# Caring for a Paraplegic Patient and Her Family

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R. DANIEL BLUESTEIN (Department of Family and Community Medicine): Today's Grand Rounds will address how the family physician approaches the continuing care of a paraplegic patient and her family. Our patient, Mrs. P., was injured several years ago and has made a remarkably successful adjustment. Much of our care has focused around childbirth, child rearing, and her maintenance of a home as a working mother with a significant handicap. Specific objectives are to identify factors important in successful adaptation to spinal trauma, and review issues pertinent to the obstetrical care of women with such injuries.

#### CASE SUMMARY

DR. DENISE DAVIS (*Third-Year Resident*): Mrs. P., who is 22 years old, married, and works as a microfilm processor, has been my patient at Ghent Family Practice since 1986. She has been paraplegic since the age of 17 years as a result of an automobile accident in which she sustained a ruptured spleen and fractures of the cervical and lumbar spines. She has a residual paraplegia at T-11 and underwent insertion of Harrington rods for spinal stability in 1983. Other medical sequelae include occasional decubitus ulcerations and recurrent urinary tract infections. Mild episodes of autonomic hyperreflexia characterized by muscle spasms, diaphoresis, and shakiness may result if she waits too long between intermittent self-catheterizations.

Mrs. P. requires a wheelchair for mobility, but is otherwise functionally independent. She drives a specially equipped van and maintains her own household. She cares for her two children, aged  $2\frac{1}{2}$  years and 7 months, without

assistance. The older child has begun to participate in the care of his younger brother.

She has been married since she was 19 years old. Her husband, a construction worker, is currently working out of state for an indefinite period of time, but remains a part of the family unit. He has a history of moderately severe asthma, but both children are in good health. Mrs. P. has a close relationship with her mother and was deeply involved in church activities until demands posed by the care of her children curtailed this participation.

She is a gravida 3 para 2 with a spontaneous miscarriage in March 1984. Her second pregnancy was complicated by two urinary tract infections and preeclampsia, for which she was hospitalized at 38 weeks' gestation. Induction of labor with oxytocin did not produce cervical dilatation, but during transfer from the delivery suite, Mrs. P. spontaneously went into active labor, precipitously delivering a 2,730-g male infant one hour later. There were no complications, the baby's Apgar scores were 8 and 9, and postpartum course was benign.

During her third pregnancy, Mrs. P. suffered a third-degree burn when her older son accidentally spilled a boiling pot onto her lap. This pregnancy was also remarkable for recurrent urinary tract infections. She was briefly hospitalized for premature labor at 30 weeks, then discharged on terbutaline. In her 36th week, membranes ruptured spontaneously, but oxytocin was needed to augment labor. She gave birth to a 2,557-g infant with Apgar scores of 7 and 9, underwent a bilateral tubal ligation immediately postpartum, and subsequently has done well.

### ADJUSTMENT TO SPINAL INJURY

DR. WALTER WADE (Assistant Professor, Department of Physical Medicine and Rehabilitation): There are approximately 120,000 spinal-cord-injured patients currently living in the United States, and with 6,000 spinal injuries of all types occurring annually, this number will increase. Hence, many family physicians will care for such patients. Most are young individuals who can expect a nearly normal life span. With proper support many can

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live independently, work, and raise a family as exemplified by the patient just presented.

Not surprisingly much of the research on factors leading to successful rehabilitation has focused on psychologic aspects. Traditionally spinal-cord-injured patients were thought to pass through stages of denial, depression, and anger before reaching eventual adjustment. Empirical evidence, however, calls this theory into question.<sup>2</sup> For example, much emphasis has been placed on the importance of depression as a stage all patients must experience, but studies using objective measurement scales have found that depression in spinal-cord-injured patients is by no means universal.<sup>3</sup> Nonetheless, many health professionals tend to overestimate depressed feelings,4 imposing a mournful psychological climate that has been cited by some spinal-cord-injured individuals as the most distressing aspect of their care. 5 It is important, therefore, for the family physician and his or her office staff to avoid this negative projection when dealing with such patients.

Research on coping now recognizes the importance of an internal locus of control for success and is beginning to address the role of social and environmental factors external to the individual.<sup>5</sup> As you might expect, the support of a spouse or other family members is invaluable.<sup>6</sup> The family plays several important roles: mediation of the degree of compliance with a rehabilitation program, provision of physical and mechanical assistance to facilitate independent living, maintenance of the patient's self-esteem, and assistance with reintegration into the community.<sup>7</sup> Though clearly not necessary in the case of Mrs. P., the family physician may be able to help families cope with their feelings of helplessness, guilt, and fear of the unknown, any of which may hinder a family's ability to provide effective support.

The family can play a negative role, however, by assuming the patient has become less of a person because of his or her injury. This misconception can take many forms, but a common manifestation is often seen during office visits. A family member or friend who accompanies the spinal-cord-injured patient will often insist on speaking for the patient, a presumption of dependence that is both offensive and potentially destructive. Physicians can avoid reinforcing this presumption, and perhaps educate caregivers, by directing conversation to the patient as they would to any competent adult.

Before leaving the subject of adjustment, I'd like to point out the importance of peer counselors. These are spinal-cord-injured individuals who are further along in the rehabilitation process but are otherwise the same age and sex as the patient and have the same level of injury. When they tell patients "I know how you feel," they really do. Generally, peer counselors live independently and have jobs; they are role models who enable patients to regain hope for the future.

MS. BETH STARLING (Family Therapist, Ghent

Family Practice): Mrs. P., I'd like to relate Dr. Wade's comments to your particular situation. What factors do you think have contributed to such a wonderful adjustment?

MRS. P.: I think my family had a lot to do with it. When I had the accident, everyone was there for me. There were times I had 17 visitors at once. People from my church came too. I never had a chance to feel down.

MS. STARLING: So, right from the beginning, you felt very supported by all your family and friends. What factors do you think have contributed to your success as a parent of two small children?

MRS. P.: I was trained by the best.

MS. STARLING: You had a lot of good training for parenthood from your own mother. That's a high compliment. (To the patient's mother.) Mrs. C., how actively involved are you in helping your daughter now?

MRS. C. (Patient's mother): I help her out when I can, but we both work full-time, so it's difficult. Sometimes she'll just come over after she gets off work, and we'll sit in the driveway and talk for awhile. Though scheduling time together is always a problem, we're there for each other.

MS. STARLING: Mrs. P., how have physicians been helpful in your care?

MRS. P.: By being flexible with office hours and appointments. Most have complimented me on my success in living independently, although some doctors insist on helping me in and out of my wheelchair even though I don't need help. I find this degrading.

DR. DAVIS: We're fortunate in our office to have a treatment room with a motorized examining table. When I examine her, I make sure her chair is secured and leave the room.

A RESIDENT: Dr. Wade, what is the effect of spinal cord injury on marital relationships?

DR. WADE: Studies of the impact of spinal trauma on marriage suggest that marriages predating the injury are at greater risk for dissolution than those commenced post-injury. The disabled spouse's mobility impairments may increase time spent at home while decreasing shared activities away from home, a change that may prove frustrating to the nondisabled partner. Health care professionals can assist couples with maintenance or even improvement of shared activities by teaching them new ways to engage in former activities or by suggesting new ones that offer potential for joint participation.

A NURSE: Would Dr. Wade comment on sexual function in spinal-cord-injured patients?

DR. WADE: Sexual functioning is abruptly altered by spinal cord injury, and perceptions of desirability as a sexual partner may be affected as well. Struggling with emotions and problems triggered by disability may leave little energy for intimacy. So, readiness for a return to sexuality is an important prerequisite. A caring partner

with whom there is open communication is a tremendous asset.<sup>7</sup>

Sexual physiologic responses such as erection and ejaculation in men and vaginal lubrication in women may be preserved depending on the level and completeness of the spinal lesion, but genital sensation is frequently lost. Nonetheless, some patients may experience vasomotor changes, muscle spasms, and visceral sensations reminiscent of orgasm. <sup>10</sup> Nearly all patients report that touching areas retaining sensation is required to experience pleasurable feelings during sexual activity. <sup>11</sup>

Spinal trauma's effect on a woman's fertility is temporary; women become amenorrheic in the first months after injury, then resume menstruation as their bodies adapt. Regardless of the type of lesion, male fertility is decreased because of a low percentage of motile spermatozoa and changes in the chemical composition of semen.<sup>12</sup>

A RESIDENT: Mrs. P., did you have any problem gaining employment; did you encounter any discrimination?

MRS. P.: Rehabilitative Services placed me but it took a while. I worked as a volunteer for a year before I was hired

DR. WADE: It's interesting that many employers view the disabled employee as more reliable than those who are able-bodied. Often the disabled employee is motivated by the need to prove his or her qualifications to ablebodied colleagues.

DR. H. DESMOND HAYES (Director, Ghent Residency Program): Mrs. P., what improvements would you like to see regarding access to public places?

MRS. P.: My work place is pretty accessible now that I've gotten them to put in a bathroom I can use on the first floor. Before that, I had to take an elevator up six stories. Also, I have found that some wheelchair ramps are too steep and can be slippery when it rains. Some doors are hard to open when I have kids in my lap.

A MEDICAL STUDENT: Have you had any difficulty caring for small children? Also, have they started to ask any questions about your handicap?

MRS. P.: I've been able to manage so far. The children notice I'm in a wheelchair, but they don't ask anything about it. (Laughing) My eldest sometimes pulls my wheelchair away from the bed in the morning before I can get in it because he likes to wheel it around. I told him he can't do that because then I can't get up, which was a mistake. This morning he told me he was going to leave me unless I did something he wanted, and then he backed my chair away from the bed.

### **OSTETRICAL CONSIDERATIONS**

DR. JAMES DROESCH (Assistant Professor, Departments of Obstetrics and Gynecology, and Family and

Community Medicine): During antepartum care of paraplegics and other spinal-cord-injured patients, urinary tract infections are a major complication that can lead to pyelonephritis and subsequent onset of premature labor. This possibility can be minimized by frequent urine cultures and antibiotic prophylaxis in women undergoing intermittent catheterization.<sup>13</sup>

Another complication is development of decubiti, which may predispose the patient both to sepsis and to premature labor. 14 Premature labor remains the leading cause of neonatal morbidity in all pregnancies both for paraplegic as well as able-bodied women. In view of the special risk of premature labor, and since tocolytics are most successful when administered early, close surveillance is vital. In the past frequent cervical examinations and patient education on abdominal palpation were the usual regimens. Now, home labor monitors, which can be surveyed by trained personnel via a telephone modem, offer a better opportunity to prevent premature delivery. 15

We must be aware that autonomic hyperreflexia is a potential complication unique to the spinal-cord-injured patient. 16 Autonomic hyperreflexia results from visceral stimulation mediated by an uninhibited spinal reflex, causing marked peripheral and splanchnic vasoconstriction, which results in severe, potentially fatal, blood pressure elevations. 17 Hypertension may be accompanied by arrhythmias, diaphoresis, agitation, headache, cerebral hemorrhages, and coma. Hence, there is potential for confusion with preeclampsia and eclampsia. Triggers for autonomic hyperreflexia include bladder catheterization or catheter obstruction, enemas, or vaginal examinations. The use of a lubricant containing a topical anesthetic may reduce such noxious stimulation. Women with cord lesions above T-7 are at greatest risk, but the syndrome must be kept in mind, as it can occur with lower-level lesions. 18

Careful monitoring of uterine contractions is also important, as there is a tendency toward very rapid progress through labor. <sup>16</sup> In external fetal monitoring, overly tight belts may precipitate autonomic hyperreflexia. If the spinal lesion is above T-10, the patient will not be aware of uterine contractions. Hence, spinal-cord-injured patients are at risk for unattended delivery. Because of the risk of autonomic hyperreflexia, a prolonged second stage of labor should be avoided, if need be, by vacuum extraction or forceps-assisted delivery. If the pelvic anatomy has been traumatically altered, pelvimetric assessment is indicated and elective cesarean section may be required.

Although there are risks, childbearing need not be discouraged for spinal-cord-injured patients. Such patients, however, need to make fully informed decisions about family size and spacing of children. It is an important responsibility for physicians to encourage their spinal-cord-injured patients' active participation in family planning and in other aspects of their overall care.

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Before prescribing, please see full prescribing information. A Brief Summary follows. CONTRAINDICATIONS: Persons who have shown hypersensitivity to any of the tetracyclines. WARNINGS: THE USE OF DRUGS OF THE TETRACYCLINE CLASS DURING TOOTH DEVELOPMENT (LAST HALF OF PREGNANCY, INFANCY AND CHILDHOOD TO THE AGE OF 8 YEARS) MAY CAUSE PERMANENT DISCOLORATION OF THE TEETH (YELLOW-GRAY-BROWN). This adverse reaction is more common during long term use of the drugs but has been observed following repeated short term courses. Enamel hypoplasia has also been reported. TETRACYCLINE DRUGS, THEREFORE, SHOULD NOT BE USED IN THIS AGE GROUP UNLESS OTHER DRUGS ARE NOT LIKELY TO BE EFFECTIVE OR ARE CONTRAINDICATED

Results of animal studies indicate that tetracyclines cross the placenta, are found in fetal tissues and can have toxic effects on the developing fetus (often related to retardation of skeletal development). Evidence of embryotoxicity has been noted in animals treated early in skeletal development). Evidence of embryotoxicity has been noted in animals treated early in pregnancy, if any tetracycline is used during pregnancy or if the patient becomes pregnant while taking these drugs, apprise the patient of potential hazard to the fetus. As with other tetracyclines, doxycycline forms a stable calcium complex in any bone-forming tissue. A decrease in the fibula growth rate has been observed in prematures given oral

tetracycline in doses of 25 mg/kg q6h. This reaction was shown to be reversible when the

drug was discontinued.

Photosensitivity manifested by an exaggerated sunburn reaction has been observed in some individuals taking tetracyclines. Patients apt to be exposed to direct sunlight or ultraviolet light should be advised that this reaction can occur with tetracycline drugs, and

the antianabolic action of the tetracyclines may cause an increase in BUN. Studies to date indicate that this does not occur with the use of doxycycline in patients with impaired renal

PRECAUTIONS: As with other antibiotic preparations, use of this drug may result in

overgrowth of nonsusceptible organisms, including fungi. If superinfection occurs, discontinue the antibiotic and institute appropriate therapy All infections due to group A beta-hemolytic streptococci should be treated for at least

10 days.

Laboratory tests: In venereal disease when coexistent syphilis is suspected, dark-field

examination should be done before treatment is started and the blood serology repeated monthly for at least 4 months

In long term therapy, periodic laboratory evaluation of organ systems, including

hematopoietic, renal and hepatic studies should be performed.

Drug interactions: Because tetracyclines have been shown to depress plasma prothrombin activity, patients who are on anticoagulant therapy may require downward adjustment of their anticoagulant dosage.

Since bacteriostatic drugs may interfere with the bactericidal action of penicillin, it is

advisable to avoid giving tetracyclines in conjunction with penicillin

For concomitant therapy with antacids or iron-containing preparations and food see "Dosage and Administration" section. Carcinogenesis, mutagenesis, impairment of fertility: Long term studies are currently being conducted to determine whether tetracyclines have carcinogenic potential. Animal studies conducted in rats and mice have not provided conclusive evidence that tetracyclines may be carcinogenic or that they impair fertility. In two mammalian cell assays (L51784 mouse lymphoma and Chinese hamster lung cells in vitro) positive responses for mutagenicity occurred at concentrations of 60 and 10 mcg/mL respectively. In humans no association

between tetracyclines and these effects has been made. **Pregnancy:** Pregnancy Category D (See Warnings section).

Nursing mothers: Tetracyclines are present in the milk of lactating women who are taking a drug in this class. Because of the potential for serious adverse reactions in nursing infants drug in this class. Because of the potential for serious adverse reactions in nursing infants from the tetracyclines, decide whether to discontinue nursing or discontinue the drug, taking into account the importance of the drug to the mother (see Warnings section).

Pediatric use: See Warnings and Dosage and Administration sections.

ADVERSE REACTIONS: Due to oral doxycyclines virtually complete absorption, side effects to the lower bowel, particularly diarrhea, have been infrequent. The following adverse reactions have been observed in patients receiving tetracyclines:

Gastrointestinal: Anorexia, nausea, vomiting, diarrhea, glossitis, dysphagia, enterocolitis, and inflammatory lesions (with monilial overgrowth) in the anogenital region. These reactions have been caused by both oral and parenteral tetracycline administration. Rare instances of esophagitis and esophageal ulcerations have been reported in patients receiving capsule and tablet forms of drugs in the tetracycline class. Most of these patients took medications

immediately before going to bed. (See Dosage and Administration).

Skin: Maculopapular and erythematous rashes. Exfoliative dermatitis has been reported but

is uncommon. Photosensitivity is discussed above (see Warnings).
Renal toxicity. Rise in BUN has been reported and is apparently dose related. (See Warnings).

Hypersensitivity reactions: Urticaria, angioneurotic edema, anaphylaxis, anaphylactoid purpura, pericarditis, and exacerbation of systemic lupus erythematosus.

Bulging fontanels in infants and benign intracranial hypertension in adults have been reported in individuals receiving tetracyclines. These conditions disappeared when the drug was discontinued

Blood: Hemolytic anemia, thrombocytopenia, neutropenia, and eosinophilia have been

reported with tetracyclines.

When given over prolonged periods, tetracyclines have been reported to produce brownblack microscopic discoloration of thyroid glands. No abnormalities of thyroid function are

DOSAGE AND ADMINISTRATION: THE USUAL DOSAGE AND FREQUENCY OF ADMINISTRATION OF DOXYCYCLINE DIFFERS FROM THAT OF THE OTHER TETRACYCLINES, EXCEEDING THE RECOMMENDED DOSAGE MAY RESULT IN AN INCREASED INCIDENCE OF SIDE EFFECTS.

Administration of adequate amounts of fluid along with capsule and tablet forms of drugs in the tetracycline class is recommended to wash down the drugs and reduce the risk of esophageal irritation and ulceration (see Adverse Reactions).

If gastric irritation occurs, it is recommended that doxycycline be given with food or milk. The absorption of doxycycline is not markedly influenced by simultaneous ingestion of food or milk. Please see full prescribing information for dosing instructions in all indications.

Concomitant therapy: Antacids containing aluminum, calcium or magnesium, sodium bicarbonate, and iron-containing preparations should not be given to patients taking oral

Studies to date indicate that administration of doxycycline at the usual recommended doses does not lead to excessive accumulation of the antibiotic in patients with renal impairment. Caution - Federal law prohibits dispensing without prescription.

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#### PARAPLEGIC PATIENT AND FAMILY

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DR. LUCIAN CAPOBIANCO (Director, Portsmouth Residency Program): Dr. Droesch, are there special risks of oral contraception in a paraplegic patient?

DR. DROESCH: In paraplegic patients, venous return from the legs by muscle contraction cannot occur. In view of the time spent by such patients in wheelchairs, their legs are dependent and more prone to development of phlebitis. Nowhere on the package insert for oral contraceptives does it say paraplegia or quadraplegia is a relative or absolute contraindication, but sometimes we have to individualize management decisions.

DR. HAYES: Should consideration be given to longterm use of support hose to prevent stasis? I know they are not very pretty.

MRS. P.: They cut my legs and, no matter what length they are, transferring from the wheelchair makes them roll down. So, I don't wear them.

DR. DROESCH: I want to add a brief comment about the relationship of family physician and obstetrician. Even though paraplegic women are high-risk patients, the primary care physician still has an important role in their care by coordinating the variety of services needed for a successful outcome. The family physician has the breadth of experience and the interest to provide this integrating role. Also, the emotional support contributed by the family physician is just as crucial as the coordinating role.

DR. PATRICIA MOORE (Faculty, Ghent Residency): Dr. Droesch, that's an eloquent description of the family physician's role in managing a pregnant paraplegic patient. Additionally, the family physician can provide a family perspective, continuity of care, and anticipatory guidance. All these points form a cogent argument for "consultation" rather than "referral," so we can remain involved in our patients' care.

MRS. P., I understand you've taken a very active role in your care as well. I would like to hear more from you and Dr. Davis about your partnership through the pregnancy and beyond.

DR. DAVIS: Mrs. P.'s independence helped me quite a lot. She is also a good judge of her condition. During her pregnancy, she alerted me right away when she was developing urinary tract infection symptoms. She also was able to identify contractions and call me at once, so that we were able to start tocolytics for premature labor fairly

Regarding her family, I find that she is an excellent mother. The first time I met her, her older son was sliding out of her lap, and I thought he was falling. When I rushed over, she gave me a look that said, "What's the problem? He's perfectly safe." That was my first lesson on how she and her family had adjusted to her disability. I think she has done wonderfully, and I have learned quite a bit as well.

DR. SAMUEL WITTENBERG (Faculty, Ghent Residency): I'd like to reinforce what Dr. Davis just said. Many people with an involved illness are knowledgeable about their conditions. I think this case is a good example of how such patients not only can contribute to their care,

but also can provide ongoing education for their physicians.

DR. MOORE: Mrs. P., I wonder whether you can share any attitudes Dr. Davis demonstrated as your family physician that were especially helpful to you.

MRS. P.: I consider Dr. Davis more like a family member than a doctor because anytime I needed her, she was there. Even when she was off duty, she'd make house calls because I can't take off very much time from work. I'm not saying that everybody should do this, but it was a big help for me. Otherwise, I might have lost my job.

DR. MOORE: So, availability was a big factor. Have you suggestions for nurses as well?

MRS. P.: I'd like to see nurses be as understanding as Dr. Davis has been. I've had some problems with nurses, though not here at Ghent Family Practice. When I was in labor with my first child, a hospital nurse was mad at me for getting pregnant and demanded to know why I would want to bring a child into this world with what I have to offer.

MRS. C.: All children should have what she has to offer. Regardless of the parent's handicap, as long as the child is loved and cared for, what else matters?

MS. STARLING: Mrs. P., when you think about the future, what do you consider?

MRS. P.: I don't worry much about the future, but in the past I have had some moments of depression. Sometimes, I think of things I can't do, like walking on the beach with my husband or running with my children. I have pictures of my accident, and when I get depressed, I look at them. It cheers me up because I realize I'm lucky to be alive, much less to have children. I don't stay depressed very long.

DR. BLUESTEIN; On that positive note, we would like to bring this session to a close. Thank you for your interest and questions. We especially thank Mrs. P. and her mother for their participation.

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