

Patients with Autism Spectrum Disorder: A Descriptive Phenomenological Study of their Surgical Experiences

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Background


- Between 1:100 and 1:300 (avg 1:150) children in US diagnosed with an Autism Spectrum Disorder (ASD)
- Exact number of children with ASD having surgery per year is unknown
- Common surgeries for children include:
 - Insertion of ear tubes (667,000 per year)
 - Tonsillectomy with or without adenoidectomy (530,000 per year)
 - Adenoidectomy without tonsillectomy (132,000 per year)

(CDC, 2009)






Research Question and Aim of Study

- Nursing literature lacks research on this topic – this study will help fill this gap
 - Research question: What are the experiences that families and patients with ASD have when going to a hospital for surgery?
 - Aim of study is to understand these experiences and relate them to nursing professionals to help improve the surgical experiences of patients with ASD
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Literature Review

- Very little in nursing research literature
 - Nelson and Amplo (2009) in their expert opinion article relate that the challenges of caring for individuals with ASD include:
 - Managing the environment
 - Communication issues
 - Safety issues
 - Understanding the impact of external stimuli on the patient with ASD
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Literature Review cont...

- Beard-Pfeuffer (2008) emphasizes the importance of parental/guardian involvement when caring for patients with ASD in the hospital setting
 - Stresses the importance of including parents and child in decisions and listening to their preferences
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From Case Studies

- Issues from behavioral problems (sometimes considered “non-compliance” by nursing staff) (Allison & Smith, 1998)
 - Surgical scheduling delays (increased anxiety and behavioral problems) (Carter, 2001)
 - Hospital acquired infections (increased risk due to prolonged sedation and intubation) (Dell, et al., 2008)
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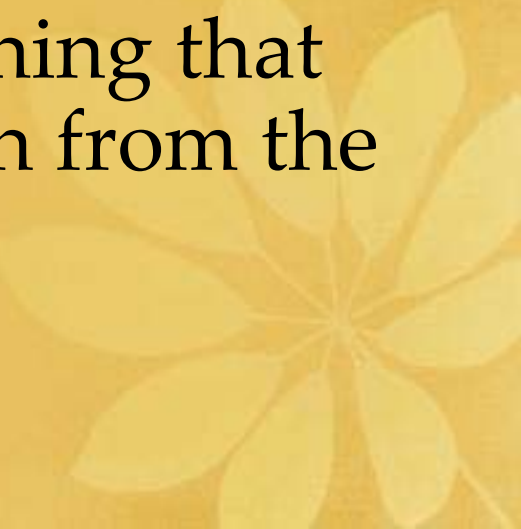


From Case Studies

- Increased need for sedation (often given by IM injection or orally – before placement of IV) (Gabriel & Gluck, 1973)
 - Challenging pain assessments (altered pain responses and communication barriers) (Inglese, 2008)
 - Increased use of physical restraint (risk of injury) (Christiansen & Chambers, 2005; Folkes, 2005)
 - Emotional distress (Courtman & Mumby, 2008)
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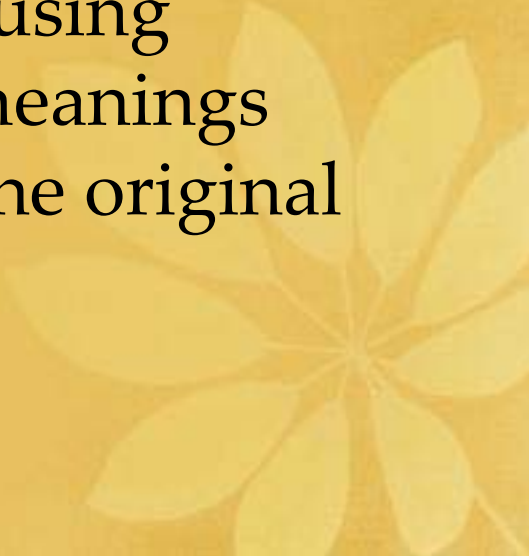
Method

- Edmund Husserl (1970) a philosopher suggests, “that which is self-evidently given is, in perception, experienced as ‘the thing itself’” (Crisis of Transcendental Phenomenology p.127-128)
 - Descriptive phenomenology – allows the researcher to understand something that human beings are living through from the perspectives of the participants.
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Technique of Paul Colaizzi (1978)

7 steps

1. All descriptions are read to get a feeling for them, to try to make sense of the contents
 2. Phrases or sentences are extracted (called significant statements)
 3. Formulated meanings are written using creative insight to illuminate the meanings hidden in the various contexts of the original texts.
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Steps cont...

4. Repeat above steps for each of the email interview texts.
 - Try to deduce clusters of themes
 - Look for emerging themes that are common to those found in the preceding analysis
 5. The examined and identified themes are summarized into an exhaustive description of the investigated phenomenon.
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Steps cont...

6. Represent the fundamental structure of the phenomenon by re-formulating the exhaustive description until it has the best fit.
 7. The researcher would also:
 - Return to the participants to validate the findings
 - Seek their input on the final description
 - Any new data obtained from the participants would be worked into the analysis by repeating some or all of the above steps.
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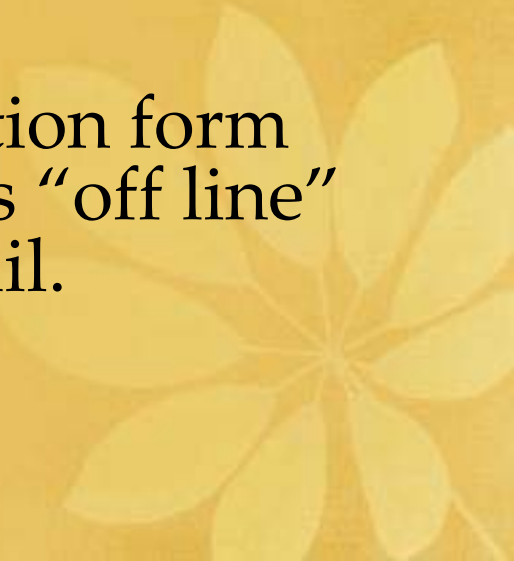


Sample

- Individuals (over age 18) with ASD who have had surgery and can read and write in English
 - Parents of children (under age 18) with ASD who have had surgery. Parents must read and write English
 - Recruitment through website postings and word of mouth
 - Estimated number of participant needed: 15 to 30
 - Must have access to computer with email capability
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Data Collection

- Interview style data collection is done through email exchange
 - All emails are cut and pasted onto blank word documents with all names and identifying information removed to de-identify data
 - Email data collection is possibly less stressful than face-to-face interview and allows participants to go at their own pace.
 - This is an asynchronous communication form and they can work on their responses “off line” and then attach or paste these to email.
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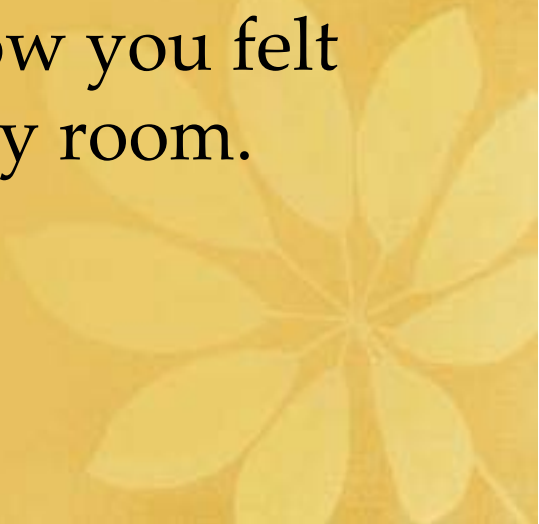


Current status of project

- Approved by UConn IRB on 10-9-2009
 - Actively recruiting (If you know of anyone who would like to participate, please share my contact information with them)
 - Email: jenhehl@gmail.com
 - Data collection has begun (two participants have completed interviews)
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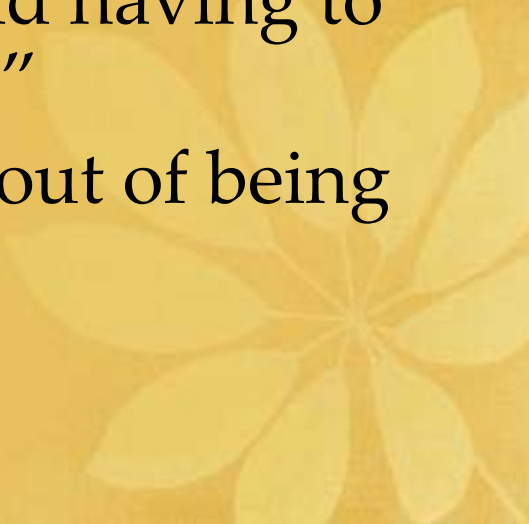


Samples from study

- Sample questions from researcher:
 - Please try to tell me about your surgery in as much detail as you can remember from who took care of you in the emergency room, how you were transported to the operating room, including anything you can remember about receiving anesthesia...and then how you felt when you woke up in the recovery room.
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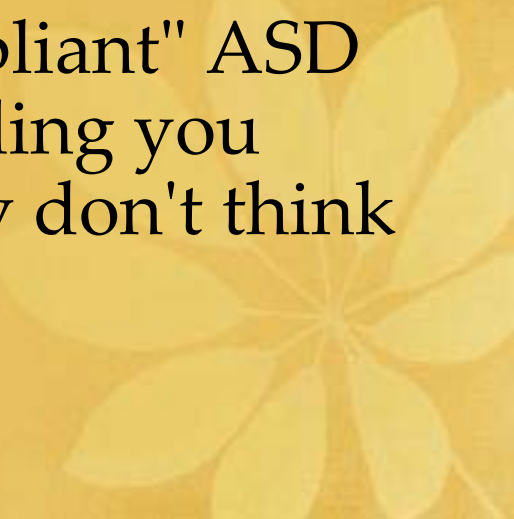


Samples from study

- Respondant 001:
 - “I was really scared and overwhelmed, mostly about going under anesthesia.”
 - “but I really don't like taking medicine (physically and on principle) so I avoided taking more, and ended up waking up at night and being in a lot of pain and having to take more and wait for it to work.”
 - “...I don't like to make a big deal out of being in pain.”
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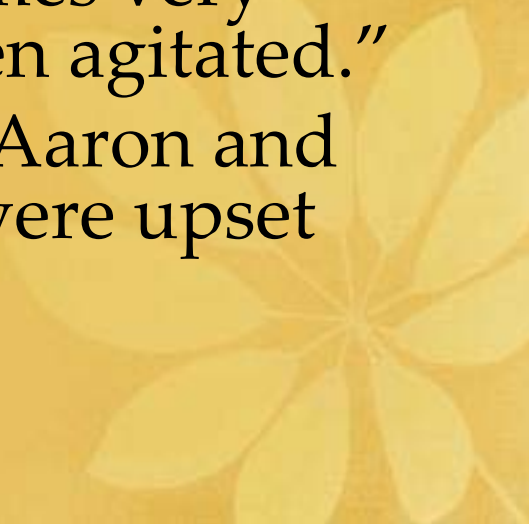


Samples from study

- “When I was little lots of things made me uncomfortable, like getting my hair washed, and I would complain a lot and basically throw a tantrum. After a while, I understood that this was considered bad behavior, so over time I stopped doing it “
 - “So maybe it's important to err on the side of caution with high-functioning/"compliant" ASD people because they might not be telling you everything that's wrong because they don't think it matters”
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Samples from study

- “Aaron (name changed to protect identity) frequently experiences an extremely high level of anxiety in a medical environment, as well as in situations where he feels social pressure.”
 - “We were allowed into the PACU. We told the nurse administering the sedative about Aaron having behavioral concerns, so that she would understand more fully that he becomes very physical and sometimes violent when agitated.”
 - “But the nurse still spoke sternly to Aaron and told him not to thrash around. We were upset about this...”
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Next Step

My next research step:

- A National Survey of US Children's Hospitals' Policies and Procedures for the Care of the Surgical Patient with Autism Spectrum Disorder (dissertation proposal)
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