Health risk behaviors in spina bifida: the need for clinical and policy action

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Health risk behaviors (HRBs) in adults with spina bifida such as poor diet, reduced physical activity, increased television viewing time, and substance abuse often have their genesis in early childhood. They are potentially preventable but if not addressed aggressively may continue to progress across the lifespan. An alarmingly high level of select HRBs in emerging adults are reported from a population-based study by Soe et al.[1] These compelling findings highlight the need for a clinical and policy focus on prevention of HRBs, early school and community-based interventions, and transition services for the emerging adult.

Obesity for those with spina bifida adds further challenges in self-management, social activities, and full participation in life. Participants in this study experienced the triad of risks for obesity: a poor diet low in grains, fruits, and vegetables; decreased physical activity; and high television viewing time.[1] A healthy diet and physical activity also optimize bowel health. Unfortunately, emerging adults continue to have frequent bowel incontinence, a major deterrent to employment and social life.[2] From infancy, all children should be taught to eat a healthy diet. Complicating the issue of diet, children with spina bifida can have texture sensitivities leading to more persistent food avoidance. Children need opportunities to try new food textures without fear of punishment. In addition, individuals with spina bifida and their families would benefit from counseling by health care professionals experienced in feeding issues.

Seeking opportunities to explore the environment in toddlerhood is foundational to later physical activity. Yet mobility impairments may contribute to the challenges of finding developmentally appropriate physical activities. More physically active time is directly related to less television viewing. Families need to be empowered from an early age with the expectation that their children can be physically active and provided with the tools to achieve those expectations. For some families this may take a specific activity plan.

Depressive symptoms are more prevalent for emerging adults with spina bifida than for their peers or for adolescents with spina bifida[3] and Soe et al.[1] suggest depressive symptoms may be related to the use of alcohol. Yet screening for depressive symptoms in spina bifida is underutilized in clinical practice. From a research perspective, study of depressive symptoms in spina bifida is complicated by the number of instruments with different scoring systems, making it difficult to compare different levels of depressive symptoms. In the future, using measures of depressive symptoms based on item response theory, such as the Patient Reported Outcomes Measurement Information System measures developed by the National Institutes of Health (which have item-weights and thus can be compared across sites or studies), will advance our understanding of depressive symptoms.[4] Additionally, it would be important to include not only risk factors but protective factors (such as self-efficacy, hope, attitude, or self-confidence) to fully understand the development of depressive symptoms.

Reduction of HRBs through the lifespan calls for new models of co-management between primary care providers, spina bifida-specific providers, and community partners. It is possible that there is so much for families to learn and do related to spina bifida at young ages that they do not realize that healthy eating and activity are also priorities. As children grow up, families may not be aware of the need to monitor for psychosocial adjustment. Health care professionals should discuss these issues and screen for barriers to achieving healthy behaviors.

There is a great need for policy changes, programs, and support services to optimize the lives of emerging adults with spina bifida. The study by Soe et al.[1] and others[5] suggest these young adults reach developmental milestones years later than their peers. In addition, the substance abuse risks continue to rise into the third decade of life whereas these behaviors in their peers tapers off.[1] This would suggest that most school, adolescent or community-based services are ending just when these adults could more effectively engage in them.[2,3] Coordinated health care services with strong community linkages and support services are needed for this population. Individuals, families, and health care professionals can advocate for policy changes at the local and national levels which promote interagency collaboration aimed at improving outcomes for emerging adults.

In summary, prioritizing strategies that decrease HRBs and depressive symptoms should be actively addressed in the health care of individuals with spina bifida across the lifespan. If we do not, they, more than the spina bifida itself, may be the major cause of morbidity in young adulthood.

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Book Review: Childhood Epilepsy: Management from Diagnosis to Remission

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There are over 800 books on epilepsy that have been published during the past 4 years, so each new book on this topic faces a challenge to justify its existence. *Childhood Epilepsy: Management from Diagnosis to Remission* meets this challenge admirably. It is a concise book that offers guidance not only on initial diagnosis and treatment but also, importantly, on the longer-term management of childhood epilepsy and its comorbidities through to remission or transfer to adult services.

Three core chapters cover epilepsy beginning in infancy, middle childhood, and adolescence. The main epilepsies and epilepsy syndromes in each age group are well described. Advice on management not only addresses seizure treatment but also the psychosocial and cognitive implications of epilepsy as well as family adjustment. Of particular value is the guidance on first, second, and subsequent lines of treatment for intractable epilepsies, with advice on when to refer to more specialist colleagues. The section on transfer to adult services in the adolescence chapter is especially useful, and considers two broad categories of adolescents: those with relatively normal intelligence and those with significant learning difficulties.

There are additional, helpful chapters on more general aspects of epilepsy that cover diagnosis, risks and hazards, and status epilepticus (both convulsive and non-convulsive). A chapter on prevention begins by considering how some epilepsies might be avoided altogether and then moves on to discuss avoidance of an incorrect diagnosis of epilepsy or inappropriate choice of medication. These cautionary themes are developed further in the final medico-legal chapter. For its size, this book offers a great deal of information on the management of childhood epilepsy. Of course, it does not pretend to provide a comprehensive account of epilepsy and so discussion of pathophysiology, genetics, classification, and controversies in management needs to be sought elsewhere, although these issues are all touched on in the book.

An author from North America has been paired with one from the UK for each chapter and whilst the principles of epilepsy management are universal, local differences are covered (such as preferred first- and second-line medication, or information about national guidelines and support groups). Practical tips from the experienced authors shine through in comments such as the oldest female relative usually gives the best family history, children may describe the onset of seizures in benign childhood epilepsy with centrotemporal spikes (BECTS) as a fizzing of the tongue, and a warning that the benefit of identifying epilepsy syndromes does not justify bending the criteria to squeeze in a diagnosis.

This book is intended for general paediatricians responsible for the care of children with epilepsy – but it is also relevant to neurodisability paediatricians and ought to serve as a useful introduction to epilepsy management for paediatric neurologists in training. The emphasis on practical guidance through to remission or transfer to adult services makes this a welcome book that should be greatly appreciated by its target audience.

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