et al., 2007).

The qualitative studies have attempted to address motherhood with an inflammatory
arthritic condition through personal accounts and interviews as a method to understand this
dynamic further (Backman et al., 2007, Del Fabro Smith et al., 2011; Mitton et al., 2007; Vallido
et al., 2010). Several major themes were consistent throughout this research, including the
variability and occasional inability of a women’s engagement in maternal occupations.
(Backman et al., 2007; Del Fabro Smith et al., 2011). A consistent coping mechanism reported
by mothers included adapting their ways of engaging with their children. This accommodation
included engaging through observation rather than physical involvement (Del Fabro Smith et al.,
2011). Mothers reported weighing the importance of the activity before readjusting to meet the
needs of their child (Backman et al., 2007; Del Fabro Smith et al., 2011). Integrating the
significance of a situation helped them to plan their participation when arthritis flareups arose
sporadically. Secondary themes that arose included different levels of support, impact on family,
feelings of guilt, contextual factors, inner strength, depression, labeling, feelings of inadequacy,
and lack of pre-and post-natal education regarding their illness (Mitton et al., 2007, White et al.,
2009).
Women also reported a decline in social interactions in an attempt to make their children their number one priority. Mothers made accommodations by canceling plans to save their energy for play with children (Del Fabro Smith et al., 2011; Mitton et al., 2007). These disruptions had harmful psychological impacts on mothers managing a rheumatological condition, including sadness, thoughts of self-harm, and a yearning for their ‘old’ life (Mitton et al., 2007). Additionally, due to a lack of recognition of the mothers’ illness from surrounding community parents, the absence of engagement in activities was associated with a dismissiveness or indifference, contributing to an already complex social perception of stigma (Mitton et al., 2007). These mothers' accommodations led to the perception and stigmatization of being an “unnormal parent” based wholly on their activity engagement. This feeling of inadequacy in their role as mothers left women feeling a sense of guilt and disappointment (Del Fabro Smith et al., 2011). Women had to be tactical in their planning and decision-making to meet the needs of their illness while fulfilling their role as a parent. Thus, it is evident mothers with inflammatory arthritis must navigate additional challenges and societal standards while fulfilling their parental role.

Mothers reported that their illness caused the most significant disability with the following parental activates: holding, lifting, carrying, bathing, feeding, changing, and dressing (Katz et al. 2003; Backman et al., 2007; Del Fabro Smith et al., 2011). One study that stratified for age found that picking up and carrying a child was the most challenging for parents with children in a younger age group while playing outdoors proved more problematic for mothers with older children (Katz et al., 2003). Mothers also reported doing fewer activities with their children than they wanted due to their inflammatory arthritis (Backman et al., 2007; Katz et al.,
Thus, women were unable to engage with their children at the level they wished due to their disease and the symptoms that coincided.

Mothers and Fatigue

Of all the themes discussed, fatigue was the primary reason women could not participate in their children’s activities (Backman et al., 2007; Del Fabro Smith et al., 2011; Iwata et al., 2018; Poole et al., 2012; Poole et al., 2014; White et al., 2009). Fatigue is defined as a systemic feeling of exhaustion encompassing physical, emotional, and cognitive functioning (Iwata et al., 2018; White et al., 2009). When taking on a parenting role, all women experience fatigue to a certain degree. However, those with chronic illness often experience exacerbated symptoms of tiredness (Evans et al., 2005; Poole et al., 2014; White et al., 2009). Fatigue was self-reported as one of the greatest hindrances to completing mothering tasks (Backman et al., 2007; Del Fabro Smith et al., 2011; Evans et al., 2005). Mothers with inflammatory arthritis specifically reported ‘going until they were prompted to rest’ either by their illness symptoms or the end of their parental duties for the day (Del Fabro Smith, 2011).

Mothers self-reported feeling unable to meet their children’s physical and emotional demands on account of fatigue (White et al., 2009; Iwata et al., 2018). The physical demands causing such fatigue included carrying children, cooking meals, engaging in playtime, and organizing children’s schedules, while the emotional demands involved disciplining a child and moral and value development (White et al., 2009). Mothers with inflammatory arthritis across many studies vocalized that fatigue disrupted their parental experience and ability to participate at the level they wished to (Del Fabro Smith et al., 2011; Mitton et al., 2007; White et al., 2009).

A study comparing maternal fatigue and its impact on the caregiving environment found that this perpetual exhaustion had extensive impacts on a child’s parental experience. Fatigue was proven to have impacted inflammatory mothers’ receptivity and sensitivity to their children’s needs at a
higher level than a well mother (White et al., 2009). In addition, it has been consistently reported that mothers parenting children younger than 5 years old experience exacerbated exhaustion when compared to mothers parenting older children (Barlow et al., 1999; Del Fabro Smith et al., 2011; Poole et al., 2014; White et al., 2009). No research has yet to factor out this age range of children 0-5 years within the population of mothers with inflammatory arthritis. Furthermore, fatigue was a predictor for how women would handle the busy daily schedule associated with parenting. Women with inflammatory arthritis self-reported having increased stress, child behavioral problems, and lower parent satisfaction (Evans et al., 2005; Del Fabro Smith et al., 2011). Research regarding fatigue in this specific population has been limited to mainly self-report research surrounding the broad experience for mothers with inflammatory arthritis (Backman et al., 2007; Del Fabro Smith et al., 2011; White et al., 2009). Fatigue has yet to be specifically addressed in mothers with inflammatory arthritic conditions compared to mothers without chronic conditions.

It is evident that the barriers women with rheumatological conditions face impact their parental role and even disable them from completing it. This fatigue heavily affects engagement with their child and parental duties, thus indicating a potential parental disability.

**Parental Disability in Mothers**

Parental disability refers to the disruption of a parent’s ability to adequately care for their child, often due to an illness or injury (Zelkowitz et al., 2013). As noted before, women have an extreme investment in their role as mothers, and interruption of this job can cause distressing feelings. A few studies have explored how illness can affect a woman's parenting, including the women's perception of her role as a mother. The following main themes were discovered within these studies: disruption, planning participation, adapting to ways of engaging, changing
mothering role, experiencing guilt or shame, and problems with healthcare professionals (Del Fabro Smith et al., 2011; Vallido et al., 2010). Disruption of their mothering role due to hospitalizations or lack of energy invoked feelings of inadequacy among women as they claimed to lack an identity without their child (Vallido et al., 2010). These disturbances often forced women to reframe the idea of what comprised a "good mother." Mothers reported other parents or community members inferring on their capabilities as a mother based on the appearance of "normality". To cope with this expectation, many women created a new set of self-standards based on their optimum effort as a mother with an invisible chronic condition (Backman et al., 2007).

In contrast, other women reported that complying with their medical regiment or shielding their children from their illness and treatments was how they defined themselves as a "good mom" (Valido et al., 2010). These women did not define themselves as mothers with disabilities but rather just mothers (Backman et al., 2007). These dual roles posed large issues for women with their healthcare providers. Women reported that their providers were often unhelpful or judgmental in their wish to be both a patient and a mom (Valido et al., 2010). Thus, more information and better resources are necessary to aid providers in catering to this complex duality for mothers with inflammatory arthritis.

When mothering tasks were challenged or disrupted, women described this as “disrupted mothering” (Del Fabro Smith, 2011). The idea of disrupted mothering has been minimally researched within this population, although it may be a significant contributor to engaging in parental activities. Mothers with inflammatory arthritis may struggle to quickly transition to meet their child’s needs disrupting their child’s care and thus, could be labeled as parental disability (Valido et al., 2010). Similarly, disrupted mothering can occur when women feel guilt, distress,
and hopelessness as all these factors contribute to a mother’s ability to meet their child’s needs (Del Fabro Smith et al., 2011; Vallido et al., 2010).

All of these challenges affect both the women and their children. Just as fatigue affected a mother’s ability to physically engage and be emotionally present, so too does parental disability (Zelokwitz et al., 2013).

**Purpose of Study:**

The purpose of this study was to explore the concepts of fatigue and parenting disability in mothers with inflammatory arthritis. First, this study sought to compare fatigue levels in mothers with self-reported inflammatory arthritis to mothers without inflammatory arthritis. While there are numerous studies that have examined fatigue levels in people with inflammatory arthritic conditions (Backman et al., 2007; Del Fabro Smith et al., 2011; Iwata et al., 2018; Poole et al., 2012; Poole et al., 2014; White et al., 2009), there are no studies comparing fatigue levels in mothers with and without inflammatory arthritis conditions. It is hypothesized that mothers with inflammatory arthritis will experience greater fatigue than mothers without an inflammatory arthritis diagnoses.

Second, the purpose of this study was to further examine the impact of being a mother with inflammatory rheumatological conditions. Though this impact has been studied, it has been primarily limited to qualitative methods through self-report questionnaires, interviews, and narrative inquiries (Backman et al., 3007; , Del Fabro Smith et al., 2011; Mitton et al., 2007; Vallido et al., 2010). In addition, the studies that have explored the impact of a chronic condition on parenting have yet to examine the relationship between fatigue and parental disability in mothers with inflammatory arthritis. This study is unique as it utilizes a quantitative measure to attempt to validate these qualitative findings. This aspect of the study hopes to tease out
additional factors or variables that contribute to parental disability in mothers with inflammatory arthritis.
CHAPTER 3: METHODS

Sample

The study sample was restricted to mothers with inflammatory arthritis and mothers without inflammatory arthritis or any other diagnosed chronic condition. All mothers were between the ages of 18 and 50 years, had at least one child between the ages of 0 and 5 years, and were assumed to be English literate to complete the survey. Participants were included in the study if they consented to participate and completed the survey in its entirety. A copy of the survey can be found in Appendix A. Consent was obtained by participants clicking a button acknowledging the following statement, "I have thoroughly read through the information sheet regarding participation in the study" before beginning the survey. Participation was voluntary, consent implied, and subjects were able to withdraw at any point during the study. Preceding recruitment, a sample size calculation using previous Fatigue Severity Scale (FSS) data was performed. This sample size calculation estimated that 22 mothers in the inflammatory group and 22 mothers in the non-inflammatory group with a 1.6 standard deviation, 30% effect size, and 80% power, would yield a sample with statistical significance at 0.5. Full sample size calculations can be found in Appendix B.

Recruitment Strategies

Prior to the Covid-19 pandemic, the primary investigators (PIs) planned to recruit through flyer advertisements in rheumatology practices, ObGyn offices, playgroups, and various other maternal settings. However, due to research protocols restrictions and barring of non-essential activity due to the Covid-19 pandemic, online survey distribution methods were utilized.

Following approval from the University of Vermont's Institutional Review Board, the PIs utilized the social media platform Facebook as the recruitment strategy for participants. The PIs utilized Facebook for the inflammatory cohort by searching for groups using the following
keywords: mother, mothering, motherhood, rheumatoid arthritis, inflammatory arthritis, Lupus, Scleroderma, Chronic illness, Chronic pain, Ankylosing Spondylitis, Enteropathy, support, awareness. Facebook was also utilized for the recruitment of mothers in the non-inflammatory group. Primary investigators utilized the following keywords to search for Facebook Groups such as: mothers, mothering, motherhood, mom group, support group, pregnancy, breastfeeding, baby, and toddlers for the non-chronic search. The flyer contained information regarding inclusion criteria, a description of the study, and a link to the on-line survey. Flyers for both groups can be found in Appendix C. RedCap was used as the survey platform.

Subject Characteristics
A total of seventy-one mothers were recruited to participate in the study through this social media advertisement between September 2020 and October 2020. Women were recruited to either the inflammatory mothers' group or the non-inflammatory mothers' group. Women in the inflammatory group were between the ages of 18 to 50, had a child or multiple children between the ages of 0 to 5, and held a self-reported clinical diagnosis of one of the following inflammatory arthritic conditions; rheumatoid arthritis, lupus, scleroderma, or spondylarthritis. Mothers in the non-chronic group were between the ages of 18 to 50, had a child or children between the ages of 0 to 5, and did not have a self-reported chronic condition diagnosis.

Variables and Instruments
All participants received a survey that consisted of demographic questions, the fatigue severity scale (FSS) and open-ended questions. Additionally, women in the inflammatory group also received the parental disability index (PDI). All surveys were anonymous to conceal the identity of participants.

Demographic Questions
The same demographic data were collected for both groups. Demographic data were collected through self-reported general background questions. This section requested information
regarding age, ethnicity, geographical location, height, weight, education level, marital status, employment status, number of children, and breastfeeding status.

Fatigue Severity Scale

After completing the demographic data, all participants completed the fatigue severity scale (FSS). The scale can be found in Appendix D. The FSS measures the impact that fatigue has on an individual's daily living activities (Goligher et al., 2008). Participants responded to nine questions, choosing a number between (1) “completely disagree” and (7) “completely agree” that best fit the statements presented. The nine questions were then combined and averaged to produce a global fatigue score rating from 1 (no fatigue) to 7 (maximum fatigue).

Though validity and reliability of the FSS were not evaluated for individuals with inflammatory arthritis, when tested in chronic neck pain patients adequate internal consistency (0.83-0.091) and significant discriminant validity (P <0.001) was demonstrated (Takasaki & Treleaven, 2012).

Parental Disability Index

After completing the FSS, only mothers in the inflammatory group received the parental disability index (PDI). The complete PDI can be found in Appendix E. The parental disability index evaluated a participant's difficulty in performing general parental tasks. Mothers with inflammatory arthritis were instructed to respond to twenty-seven items addressing activities related to parenting. Each activity listed had six options regarding the difficulty of the task. The options included; no difficulty (0), some difficulty (1), a lot of difficulty (2), unable to do (3), and did not do for reasons other than inflammatory arthritis. Responses of did not do for reasons other than inflammatory arthritis were not calculated in the total means. The total score is the mean score for all the items. Scores above 1 on the PDI are considered to indicate moderate to severe difficulty with parenting (Katz et al., 2003; Poole et al., 2014). The PDI has been minimally utilized in research, however it has been validated in the rheumatoid arthritis
population (Zelkowitz et al., 2013). In addition, the test appeared to be valid and reliable when tested in the mothers with inflammatory arthritic conditions population (Katz et al., 2003; Poole et al., 2012; Poole et al., 2014). Mothers in the non-chronic group did not receive the PDI in their survey.

Open-Ended Questions

Four open-ended questions were present at the end of the survey for additional information regarding fatigue and parenting. The following questions were asked:

- "How different is fatigue now versus before you had kids?"
- "Does fatigue impact your daily activities? If yes, explain."
- "Think about your typical day. At what point in the day do you find mothering to be challenging and why?"
- "Describe what it is like when you need to quickly and unexpectedly transition from one activity to another."

The open-ended questions were identical for mothers in the inflammatory group and mothers in the non-inflammatory group. Mothers were not required to answer these questions to be counted as a participant in the study.

Data Analysis (Quantitative)

Study recruitment was complete and the survey was closed once the target number of 22 participants per group was reached and even surpassed. Subjects’ responses were exported. Answers were reviewed for incorrect responses and incomplete data. Two participants in the non-inflammatory group were removed for failing to complete the FSS. Mean, standard deviation, and percentages were calculated for the demographic data, FSS, and PDI. Comparative tables were created for demographic data. Statistical Package for Social Science (SPSS) was used for quantitative analysis. A non-parametric un-paired t-test was used to
compare means between the inflammatory group and non-inflammatory group. A spearman correlation was used to examine relationships within groups. Statistical significance was determined at <0.05.

Data Analysis (Qualitative)
The open-ended questions were utilized for qualitative analysis as part of the study's mixed-methods nature. An embedded design best fit this data set as the quantitative data carried more weight than the qualitative. A content analysis using a coding framework was applied to participant's responses. The statistically significant quantitative findings guided this framework. The two primary investigators and one co-author independently reviewed the participants' responses for statements that would strengthen the quantitative findings. Following separate analysis of the data, the individuals compared and contrasted results, corroborating findings that illuminated statistically significant or non-significant quantitative results.
CHAPTER 4: Results

Demographic Data

Inflammatory Group
To recruit participants for the inflammatory group, 17 Facebook groups were contacted; seven groups allowed the primary investigators to post a visual flyer for the study on their member page (41.17%). A total of 38 mothers were recruited into the inflammatory arthritis group (mean age= 36 years; range 27-48). The majority of women in the inflammatory group reported being Caucasian (74%). Of the thirty-eight women in the inflammatory group, 21% had a BMI between 25.0 and 29.9, classifying them as overweight. 32% of women had a BMI that fell in the Class 1 obesity (13%), Class 2 obesity (11%), and severely obese range (8%). The mean BMI for the inflammatory group was 30.79 ± 9.98, which is within the range of Class 1 Obesity. The majority of women in the inflammatory group were married (71%). Only 4 (10%) of subjects in the inflammatory group reported currently nursing any of their children. Refer to Table 1 for additional demographic data. Half of the mothers (50%) reported their inflammatory arthritic condition as rheumatoid arthritis. Distribution of diagnosis are represented in Table 2.

Non-Inflammatory Group
To recruit participants for the non-inflammatory arthritis group, 76 Facebook groups were contacted, and 21 groups allowed the primary investigator to post an advertisement for the study (27.63%). A total of 33 mothers without a chronic condition consented to and completed the survey. Of the completed surveys, 2 participants were disqualified for only completing demographic data and failing to complete the fatigue severity scale or the open-ended questions. Additionally, some mothers failed to respond to the demographic questions regarding height and weight which prevented the PI’s from calculating their BMI. These mothers were not disqualified from the whole survey, however they were not included in calculations regarding BMI. The resulting non-inflammatory group sample consisted of 31 mothers (mean age= 32
years; range 24-47). The majority of women reported being Caucasian (81%). The BMI fell mainly between the Normal Range (18.5-25.9) (29%) and the Overweight category (25.0-29.9) (26%). 38% of women had a BMI that fell in the Class 1 obesity (16%), Class 2 obesity (16%), and severely obese range (6%). The mean BMI was 28.03± 6.56 in the non-inflammatory group, classifying them in the Overweight range. The majority of non-inflammatory mothers were married (74%). Almost half, 14 (45%), of the mothers in the non-inflammatory group reported currently nursing one or more of their children. Subject demographic data is outlined in Table 1.

Table 1 Demographic data

<table>
<thead>
<tr>
<th>Demographic Characteristics</th>
<th>Inflammatory Arthritis Mothers Cohort (N=38)</th>
<th>Non-Chronic Mothers Cohort (n=31)</th>
</tr>
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<tbody>
<tr>
<td>Age</td>
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<tr>
<td>20-24</td>
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<td>Mean Age</td>
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<td>32 ± 6.50</td>
</tr>
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<tr>
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<td>Latino or Hispanic</td>
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<tr>
<td>Geographical Location</td>
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</tr>
<tr>
<td>18.5-24.9 (Normal)</td>
<td>16%</td>
<td>Bachelor’s Degree 39%</td>
</tr>
<tr>
<td>25.29.9 (Overweight)</td>
<td>21%</td>
<td>Master’s Degree 26%</td>
</tr>
<tr>
<td>30-34.9 (Class 1 Obesity)</td>
<td>13%</td>
<td>Terminal Degree 3%</td>
</tr>
<tr>
<td>35.0-39.9 (Class 2 Obesity)</td>
<td>11%</td>
<td>Associate Degree 3%</td>
</tr>
<tr>
<td>≥40 (Severe Obesity)</td>
<td>8%</td>
<td>High School Degree or Equivalent 11%</td>
</tr>
<tr>
<td>Did Not Answer</td>
<td>29%</td>
<td>Professional Degree 3%</td>
</tr>
<tr>
<td>Mean BMI</td>
<td>30.79 (Class 1 Obesity)</td>
<td>Some College, no degree 16%</td>
</tr>
<tr>
<td></td>
<td>28.03 (Overweight)</td>
<td>29%</td>
</tr>
</tbody>
</table>

**Education Level**

<table>
<thead>
<tr>
<th>Level</th>
<th>Percentage</th>
<th>Mean BMI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bachelor’s Degree</td>
<td>39%</td>
<td>35%</td>
</tr>
<tr>
<td>Master’s Degree</td>
<td>26%</td>
<td>16%</td>
</tr>
<tr>
<td>Terminal Degree</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>Associate Degree</td>
<td>3%</td>
<td>13%</td>
</tr>
<tr>
<td>High School Degree or Equivalent</td>
<td>11%</td>
<td>3%</td>
</tr>
<tr>
<td>Professional Degree</td>
<td>3%</td>
<td>0%</td>
</tr>
<tr>
<td>Some College, no degree</td>
<td>16%</td>
<td>29%</td>
</tr>
</tbody>
</table>

**Marital Status**

<table>
<thead>
<tr>
<th>Status</th>
<th>Percentage</th>
<th>Mean BMI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>71%</td>
<td>74%</td>
</tr>
<tr>
<td>In a domestic partnership</td>
<td>16%</td>
<td>0%</td>
</tr>
<tr>
<td>Single (never married)</td>
<td>5%</td>
<td>16%</td>
</tr>
<tr>
<td>Divorced</td>
<td>5%</td>
<td>3%</td>
</tr>
<tr>
<td>Separated</td>
<td>0%</td>
<td>3%</td>
</tr>
<tr>
<td>Did Not Answer</td>
<td>3%</td>
<td>3%</td>
</tr>
</tbody>
</table>

**Employment Status**

<table>
<thead>
<tr>
<th>Status</th>
<th>Percentage</th>
<th>Mean BMI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed full time</td>
<td>26%</td>
<td>29%</td>
</tr>
<tr>
<td>Employed part time</td>
<td>13%</td>
<td>26%</td>
</tr>
<tr>
<td>Self-employed</td>
<td>3%</td>
<td>0%</td>
</tr>
<tr>
<td>Student</td>
<td>0%</td>
<td>6%</td>
</tr>
<tr>
<td>Homemaker</td>
<td>26%</td>
<td>29%</td>
</tr>
<tr>
<td>Unemployed and not currently looking for work</td>
<td>18%</td>
<td>10%</td>
</tr>
<tr>
<td>Unable to Work</td>
<td>13%</td>
<td>0%</td>
</tr>
</tbody>
</table>

**Number of Children**

<table>
<thead>
<tr>
<th>Number of Children</th>
<th>Percentage</th>
<th>Mean Number of Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>24%</td>
<td>2.11</td>
</tr>
<tr>
<td>2</td>
<td>47%</td>
<td>1.63</td>
</tr>
<tr>
<td>3</td>
<td>8%</td>
<td>3%</td>
</tr>
<tr>
<td>4</td>
<td>13%</td>
<td>3%</td>
</tr>
<tr>
<td>5+</td>
<td>8%</td>
<td>26%</td>
</tr>
</tbody>
</table>

**Currently Nursing**

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>10%</td>
<td>45%</td>
</tr>
</tbody>
</table>

*Table 2. Inflammatory arthritis diagnosis*
Quantitative Analysis

Fatigue Severity Scale

The mean FSS score for the inflammatory group was 5.68 ±1.31 and 3.99±1.34 for the non-inflammatory group. This difference was statistically significant (z=4.765, p<0.0001).

In the inflammatory group there was a statistically significant correlation between BMI and FSS ($r_s$=0.506, $p<0.01$). This same relationship was not found in the non-inflammatory group ($r_s$=0.043, $p<0.01$).

There was a statistically significant correlation between FSS and PDI scores for the inflammatory group ($r_s$=0.460, $p<0.001$).

A summary of statistical and non-statistical results is outlined in Table 3. Mean responses for individual FSS responses in the inflammatory group and non-inflammatory group can be seen in Table 4.
Table 3 Synopsis of Significant and non-significant findings

<table>
<thead>
<tr>
<th>Type of Test</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between group relationship: Inflammatory and Non-Inflammatory Group</td>
<td>&lt; 0.00001</td>
</tr>
<tr>
<td>Two-Tailed Mann Whitney U between total FSS scores of the inflammatory group and non-inflammatory group.</td>
<td></td>
</tr>
<tr>
<td>Within group correlations: Inflammatory Group</td>
<td></td>
</tr>
<tr>
<td>BMI and FSS</td>
<td>0.007</td>
</tr>
<tr>
<td>FSS and PDI</td>
<td>0.004</td>
</tr>
<tr>
<td>FSS and employment status</td>
<td>0.084</td>
</tr>
<tr>
<td>Within group correlations: Non-Inflammatory Group</td>
<td></td>
</tr>
<tr>
<td>BMI and FSS</td>
<td>0.828</td>
</tr>
<tr>
<td>FSS and employment status</td>
<td>0.943</td>
</tr>
</tbody>
</table>

BMI= Body Mass Index; FSS= Fatigue Severity Scale; PDI=Parental Disability Index

*Boldface indicates statistically significant at $p < 0.05$ level

Table 4 Mean scores on Individual FSS questions between inflammatory and non-inflammatory group

<table>
<thead>
<tr>
<th>Questions</th>
<th>Mean Response Inflammatory Arthritis Mothers Cohort (n=38)</th>
<th>Mean Response Non-Inflammatory Arthritis Mothers Cohort (n=31)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FSS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. My motivation is lower when I am fatigued</td>
<td>6.74±0.64</td>
<td>5.94±1.79</td>
</tr>
<tr>
<td>2. Exercise brings on my fatigue</td>
<td>4.76±1.95</td>
<td>2.71±1.60</td>
</tr>
<tr>
<td>3. I am easily fatigued</td>
<td>5.87±1.26</td>
<td>3.90±1.72</td>
</tr>
<tr>
<td>4. Fatigue interferes with physical functioning</td>
<td>6.03±1.24</td>
<td>4.42±2.13</td>
</tr>
<tr>
<td>5. Fatigue causes frequent problems for me</td>
<td>5.77±1.44</td>
<td>3.58±1.86</td>
</tr>
<tr>
<td>6. My fatigue prevents sustained physical functioning.</td>
<td>5.55±1.83</td>
<td>2.97±1.99</td>
</tr>
<tr>
<td>7. Fatigue interferes with my carrying out certain duties and responsibilities.</td>
<td>5.71±1.63</td>
<td>3.84±1.93</td>
</tr>
<tr>
<td>8. Fatigue is among my most disabling symptoms.</td>
<td>5.21±1.96</td>
<td>3.32±2.09</td>
</tr>
<tr>
<td>9. Fatigue interferes with my work, family, or social life.</td>
<td>5.76±1.76</td>
<td>3.52±2.01</td>
</tr>
<tr>
<td>10. What number would you describe your global fatigue with 0 being the worst and 10 being normal.</td>
<td>5.42±3.08</td>
<td>5.71±2.72</td>
</tr>
<tr>
<td><strong>Total Score</strong></td>
<td>5.68±1.03</td>
<td>3.99±1.34</td>
</tr>
</tbody>
</table>

FSS= Fatigue Severity Scale
The mean for total PDI score was 1.12±0.50. Each question in the PDI was further broken down into mean responses reported for each individual activity to illuminate which parental occupations were most difficult for mothers (see Figure 1). Mothers self-reported having the most difficulty with ‘getting up and down to the floor to play with your child’, ‘doing household chores and shopping’, and ‘picking up or carrying your child’. Mothers reported the least difficulty with ‘keeping your child out of unsafe situations’ and ‘taking care of your child when they are sick.’ Scores above 1 on the PDI are considered to indicate moderate to severe difficulty with parenting (Katz et al., 2003; Poole et al., 2014). Mothers with inflammatory arthritis had scores above 1 for 15 of the 19 activities in the PDI (78.95%).

Figure 1  Self-rating of PDI activities

Self-rated difficulty with activities.

Getting up and down to the floor to play with your child.
Doing household chores or shopping.
Picking up or carrying your child.
Playing with your child outdoors.
Getting up with child.
Taking your child out in the car.
Taking your child to social events or recreational activities.
Having other children in your home.
Taking care of your child out of the house.
Opening medicine or childproof containers.
Opening safety latches or locks.
Taking care of your child's hygiene needs.
Diapering or Dressing.
Using a car seat.
Maintaining discipline with your child.
Using a stroller.
Feeding your child.
Keeping your child out of unsafe situations.
Taking care of your child when they are sick.

Mean of scores: Higher score = greater challenge

PDIs = Parental Disability Index
*Scores above 1 indicate moderate to severe difficulty with parenting
Analysis of Open-Ended Questions

The survey ended with four open-ended questions that allowed mothers to further elaborate on their parental experience. After reading and disseminating through responses, a qualitative matrix was created using a coding framework to organize qualitative findings. A matrix was created using the eleven quantitative findings that were then used as trend categories (see Table 5). Qualitative responses were then analyzed for responses that illuminated quantitative findings. The two main statistically significant quantitative findings that were illuminated by qualitative findings include; mothers with inflammatory arthritis experienced more significant fatigue than mothers without inflammatory conditions and for mothers with inflammatory arthritis there was a correlation between fatigue and parental disability. All quantitative statistically significant findings, their significance values, qualitative responses supporting the quantitative findings, and additional qualitative trends can be seen in Table 5.

<table>
<thead>
<tr>
<th>Quantitative Findings</th>
<th>Significance Values</th>
<th>Qualitative Responses that Supported Quantitative Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>FSS</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>1.</strong> Mothers with inflammatory rheumatological conditions experienced more significant fatigue than women without inflammatory conditions.</td>
<td>( P = &lt; 0.0001^* )</td>
<td>“My fatigue makes me feel like I have a lead body suit on, even if I didn’t push myself that day,” “considerably more fatigued” “much more intense”</td>
</tr>
<tr>
<td><strong>2.</strong> Women in the non-inflammatory group experienced less fatigue than women with inflammatory conditions.</td>
<td></td>
<td>“slightly more fatigue” “a different kind of fatigue,” “easier to tolerate”</td>
</tr>
<tr>
<td><strong>3.</strong> There is a relationship between weight and fatigue for mothers</td>
<td>( P = 0.007^* )</td>
<td>Not explored qualitatively</td>
</tr>
</tbody>
</table>
with inflammatory arthritis.

<table>
<thead>
<tr>
<th>4. There is no relationship between weight and fatigue for mothers without inflammatory arthritis conditions</th>
<th>$P = 0.828^*$</th>
<th>Not explored qualitatively</th>
</tr>
</thead>
</table>

**FSS and PDI**

<table>
<thead>
<tr>
<th>5. There is a relationship between fatigue and perceived parental disability in mothers with inflammatory arthritic conditions</th>
<th>$P = 0.004^*$</th>
<th>“I get easily fatigued so I have to be careful with my plans,” “everything takes me two or three times longer than I think it should, I drag myself from one thing to the next,” “fatigue “restricts and effects everything I do,”</th>
</tr>
</thead>
</table>

**PDI**

<table>
<thead>
<tr>
<th>6. Household chores or shopping was highly difficult for mothers with inflammatory arthritic conditions.</th>
<th>1.763**</th>
<th>“not being able to stand up for more than 1 hour for ex. cooking,” “struggle to keep up with housework,” “so tired I cannot tackle all the chores and activities,”</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>7. Getting up and down to the floor to play with your child was highly difficult for mothers with inflammatory rheumatological conditions</th>
<th>1.842**</th>
<th>“trouble playing with daughter,” “my joints hurt more as the day goes on, and after a day of playing,” “when it comes time for playing on the floor or going to play outside…. I am in constant pain and unable to walk so just the smallest activity takes a lot for me to do.”</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>8. Picking up or carrying your child was highly difficult for mothers with inflammatory rheumatological conditions</th>
<th>1.684**</th>
<th>“I find it challenging to hold and carry my newborn or help my toddler into her car seat,” “trouble walking up the stairs with my daughter”</th>
</tr>
</thead>
</table>
9. Taking care of your child when they are sick was the least difficult for mothers with inflammatory rheumatological conditions 0.421** Not found qualitatively

10. Keeping your child out of unsafe situations was the least difficult for mothers with inflammatory rheumatological conditions 0.806** Not found qualitatively

11. Employment status did not impact fatigue in mothers regardless of having an inflammatory rheumatological condition or not $P= 0.084^*$ (inflammatory group) $P= 0.943^*$ (non-inflammatory group) Not found qualitatively

**Qualitative Trends not Explored Quantitatively**

Mothers with inflammatory arthritis could not pinpoint the most challenging part of the day N/A “all day every day. My whole body hurts all the time.”, “Morning because I’m stiffer then. Evening because I’m more exhausted.”

Mothers without inflammatory arthritis were able to pinpoint as early evening and nighttime as the most challenging part of the day. N/A “Most nights it’s a challenge to get my child to lay down/settle down” “Late afternoon to evening. It’s usually when my baby is getting fussy before bed” “my son experiences long temper tantrums and it can be hard to redirect them. When it occurs it’s the hardest part of my day.”
Mothers with inflammatory arthritis related transitions with their child to their illness. & N/A & “It takes a great toll on my body and ability to function” “It’s like I will my body to get up and do what’s needed, it’s just not done well” “difficult. I don’t move quickly”

Mothers without inflammatory arthritis related transitions to their child’s behaviors. & N/A & “My daughter is 2.5 years old. She has a complete meltdown.” “It’s a challenge. Tears are often involved from my child”, “As long as it’s just me it’s no big deal. My son can get tantrums from switching activities.”

*Statistically significant at p<0.05 level

**Scores above 1 indicate moderate to severe difficulty with parenting

BMI= Body Mass Index; FSS= Fatigue Severity Scale; PDI= Parental Disability Index

Mothers with Inflammatory Conditions Experienced Greater Fatigue

This trend was consistently reported by mothers in the inflammatory group throughout all four open-ended questions. Responses clearly indicated elevated fatigue relating to their inflammatory arthritic condition. When self-reporting on the question “How different is fatigue now versus before you had kids?”, mothers indicated being “Full of energy before kids”, “considerably more fatigued”, “much more fatigue now”, fatigue being “much worse”, “much more intense”, “much more prevalent”. Responses stated, “My fatigue makes me feel like I have a lead body suit on, even if I didn’t push myself that day,” and “The fatigue from RA and auto immune disorder is a different type of tired. It is bone tired with no end and sleep doesn’t help,”.

Furthermore, some women reported variability between when they received their diagnosis in relation to when they had children, making it difficult to decipher which caused fatigue first. Statements included, “I was diagnosed postpartum so hard to say”, “my illness came
after my delivery. Before I was fit and with no kids.”, and “I was diagnosed after I had kids so my fatigue from arthritis has only been while parenting.”

Women in the Non-Inflammatory Group Experienced Less Fatigue

In contrast, overall, women in the non-inflammatory group reported experiencing less fatigue as a mother. When responding to, “How different is fatigue now versus before you had kids?” mothers indicated only having “slightly more” fatigue, “a different kind of fatigue,” “easier to tolerate”. Furthermore, when asked “does fatigue impact your daily activities?” mothers without chronic conditions reported, “not too much,” “rarely,” “occasionally,” “not really,” “no,” “once every few months maybe,” and “motivation is most affected by fatigue rather than physical barriers.”

Relationship Between Fatigue and Perceived Parental Disability in Inflammatory Group

Mothers also reported that fatigue significantly impacted their daily activities. Statements included, “I can only do a few things a day,” “I get easily fatigued so I have to be careful with my plans,” “limits what I can do and how long,” “everything takes me two or three times longer than I think it should, I drag myself from one thing to the next,” fatigue “restricts and effects everything I do,” and “I mostly stay in bed, being able to get up just seems like too much at times.” They also included some of the accommodations they must make in response to their fatigue, “Our day is structured so that I can lay down mid-day and that my husband takes over primary parent roll as soon as he’s done work so I can sit or lay as needed,” “I am needing a nap by 1:00ish, and I have a hard time getting going again after,” “I have to take small breaks here and there to complete a task. Sometimes I can’t complete a task because of the fatigue,” “I ask for help. I have older kids/husband that help… But without them it would be a struggle for me,” and “And if I’m feeling well, I have to be careful not to overdue because then it’ll be much worse the following days.”
Mothers with inflammatory conditions also reported high levels of perceived parental disability in relation to their illness. Two sub-trends emerged within this category. The first was an inability for mothers to be as present or active as they desired with their child. Mothers reported being highly affected by their inability to engage with their children consistently. Statements included, “I feel that I am not able to be the mom I want to be because I am constantly tired and not able to be that active,” “Each day is a challenge, the most heartbreaking is when I am not able to accompany my son with the group of pupils for outing,” “When I have a flare it’s hard when you can’t do things for kids like brush there hair because your hands are swollen,” “It is very discouraging to not feel up to doing what I should be able to do easily and quickly (like running up the stairs to help a crying child),” and “I always feel I don't do as much as other mums but I push through what I need to”

Parental Disability Index- Highly Difficult Activities

The second sub-theme included a consistency in mothers with inflammatory arthritis reporting specific parental activities that proved to be highly difficult for them to complete. Household Chores or Shopping

Mothers reported by far the highest difficulty with household chores or shopping. Mothers with inflammatory arthritic conditions overwhelmingly self-reported difficulty with the following, “not being able to stand up for more than 1 hour for ex. cooking,” “struggle to keep up with housework,” “when it comes time for cooking… I am in constant pain and unable to walk so just the smallest activity takes a lot for me to do.” “I can only do a few things a day and older kids help with chores” “By dinnertime every day I have run out of functionality. I can’t always cook and all evening is virtually impossible.”, “so tired I cannot tackle all the chores and activities,” and “fatigue affects motivation to take care of the basics”.
Getting Up and Down to the Floor to Play with Child

Mothers also described getting up and down to the floor to play with their child as highly difficult. Some of the statements included, “trouble playing with daughter,” “my joints hurt more as the day goes on, and after a day of playing,” “when it comes time for playing on the floor or going to play outside…. I am in constant pain and unable to walk so just the smallest activity takes a lot for me to do.”

Picking Up or Carrying Your Child

Similarly, mothers also reported challenges with picking up or carrying their child. This activity was rated as highly difficult through the PDI and reiterated with the following statements, “I find it challenging to hold and carry my newborn or help my toddler into her car seat,” and “trouble walking up the stairs with my daughter.”

Quantitative Findings Not Supported by Qualitative Analysis.

The remaining statistically significant quantitative findings were not specifically illuminated by any open-ended responses. This can be attributed to the PI’s not asking probing questions within the qualitative section. Thus, respondents were instructed to reflect on their overall experience as a mother and were not directed to elaborate on certain areas including: weight, employment status, and specific parenting activities. Future studies may utilize more in-depth interviewing in order to further explore these specific variables.
In our study, mothers with self-reported inflammatory arthritis reported significantly greater fatigue levels than mothers without inflammatory arthritis. This finding is similar to other studies that have compared fatigue levels in mothers with and without chronic pain (Evans et al., 2005; Katz et al., 2003). This finding supports the hypothesis that mothers with inflammatory arthritis experienced more significant fatigue than mothers without inflammatory conditions.

The literature supports the fact that all mothers experience a certain level of fatigue, understanding fatigue differences between mothers with and without chronic conditions can help understand how mothering may be impacted when chronic conditions exist (Evans et al., 2005; Mitton et al., 2007; White et al., 2009; Zelkowitz et al., 2013). Past research has reported fatigue as one of the most disabling symptoms for mothers with inflammatory arthritis (Evans et al., 2005; Poole et al., 2014; White et al., 2009). In our study, there was a relationship between fatigue levels and self-reported parenting disability in mothers with inflammatory arthritis. Our findings suggest that not only are mothers with inflammatory arthritis more fatigued, this fatigue may impact their ability to feel successful in fulfilling their parenting responsibilities. The findings of this study suggest that mothers with inflammatory arthritis are significantly more tired than mothers without chronic conditions contributing to their perceived ability to successfully parent.

This relationship between fatigue and parental disability was uniquely explored in this study. Past research has been limited to the relationship of fatigue and parental disability solely in the lupus population (Poole et al., 2012). Higher scores on the PDI are considered to indicate moderate to severe difficulty with parenting (Katz et al., 2003; Poole et al., 2014). Using this scoring system in our study, mothers in the inflammatory arthritis group reported the most
moderate to severe difficulty with ‘getting up and down to the floor to play with your child’,
‘doing household chore or shopping’, and ‘picking up or carrying your child.’ These findings are
consistent with previous research within the population of mothers with inflammatory arthritis.
Zelkowitz et al. (2013) found that tasks such as lifting a child from the floor were the most
difficult for mothers with inflammatory arthritis. Similarly, Poole et al. (2011) reported mothers
with children aged 0-5 who had a lupus, a type of inflammatory arthritis, had the most difficulty
with ‘getting up and down from the floor to play with your child’ and ‘picking up and carrying a
child.’ From a clinical perspective, these physically challenging tasks should be the focus for
treatment plans. Mothers may benefit from care plans that incorporate adaptations such as energy
conservation tactics, equipment to assist with transporting their children, or therapeutic exercises
to reduce inflammation.

One discrepancy within our findings was that ‘feeding you child’ was rated as one of the
least difficult activities for mothers with inflammatory arthritis whereas Poole et al. (2014)
reported this as one of the most difficult activities for mothers with younger children. That study
solely focused on mothers with systemic lupus erythematosus (SLE), indicating that certain
activities may be more difficult for mothers depending on specific inflammatory arthritis
diagnosis. Future research may consider evaluating the difference in parental disability levels
based on specific inflammatory arthritis conditions.

This study also evaluated statistically significant quantitative findings that were not
discussed by participants within the open-ended section. There was a significant relationship
between BMI and fatigue for mothers in the inflammatory arthritis group but no significant
relationship between BMI and fatigue for mothers without chronic conditions. This may indicate
that weight has a stronger effect on fatigue for mothers with inflammatory arthritis. This finding
suggest that nutrition, exercise, and wellness may play a role in reducing levels of fatigue and
may be a crucial aspect of treatment plans for mothers with inflammatory arthritis. Furthermore,
it should be noted that 11 of the 38 (28.95%) mothers in the inflammatory group did not respond
to questions regarding weight and height so it is unclear how this may or may not have impacted
the results.

Furthermore, it should be noted that 11 of the 38 (28.95%) mothers in the inflammatory group did not respond
to questions regarding weight and height so it is unclear how this may or may not have impacted

In addition, research found no correlation between fatigue and employment status. The
PI’s speculated that differing levels of occupation may contribute to overall fatigue. For
example, a mother working full time may experience higher levels of fatigue when compared to
a mother working part time. However, no relationship was found which may indicate that
mothers are fatigued regardless of their employment status.

There were many trends that emerged within the open-ended questions that were not
evaluated quantitively. When asked about the most challenging part of their day, mothers with
inflammatory arthritis were unable to pinpoint a time that was most difficult. Mothers reported a
variety of times as challenging. In addition, mothers related this question to their physical illness.
Several responses include, “all day every day. My whole body hurts all the time.”, “It’s hard on
my back, thumb, and shoulders.”, “when my fatigue is the worst”, “Morning because I’m stiffer
then. Evening because I’m more exhausted.” Responses were centralized to how their bodies
responded to differing times of the day due to their condition. In comparison, the majority of
mothers without inflammatory arthritis reported the early evening, the end of the day, and
nighttime as the most challenging. Mothers without inflammatory arthritis related their
experiences with time of day to their child’s behavior. Responses included; “Most nights it’s a
challenge to get my child to lay down/settle down”, “Late afternoon to evening. It’s usually
when my baby is getting fussy before bed”, “my son experiences long temper tantrums and it can
be hard to redirect them. When it occurs it’s the hardest part of my day.” These answers indicate that the child’s behavior and attitude were the main factor in determining how challenging a day could be for mothers without inflammatory arthritis. This may suggest that mothers with inflammatory arthritis must consider their physical limitations due to their conditions throughout the day. Past research has supported this finding and indicated that mothers had to plan their participation with children due to the uncertainty of their illness (Del Fabro Smith et al., 2011). In addition, this finding supports the idea in Backman et al. (2007) study of mothers reporting participating in parental tasks as, “sometimes I can, sometimes I can’t.” From a clinical perspective this is a significant finding as mothers without inflammatory arthritis may be able to ‘predict’ when parenting may be more challenging (ex. child’s behavior) and plan accordingly while mothers with inflammatory arthritis do not necessarily have this option as there are multiple variables that may present challenges throughout the day (ex. child’s behavior; arthritic flareups; illness symptoms).

A similar finding was revealed when women were asked about transitions with their children. Mothers with inflammatory arthritis reported the inability to successfully transition with their children due to the restraints of their illness including pain, fatigue, and speed of adaption. Some responses highlighting this trend included; “It takes a great toll on my body and ability to function”, “It’s like I will my body to get up and do what’s needed, it’s just not done well”, “difficult. I don’t move quickly”, and “like being knocked out unexpected or coming off a rollercoaster.” These transitions may be categorized as disrupted mothering. Past research has supported this same finding that disrupted mothering became most apparent for mothers with inflammatory arthritis when they needed to engage in physical activities that needed energy and speed (Del Fabro Smith et al., 2011). In comparison, mothers without inflammatory arthritis
once again related this question to the behavior and mood of their child during the transition.

Responses to the open-ended question regarding transitioning with your child included; “My daughter is 2.5 years old. She has a complete meltdown.”, “Lots of explaining and patience because I have a toddler”, “It’s a challenge. Tears are often involved from my child”, and “As long as it’s just me it’s no big deal. My son can get tantrums from switching activities.”

Disrupted mothering plays a larger role for mothering occupations for women with inflammatory arthritis indicating an unmet need in this population. Mothers often must quickly transition to activities with their children, a skill those with inflammatory arthritis are unable to do. This may indicate a need for mothers with inflammatory arthritis to receive more support around these transition times. Support may include partner assistance, incentivizing children as a coping mechanisms to make it through these transitions or connecting mothers with inflammatory arthritis to support groups for additional resources.

This study limited participation to mothers with children ages 0-5, as fatigue has been reported as most severe during this time of development (Katz et al., 2003; Poole et al., 2014; Zelkowitz et al., 2013). This may be due to the additional hand strength and dexterity needed to physically care for younger children (Poole et al., 2014; Katz et al., 2003). This was consistent with our findings as the parental activities reported as most difficult for mothers with inflammatory arthritis were ‘getting up and down to the floor to play your child’ and ‘picking up or carrying your child’, which both require a great deal of hand-use.

An interesting aspect that emerged within the quantitative data was the discrepancy between the two groups for mothers who reported nursing their children. Only 10% of mothers with inflammatory arthritis reported nursing their children in comparison to 45% of the non-inflammatory mothers. Though this difference was not tested statistically, it is an important
aspect to note as it has been previously reported that mothers with inflammatory arthritis are advised to avoid breast-feeding while receiving treatments (Mitton et al., 2007). This could be one factor that contributed to a lower rate of nursing reported. In addition, it is an activity that also requires hand strength similar to ‘picking up and carrying your child’, a highly difficult activity for mothers with inflammatory arthritis. Further research may utilize in-depth interviews to further understand this lower rate of breast feeding for mothers with inflammatory arthritis.

**Limitations**

There were several limitations to the study. Primarily, mothers were asked to self-report their diagnoses and symptoms which were unconfirmed by a doctor. Secondly, the subject participation was primarily Caucasian which does not reflect the prevalence of diagnosed arthritis being higher among other racial groups. For example, from 2002-2011, 30% of doctor-diagnosed arthritis was in the American Indian/Alaska Native population, 27% was in the non-Hispanic black category, and 26% was in the non-Hispanic White community (United States Bone and Joint Initiative, 2016; Bolen et al., 2010). This indicates a need for research that is more directed at minority and marginalized populations as they are facing incidence of arthritis at a higher rate than the Caucasian population. Third, the majority of women in this study were married which could indicate a higher level of support surrounding parental tasks. Lastly, the study included women outside of the U.S which could have affected responses in the data as treatment and diagnosing may differ depending on country.

**Future Research**

Although there is evidence that arthritis impacts parenting, further exploration on its effect on managing disrupted mothering would be valuable. Future research examining if it is easier to shift the needs of your children if you are not managing a chronic condition would assist both mothers and providers with developing strategies to accomplish their concurrent roles; as this is a
unique barrier to the inflammatory arthritis population. Future research may also examine the impact of weight on mothers with inflammatory arthritis and the effect that a higher BMI may have on fatigue and parental disability. Lastly, future research examining the impact of fatigue and disability factoring out inflammatory arthritic diagnosis would be helpful in identifying the most critical needs for each arthritic condition.

Conclusion

The results of our study showed that all mothers experience a certain level of fatigue however it is significantly more difficult for mothers with inflammatory arthritis. Furthermore, the study indicated that mothers with inflammatory arthritis experience a relationship between fatigue and their perceived parental disability. These findings suggest the importance of incorporating a women’s occupation of mothering into occupational therapy treatment plans and interventions.
REFERENCES


Iwata, H., Mori, E., Sakajo, A., Aoki, K., Maehara, K., & Tamakoshi, K. (2018). Course of maternal fatigue and its associated factors during the first 6 months postpartum: a

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Appendix A: The Survey

Introduction

You are being invited to take part in this research study because you are a mother between the ages of 18-50, you also have a child between the ages of 0-5. You either have an inflammatory rheumatological arthritic condition or you are a mother without a chronic condition. This study is being conducted by Chrystina Bonelli and Dr. Victoria Priganc at the University of Vermont.

Purpose

The purpose of this study is to learn more about parenting in mothers with inflammatory arthritic conditions. We want to learn more about their fatigue and parental disability. Mothers without any chronic conditions will help to be a comparison.

To Be in The Study:

To be eligible for participation in study you must meet the inclusion criteria for a women in the inflammatory arthritis group or for a women in the non-inflammatory arthritis group.

Inclusion Criteria for women inflammatory arthritis group:

- Biological gender of female
- Females ages 18-50
- Females who are mothers to any number of children ages 0-5
- Females whom have received a clinical diagnosis of the following conditions: rheumatoid arthritis, lupus, scleroderma, or spondylarthritis
- Females who are English speaking
- Females who can read English

Exclusion Criteria for women inflammatory arthritis group:

- Women who are 51 or older
- Women whose children are older than 5 years of age
- Women who are grandparents taking on the role of motherhood
- Any aged men
- Women who may have a clinical diagnosis of; rheumatoid arthritis, lupus, scleroderma, or spondylarthritis but do not have children
- Women who had/have a clinical diagnosis of; cancer, respiratory diseases, or any other chronic disease
- Women who cannot read English

**Inclusion Criteria for women in non-inflammatory arthritis group:**
- Biological gender of female
- Females ages 18-50
- Females who are mothers to any number of children ages 0-5
- Females who are English speaking
- Females who can read English

**Exclusion Criteria for women in non-inflammatory arthritis group:**
- Women who are 51 or older
- Women whose children are older than 5 years of age
- Women who are grandparents taking on the role of motherhood
- Any aged man
- Women who have a clinical diagnosis of; rheumatoid arthritis, lupus, scleroderma, spondylarthriti; cancer, respiratory disease, obesity, or any other chronic disease
- Women who do not have children
- Women who cannot read English

**Study Procedures**

If you take part in the study, you will be asked to use an electronic device of your choice to complete a survey. The survey will have questions about your experience as a mother.

The study will test two different groups- mothers with inflammatory arthritic conditions and mothers without a chronic condition. This study cannot cause any harm to you. The survey can be completed in anywhere from 10-30 minutes depending on the participant.

If you are a mother **without** an inflammatory arthritic condition you will be given a survey that contains background questions, the Fatigue Severity Scale, and open-ended questions about your experience as a mother.

If you are a mother **with** an inflammatory arthritic condition diagnosis you will be given a survey that contains background questions, the Fatigue Severity Scale, the Parental Disability Index, and open-ended questions regarding your experience as a mother.

The survey time will vary by individual. You can take the survey in the location and at the time of your choice. You may also stop the survey at any time. If you decide to participate, answers from your survey will be used in the research study.

**Example of Questions:**

Here are examples of some of the questions you will be asked.

**Background Questions-**
1. What is your age?
2. How many children do you currently have?
Fatigue Severity Scale-
You will rate the severity of your fatigue from 1-7. 1 is strongly disagree and 7 is strongly agree.
1. I am easily fatigued (rate from strongly disagree to strongly agree)
2. Exercise brings on my fatigue (rate from strongly disagree to strongly agree)

Parental Disability Index-
ONLY FOR MOTHERS WITH AN INFLAMMATORY ARTHRITIC DIAGNOSIS
You will respond to each activity listed with the following options: no difficulty, some difficulty, a lot of difficulty, unable to do, did not do for reason other than inflammatory arthritis.
1. Diapering, dressing, or helping your child with dressing
2. Picking up or carrying your child

Benefits
As a participant in this research study, there may not be any direct benefit for you; however, information from this study may benefit other people now or in the future.

Risks
We will not collect any information that will identify you to protect your confidentiality
- **Data Breach:** Every effort will be made to make the data untraceable to individuals, thereby removing the potential for an accidental breach of confidentiality.
- **Unintended Emotional Response:** Mothers with inflammatory arthritis may experience some emotional reactions in response to the survey. Participation is completely voluntary with the option to skip a question or stop at any time.

Costs
There will be no costs to you for participation in this research study other than your time.

Compensation
You will not be paid for taking part in this study.

Confidentiality
All information collected about you during the course of this study will be stored without any identifiers. No one will be able to match you to your answers. The researcher will minimize the risk of breach of confidentiality by using Safe Data to protect all the information collected from the study. When the research is completed, our research team may save the study records for use in future research. We will retain this study information for up to 3-5 years after the study is over.

Voluntary Participation/Withdrawal
Taking part in this study is voluntary. You are free to not answer any questions. Due to your data being de-identified at the time of collection, your data cannot be withdrawn from the study and will be used.
Questions

If you have any questions about this study now or in the future, you may contact the investigators of the study, Chrystina Bonelli at the following phone number (203)-859-8863, or Dr. Victoria Priganc at (802)-656-8146. If you have questions or concerns about your rights as a research participant, then you may contact the Director of the Research Protections Office at (802) 656-5040.

It is recommended you print this information sheet for your records before continuing.

1) By Clicking this button you are agreeing to that you through the information have read the information sheet. participation in this study.

☐ I have thoroughly read sheet regarding

Demographic Questions

Please answer the following demographic questions.

These will not be used as identifying information.

2) What is your current age?

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3) Please specify your ethnicity.
   - Caucasian
   - African-American
   - Latino or Hispanic
   - Asian
   - Native American
   - Native Hawaiian or Pacific Islander
   - Two or More
   - Other/Unknown
   - Prefer not to say

4) What town do you currently live in?

5) What state do you currently live in?

6) What is your current height? (Optional Question)

7) What is your current weight? (Optional Question)

8) What is the highest degree or level of education you have completed?
   - Less than a high school diploma
   - High school degree or equivalent (e.g., GED)
   - Some college, no degree
   - Associate degree (e.g., AA, AS)
   - Bachelor's degree (e.g., BA, BS)
   - Master's degree (e.g., MA, MS, MEd)
   - Professional degree (e.g., MD, DDS, DVM)
   - Terminal Degree (e.g., PhD, EdD, JD)

9) What is your current marital status? (Optional Question)
   - Single (never married)
   - Married
   - In a domestic partnership
   - Widowed
   - Divorced
   - Separated

10) What is your current employment status?
    - Employed full time (40 or more hours per week)
    - Employed part time (up to 39 hours per week)
    - Unemployed and currently looking for work
    - Unemployed and not currently looking for work
    - Student
    - Retired
    - Homemaker
    - Self-employed
    - Unable to work

11) How many children do you currently have?
    - 1
    - 2
    - 3
    - 4
    - 5+
For each of your child/children ages listed, please answer if you are their biological mother. Question is optional. Please only click yes, no, or prefer not to answer if you have a child this age.

<table>
<thead>
<tr>
<th>Age</th>
<th>Yes</th>
<th>No</th>
<th>Prefer not to Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>12) 0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>13) 1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>14) 2</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>15) 3</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>16) 4</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>17) 5</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

18) Are you currently nursing any of your children? ☐ Yes ☐ No
**Fatigue Severity Scale**

Please choose the number between 1 and 7 which you feel best fits the following statement. This refers to your usual way of life within the last week.

1 indicates “strongly disagree” and 7 indicates “strongly agree”.

19) 1. My motivation is lower when I am fatigued.  
20) 2. Exercise brings on my fatigue.  
21) 3. I am easily fatigued.  
22) 4. Fatigue interferes with my physical functioning.  
23) 5. Fatigue causes frequent problems for me.  
24) 6. My fatigue prevents sustained physical functioning.  
25) 7. Fatigue interferes with carrying out certain duties and responsibilities.  
26) 8. Fatigue is among my most disabling symptoms.  
27) 9. Fatigue interferes with my work, family, or social life.  
28) 10. Which number describes your global fatigue with 0 being the worst and 10 being normal.
## Parental Disability Index

Do you have a current clinical diagnosis of inflammatory arthritis?
- Yes
- No

Which of the following inflammatory arthritis conditions do you have?
- Rheumatoid arthritis
- Lupus
- Sclerosis
- Spondylarthritis
- Other

Please specify "other":

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Please rate your difficulty with the following activities listed. Response options are: no difficulty, some difficulty, a lot of difficulty, unable to do, did not do for reasons other than inflammatory arthritis.

1. Diapering, dressing or helping your child with dressing.
   - no difficulty
   - some difficulty
   - a lot of difficulty
   - unable to do
   - did not do for reasons other than inflammatory arthritis

2. Taking care of your child’s hygiene needs; for example, bathing or helping with bathing, brushing teeth or hair, or cutting nails.
   - no difficulty
   - some difficulty
   - a lot of difficulty
   - unable to do
   - did not do for reasons other than inflammatory arthritis

3. Feeding your child; for example, preparing formula or bottles, holding your child for feeding, cutting food for child using utensils to feed your child, or preparing food.
   - no difficulty
   - some difficulty
   - a lot of difficulty
   - unable to do
   - did not do for reasons other than inflammatory arthritis

4. Picking up or carrying your child.
   - no difficulty
   - some difficulty
   - a lot of difficulty
   - unable to do
   - did not do for reasons other than inflammatory arthritis

5. Taking care of your child out of the house; for example, carrying things you might need, changing diapers, feeding.
   - no difficulty
   - some difficulty
   - a lot of difficulty
   - unable to do
   - did not do for reasons other than inflammatory arthritis
<table>
<thead>
<tr>
<th>Activity</th>
<th>Difficulty Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting up and down to the floor to play with your child.</td>
<td>○ no difficulty ○ some difficulty ○ a lot of difficulty ○ unable to do ○ did not do for reasons other than inflammatory arthritis</td>
</tr>
<tr>
<td>Keeping your child out of unsafe situations; for example, away from stairs or the street, running after them, or keeping track of them outdoors or in stores.</td>
<td>○ no difficulty ○ some difficulty ○ a lot of difficulty ○ unable to do ○ did not do for reasons other than inflammatory arthritis</td>
</tr>
<tr>
<td>Getting up with child, either during the night or early in the morning.</td>
<td>○ no difficulty ○ some difficulty ○ a lot of difficulty ○ unable to do ○ did not do for reasons other than inflammatory arthritis</td>
</tr>
<tr>
<td>Playing with your child outdoors; for example, going to the playground, throwing balls, or practicing sports.</td>
<td>○ no difficulty ○ some difficulty ○ a lot of difficulty ○ unable to do ○ did not do for reasons other than inflammatory arthritis</td>
</tr>
<tr>
<td>Having other children in your home; for example, having birthday parties or other children over to play.</td>
<td>○ no difficulty ○ some difficulty ○ a lot of difficulty ○ unable to do ○ did not do for reasons other than inflammatory arthritis</td>
</tr>
<tr>
<td>Taking your child to social events or recreational activities; for example, taking your child to play groups or other children's birthday parties, or going to family events, museums, or swimming pools.</td>
<td>○ no difficulty ○ some difficulty ○ a lot of difficulty ○ unable to do ○ did not do for reasons other than inflammatory arthritis</td>
</tr>
<tr>
<td>Taking care of your child when s/he is sick; for example, giving medicine, using a thermometer.</td>
<td>○ no difficulty ○ some difficulty ○ a lot of difficulty ○ unable to do ○ did not do for reasons other than inflammatory arthritis</td>
</tr>
<tr>
<td>Activity</td>
<td>Difficulty Options</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Maintaining discipline with your child; for example, managing tantrums</td>
<td>○ no difficulty&lt;br&gt;○ some difficulty&lt;br&gt;○ a lot of difficulty&lt;br&gt;○ unable to do&lt;br&gt;○ did not do for reasons other than inflammatory arthritis</td>
</tr>
<tr>
<td>or setting and enforcing limits.</td>
<td></td>
</tr>
<tr>
<td>Doing household chores or shopping; for example, cleaning, vacuuming,</td>
<td>○ no difficulty&lt;br&gt;○ some difficulty&lt;br&gt;○ a lot of difficulty&lt;br&gt;○ unable to do&lt;br&gt;○ did not do for reasons other than inflammatory arthritis</td>
</tr>
<tr>
<td>laundry, ironing, shopping, or errands.</td>
<td></td>
</tr>
<tr>
<td>Using a stroller.</td>
<td>○ no difficulty&lt;br&gt;○ some difficulty&lt;br&gt;○ a lot of difficulty&lt;br&gt;○ unable to do&lt;br&gt;○ did not do for reasons other than inflammatory arthritis</td>
</tr>
<tr>
<td>Using a car seat.</td>
<td>○ no difficulty&lt;br&gt;○ some difficulty&lt;br&gt;○ a lot of difficulty&lt;br&gt;○ unable to do&lt;br&gt;○ did not do for reasons other than inflammatory arthritis</td>
</tr>
<tr>
<td>Opening safety latches or locks.</td>
<td>○ no difficulty&lt;br&gt;○ some difficulty&lt;br&gt;○ a lot of difficulty&lt;br&gt;○ unable to do&lt;br&gt;○ did not do for reasons other than inflammatory arthritis</td>
</tr>
<tr>
<td>Opening medicine or childproof containers.</td>
<td>○ no difficulty&lt;br&gt;○ some difficulty&lt;br&gt;○ a lot of difficulty&lt;br&gt;○ unable to do&lt;br&gt;○ did not do for reasons other than inflammatory arthritis</td>
</tr>
</tbody>
</table>

**Qualitative Questions**

Please answer the following questions regarding your experience as a mother.

51) How different is fatigue now versus before you had kids?  

52) Does fatigue impact your daily activities? If yes, explain.  

53) Think about your typical day. At what point in the day do you find mothering to be challenging and why?  

54) Describe what it is like when you need to quickly and unexpectedly transition from one activity to another.
### Appendix B: Sample Size Calculations

#### Mean FSS score vs. 30% difference

<table>
<thead>
<tr>
<th>Std Dev</th>
<th>Power</th>
<th>N per Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>0.8</td>
<td>13</td>
</tr>
<tr>
<td>1.2</td>
<td>0.8</td>
<td>17</td>
</tr>
<tr>
<td>1.4</td>
<td>0.8</td>
<td>17</td>
</tr>
<tr>
<td>1.6</td>
<td>0.8</td>
<td>22</td>
</tr>
<tr>
<td>1.8</td>
<td>0.8</td>
<td>27</td>
</tr>
<tr>
<td>2</td>
<td>0.8</td>
<td>24</td>
</tr>
<tr>
<td>1</td>
<td>0.95</td>
<td>11</td>
</tr>
<tr>
<td>1.2</td>
<td>0.95</td>
<td>15</td>
</tr>
<tr>
<td>1.4</td>
<td>0.95</td>
<td>19</td>
</tr>
<tr>
<td>1.6</td>
<td>0.95</td>
<td>25</td>
</tr>
<tr>
<td>1.8</td>
<td>0.95</td>
<td>31</td>
</tr>
<tr>
<td>2</td>
<td>0.95</td>
<td>38</td>
</tr>
<tr>
<td>1</td>
<td>0.9</td>
<td>12</td>
</tr>
<tr>
<td>1.2</td>
<td>0.9</td>
<td>17</td>
</tr>
<tr>
<td>1.4</td>
<td>0.9</td>
<td>23</td>
</tr>
<tr>
<td>1.6</td>
<td>0.9</td>
<td>29</td>
</tr>
<tr>
<td>1.8</td>
<td>0.9</td>
<td>39</td>
</tr>
<tr>
<td>2</td>
<td>0.9</td>
<td>44</td>
</tr>
<tr>
<td>1</td>
<td>0.95</td>
<td>15</td>
</tr>
<tr>
<td>1.2</td>
<td>0.95</td>
<td>21</td>
</tr>
<tr>
<td>1.4</td>
<td>0.95</td>
<td>27</td>
</tr>
<tr>
<td>1.6</td>
<td>0.95</td>
<td>35</td>
</tr>
<tr>
<td>1.8</td>
<td>0.95</td>
<td>44</td>
</tr>
<tr>
<td>2</td>
<td>0.95</td>
<td>65</td>
</tr>
</tbody>
</table>

#### Two-Sample t Test for Mean Difference

![Graph showing sample size vs. power for different standard deviations](image)
Appendix C: Recruitment Flyers

Mothers with Inflammatory Arthritis Flyer

ARE YOU A MOTHER LIVING WITH AN INFLAMMATORY ARTHRITIC CONDITION?

COMPLETE A 20-MINUTE SURVEY to help clinicians understand life for mothers with inflammatory arthritis

SEEKING WOMEN VOLUNTEERS TO PARTICIPATE IN A RESEARCH STUDY:
- BETWEEN THE AGES OF 18-50
- WITH A CHILD OR CHILDREN AGES 0-5
- HOLDING A CLINICAL DIAGNOSIS OF ONE OF THE FOLLOWING
  - RHEUMATOID ARTHRITIS
  - LUPUS
  - SCLERODERMA
  - Spondylarthritids

ACCESS THE SURVEY BY USING THE FOLLOWING LINK or SCAN THE QR CODE BELOW:
https://reicap.med.uvm.edu/surveys/3wKWRP3A0Y1

For more information, contact
Chrystina Bonelli
203-856-8863 or chonelli@uvm.edu

OR
Dr. Victoria Priganc
(802)-656-8146 or victoria.priganc@med.uvm.edu

Research supported by the University of Vermont Honors College.
ARE YOU A MOTHER WHO WANTS TO HELP OTHER WOMEN?

COMPLETE A 10 MINUTE SURVEY to help clinicians understand life for mothers with inflammatory arthritis

SEEKING WOMEN VOLUNTEERS TO PARTICIPATE IN A RESEARCH STUDY:
- BETWEEN THE AGES OF 18-50
- WITH A CHILD OR CHILDREN AGES 0-5
- WHO DO NOT HAVE A CHRONIC CONDITION DIAGNOSIS

ACCESS THE SURVEY BY USING THE FOLLOWING LINK OR SCAN THE QR CODE:
https://redcap.med.uvm.edu/survey/?id=6592030492

For more information, contact Chrystina Bonelli 243-859-8863 or cbonelli@uvm.edu

OR

Dr. Victoria Priganc (802)-656-8146 or victoria.priganc@med.uvm.edu

Research supported by the University of Vermont Honors College.

The University of Vermont
Appendix D: The Fatigue Severity Scale

FATIGUE SEVERITY SCALE (FSS)

Date __________________________ Name ________________________________

Please circle the number between 1 and 7 which you feel best fits the following statements. This refers to your usual way of life within the last week. 1 indicates “strongly disagree” and 7 indicates “strongly agree.”

<table>
<thead>
<tr>
<th>Read and circle a number.</th>
<th>Strongly Disagree</th>
<th>→</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My motivation is lower when I am fatigued.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Exercise brings on my fatigue.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I am easily fatigued</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Fatigue interferes with my physical functioning</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Fatigue causes frequent problems for me.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. My fatigue prevents sustained physical functioning.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Fatigue interferes with carrying out certain duties and responsibilities.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Fatigue is among my most disabling symptoms.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Fatigue interferes with my work, family, or social life.</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

VISUAL ANALOGUE FATIGUE SCALE (VAFS)

Please mark an “X” on the number line which describes your global fatigue with 0 being worst and 10 being normal.

| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
Appendix E: Parental Disability Index

APPENDIX E: PARENTING BEHAVIORS QUESTIONNAIRE

Did you have any trouble or difficulty with the following? (Response options: no difficulty, some difficulty, a lot of difficulty, unable to do, did not do for reasons other than rheumatoid arthritis [RA].)

Did you do less of _____ because of your RA?

Young child(ren) (ages 0-5 years)
- diapering, dressing, or helping your child with dressing
- taking care of your child's hygiene needs; for example, bathing or helping with bathing, brushing teeth or hair, or cutting nails
- feeding your child; for example, preparing formula or bottles, holding your child for feeding, cutting food for child, using utensils to feed your child, or preparing food
- picking up or carrying your child
- taking care of your child while out of the house; for example, carrying things you might need, changing diapers, feeding
- taking your child out in the car; for example, getting child in and out of car, using car seat
- getting up and down to the floor to play with your child
- keeping your child out of unsafe situations; for example, away from stairs or the street, running after them, or keeping track of them outdoors or in stores
- getting up with your child, either during the night or early in the morning
- playing with your child outdoors; for example, going to the playground, throwing balls, or practicing sports
- having other children in your home; for example, living birthday parties or having other children over to play
- having your child to social events or recreational activities; for example, taking your child to play groups or other children's birthday parties, or going to family events, museums, or swimming pools
- taking care of your child when she is sick; for example, giving medicine, using a thermometer
- maintaining discipline with your child; for example, managing tantrums or setting and enforcing limits
- doing household chores or shopping; for example, cleaning, vacuuming, laundry, ironing, shopping, or errands

Equipment:
- using a stroller
- using a car seat
- opening safety latches or locks
- opening medicine or childproof containers

Older child(ren) (ages 6-18 years)
- taking your child to all the places she needs to go
- being involved in your child's school functions; for example, attending school conferences, open houses, performances, or other events; volunteering in the classroom or for fundraising; participating in field trips
- helping your child with homework or school projects
- playing with your child outdoors; for example, going to the playground, throwing balls, or practicing sports
- having other children in your home; for example, having birthday parties or having other children over to play
- going with your child to social events or recreational activities; for example, taking your child to sports activities, girl/boy scouts, or other children's birthday parties, or going to family events, museums, or swimming pools
- getting up with your child, either during the night or early in the morning
- taking care of your child when she is sick; for example, giving medicine, using a thermometer
- keeping your child out of unsafe situations; for example, keeping them away from stairs or the street, running after them, or keeping track of them outdoors or in stores
- maintaining discipline with your child; for example, managing tantrums or setting and enforcing limits or curfews
- doing household chores or shopping; for example, cleaning, vacuuming, laundry, ironing, shopping, or errands

* These questions were asked referring to young children for current parents who had young children only. For parents in the current group who had children in both age groups and for all parents in the retrospective group, these questions were asked a single time, with the older age group questions.*

*Only the Young Children ages (0-5 years) section was used in this study