

**Nursing and Allied Health Abstracts**

**Title:** A FAMILY INTERVENTION TO ENHANCE INVOLVEMENT IN CONDITION MANAGEMENT OF YOUTH WITH SPINA BIFIDA: A PILOT STUDY

**Presenting Author:** Rachel Neff Greenley, Medical College of Wisconsin

**Background:** This study examined feasibility data on a family-based problem solving intervention to enhance youth involvement in condition management and family functioning among youth with spina bifida. Although deficits in the self management skills of youth with spina bifida have been documented, no published studies have intervened to promote child involvement in condition management.

**Method:** Ten children with spina bifida and their parents participated in the study which was a single group pre/post intervention design. Participants ranged in age from 8 to 16 years ( $M (SD) = 12.3 (2.7)$ ), were predominantly female (70%), Caucasian (70%), and from middle class backgrounds. Families completed pre and post intervention questionnaires. The intervention consisted of two manualized tailored problem solving interventions focused on enhancing adaptive family communication and child involvement in decision making (session 1) and knowledge deficits and maladaptive beliefs (session 2). Measures utilized in the present study included parent report of youth self management skills via the Kennedy Independence Scale for Children, parent and child report of condition-related beliefs, parent report of condition related family burden via the Family Burden in Spina Bifida Questionnaire, and parent and youth report of program satisfaction.

**Results:** All parents (100%) and the majority of youth (80%) viewed the intervention as enjoyable. Over 70% of parents reported that the intervention was useful in improving key areas of functioning including enhancing child self management skills, problem solving skills, and family communication. Children's ratings of helpfulness paralleled parent ratings. Moderate effect sizes were documented for improvements in child self management skills ( $d = .53$ ) and reductions in parent perceived burden ( $d = .66$ ) from pre to post intervention.

**Conclusion:** A family-based tailored problem solving intervention may be an acceptable intervention for families of youth with spina bifida and may enhance youth self management skills and reduce perceived parental burden.