The Experience of Illusory Beliefs in Parents of Children with Developmental Disabilities

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Developmental disabilities are becoming more prevalent.
Parents are raising children with disabilities at home as institutions have closed.
Parents are stressed by the experience.
Patient-centered care requires that healthcare providers know and support POCDD as members of the healthcare team.
Little research into what helps POCDD adapt to/persist in caregiving.

Why research POCDD?
- Developmental disabilities are becoming more prevalent.
- Parents are raising children with disabilities at home as institutions have closed.
- Parents are stressed by the experience.
- Patient-centered care requires that healthcare providers know and support POCDD as members of the healthcare team.
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Theory of Cognitive Adaptation
This theory suggests that:
A. When faced with a threatening event people adjust psychologically through three processes:
1. The finding of meaning in the experience.
2. The gaining of mastery over the experience.
3. The enhancement of self-esteem as the result of the experience.
B. These three processes depend on illusory beliefs.
Illusory beliefs are defined by Taylor (1983) as beliefs that are not contrary to fact, but that depend on looking at known facts in a particular light. Looking at the known facts in a different light might yield a less positive picture of the future (Taylor, 1983, p. 116).

What are Illusory Beliefs?

- Individuals with breast cancer
- Individuals with rheumatoid arthritis
- Individuals with heart disease
- Individuals with multiple sclerosis
- Individuals who suffered a stroke

Purpose of the Study

This research was undertaken to answer the question: What is the lived experience of illusory beliefs in (POCDD)?
Research Questions

- Are illusory beliefs present in these parents' experience?
- What role do they play in these parents' lives?
- Is there a fit with cognitive adaptation theory?
- What are the care and research implications?

Methodology

- Literature review
- Qualitative study
- Convenience sample of 5 mothers
- In-depth recorded telephone interviews
- Iterative review of transcribed interviews
  - Identify and group challenges and illusory beliefs
  - Test for fit with Taylor’s cognitive adaptation theory
- Discuss implications for nursing care and research

Interview Questions

- What can you tell me about your experience in raising a child with developmental disability?
- What are some of the challenges?
- What helps you cope with these challenges (do you have helpful attitudes or beliefs)?
- Do others perceive your child the way you do?
- Has the experience of raising your child been beneficial in any way?
- Does anything make you think that you were chosen to be the parent of a child with disabilities?
- Have members of the larger community the healthcare team supported or challenged your beliefs about your child?
- Do you ever compare yourself to other parents of children with developmental disability? If so, how do you compare?
Findings: Challenges

Two Central Challenges Emerged

Being Alone
- Social isolation
- Isolated perspective about child as a person
- Isolated perspective not being different
- Isolated perspective about child’s value

Struggling to Find Balance

Findings: Illusory Beliefs

50 Illusory Beliefs (IBs) Identified

Four Meta-Categories Emerged
- My Child is Typical
- My Child is Making a Contribution
- As a Parent I Have a Mission
- As a Parent I Am Up to the Challenge

Dimensions of Cognitive Adaptation

- Finding Meaning
- Establishing Mastery
- Building Self-Esteem
IBs in Study Group had Strong Fit with Cognitive Adaptation

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<th>IBs Relevant to</th>
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<th>Mastery</th>
<th>Self-Esteem</th>
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Care Implications

IBs may be a useful resource for parents

Nurses might:
- Encourage parents to recognize and use illusory beliefs
- Explicitly validate parents’ illusory beliefs
- Help parents find meaning and value in being a POCDD
- Defer to parents’ expertise about their child when appropriate

Research Implications

Expand Study Beyond Convenience Sample

Areas for Potential Additional Inquiry
- Does provider commendation (of parent strengths, child attributes, etc) enhance psychological adaptation in POCDDs?
- Is improved provider awareness of POCDD IBs associated with improved provider relationships with POCDDs?
- Can IBs reduce boundary ambiguity to reduce stress in POCDDs?
- Do parents protect their IBs? How?
Illusory Beliefs and Boundary Ambiguity

Ambiguous Loss: An unclear loss which results in boundary ambiguity

Boundary Ambiguity: Confusion within the family and between family and community about roles. Boundary ambiguity causes stress.

The birth of a child with developmental disabilities is an ambiguous loss
- Are some IBs adopted by POCDD to reduce boundary ambiguity (establish personhood)
- Is the support of IBs a nursing intervention that could reduce stress related to boundary ambiguity?