

IDENTIFYING AND MANAGING COMORBIDITIES COMPROMISING NORMAL BLADDER AND BOWEL FUNCTION IN ADOLESCENTS AND YOUNG ADULTS WITH DISABILITIES. HOW SHOULD WE DEAL WITH TRANSITION?

Hypothesis / aims of study:

The management of bladder and bowel dysfunction is complex. The challenge becomes more difficult during the transition between childhood and adulthood. Adolescents and young adults affected by bladder and bowel issues, such as incontinence, constipation, soiling, dysfunctional voiding, faecal soiling, neurogenic bladder and neurogenic bowel, don't receive adequate care in hospitals and satisfactory home-care, in many geographical areas. The challenges become enormous if adolescents and young adults are also disabled with unique comorbidities associated and/or leading to bladder and bowel problems. In presence of obvious physical (motility/sensitivity) and psychological (neuro-developmental delays, autism, etc.) additional limitations, tailored management needs to be defined. We intend to highlight the importance of identifying comorbidities associated to bladder and bowel problems during the transitional phase of adolescence, in individuals affected by disabilities and to suggest adequate management.

Study design, materials and methods:

Our Team is represented by a Paediatric Urologist and a Continence Advisor. Review of scientific literature both from scientific magazines and from the web has been performed. Data were also extracted from the review of two forums on neurogenic bladder, neurogenic bowel and incontinence on a well-known social website, based on patients and their relatives' impression of the care received, in different geographical areas. The most frequent types of disabilities presenting with comorbidities contributing or generating bladder and bowel issues were identified. Suggestions to provide adequate hospital and home-care to the patient were identified and listed as a trace for future effective development of integrated care pathways.

Results:

Forty conditions were chosen in a list of 203 causes of urinary incontinence (<http://symptoms.rightdiagnosis.com/cosymptoms/bladder-incontinence-all.htm>). Meningo-myelocele (MMC), Trisomy 21 (DS), Cerebral Palsy (CP), S. Filippo Syndrome (SFS), Becwith-Wiedemann Syndrome (BWS), Diabetes and Obesity were used as samples of the most common disabilities, to identify comorbidities associated to bowel and bladder problems; (CP: cognitive function, motility issues, gastro-intestinal motility, feeding issues, failure to thrive, speech impairment, and wheelchair bound status, dexterity issues; SFS: increased amount of urine produced and urine output, motility limits, osteomalacia, wheelchair bound status, dexterity issues, neurogenic bowel/bladder; DS: congenital anomalies of the urinary system or of the enteric plexus (Hirschsprung), celiac disease, cognitive impairment, speech and hearing impairment, etc; BWS: urinary abnormalities, renal disease, incontinence, adrenal hyperplasia, renal tumours; Diabetes: polyuria and polydipsia, peripheral neuropathy leading to constipation and overactive bladder, chronic kidney disease. Kidney disease and stress incontinence are associated to morbid obesity and the comorbidities associated to MMC are well known). Our review of literature showed the higher incidence of lower urinary tract symptoms in children with physical and learning difficulties. In particular it was suggested that boys with Down's syndrome have bladder outflow obstruction secondary to detrusor sphincter dyssnergia, with high potential for renal injury. Other studies highlighted that individuals with moderate to severe learning disabilities present with risk factors for developing post void residual higher than the control population and that a third of all cases with Cerebral Palsy in young age have significant post void residual. From the review of numerous messages on the social network groups it was concluded that in Europe and North America as well as in Eastern Countries, Africa and South Asia, the provision of home-care for continence issues is limited and also the institution of the "Continence Advisor" is not as developed and efficient for adolescents and young adults as it is for the paediatric age. Moreover the availability of essential medication and equipment for home-care and for bowel and bladder management is limited. The situation becomes as severe as a "Cry For Help" in those cases affected by CP, Tetraplegia or a combination of various disabling conditions, frequently present in adolescents and young adults.

Interpretation of results:

Late diagnosis only when the symptoms and signs become severe (pyelonephritis, enterocolitis, tethered cord and related symptoms, etc.), the difficulty of verbalising problems, limits in performing self-clean intermittent catheterization and bowel wash-outs, lack of knowledge at primary care level, when "dry" is confused with "normal bladder" and confusing definitions of constipation, multi-persons care of the disable individual, especially in the Middle-East and Southern-European Countries and Africa, lack of Multispecialistic Integrated Care Pathways and dedicated guidelines, tailored to the limitations experienced by the disabled teenager and young adult, are outstanding issues reducing the efficacy of continence, bowel and bladder issues management, at present.

Concluding message:

Physical and learning disabilities are challenging conditions which require a continuum of care and integrated care pathways from the younger age to adulthood and old age. The transition from Paediatric Care to Adult Medicine Care is slower and more complex in these individuals. Normally, Transition Care addresses the needs for privacy, responsibility, self-care, and treatment compliance. In disabled individuals with bladder and bowel issues, the management of comorbidities generating the issues or contributing to them is more complex. Specific care pathways should be created to target each step and detail of bladder and bowel care in this special needs area, during the transition to adulthood.

Disclosures

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