

Oral presentation

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Severity of illness, functional status, and health-related quality of life in youth with spina bifida

Robin R Leger

Address: University of Connecticut Health Center, Connecticut, USA
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Background

As youth with spina bifida age out of pediatrics, they have difficulty transferring care to adult providers. Care is fragmented with a loss of follow-up. Clinicians in adult health care are untrained in historically, pediatric conditions. Understanding health status, functional status, and health-related quality of life [1] in spina bifida is important in a life-span approach to care.

Methods

A descriptive study of 60, 15–25 year olds with spina bifida, from the Northeastern USA examined for Health Status, Functional Status, and self-perceived HRQOL.

Results

Results indicate and describe that 28% of youth were primarily healthy, 72% reported secondary health conditions and 32% reported co-morbidity. Functional status (FIM) was high with a mean of 116.8 ($SD = 7.07$, range 90–126) however, areas of bowel and bladder incontinence, inability to traverse stairs, and memory deficits were limitations. Youth reported high HRQOL; mean = 200.8 ($SD = 19.54$, range of 155 – 232). A regression analysis with HRQOL entered as the criterion variable results were not statistically significant ($r^2 = .02$, $df = 2, 57$, $p = .57$). Main and ancillary variables show statistically significant correlations important for future research.

Conclusion

This study identifies that youth with spina bifida report a high level of HRQOL, participate in recreation, sport activities, college, adult living, and yet, experience secondary health conditions that leave them with concerns for their future.

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