

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

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Introduction & Significance



- 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; Zablotzky, Black, Maenner, Schieve, & Blumberg, 2015; Lakin, Larson, Salmi, & Webster, 2010; Heller, Staffor, Davis, Sedlezky, & Gaylord, 2010

Purpose

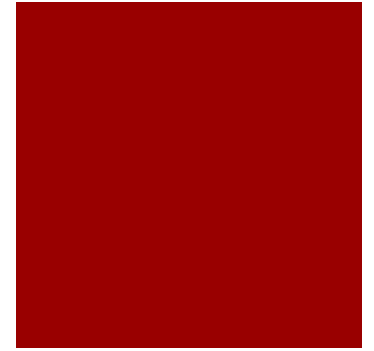
- To explore the early adult's experience of having a sibling with a developmental disability and to describe the experience



Methods

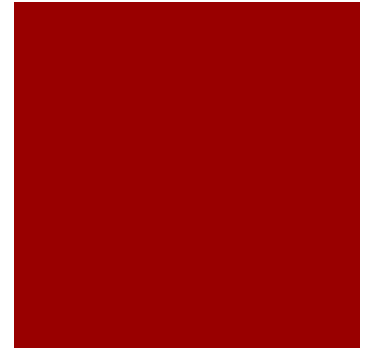
- Qualitative study
- Hermeneutic phenomenology expounded by Max van Manen
- Approaches
 - Wholistic
 - Selective
 - Detailed

Van Manen, 1990



Limitations

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



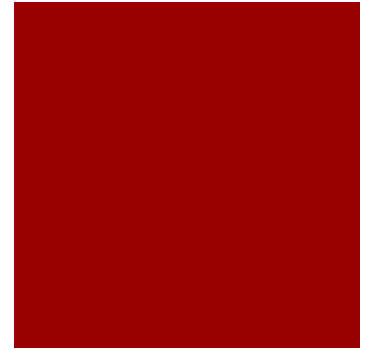
Literature Review



- 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)

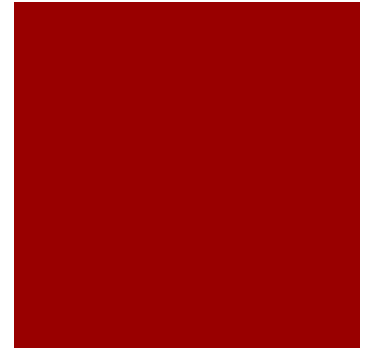
Study Design

- Setting
- Instruments
 - Researcher
 - AudioNote application



Study Design cont'd

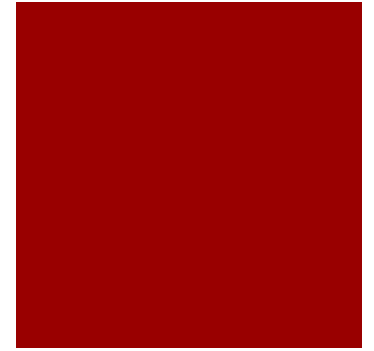
- Participants
 - Inclusion criteria
- Data Collection
- Protection of Participants



Study Design cont'd

- Analysis
- Methodological Rigor
 - Credibility
 - Transferability
 - Confirmability

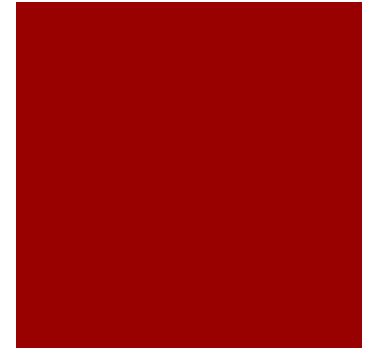
van Manen, 1990; Munhall 1994



Research Question

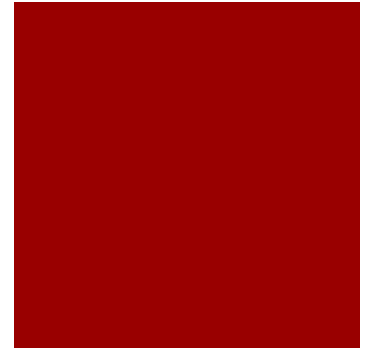
- The research question was:

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



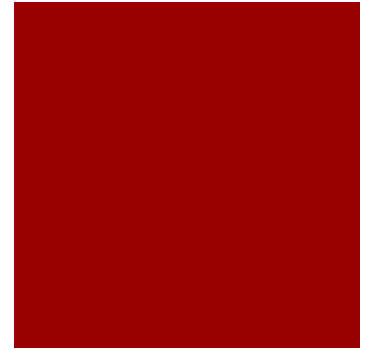
The Future



- Variations:
 - Children
 - Financial responsibility
 - Living arrangements
 - Managing care

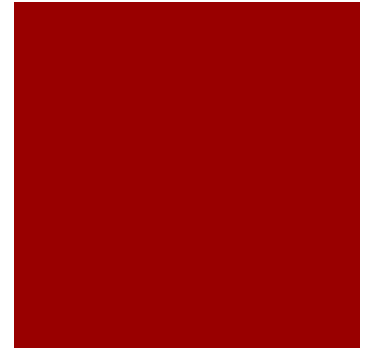
Intimate with Sibling

- 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



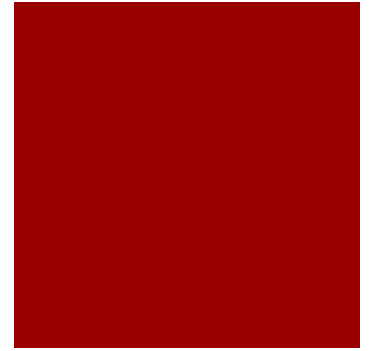
Influences

- 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?

