The Early Adulthood Experience of Having a Sibling with a Developmental Disability

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The sibling relationship is unique.

Early adulthood is an important stage in development.

There is an increase in number of individuals with developmental disabilities.

There is an increase in deinstitutionalization.

Few previously published studies were found.

Glover, 2000; Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015; Lakin, Larson, Salmi, & Webster, 2010; Heller, Staffor, Davis, Sedlezyk, & Gaylord, 2010
Purpose

- To explore the early adult’s experience of having a sibling with a developmental disability and to describe the experience
Methods

- Qualitative study

- Hermeneutic phenomenology expounded by Max van Manen

- Approaches
  - Wholistic
  - Selective
  - Detailed

Van Manen, 1990
Limitations

- Location of interview
- Tape Recorder presence
- Intentional and clear wording of questions
Literature Review

- Sibling Relationships in Early Adulthood
  - Furman, Lanthier, & Stocker (1997)
  - Conger & Little (2010)
  - White (2001)

- Sibling Relationships in Adulthood with a Sibling with a Developmental Disability
  - Floyd, Costigan & Richardson (2016)
  - Heller & Kramer (2009)
  - Burbidge & Minnes (2014)
  - O’Neill & Murray (2016)
  - Arnold, Heller, & Kramer (2012)
  - Davys, Mitchell, & Haigh (2016)
Study Design

- Setting

- Instruments
  - Researcher
  - AudioNote application
Study Design cont’d

- Participants
  - Inclusion criteria

- Data Collection

- Protection of Participants
Study Design cont’d

- Analysis
- Methodological Rigor
  - Credibility
  - Transferability
  - Confirmability

van Manen, 1990; Munhall 1994
Research Question

- The research question was:

What is the early adulthood experience of having a sibling with a developmental disability?
Essential Themes

- Lessons Learned
- Protective
- The Future
- Intimate with Sibling
- Pragmatism
Lessons learned

- Variations:
  - A lesson to learn from my sibling
  - Something for others to learn from my experience
Protective

- Variations:
  - Concern
    - Safety and well-being
    - Independence in lifestyle
  - Advocating
    - Don’t mess with my sibling
    - Don’t underestimate my sibling
    - Social facilitation
The Future

- Variations:
  - Children
  - Financial responsibility
  - Living arrangements
  - Managing care
Intimate with Sibling

- Frequent contact & continuous communication
- Strong bonds that could overcome obstacles
- A true friendship
Pragmatism

- Accepted good and bad in life
- Made accommodations for siblings
- Situation could be worse
Influences

- Normal to me
- Parents
Normal to Me

- Normalcy of their own family situation
- Recognition of differences from other families
Parents

- Facilitated sibling relationship
- Modeled accommodations and approaches to the situation
Discussion & Implications

- Limitations to Transferability

- Implications
  - Practice
  - Education
  - Research
Comparison of Experiences

Early Adults with Sibling with Developmental Disability (DD)
Adolescents with Sibling with Angelman Syndrome (AS)
Comparison of Themes

**Early Adult Experience (DD)**
- Lessons Learned
- Protective
- The Future
- Intimate with Sibling
- Pragmatism

**Adolescent Experience (AS)**
- Brought happiness
- Thoughts of the future
- Increased workload & level of responsibility
- Pragmatism
- Intense Love (included protective)
- Embarrassment
- Experience taught patience, understanding, how to face adversity
Comparison of Influences

Early Adult (DD)
- Parents
- Normal to Me

Adolescent (AS)
- Knowledge Level
- Behaviors
- Ability to Communicate
- Medical Acuity
- Parent’s response
Similarities between the experience of the adolescent and early adult potentially point to areas to focus on as early as possible and in an age appropriate manner

- How to manage behaviors
- How to advocate
- Keeping the sibling informed
- The future (finances, living arrangements, managing care, future plans)

The parents’ response is important
Questions?