INTRODUCTION

Most Americans will experience a critical illness or injury during their lifetime, either as a parent, family member, or friend (Anderson et al., 2012). This group now consists of more than 54 million Americans, along with their often overlooked families. With medical treatment advances and longer life-spans, this number will very likely increase. Yet this is a group for which research on the presence of parental disability or chronic illness, strikingly little research exists.

Approximately 80% of Americans will experience a critical illness or injury during their lifetime. In the older population, this percentage is even higher, as the elderly are more vulnerable to the effects of chronic illness (Anderson et al., 2002). Of these, approximately 400,000 Americans have been diagnosed with multiple sclerosis (MS) (NMSS, 2013).

Multiple Sclerosis is a currently incurable, chronic, degenerative disease that disrupts the efficiency of the central nervous system, often leading to a variety of physical, psychological, and social changes. As women and men are typically diagnosed between the ages of 20-50 years (NMSS), often the most productive years of career and family development, with many social and financial responsibilities. Although its cause is currently unknown, MS is one of the most disabling and most currently encountered neurological diseases, affecting over 2.5 million worldwide (NMSS, 2013; Mair, 2003).

The most commonly reported symptom is fatigue and people with MS have reportedly difficulty describing this pervasive weakness to others as it differs from physical weakness (Anderson et al., 2020; Jem, Gisson, Jewell, & Soderberg, 2005). Other symptoms include blurred vision, numbness, and weakness, but can also include any combination of speech problems, problems with balance, tremor, mood swings, sleep disturbances, depressive symptoms, and swallowing disorders, spasticity, and paraplegia (NMSS, 2013).

Decades of research yield few results

- 1979: Arnold first lack of systematic study in the influence a parent's illness might have on their child’s life (Eeltink & Duffy, 2004).
- 1984, Rusted reported it in clinical research toward the patient alone with comparative interest to the child
- 1995, Arasteh et al. described a field of study in its infancy
- 2005, Yahoh found true notion of parental illness in existing literature

The study of parenting with disability has often involved a search for negative outcomes (Cheung & Trapnell, 2000). It seems probable that this search will continue when based on the available evidence.

- “speculative literature” (Girvan, 1980, p. 14)
- “presumptions of dependency” (Nelis, 1997, p. 105)
- “pathological assumptions” (Crawford, 2003, p. 68)
- “stigma” (Eeltink & Duffy, 2004)

This research provides only scant information about a few factors that may influence the effects of parental chronic illness (p. 186). A more recent review found similar results, describing, “a visibly small scale of translated, presented, and used epidemiological and clinical data at micros, meso, macro, and societal level.” (Anderson et al., 2022, p. 25).

FAMILY STRESS THEORY (FSST)

Steele and Duffy (2004) found analogous efforts to reframing the “uncertainty of MS as a condition of life rather than a condition of disease” (p. 282). Such a redefining process can give rise to uniquely intense intergenerational internal trends and traditional life stress in both the family and the new patient. (Kasper & Wester, 1999). So, it is conceivable that the necessity and increased intensity of the illness will be experienced differently depending on the level of stress perceived by each participant.

Steele (1994) – With the onset of a chronic illness, it is a strength that should be understood that the restrictions of the illness also produce stress and not the physical symptoms alone. Using the restrictions of the illness as a stressor is a form of conscious coping, evidence that the individual viewed the restrictions they had to maintain – an established equilibrium due to the illness as a stressor.

The self-report nature of the FSST implies that participant family members recognized and assimilated (C), at least in part, as specific strengths and weaknesses in their family interaction. Although families report what they are experiencing and the amount of change they are experiencing in the illness over time; the assumptions of the family's experience with chronic illness may vary significantly by time and sometimes be more predominant and stronger than the illness itself.

There is a need for the illness to be viewed as a consequence on the family. This may differ from those that are more severe, such as those that are potentially catastrophic and may require a particular level of attention. A family's score on the General Scale of FAM functioning reported here, it is also feasible that the FAM-II scores of participant families, which might relate primarily to how a family perceived the illness and how it defined the illness reported in a study.

BIOELECTROCHEMICAL THEORY

The Process-Person-Context-Time (PPT) model is an extension by Bronfenbrenner (2005) on his earlier work, postulating proximal processes to promote development, and the strength of their influence dependent on person, context, and time. This stage of development is influenced by the environment that promote individual development, producing either competence or dysfunction. The PPT model provides an individual as a concentration of both people and products of development. Reflected here in comparisons between families with a male or female parent with MS, families in which the patient is MS is a female demonstrated lower levels of functioning. This difference may stem from the need to redefine gender roles in family life.

The context refers to relevant components of the environment, both objective and subjective. Context includes the familiar nested systems of the earlier Ecological Theory. Using data from multiple family members, a more accurate picture of family functioning was formed. Most of MS typically occurs at about thirty-five to forty years of age at which time and family demands are high and interacting with each other in the household and are influenced by factors in the ecosystems and macro systems.

Table 1: Demography of the Sample

<table>
<thead>
<tr>
<th>Participant</th>
<th>Comparison</th>
</tr>
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<tbody>
<tr>
<td>Father’s age</td>
<td>46.7 (6.4)</td>
</tr>
<tr>
<td>Mother’s age</td>
<td>44.5 (6.8)</td>
</tr>
<tr>
<td>Education</td>
<td>4.43 (1.9)</td>
</tr>
<tr>
<td>Child’s age</td>
<td>15.7 (3.0)</td>
</tr>
<tr>
<td>Child gender</td>
<td>268-F</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>82%-14%-4%</td>
</tr>
</tbody>
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Theoretical understanding of family functioning with Multiple Sclerosis: Accrued disability and chronic uncertainty

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METHOD

Participants families, with a parent diagnosed with MS, were recruited with the help of the MS Association in Chicago, the Illinois Society in Bloomington, andday, or the parents of children who were at least 15 years old (Steele & Duffy, 2004). The sample was recruited from three Parent Teacher Organizations within the state. The parents, partners, and other significant others were invited to complete the Family Assessment Measure - Version III (Gavaghan et al., 2000). The General Scale of the FAM-II was utilized in this study and consists of 50 items relating to family relationships and health from a theoretical perspective. The highest and lowest 10% of the distribution were standardized to have a mean of 0 and a standard deviation of 1 (Steele & Duffy, 2004).

Scores ranging from 40 to 60 indicate normal family functioning based upon results from non-clinical families. Scores above 60 indicate potentially serious concerns about family functioning. Scores below 40 indicate very healthy family functioning and virtually no clinical concerns.

RESULTS

It was hypothesized that there would be no statistically significant difference in family functioning between participating families with MS (F = 5.3, M = 54.9, SD = 6.43) and comparison families (N = 49, F = 49.32, M = 49.92, SD = 5.63). The results were significant, F(2, 99) = 9.04, p < .05. Post hoc Scheffé test, indicated that the difference was the pairwise comparison of participant families with female patients and the comparison families alone. Patient gender created no significant effect within families with MS. See Table 3 below.

A second-way ANOVA revealed a significant effect for time since illness, F(3, 98) = 6.81, p < .05, post hoc Scheffé test indicated that this effect is attributable to the comparison vs. 5 years since illness onset, at the pairwise level.

It was also hypothesized that there would be no statistically significant difference between the family functioning of participants with MS (F = 5.3, M = 54.9, SD = 6.43) and comparison families (N = 49, F = 49.32, M = 49.92, SD = 5.63). The results were significant, F(2, 99) = 7.09, p < .05. Post hoc Scheffé test indicated that this effect is attributable to the comparison vs. 5 years since illness onset, at the pairwise level.

The negative impact here is not one of experience or of growing as some have suggested. Neither does it reflect a ‘illness’-that is considerable pathologizing or as a conscious experience. Rather, it is the experience, whatever the form or intensity, that may possibly generate a ‘illness’-in the same way that some have suggested. It is not the illness itself, but rather the experience or the way the illness is experienced, that may be the critical factor in understanding the negative impact on family functioning.

Some have clarified the impact on the family as the primary consequence of MS (Cheung & Trapnell, 2000) and, too many of their unique challenges (Gavaghan et al., 2018). Results of this study supported the idea that parent multiple sclerosis is a highly significant impact on family functioning. Participant families exhibited a greater or lower level of family functioning as assessed by the FAM-II and as compared to the control group.