

Adolescent Perspective of Family Functioning When Living With a Sibling With Autism



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Review of Literature



- ❧ Prevalence of autism is 1 in 110 children
- ❧ Increased prevalence worldwide
- ❧ Challenges for families of children with autism
 - ❧ Behaviors of child with autism
 - ❧ Effects on family
 - ❧ Effects on siblings

Siblings of Children with Chronic Illness or Disability

- ❧ Importance of the sibling relationship
- ❧ Sibling outcomes when living with a child with a disability
- ❧ Use of parent proxy

Developmental Considerations



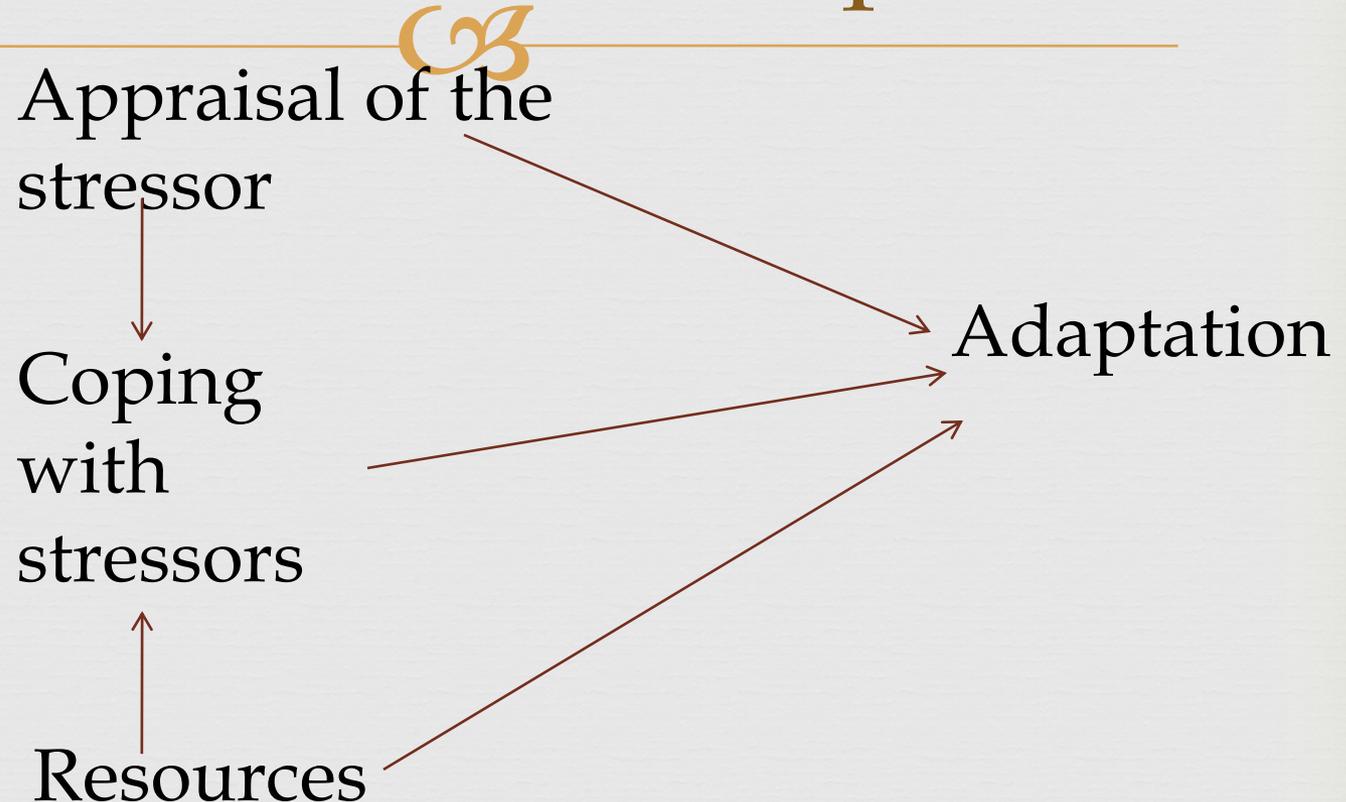
- ❧ Developing their identity
- ❧ Connecting with peers
- ❧ Transitioning to adult roles
- ❧ Cognitive understanding of sibling's disability

Family Functioning



- ❧ Broad concept
- ❧ Defined as the way that families work together to accomplish critical tasks
 - ❧ Pursuing goals
 - ❧ Family activities
 - ❧ Agreeing on family routines
- ❧ Preechawong, et al. 2007
- ❧ Importance of family functioning

Resiliency Model of Stress, Adjustment, and Adaptation



McCubbin, 1993

Specific Aim



☞ Aim: Determine how adolescents with siblings with autism perceive their family functioning

Research Questions



- ❧ Research Question 1: How do adolescents who have a sibling with autism perceive that their family is functioning as measured by Family Assessment Device (FAD)?
- ❧ Research Question 2: Do the perceptions of family functioning of adolescents who have siblings with autism differ by age and gender?

Design and Sample



- ❧ Exploratory, correlational design
- ❧ Inclusion criteria
 - ❧ 11-20 years of age
 - ❧ Have a sibling with autism
 - ❧ Have sufficient command of English language
 - ❧ Have access to a computer with internet
- ❧ Exclusion criteria
 - ❧ History of developmental or language delay

Measures



- ❧ Background information
- ❧ Qualitative information
- ❧ *Family Assessment Device (FAD)* (Epstein, Baldwin, & Bishop, 1983)

Family Assessment Device



- ❧ Problem Solving
- ❧ Communication
- ❧ Roles
- ❧ Affective Responsiveness
- ❧ Affective Involvement
- ❧ Behavior Control
- ❧ General Functioning Scale

Subject Recruitment



- ❧ IRB approval through University of Michigan and Western Michigan University
- ❧ Recruited through Interactive Autism Network (IAN)
- ❧ Parent consent
- ❧ Adolescent assent
- ❧ 18-20 year old consent

Sample Description



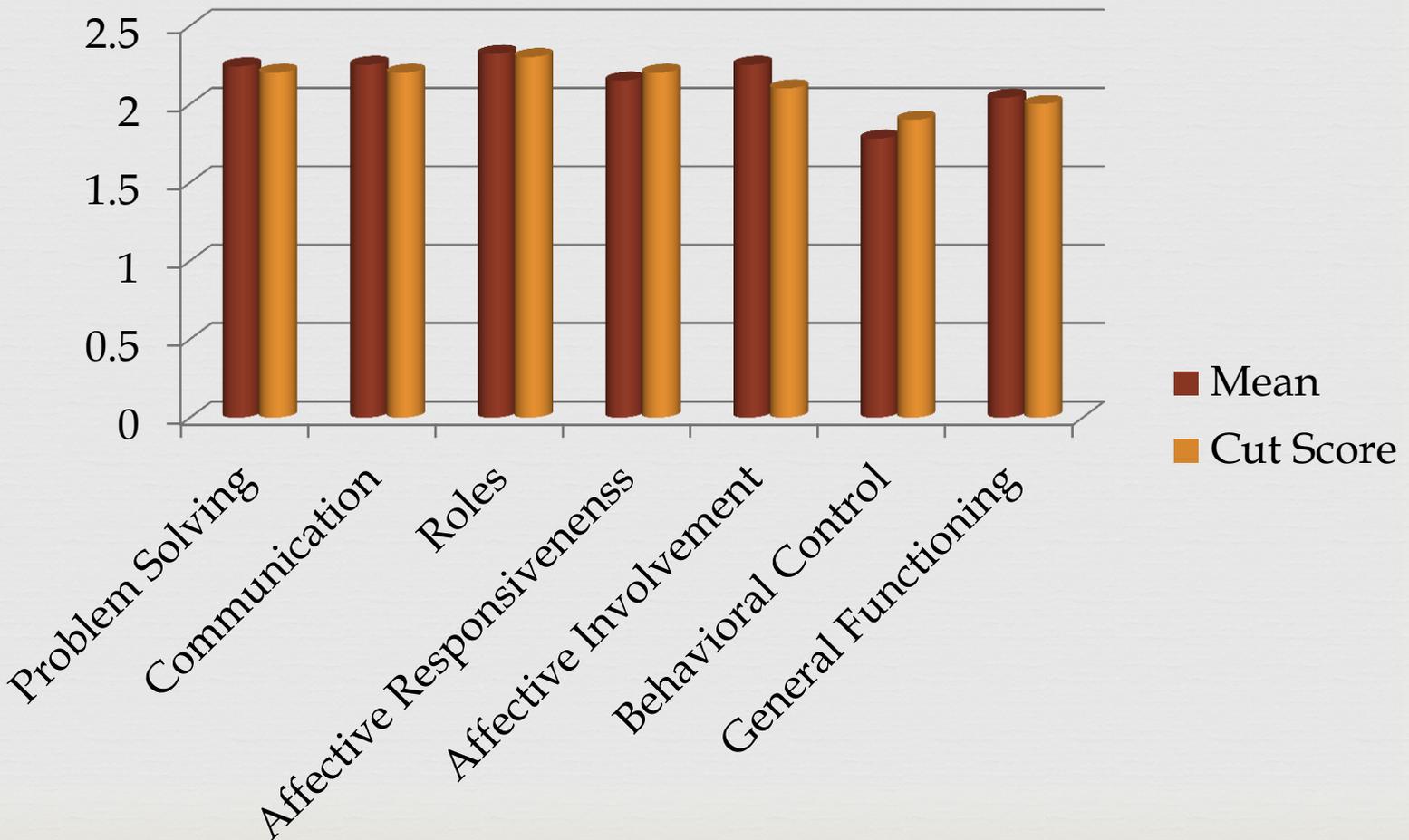
	Mean	Range
Age of Adolescent	14.3 years	11-19 years
Age of Sibling with Autism	10.8 years	3-18 years

Sample Description

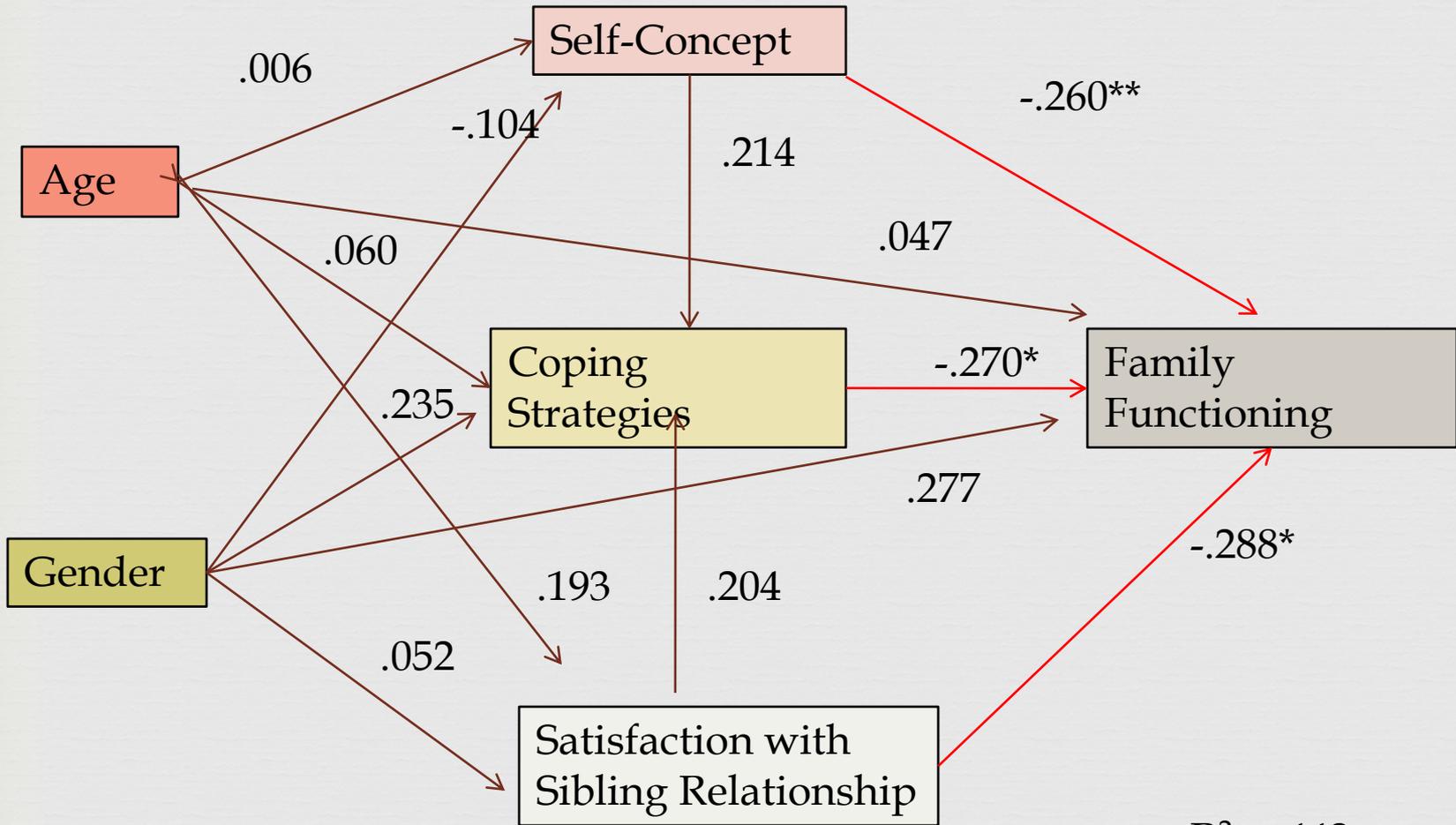


Race	N	%
Caucasian	85	87.6%
Hispanic	7	7.2%
African American	1	1%
Asian	1	1%
Other	2	2.1%

Perception of Family Functioning



Path Analysis using Multiple Regression



$R^2 = .442$

* $p < .05$

** $p = .001$

Limitations



- ❧ Convenience sample
- ❧ Homogenous sample
- ❧ Lack of a control group

Implications for Practice



- ❧ Communication
 - ❧ Examine strengths of family
 - ❧ Examine challenges of family
 - ❧ Networking with other families
- ❧ Ensure adolescents have time to be adolescents
- ❧ Family time

Future Research



- ❧ Perception of family functioning in adolescents of siblings of children without disabilities
- ❧ Examine adolescent and parent perceptions of family functioning

References



- ❧ Autism Society of America. (2009). <http://www.asa.org>.
- ❧ Cox, A. H., Marshall, E. S., Mandleco, B., & Olsen, S. F. (2003). Coping responses to daily life stressors of children who have a sibling with a disability. *Journal of Family Nursing*, 9(4), 397-413.
- ❧ Dellve, L., Cernerud, L., & Hallberg, L. (2000). Harmonizing dilemmas; siblings of children with DAMP and asperger syndrome's experiences of coping with their life situations. *Scandinavian Journal of Caring Science*, 14, 172-178.
- ❧ Epstein, N. B., Baldwin, L. M., & Bishop, D. S. (1983). The McMaster family assessment device. *Journal of Marital and Family Therapy*, 9, 171-180.
- ❧ Gallo, A. M. & Szychlinski, C. (2003). Self-perception and family functioning in healthy school-age siblings of children with asthma and diabetes, and healthy children. *Journal of Family Nursing*, 9(4), 414-434.
- ❧ Glasberg, B. A. (2000). The development of siblings' understanding of autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 30(2), 143-156.
- ❧ Gray, D. E. (1998). *Autism and the family*. Springfield, IL: Charles C. Thomas.

References



- ❧ Hamama, R., Ronen, T., & Feigin, R. (2000). Self-control, anxiety, and loneliness in siblings of children with cancer. *Social Work in Health Care, 31*(1), 63-83.
- ❧ Harris, S. L., & Glasberg, B. A. (2003). *Sibling's of children with autism. A guide for families* (2nd ed.). Bethesda: Woodbine House.
- ❧ Lobato, D., Faust, D., & Spirito, A. (1988). Examining the effects of chronic disease and disability on children's sibling relationships. *Journal of Pediatric Psychology, 13*(3), 389-407.
- ❧ McCubbin M.A. (1993). Family stress theory and the development of nursing knowledge about family adaptation. In S. L. Feetham (ed.). *The nursing of families: Theory/research/education/practice*. Newbury Park, CA: Sage Publications.
- ❧ McHale, S. M., & Gamble, W. C. (1987). Sibling relationships and adjustment of children with disabled brothers and sisters. *Journal of Children in Contemporary Society, 19*(3), 131-158.
- ❧ McHugh, M. (2003). *Special siblings: growing up with someone with a disability*. Baltimore: Paul H Brooks Publishing.
- ❧ Preechawong, S., Zauszniewski, J. A., Heinzer, M. M., Musil, C. M., Kerksmar, C., & Aswinanonh, R. (2007). Relationships of family functioning, self-esteem, and resourceful coping of Thai adolescents with asthma. *Issues in Mental Health Nursing. Special Issue: Adolescent Mental Health, 28*(1), 21-36.

References



- ❧ Rau, J. D. (2003). Is it autism? [Electronic Version] *Contemporary Pediatrics*, 20(4), 1-23.
- ❧ Rodrigue, J. R., Geffken, G. R., & Morgan, S. B. (1993). Perceived competence and behavioral adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders*, 23(4), 665-673.
- ❧ Tomanik, S., Harris, G., & Hawkins, J. (2004). The relationship between behaviors exhibited by children with autism and maternal stress. *Journal of Intellectual and Developmental Disability*, 29(1), 16-26.
- ❧ Verte, S., Roeyers, H., & Buysse, A. (2003). Behavioural problems, social competence and self-concept in siblings of children with autism. *Child: Care, Health & Development*, 29(3), 193-205.