



A Qualitative Descriptive Study Exploring the Adaptation of Families of Children with Multiple Sclerosis from the Perspective of Caregivers

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Problem/Significance

- 2-5% of the 400,000 US individuals with MS are less than age 18 at diagnosis
- Most pediatric onset multiple sclerosis (POMS) cases take on a relapsing remitting course with unpredictable cognitive and physical disability leading to school absences, hospital and outpatient visits, poor academic performance and interruption in normal social activity
- Initially, families may adjust by making day-to-day changes and overtime, they learn to adapt their functioning to meet the demands of the unexpected nature of the disease
- There has not been any research to explore factors that influence the adaptive process that takes place in families of children with POMS

Specific Aims

The specific aims of the study are to:

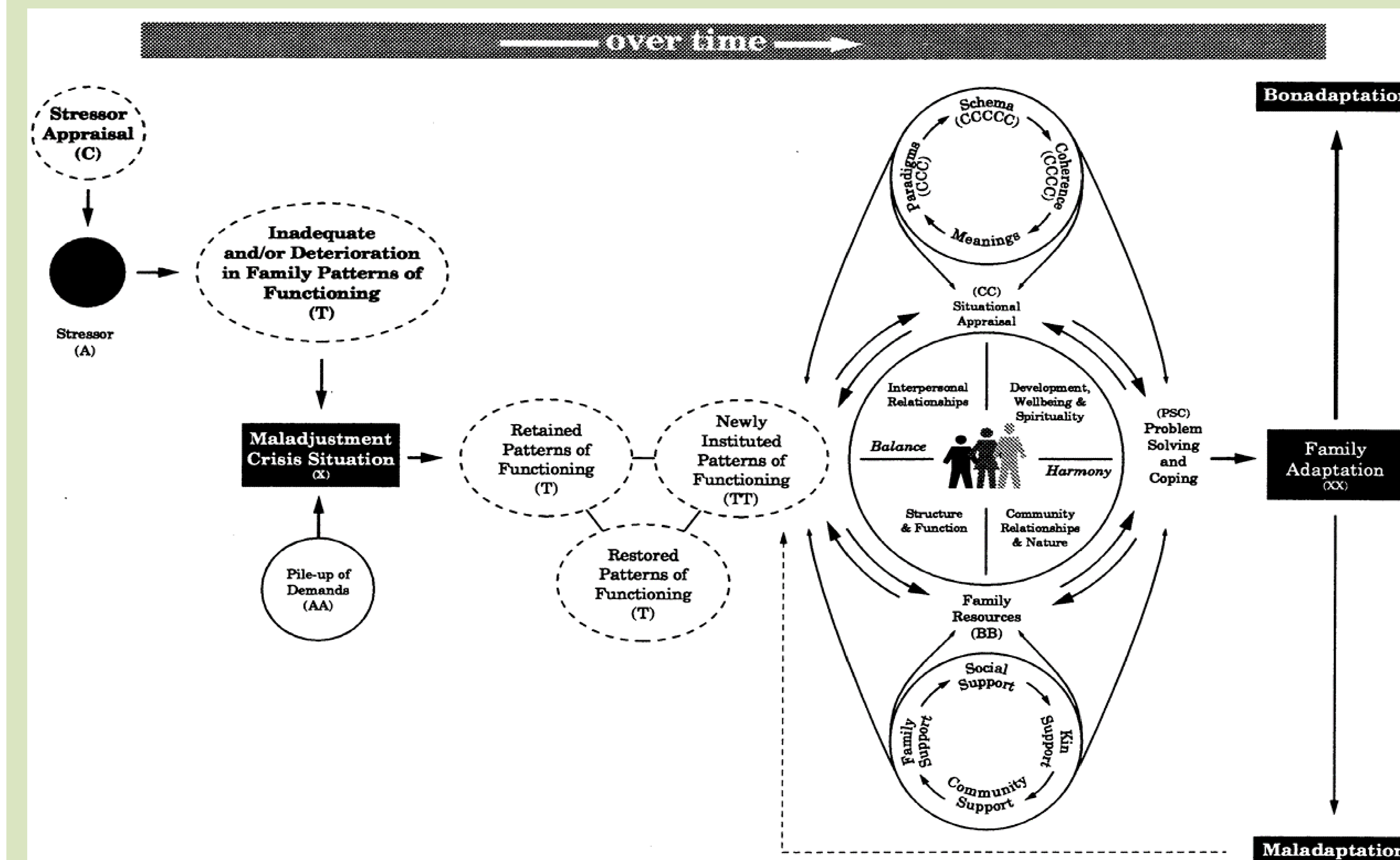
- 1) Explore the initial and ongoing psychosocial, financial, emotional and behavioral impact on families who have a child with POMS;
- 2) Explore how the family adjusts to raising a child with POMS;
- 3) Explore strategies that are utilized for coping and balancing the needs of the child with POMS and their family; and
- 4) Identify the resources that are available to families to assist in caring for a child with POMS.

Research Question

Central Research Question: How do family factors influence adaptation in families of children diagnosed with multiple sclerosis?

Theoretical Framework with Conceptual Model

The Resiliency Model of Family Stress, Adjustment and Adaptation



Source: McCubbin, H., Thompson, A. & McCubbin, M, (1996).

Study Design

- A Qualitative Descriptive Study will be conducted to gather rich and in-depth accounts of the factors that influence that adaptation of families of children with POMS, which is a phenomenon that has never been explored before.

Sample/Recruitment

- Purposeful sampling of 10-20 family caregivers of children or young adults who meet the diagnosis of POMS
- Participants will be recruited until data saturation is reached
- Site of recruitment will be the Center for Pediatric Onset Demyelinating Disease and the UAB Adult MS Center

Inclusion/Exclusion Criteria

Inclusion Criteria

1. A family caregiver lives in the household with a child diagnosed with POMS (≥ 6 months)
2. The child of the family caregiver has:
 - a. Received ongoing care and/or consultation in the last 2 years at CPODD
 - b. Transitioned from CPODD to the UAB Adult MS Clinic for routine care
3. The family caregiver can read and speak English

Exclusion Criteria

1. Primary language of the family caregiver is other than English
2. The child of the family caregiver is diagnosed with a clinically isolated syndrome but is being treated with a disease modifying therapy

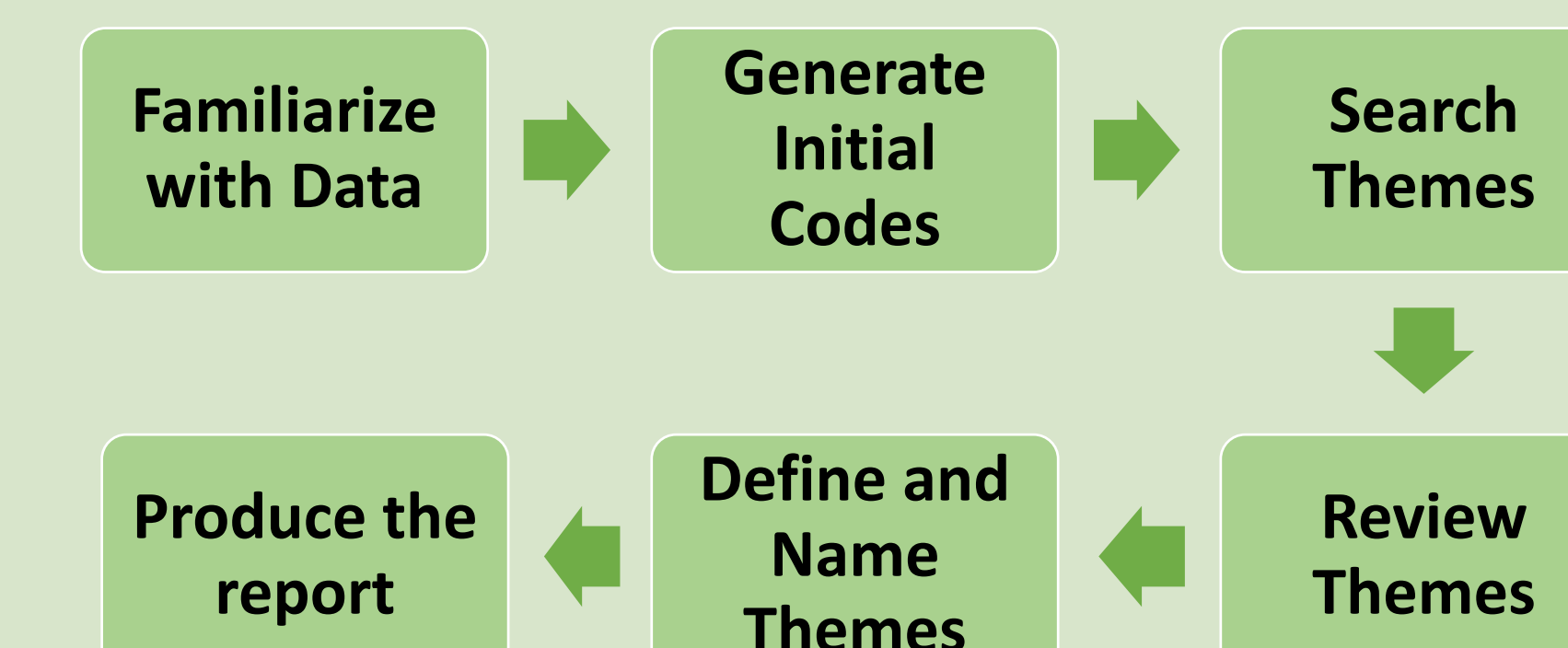
Instruments

- One-on-one, in depth, semi-structured interviews
- 50- item sociodemographic data form

Data Analysis

Interviews

Braun & Clark's 6 Steps to Thematic Analysis



Socio-Demographics

Statistical Analysis



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