

Transition Abstracts

Title: ASSESSMENT OF SPINA BIFIDA CARE FOR ADOLESCENTS AND YOUTH: A QUALITY IMPROVEMENT TOOL FOR SPINA BIFIDA CENTERS

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Background: A multi-center consortium funded by the SBAA to develop strategies for improving transition care for adolescents with spina bifida has developed a quality improvement measure that can be used by regional spina bifida centers to rate the quality of care that is provided to adolescents.

Method: Health care professionals at six regional spina bifida centers as well as youths and adults with spina bifida participated in this initiative. Our 35-item instrument was adapted by the consortium from a validated quality improvement measure that is based on the Chronic Illness Care Model. Domains include (a) Organization of health care system, (b) Community linkages, (c) Self management, (d) Decision support, (e) Delivery system design, and (f) Clinical information systems. Health care professionals from a variety of disciplines rated quality of care for these domains at each of the six participating centers. Comparisons were made across the six centers and among four professional subgroups 1) medical directors, 2) nurse coordinators, 3) allied health professionals (PT, OT, SW) and 4) surgical specialists.

Results: Professionals at the six centers consistently rated “Community linkages” as a strength and “Organization of health care system” and “Decision support” as areas of weakness for the health care they currently provide to adolescents with spina bifida. The mean overall quality of care grade was “C” for five of the six centers. No differences in ratings were noted across professional subgroups.

Conclusion: “Assessment of Spina Bifida Care for Adolescents and Youth” can be used by health care teams at regional spina bifida centers to evaluate their adolescent self-management and transition-readiness services. It can also be used by researchers as an outcome of system-based interventions and to control for local variation in health care when assessing health outcomes for youth with spina bifida in multi-center studies.