

Developmental Pediatrics

Title: PARENT'S REPORT OF ADOLESCENT/YOUNG ADULT (AYA) DEMOGRAPHIC AND CLINICAL STATUS IN A LARGE MULTI-SITE DESCRIPTIVE STUDY

Presenting Authors: Timothy Brei, Clinical Pediatrics, Indiana University School of Medicine and Riley Hospital for Children and Kathleen Sawin, Nursing of Children, Children's Hospital of Wisconsin and college of nursing, University of Wisconsin-Milwaukee

Additional Authors:

- Thomas Webb, Division of Internal Medicine, University of Cincinnati
- Eugenio Monasterio, Physical Medicine and Rehabilitation, School of Medicine, Virginia Commonwealth University
- Karen Rauen, Pediatric Urology/Spina Bifida, Children's Hospital of Wisconsin

Background: The purpose of this paper is to describe the demographic and clinical characteristics of AYAs with spina bifida who participated in a multi-site cross-sectional descriptive mixed method study.

Method: 139 parents and 138 adolescents, a total of 135 pairs participated in this study. Participants were interviewed using standardized scripts by trained staff. Data reported here was obtained from participant recall, except for level of lesion which was abstracted from chart review by investigators.

Results: Of the parents who participated 91% were female. The sample was predominantly Caucasian and married, 62% had private insurance, with 28% reporting Medicaid and 11% reporting SSI for secondary income. 50% of the families had an annual income of \$50,000 or more. AYA were aged 12-25, M=15.5 (SD=3.24), 48% were male. Report of level of lesion included 32% thoracic/high lumbar, 25% lumbar, 14% lumbar/sacral and 9% other or missing. 40% of AYA walked with or without crutches, 7% walked with crutches but used a wheelchair for sports or distance, 42% used a manual chair and 11% used a power chair for ambulation. 85% of the AYA had a shunt.

Clinical data reported will include a history of skin breakdowns, urinary tract infections (UTIs), pain, scoliosis and the impact of these conditions on school, job or recreation. History of surgeries, latex allergy and measures of independence such as driving and managing money will also be reported.

Conclusion: The descriptive data profiles AYA with spina bifida and their parents from four different spina bifida programs. A substantial number of participants reported doing well with no: skin breakdown (53%); UTIs (36%); pain (51%); or scoliosis (40%) in the past year. When these problems occurred 25-27% of participants reported they interfered with school job or recreation.