Discovering the Lived Experience of Licensed Medical Foster Parents of Children with Special Medical Needs

NSU Quality of Life Faculty Community-Based Applied Research Grant FY 2011

Barbara Packer-Muti, Ed.D. Principal Investigator
954-262-5398
Email: packerb@nova.edu
Additional Researchers and Community Partner

• Co-Investigator: Dr. Ronald Chenail
• Co-Investigator: Dr. Robin Cooper
• Community Partner: Guardian ad Litem Program, 7th Judicial Circuit
• Student Research Assistant: Andrew Wolfson
Objectives

• To discover the lived experiences of medical foster caregivers actively engaged in providing day-to-day care for children with special health needs
• To discover the experiences of medical foster caregivers relatives to the complex issues facing them (including training and support available, respite care, and interactions with the multiple professionals with whom they deal)
• To discover the impact of medically challenging foster children on the balance of the foster caregivers’ families
• To share the findings with the appropriate agencies
• To contribute to the gap in the research literature about licensed medical foster caregivers
Project/Research Design
Participants

• 7 Medical Foster Caregivers in Broward County
  – Women
  – Various racial/ethnic backgrounds
  – 2 to 15 years experience as medical foster caregivers
• Recruitment took place via contacts with ChildNet, the Guardian ad Litem program and the licensing agencies for medical foster care in Broward.
• Snowball sampling technique
• Important: Phenomenology studies typically use a sample size of 10 or less
• By 7th interview, researchers confident thematic saturation reached
Data Collection

• Individual phenomenological interviews conducted, digitally recorded
• Three month timeframe
• Outset, each interviewee read & signed consent form
• Demographic questions
• Interview Guide comprised of a series of open-ended questions, such as:
  – What kind of training did you receive?
  – What interested you in becoming a medical foster parent?
• Principal Researcher is clinically trained to conduct in-depth interviews with clients based on background and training.
Data Analysis

• PI and Student to transcribe each interview
• PI and Co-Investigator will separately code the first interview to establish inter-rater reliability
• Coded data analysis guided by model of existential phenomenology outlined by Pollio et al. (1997) and further modified by Cooper (2010)
• Both PI and Co-I reviewed transcripts multiple times
Data Analysis Continued

• Researchers read transcripts for meaning units (words and phrases)
• Used highlighting feature to reduce to meaning units (horizons)
• Continued until no further invariant meaning units
• Utilized “comment balloons” to develop coding system – based on focus of methodology (lived experience & meaning) as well as guiding research questions
Codes Developed

• “E” – experience
• “M” – meaning
• “Care”
• “System”
• “Balance”
• QoL” (Quality of Life)
Second Stage of Analysis

• Clustering initial horizons under themes, then grouped all horizons under themes that reflected the meaning expressed by participants
• Next, thematic clusters used to write an individual textural description for each participant
• Each textural description contained demographics/summary followed by each participant’s experience & meaning according to the four identified themes
Final Stage of Analysis

- Overall thematic structure representing participants’ experience
Results

Over-arching essence of the phenomenon

“Devotion” – Living a life of devotion

Outward dimensions: time, energy, physical labor, ceaseless activity

Inward dimensions: internal commitment, vision, & deep love
Theme One: Devoted to Providing Care for Children

- Around the clock care for kids with special needs
  
  “You really have to work at it”
  “Organized chaos”
  “a lot of sleepless nights”
  “on the job training”
Theme Two: Devoted Advocates within the Medical Foster Care System

Dealing with the System (healthcare, social services, educational, legal)

“a training session then it’s all fly by the seat of your pants”

“they are not seeing the child as a whole. The PT would come in and see feet”

“the court system, in my opinion, takes way too long getting these kids through”
Theme Three: The Sacrifices of Devotion

24/7 nature of the work – all consuming

“my life kind of stopped when I took on the kids”
“friends don’t come over...they don’t want to be around screaming kids”
“I don’t have a lot of support....I’m stressed out most of the time”
“my life has been made complete”
Theme Four: Making a Difference in Quality of Life

Firm belief that they are making a positive difference in the quality of life of these kids

“since he’s gotten all this love all these months, he’s very much loved… it’s much better”

“kids don’t belong in a hospital room”

Expression of Christian faith: “the Lord healed him” and “you would never know anything ever happened to him, thank God”
“at one point, he, he just had to share with me, and I don’t remember exactly what he said, but it was basically... and he’s three, four, at the time he said this. He said, you know... he was thanking me for taking care of him, and I thought well how could you not?”
Community Impact
External Funding/Sustainability of the Project