

Oral presentation

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Young adults with spina bifida: does a specialized outpatient program make a difference in functional status and quality of life?

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Background

Patients born with spina bifida have increasingly longer life expectancies. However, little is known of the health outcomes for young adults transitioning to adult health services. We sought to compare the status of young adults followed with a multidisciplinary approach in an Adult Spina Bifida Clinic (ASBC) to those followed in a community setting two to ten years after leaving a pediatric specialty clinic (PSC).

Materials and methods

The cohort included persons with spina bifida born in the Washington area between 1968 and 1988 and enrolled in a longitudinal database. Outcome data included demographics, general functional status, and secondary conditions. The Functional Independence Measure, SF-36, and Perceived Quality of Life Scale were administered. Descriptive statistics were used to summarize demographics. Multivariate analyses were conducted on outcomes measures.

Results

Young adults utilizing the ASBC and adolescents utilizing the PSC were significantly more likely to have more severe primary impairments, more prevalent secondary conditions, poorer functional status, and lower quality of life compared to patients in the community. Overall, young

adults have more secondary conditions, poorer functional status, and lower quality of life compared to adolescents with similar primary impairments.

Conclusion

Adolescents and young adults who are seen in the community setting tend to have less severe primary and fewer secondary conditions. Regardless of care setting, young adults with spina bifida have poorer functional and quality of life outcomes than adolescents with similar primary conditions. More robust transitioning from pediatric care to an integrated adult care system may alleviate these differences.