

# The Lifetime Influence of Families in the Lives of Women with Cerebral Palsy

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# Purpose

- To examine the perceptions of 8 adult women with cerebral palsy on ways their families and individual family members contributed to their overall quality of life and adaptation to CP



# Participants

- 8 women with cerebral palsy
  - 22 years to 55 years; mean = 36.88 years ( $SD = 12.98$ )
  - Two currently in college
  - One worked full time
  - Two worked part-time
  - Types of cerebral palsy
    - spastic quadriplegia (n = 4)
    - athetoid cerebral palsy (n = 2)
    - spastic diplegia (n = 1)
    - spastic left hemiplegia (n = 1)



# Methods

- Feminist biographical method
  - Two interviews
  - Inclusion of personal writings
- Data analysis
  - Within-case analysis
  - Across-cases analysis



# Results

- Helpful family
- Non helpful family



# Helpful family

- An advocate; taught advocacy
- Promoted inclusion and acceptance
- Integrated therapy into daily life
- Siblings were friends and mentors



# An advocate, taught advocacy

- Advocacy: ensuring physical, emotional, or educational needs were met
- Family members
  - were advocates
  - taught participants to become advocates



# Family Members and Advocacy

- Parents: interceded with school personnel when participant mistreated by other students or denied opportunities to enroll in a specific class
- Extended family: negotiated a way for a participant to receive therapy not available in participant's hometown
  - “I had another aunt in another big city so I went there for the summer so I could have speech and physical therapy.”





# Teaching advocacy

- Parents modeled advocacy
  - Mothers: “My mother is a strong fighter. She won’t take no for an answer. She instilled that in me. That courage to fight.”
  - Fathers: One father modeled the steps of advocacy after his daughter was not allowed to use a floatation device in a public pool
    - First, he validated there was a law forbidding the use of floatation devices in public pools.
    - Then he researched the steps needed to change the law.
    - Finally, through his actions the law was changed



# Promoted Inclusion and Acceptance

- Family members treated participants as a regular part of the family and made sure participants were included in family activities
  - “I felt very accepted by my family.”
  - Carried in a backpack on family outings
  - Assigned chores/disciplined like siblings



# Integrated Therapy into Daily Life

- Accessed therapy
- Home-based therapies



# Siblings

- Friends
  - “It was very lonely but my brothers played with me.”
- Mentors
  - Showing participants how to crawl, use a spoon, and read



# A Brother Mentor

- “You know Dorothy, the world is made up of two kinds of people. There are big people and little people. The little people are those who get up in the morning, get dressed, go to school or to work, come home, eat dinner, watch TV, and go to bed. They don’t mean anything to the world and the world doesn’t mean anything to them. You don’t need to worry about them. It’s the big people you need to worry about. They care about the world, and make decisions to try to make it a better place to live. They are successful in living and not just making a living. But you don’t even have to worry about them because if they are truly big people they will have big enough hearts to love you and accept you as you are.”



# Non Helpful Family

- Parents did not advocate or teach advocacy
- Did not believe was member of family; had an almost non-existent relationship with brother
  - Often excluded from activities
  - Never received therapy
- As an adult, focused on negative



# Implications for Nurses

- Assist families support children with CP
- Encourage families to be advocates
- Teach families to treat children with CP as normal family members
- Discuss inclusion strategies
- Promote physical, speech, and occupational therapy
- Support healthy sibling relationships

