

SEX, LIES AND ANDROGEN INSENSITIVITY SYNDROME

In her essay "Medical ethics and truth telling in the case of androgen insensitivity syndrome" (*Can Med Assoc J* 1996; 154: 568-570), Anita Natarajan argues that women who bear this syndrome should not be told of their condition. Her argument, crafted from a scholarly, philosophical base, is seriously flawed in human terms.

As a social worker with more than 35 years' experience and a woman who has borne androgen insensitivity syndrome (AIS) for 63 years, I find this essay deeply disturbing.

I know from my social work experience that secrecy as a method of handling troubling information is primitive, degrading and often ineffective. Even when a secret is kept, its existence carries an aura of unease that most people can sense.

As well, this essay confirms for me the inappropriate expectations of physicians in our society. People have traditionally expected physicians to have limitless wisdom, and physicians have been ready to accept this cloak of magical expectations. This has caused as much harm to physicians as it has to their patients. Happily, today many physicians recognize the spuriousness of such expectations, and they expect their patients, with the assistance of other skilled professionals, to face the difficult questions of their medical conditions.

Many of us know of our condition and are prepared to talk about our experiences. Medical practitioners wishing to cast off the barrier of secrecy can draw on our experience and strength. Physicians and their patients with AIS can deal with this anomaly in a healthy, constructive way.

I knew there was a secret about me. Not knowing what it was, I lived under an undefined shadow of fear that diminished enjoyment of every part of my life, hobbled my enthusiasm and, ultimately, affected my suc-

cess in handling life's challenges. I had innumerable hours of psychiatric treatment, which were essentially unsuccessful because my psychiatrist shared the traditional view that patients should be protected from knowledge of AIS.

Decades later, when I first heard the words "testicular feminization," I found excellent help in dealing with reality from social-work and psychological counselling and therapy. Having recently learned the more respectful term "androgen insensitivity syndrome" and discovered an international self-support group, a whole world of self-acceptance has opened up for me. My big regret is that I did not receive this knowledge and help as a youngster. I had the psychological strength to deal with my sex ambiguity, had I been given the chance. I did not have this chance. Secrets crippled my life — secrets like those Natarajan advocates.

Natarajan's misguidedness is troubling because she is an embryonic professional with years of patient treatment in front of her. It is furthermore disturbing that her essay was judged as suitable for an award in the Logie essay contest.

I have two hopes: to bring the issues of abused AIS bearers to the attention of relevant professionals so that healthy, constructive advice and counselling, based on openness, will be available; and to see AIS bearers come to respect our uniqueness and live as fully appreciated members of this society. Together, we must all lift the cloak of secrecy.

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I am the US representative for the AIS Support Network, which has 70 members world wide. I write not to represent the group but to relate my own experience, which demonstrates the shortcomings of Natarajan's article.

At age 11 I was told lies about

AIS. This was not mere "deception" — a convenient term employed as a licence to lie to the patient. Telling me that I had "twisted ovaries" was a lie. The lies just did not add up. And so I found myself at age 20 in a medical school library unearthing the truth. Natarajan is correct: learning the truth about AIS is traumatic. But learning the truth alone and scared in the stacks of a library is shockingly inhumane. When physicians and parents abdicate their responsibility to speak the truth they not only allow this to happen, they virtually ensure that it will.

It is almost inevitable that the patient will learn the truth. The real question is how and when we want her to do so.

When I discovered I had AIS the pieces finally fit together. But what fell apart was my relationship with both my family and physicians. It was not learning about chromosomes or testes that caused enduring trauma, it was discovering that I had been told lies. I avoided all medical care for the next 18 years. I have severe osteoporosis as a result of a lack of medical attention. This is what lies produce.

As an attorney, I would be remiss not to emphasize that informed consent laws mandate that the patient know the truth before physicians remove her testes or reconstruct her vagina. I believe that the proposed breaches of medical ethics and legal duty advocated in Natarajan's article result in legal exposure for any surgeon who is silent. But such legalities only underscore the more fundamental issue of human dignity.

The members of our support group communicate freely, and the greatest source of anxiety is not our gonads or karyotype. It is shame and fear resulting from an environment in which our condition is so unacceptable that caretakers lie. Euphemisms also deny us legitimacy and meaning. Ultimately, I believe they have the potential to destroy the patient herself.