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Renal Care in Children with Spina Bifida: A Retrospective Cohort Study

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Problem: Spina bifida is a congenital abnormality, with many affected children suffering renal complications.

Purpose: To explore associations between nursing care of children with spina bifida and progression of renal complications.

Design/Methods: A retrospective cohort study of the medical case notes of all children diagnosed at birth with spina bifida between 1993-2008, at one large pediatric hospital. To explore changes in practices over time, children were stratified into three 5-year groups: 1993-1998, 1999-2003, 2004-2008. Demographic, hospital admissions, surgery, diagnostic and psychosocial data were recorded. Descriptive statistics were performed and Kruskal-Wallis tests to determine differences between groups.

Results: Forty five cases met inclusion criteria: 53% female; 16% deceased at 2013. Without early intervention using clean intermittent catheterization, patients experienced increased renal associated complications: urinary tract infections (51%), hydronephrosis (13%), deteriorating neurogenic bladder (27% in age 1-5; 13% in age 6-10), pyelonephritis (13%), and renal/bladder surgery 17.8%. A secondary finding was feelings of anxiety, grief, deconditioning and low self-esteem amongst children. Parents/caregivers experienced anxiety and depression associated with responsibility of caring for the child.

Conclusion: This study provides evidence that nurses providing timely and effective clean intermittent catheterization can prevent long-term renal deterioration in children with spina bifida. Furthermore, multidisciplinary support and ongoing education for patients and parents/caregivers is paramount in long-term care for children with spina bifida.

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