

**Nursing and Allied Health Abstracts**

**Title:** FAMILY MANAGEMENT OF A CHRONIC CONDITION: PERSPECTIVES OF ADOLESCENTS WITH SPINA BIFIDA

**Presenting Author:** Josanne (Josie) Wollenhaupt, University of Wisconsin -Milwaukee, College of Nursing, MSOE School of Nursing

**Additional Authors:**

- Kathleen Sawin, University of Wisconsin -Milwaukee, College of Nursing, MSOE School of Nursing
- Beth Rodgers, University of Wisconsin -Milwaukee, College of Nursing

**Background:** There are approximately 1,300 infants born with spina bifida every year in the U.S. They live their lives in families who deal with the demands of a chronic condition while faced with the stressors of family life. As both recipient and participant in the management of a chronic condition, adolescents with spina bifida have distinctive experiences. The aim of this secondary analysis was to ascertain the adolescent's perspective of family management of their chronic condition

**Method:** Participants in this descriptive qualitative analysis were adolescents with spina bifida (n=25) from a study addressing adaptation (Sawin, Brei, Buran, Fastenau, 2002). This exploratory analysis used systematic examination of existing transcripts for adolescent exemplars of themes from the Family Management Framework (FMF).

**Results:** Exemplars were identified for each of the conceptual themes of the FMF. Definition of the situation included descriptions of a positive perception of self for some participants while others described negative self perception focused on mobility issues such as gait pattern or use of the wheelchair. They described the impact of spina bifida on themselves and their family. Management behaviors focused on the skills they had to learn necessitated by the presence of spina bifida as well as their families' strategies for the routine and the non-routine. Perceived consequences centered on college, marriage and families intermingled with concern about the ability to live on their own and the future impact on their family of origin.

**Conclusion:** Adolescents with spina bifida are knowledgeable about their condition and their families. Inclusion of adolescents with spina bifida in future study of families may reveal how adolescents interact with and contribute to family management.