

Nursing and Allied Health Abstracts

Title: THE EXPERIENCE OF SELF-MANAGEMENT IN TRANSITION-AGE WOMEN LIVING WITH SPINA BIFIDA

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Background: The development of self-management skills in youths with chronic health conditions like spina bifida (SB) is regarded as essential to combating vulnerability, achieving self-sufficiency, and transitioning to adulthood. However, data from the Center for Women with Disabilities suggest that the development of self-management may be a particular challenge for young adolescent women with a chronic health condition. The purpose of this qualitative component of a larger investigation of adaptation in transition-age individuals with SB was to explore the experience of self-management for transition-age women living with SB.

Method: Thirty-one transition-age women with SB (Mean age = 15.84 years) participated in semi-structured interviews to explore what self-management activities they performed, how responsibility for those activities was decided in their family, and what they thought they needed to become independent. Content analysis was conducted by members of the interdisciplinary team to examine the responses for common themes.

Results: Three themes emerged that encompassed these young women's experiences in self-management: (1) Opportunities to Engage in Self-Management Activities: Knowledge, Skills and Aspirations; (2) Dance of Individuation: Parental Impact on Self-Management; and (3) Advocacy within Self-Management: Confronting Discrimination and Stigma. Findings suggested that self-management is complex and pervasive in everyday life, but it is not the driving force in the lives of these young women. Participants' stories revealed diverse vulnerabilities and barriers to participating in self-management activities, including limited opportunities to manage money, build job skills, or develop autonomy in self-care decisions, sometimes reflecting protection by parents.

Conclusion: Adolescent women living with SB require planned, incremental responsibility for self-management. Patient-and family-centered intervention programs that are geared toward equipping young women with SB, their families, and healthcare professionals with the knowledge and skills for shared decision-making is essential to ensure that these young women have the optimal knowledge, skills and competencies for successful transition into adulthood.

Reference Work:

Sawin, K. J., Bellin, M. H., Roux, G., Buran, C. F., & Brei, T. J. (2009). The experience of self-management in adolescent women with spina bifida. *Rehabilitation Nursing, 34*, 26-38.