U.S vs. Canadian perspective on transition of care for spina bifida patients

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This paper provides a nice snapshot of the current state with respect to adult spina bifida (SB) care in modern healthcare systems. The purpose of this study was to assess the current state of transition as it relates to adults with SB in Canada. The authors report that over two-thirds of pediatric urologists who responded to a nationwide survey reported a process for transition and the majority (82%) had identified an adult “recipient” urologist. Despite the fact that readiness tools are readily available (e.g., http://www.gottransition.org/providers/index.cfm) a minority of providers (14%) use them to assess or prepare patients for transition. Thirty-nine percent reported that transition should not begin until age 18 or older, despite the recommendation of the American Academy of Pediatrics/American Academy of Family Practice/American College of Physicians that transition should be introduced around age 12–14.

We investigated adult SB care practices in the U.S. via an email survey to urologists registered in the Genitourinary Congenitalism database and Spina Bifida Association registry. Unlike the Canadian survey, the respondents included both pediatric (55%) and adult urologists. Nonetheless, the majority of respondents mirrored the Canadian respondents by identifying 18–21 to be the appropriate age of transition, suggesting there may be intrinsic beliefs and practices driving later transition among urologists as compared to pediatricians in North America. Could the wider spectrum of adult urological care (e.g., sexuality, fertility) be influencing this delay?

Another interesting finding was the difference reported in the use of adult multidisciplinary clinics for adult SB patients. In our data set, only 14% of respondents treated adults with SB in an “adult-only multidisciplinary clinic,” which is the model identified as the “best” by 75% of Canadian pediatric urologists. Are there intrinsic differences in the two healthcare systems that may be influencing this difference? Certainly the infrastructure and resources available to adult specialists are dissimilar to those available to pediatric specialists in the U.S., especially as they relate to care coordination and resources for integrated care. I wonder what we can learn from the two systems on how to provide the highest value care for adults with SB?

Further investigation into both of these observations will allow us to continue to strive to provide the level of healthcare that these patients have come to expect and need into adult life.

Competing interests: The author reports no competing personal or financial interests.

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