Epidemic Incidence of a Little-Known Disorder

By, William Rutan

As many as 20 million young American women may be silently suffering from a debilitating disorder that few have heard of and even fewer admit to. That disorder is BCD, or Bowel Control Disorder.

Although the prevalence of bowel control disorder and the extent of its impact on quality of life are drastically under-reported, there are several significant facts about it that are known. Chief among them are that BCD can be a severely debilitating condition, and that it overwhelmingly targets women—particularly women who have had children. What’s unknown is exactly how many women are affected. The commonly accepted estimate in population-based studies is that one in 13 people suffers from BCD. Considering the population as a whole this may be accurate, but looking specifically at the high-risk population for BCD—that is women, and in particular women who have given birth—the numbers may well be four times that of the overall population estimate.

Assuming this estimate is correct, or even close to correct, undiagnosed BCD is an epidemic of greater proportion than undiagnosed Type II diabetes, which is believed to exist in seven million Americans. And though BCD is not life threatening, like diabetes it can have a tremendous effect on quality of life. BCD, in fact, is a common side effect of poorly managed diabetes.

A major factor in the under-reporting of BCD is the silent suffering due to the embarrassment of those affected. Data demonstrate that only one in five younger female patients is willing to initiate a discussion related to incontinence with their primary caregiver. Sufferer silence thus gives way to primary caregivers’ lack of awareness of disorder prevalence, which then prevents patient referral to specialists with knowledge of the latest methods of treatment. This cycle most often ends unresolved, resulting in absurdly low numbers of sufferers getting the counselling and treatment they desperately need.

With regard to caregiver awareness, a common misconception among physicians is that bowel incontinence is a disease of “little old ladies”. Undoubtedly this is because elderly women tend to be the only women who seek treatment. Although it’s a fact that nearly 50 percent of nursing home residents have bowel incontinence, BCD is hardly a disorder of the elderly. A series of studies document that not only does BCD occur widely in women of childbearing age, but that by and large younger sufferers accept a poor quality of life rather than broach this subject with their doctor.

“Incidence of Fecal Incontinence After Childbirth”, published in Obstetrics and Gynecology, February 2007 presented the following: In this study group of women who delivered babies in Oregon in mid-to-late 2002, twenty-nine percent of the 8000+ respondents experienced bowel incontinence after childbirth. Nearly half of these women reported an incontinence event during intercourse.

“Anal Incontinence after Vaginal Delivery: A Five-Year Prospective Cohort Study”, published in American Journal of Obstetrics and Gynecology, December 2004, studied first-time mothers with and without sphincter tears. It was determined that in both groups the incidence and symptoms of BCD at five months, nine months and five years post delivery was high, and worsened over time. Success rates in primary repair of sphincter injuries was frequently disappointing, with incontinence developing in approximately 40 percent of patients.

“Anal Incontinence in Women Presenting for Gynecologic Care: Prevalence, Risk Factors and Impact upon Quality of Life”, published in American Journal of Obstetrics and Gynecology, November 2004 demonstrated that BCD is prevalent among women presenting for routine GYN visits, that only 11 percent of sufferers had sought care for the problem and 83 percent had never been asked BCD questions by their physician.
Given the stigma associated with BCD, it cannot be left to patients to initiate a discussion of the disorder. In every primary care visit by women of childbearing age or older, physicians need to ask the question, “In the last year have you experienced symptoms of bowel control disorder?” This should be followed by the statement, “It’s much more common than you may think”.

For the few patients who have actively sought help for their disorder, depending on the severity of their symptoms the treatment pathway usually has begun conservatively. Initial treatment has included dietary changes, constipating drugs, exercises and biofeedback. If these measures failed, with no other option, the next step has been a significant leap to invasive surgery, such as sphincter repair, an artificial sphincter or a colostomy—expensive, marginally effective and/or disfiguring. Many patients appear not to have chosen that option.

Assuming the estimate of 20 million young, female BCD sufferers is accurate, the following study validates the enormous gap between the number of sufferers, and the number of surgical treatments for the condition.

The Study, “National Trends and Costs of Surgical Treatment for Female Fecal Incontinence”, presented at The Society of GYN Surgeons in April, 2007, showed that during the five-year study period (1998 to 2003) the number of annual surgical procedures for BCD remained flat at approximately 3,500, while costs continued to escalate.

In summary, bowel control disorder will never be proper dinner-table conversation, or perhaps ever be an appropriate topic for television commercials, but it needs to come out of the bathroom and into the offices of primary care physicians. Only then, when the disorder is routinely discussed with female patients of childbearing age or older, can the stigma lessen and the epidemic proportions of this now-little-known disorder be diminished.

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