

THROUGH SIBLING EYES: GROWING UP WITH SIBLINGS WITH SCHIZOPHRENIA

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OBJECTIVES



- ✓ Impact of growing up with a sibling with Schizophrenia – study
- ✓ Methods
- ✓ Results
- ✓ Conclusions

Why this project?

- ✓ Lack of specific literature in this area
- ✓ Recognition as an occupational therapist that schizophrenia may have a “family burden” beyond the parents
- ✓ Potential future caregiver issues for sibling
- ✓ Recognized deficit in my own teaching

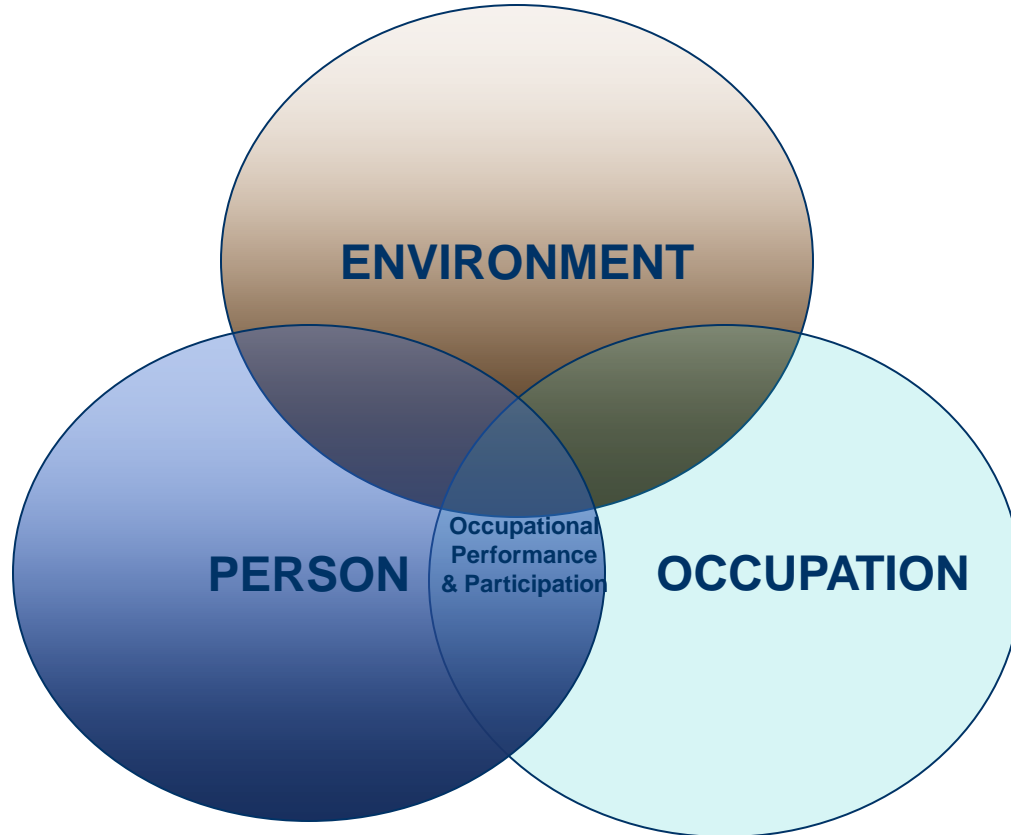
Purpose of the Research

- To understand the sibling's experience of the impact of schizophrenia on their lives
- To understand what the sibling perceives as important events and factors in the relationship that impact their adult lives
- To understand coping strategies used by the well sibling
- To understand what supports would benefit the sibling

Research Questions

- How can the life history of a sibling living with a sibling with schizophrenia be described and analyzed?
- How does living with a sibling with schizophrenia influence a person's day-to-day occupations?
- How can this understanding be used to inform how professionals we work with affected families in practice and in education?

PERSON – ENVIRONMENT – OCCUPATION MODEL OF PRACTICE



Impact of schizophrenia on a sibling – An overview

- **Impact on overall quality of life and well being of entire family** (Teschinsky, 2000)
- **Barriers to family communication that does not occur with other disabilities** (Lukens, E.; Thorning, H. & Lohrer, S. (2002)
- **Social models change** (Stalberg, Ekerwakt & Hultman, 2004)
- **Care burden expectation increases over time** (Hatfield & Lefloy, 2005)

Impact of schizophrenia on a sibling – An overview (continued)

- Increased need for activities external to the home (Kinsella, Anderson & Anderson, 1996)
- Stigmatization and social isolation may occur (Techinsky, 2000)
- Younger children (under 10) have later negative coping skills (Marshall et. Al, 1997)
 - Repression of emotion
 - Addictive behavior
- Difference roles than typical of children growing up (Cicirelli, 1995; Marshall et. al, 1997)

Participants

- 3 INDIVIDUALS goal, 4 actual participants
- Have lived with an older sibling in the same residence for at least one year
- Use of purposeful sampling:
 - 1. one who is involved with ill sibling
 - 2. one who chooses not to be involved
 - 3. one who vacillates between

Data Collection

- Data gathered by means of an in-depth semi-structured interview (“conversation”)
- Role adopted by myself was one of a traveller
- A **Traveller** begins a journey that leads to a story to be told on return
- My task was to enter into a conversation with the participants with the goal to listen, understand and capture their experience in their words

(Kvale, 1996)

Research Method & Analysis

- Biographical life history (Denzin, 1989)
- Polkinghorne (1988)
 - Will combine his two concepts
 - Paradigmatic analysis
 - STORIES TO THEMES TO GENERAL CONCEPTS
 - Use of plot to tie individual experiences together
 - GIVES UNDERSTANDING AND MEANING TO EXPERIENCE

Subject Descriptions

- Women between 35-45 years
- First time “telling story”
- Value contributions as caregivers
- Employed in helping professions
- 1 other but describes it as “helping”

Interviews

- All but 1 subject interviewed at home
- 1 subject chose my office
- Sessions ranged from 2-5
- Minimum interview length 2 hours

Results

Relationships	Described Impact on Adulthood	Occupational Function
Inherited stigma	Choosing a comfortable social environment is often difficult and approached in a guarded way to avoid stigmatization	Significant trust issues in all relationships; life accomplishments (such as vocational choice) become more essential to defining one's occupational
Ongoing grief & fear	Hyper vigilant checking behavior for symptoms of schizophrenia and children (if have)	Over exaggeration of everyday behavioral symptoms; particularly in view of emotional states; tendency to misinterpret playful behavior

Results

Relationships	Described Impact on Adulthood	Occupational Function
Loss of childhood roles	Instant adulthood when the illness is diagnosed so memories of childhood are few. Childhood is remembered as having adult roles and major care giving responsibilities	Difficulty in creating new “happy” memories with own children; feel like a “phony” at celebrations. Leisure becomes a critically important coping mechanism early when the first symptoms of the illness appear

Results

Relationships	Described Impact on Adulthood	Occupational Function
The missing person, Aka. "I'm invisible"	Sense of self disappears as one's importance in the family is eroded by the impact of the illness	Difficulty in creating new "happy" memories with own children; feel like a "phony" at celebrations. Leisure becomes a critically important coping mechanism early when the first symptoms of the illness appear
Difficulty in relating to one's own sense of emotion	Basic emotions are not able to be displayed, little understanding of difference of grief and anger	Innate sense of being nonexistent in family as focus shifts to ill

Results

Relationships	Described Impact on Adulthood	Occupational Function
Change in Interpersonal Relationships	Difficulty in interpersonal relationships often created by lack of trust	Few intimate friendships, often use self help groups such as the Schizophrenia Society to substitute for close relationships (even in functioning marriages)
Perceived Lack of Support by Health Care System	Mistrust of system and the support offered to self or sibling	Anger with the health care system and avoidance of use of even effective strategies offered for the sibling; “do it myself” even when supporting sibling
Significant Burden of Care	Recognition of the need to become caregivers both from an emotional and financial perspective	Fear of personal losses for self and family; avoidance of dealing with issues around personal aging as caregiving is overwhelming

Implications

- Significant occupational impact on all aspects of sibling lives
- Intervention with sibling as a family member is critical
- Early education required both in health & school system
- Community support groups essential
- FOIPP is an issue that impacts later relationships with health professionals

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Questions



