



Fathers' Experience with Autism Spectrum Disorder (ASD)

Linda Frye PhD, RN, CPNP

University of Texas at Arlington College of Nursing and Health Innovation



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

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

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



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

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

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