Fathers’ Experience with Autism Spectrum Disorder (ASD)
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Purpose/Background/Significance
- Describe experience of fathers of children with ASD, fathers’ depression and anxiety, its source, & resources required to help them actively engage in roles as fathers of children with ASD

Background & Significance of ASD
- ASD characteristics include impairments in
  - Communication skills
  - Social interactions and
  - Restrictive, repetitive, unusual behaviors
  - Lifelong neurological disorder
  - 85% require lifelong caregiver
  - Prevalence rate significant increase
    - 1:68 children (2010)
    - 1:88 children (2008)
    - No clear cause for prevalence increase

Significance of Fathers
- Children with developmental delays (early warning sign for ASD) and actively engaged fathers (AEF) resulted in
  - Better therapy attendance
  - Significant & sustained improvement in emotional regulation, cognitive gains, & language development
  - Improved family cohesion
  - Improved well-being for entire family
  - Single father homes increased by 60%
  - Fathers as primary caregivers increasing

Research Findings
- First time fathers were asked about their experience with ASD
- Family Life: Making Adjustments
- Father’s Needs
  - Money for ASD care & services
  - Teamwork with health care & family
  - Honest answers from providers
  - Information about treatment/future
  - Get involved/Take action to be heard
  - Time with family & attend meetings
- Grief and Loss: typical child, future, hope
  - Denial & Isolation
  - Anger
  - Bargaining
  - Depression
  - Acceptance

Review of Literature Findings
- Fathers underrepresented in ASD research
- No studies found using fathers’ words to describe their experience with ASD or resources required to help them actively engage as fathers of children with ASD
- Common Themes
  - Economic Burden
    - Cost $11.5 billion annually (2011)
  - 43% of families report financial problems
  - Mental Health of Parents
  - Increased depression & anxiety
  - Consequences to Family
  - Increased divorce rates
  - Decreased family cohesion
  - Role Changes
    - Working extra to pay for services
    - Become fulltime caregiver
    - Poor outcomes when needs unmet

Nursing Implications
- Listen & address concerns
- Advocate for children & families
- Include fathers in discussions & decisions
- Encourage active engagement
- Identify & acknowledge grief & loss
- Encourage teamwork: families & providers
- Educate about
  - Diagnostic testing
  - Education
  - Therapies & services
  - Parenting resources
  - Options as children grow up
  - Funding sources
  - Laws and legal rights
  - Support groups: parents & siblings
  - Respite and child care
  - ASD friendly activities
  - Movies, restaurants, parks

Design
- Phenomenological case study method
- UTA IRB approved
- Data sources
  - Interviews, Field Notes, & Observation
  - Rigor
  - Credibility, Applicability, Dependability & Neutrality maintained
  - Triangulation: Method & Investigator
  - Funded by Ferne Kyba Nursing Fellowship