

Difficulty in Securing Treatment for Degenerative Hip Disease in a Patient with Down Syndrome: The Gap Remains Open

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In 2002, the office of the U.S. surgeon general published a report detailing the discrepancies between the quality of healthcare afforded to persons with and without mental retardation. This article examines the case of a female resident of a developmental center with profound mental retardation due to Down syndrome and degenerative hip disease. Although she was in urgent need of a total hip replacement, the operation was denied or delayed by several different surgeons. Using a survey of physician attitudes, we examine several possible motivations behind the surgeons' reluctance to perform the procedure and conclude that these reasons were not appropriate in this case. Finally, we reiterate the surgeon general's call to eradicate preconceptions held in the medical community about the population of persons with mental retardation that result in similar failures to provide adequate care.

Key words: mental retardation ■ healthcare disparities ■ prejudice ■ degenerative hip disease

INTRODUCTION

In 2002, the then-surgeon general of the United States, David Satcher, issued a report entitled *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation*. In preparation for this report, hundreds of physicians, therapists and spokespeople for individuals with mental retardation testified as to their experiences in securing treatment for these patients, and a course of action to facilitate access was drafted. In the introduction to this report, Tommy Thompson, secretary of Health and Human Services stated that:

Americans with mental retardation, and their families, face enormous obstacles in seeking the kind of healthcare that many of us take for granted. Unfortunately, societal misunderstanding of mental retardation, even by many healthcare providers, contributes to this terrible burden... Even providers with appropriate training find our current service system offers few incentives to ensure appropriate healthcare for children and adults with special needs.¹

We report the following case to demonstrate that the principles outlined in the surgeon general's report are not currently being met.

CASE REPORT

The patient, a Medicare fee-for-service enrollee, has profound mental retardation due to Down syndrome. She was born following a full-term pregnancy with no complications. The diagnosis of Down syndrome was evident at the time of birth, and she was placed in an institution shortly thereafter. She has lived at the same center for the past 37 years. Although nonverbal, she can express her feelings and needs through gestures and facial expressions and using signs that she has learned through a speech-language program at the developmental center. The patient's medical history is significant for

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Tourette’s disorder, hypothyroidism, degenerative cervical disc disease, mild spastic paraplegia, hearing impairment, allergic rhinitis and inactive hepatitis-B surface antigen (HBsAg) carrier state. Other than the persistence of HBsAg, she has never demonstrated any increased rate of infection.

As she approached the age of 40, she developed a limp, and ambulation appeared to be painful. X-rays at that time were interpreted as showing chronic subluxation of the right hip with deformity of the right femoral head and moderate loss of joint space. The consulting orthopedic surgeon recommended antiinflammatory medication.

During the subsequent years, her arthritic symptoms progressed so that, by the age of 43, she was only able to walk for short distances using a walker, relying on a wheelchair for most locomotion. She was frequently in severe pain, especially in the morning when she could barely stand without support. At this time, x-rays demonstrated bilateral acetabular dysplasia with uncovering of both femoral heads. The right femoral head was eroded by 40%.

Because of the progression of symptoms, repeat orthopedic consultation was sought. The first orthopedic surgeon consulted, in December 2001, considered a Girdlestone procedure (excision of the femoral head) to relieve pain, but this would not allow for the possibility of restored independent ambulation. As this recommendation was not considered to be appropriate for the well-being of the patient, other opinions were sought. Both a second (December 2001) and third (January 2002) consultant seemed reluctant to accept someone with Down syndrome as a candidate for total hip replacement. Finally, a fourth orthopedic surgeon, one with previous experience with patients with Down syndrome, accepted this woman as a candidate for total hip replacement. The procedure was performed shortly thereafter, in April 2002, without complications. Following the surgery, the patient was able to resume independent ambulation, relatively free from pain (Table 1).

DISCUSSION

This report documents a case in which, if not for the persistence of the care-seekers, appropriate med-

ical care might not have been obtained for this person, possibly because of preconceptions held by certain physicians about people with mental retardation. The patient in question was in extreme pain, but she had to “doctor shop” to receive a standard treatment that probably would have been offered enthusiastically to a developmentally normal person.

The reluctant surgeons did not offer specific reasons for their disinclinations to operate on this patient, so we are left to speculate. Nevertheless, we do feel that this speculation is worthwhile if we are to understand, and then debunk, the misinformation underlying these disinclinations. To pursue this process, two surveys of physician attitudes about caring for persons with mental retardation proved helpful.^{2,3}

It is possible that some of the surgeons were concerned about an increased risk for a poor surgical outcome in a person with Down syndrome, as related to anesthesia, infection, postsurgical care or functional outcome. Although the safe administration of anesthesia to a person with mental retardation may present certain challenges,^{4,5} several reports⁶⁻⁹ have documented favorable results with this population. Reported postoperative infection rates for persons with mental retardation undergoing both nonorthopedic procedures¹⁰⁻¹⁴ and orthopedic procedures¹⁵⁻¹⁹ have not been exceptionally high.

Although lack of cooperation with physical rehabilitation following total hip replacement is a valid concern and might prove to be a challenge in some people with mental retardation, this concern has not been universally validated.¹⁹⁻²³ Moreover, the patient in question had always been extremely cooperative with the efforts of the developmental center staff and had an extensive support network. Favorable functional outcomes have been well documented following orthopedic procedures,²⁰⁻²³ including total hip replacement,^{20,23} in people with mental retardation.

Therefore, although the presence of severe mental retardation might be considered by some to be a relative contraindication to elective surgery, the literature does not validate this concern. It seems more likely that, in the absence of comorbidities, surgical risk is not materially impacted by the presence or absence of normal cognitive functioning.

Table 1. Timeline of events from diagnosis to surgery

Date	Event
June 22, 2000	X-rays reveal bilateral acetabular dysplasia with uncovering of both femoral heads; right femoral head eroded by 40%.
December 4, 2001	Orthopedic Consultation: surgeon suggests Girdlestone procedure.
December 10, 2001	Orthopedic Consultation: surgeon reluctant to accept patient as candidate for THR.
January 27, 2002	Orthopedic Consultation: surgeon reluctant to accept patient as candidate for THR.
April 2, 2002	Surgeon accepts patient and performs procedure without complications.

Some of the surgeons may have been concerned about issues surrounding informed consent for surgery. In the case reported here, the patient had a legally appointed guardian fully authorized to grant consent. In fact, in most circumstances, people with mental retardation are either capable of making their own decisions or they have surrogate decision-makers legally empowered to make medical decisions on their behalf.²⁴⁻²⁶

Alternatively, some of the surgeons may have been unsure about how their fees would be paid. The woman whose case is reported in this article had Medicare insurance. Although significant inequalities of health insurance clearly exist,^{27,28} most people with mental retardation have health coverage, be it Medicare, Medicaid, Title-V programs or private insurance.^{25,28-30}

It is also likely that some of the surgeons felt insecure in their knowledge of Down syndrome and mental retardation and did not know where to turn for support if, for example, the patient became frightened, agitated or violent in their office or in the hospital. This patient did not have such a history, and if such a problem had arisen with this patient, the developmental center was prepared to provide support.

Finally, it is possible that some of the surgeons felt it inappropriate to devote significant healthcare resources to the care of someone with a profound cognitive disability.³¹⁻³³ The public consensus in this country has evolved over the past 40 years to the point that, with very few exceptions,^{34,35} people with mental retardation are felt to be entitled to full and unencumbered access to healthcare.^{21,36-38} Even in the area of solid organ transplantation, moves toward equal access have been reported.³⁹

So far in this discussion, we have been critical of certain surgeons for their apparent reluctance to provide standard care to a person with mental retardation. On the other hand, we, the developmental center staff, need to acknowledge our own failures in this case. We should have anticipated and preventatively addressed for our consultants the issues that may have acted as impediments, thereby making the patient more welcome.⁴⁰ We should have made it very clear to our consultants that we were ready to help in the analysis of potential contraindications, that we would help with consent issues and that we were prepared to help if behavioral issues were to arise. Also, by better communicating our own commitment to this patient, we could have sent a more compelling message about the appropriateness of devoting healthcare resources to this person.

CONCLUSION

In his report, the surgeon general put forth a national agenda to improve access to healthcare for people with mental retardation. The experience just reported implies that some physicians may have

gaps in knowledge and also perhaps incorrect ideas about people with mental retardation and that these issues may be acting as barriers for people with mental retardation in their efforts to access appropriate healthcare services. In recognition of the importance of these issues, the surgeon general, as part of his national agenda, suggested that schools and institutions "integrate didactic and clinical training in healthcare of individuals with mental retardation into the basic and specialized education and training of all healthcare providers."⁴¹ A published report on the coverage currently given to mental retardation in family practice residency programs demonstrates our shortcomings in this regard.⁴¹

So far, neither the Association of American Medical Colleges nor the Accreditation Council for Graduate Medical Education has responded to the surgeon general's call to action. In contrast, it is noted that the Commission on Dental Accreditation of the American Dental Association has responded, declaring that "graduates of (dental schools and dental hygiene schools) must be competent in assessing the treatment needs of patients with special needs".⁴²

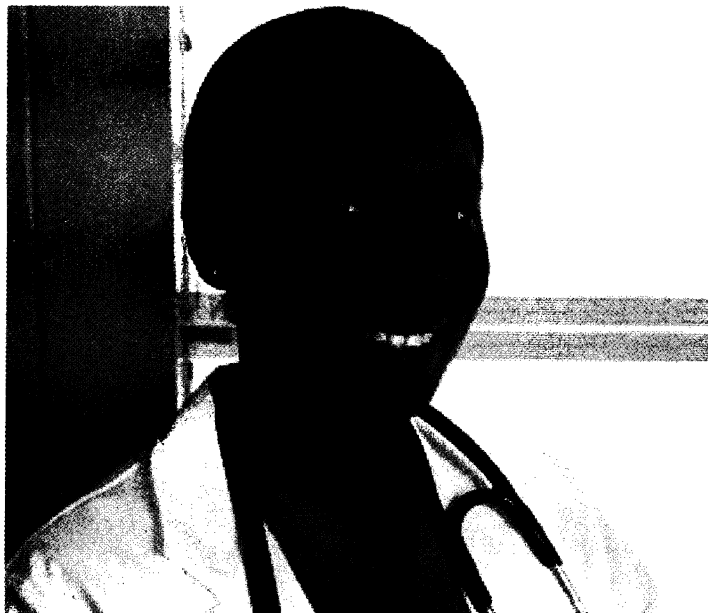
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