Family Practice Grand Rounds

Consequences for the Family in Chronic Illness

Paul S. Williamson, MD
Iowa City, Iowa

DR. PAUL S. WILLIAMSON *(Assistant Professor, Department of Family Practice)*: This Grand Rounds on low back pain syndrome will depart from the usual format of emphasizing the medical diagnostic and treatment aspects involved in the care of an individual patient. Instead, we will use the background of this particular illness to examine the broader context of what occurred in one family as one member experienced chronic pain and disability.

Family life is the social structure within which the patient becomes ill and is then dependent while ill.[1] Several problems that families and their physician face in handling a chronic illness are illustrated by this experience of the P. family. First, the illusion of the dyad in medical practice[2] can have a detrimental effect on treatment if the physician views the medical relationship as strictly a one-on-one encounter to the exclusion of other family members. Inclusion of the family and breaking out of the dyad become critical when the illness becomes chronic and role adaptation within the family will be required on a long-term basis. This is illustrated by several occasions when the concept of convening the family[3] for a conference with the patient and her husband and children would have been appropriate. Educating them about the magnitude and duration of the task they faced and enlisting family cooperation and support in the treatment process would have been immensely helpful.

Another concept that is always a potential trap is called triangulation, which can occur because the physician is not an outside observer of family processes but, when engaged in treatment, becomes a participant in family process. This produces a three-way relationship between the physician, patient, and family. In this position the physician can support patient-family bonds or fall into the trap of weakening them by focusing on the patient to the exclusion of family relationships and the needs of family members. A final point that should have received more attention with this family is the extent to which community support services could have met some of their needs.

Now let us focus on the particular circumstances that faced the P. family. Marie P., at the time of her first admission to the hospital for low back pain in September 1980, was a 27-year-old medical unit nurse. She complained of low back pain radiating down her posterior left leg. This problem began about one year prior to this admission, in the second trimester of her second pregnancy during which she had gained 30 pounds. She had quit work two months prior to her due date (earlier than she wanted) because of paresthesia and pain in the leg. Her obstetrician had told her that her symptoms were probably related to the weight of the uterus and would go away after the delivery. The pain did not disappear until about three to four months after delivery. She underwent some postpartum depression in the three- to six-

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From the Department of Family Practice, The University of Iowa College of Medicine, Iowa City, Iowa. Requests for reprints should be addressed to Dr. Paul S. Williamson, Department of Family Practice, The University of Iowa College of Medicine, Iowa City, IA 52242.

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month period following her delivery. Marie returned to work at the hospital part-time six months postpartum. With chronic re-straining of her back while lifting patients on the medical unit, the low back pain recurred as left lower quadrant pain in January 1980. The pain was so severe that she returned to her obstetrician thinking she must have a pelvic infection. All he could find was some mild vaginitis. She kept returning because the pain continued, but he found nothing additional on repeat examinations for the next two months. She continued working with the pain through the spring of 1980. Activity such as assisting a patient from bed to chair would aggravate the pain, and she would have to stop working for a week or two. She would go through a recovery period, return to work, and the cycle would repeat.

Late in July 1980, while playing with her one-year-old son and three-year-old daughter on the floor, she heard and felt something "pop" in her lower back. She had been lying on her back and flipping them up over her head. This pain was more severe than any she had ever had before, so she put the kids down for naps and tried to rest. Late in the afternoon she was awakened by the one-year-old, who was crying because he needed his diaper changed. She discovered she could not get up out of the water bed. She finally rolled over the edge of the bed and struggled to the telephone. Her husband Jeff, a policeman, was out on his evening shift in the patrol car and unavailable. She called her father, and he came over to help that evening. (See Figure 1 for the family genogram.)

The next day she went to see a chiropractor. She thought that if something had "popped out," he could just "pop" it back in. The chiropractor took full-spine x-ray films, and Marie was manipulated and went home for full bed rest with ice packs. The manipulation treatments were repeated daily for three more days and then spaced out at increasing intervals for three more weeks.

Because she wasn't getting any better, Marie went to see her family physician, Dr. B., on August 29, 1980. When he examined her, she had pronounced paraspinous muscle spasm bilaterally in her lumbar area and a positive straight–leg-raising sign at 30 degrees; however, she still had deep tendon reflexes (2+) and good leg muscle strength. His diagnosis was chronic low back strain syndrome; rule out an early disc problem. She was treated with ibuprofen (600 mg, four times a day) and acetaminophen with 30 mg of codeine, so the physician must have been impressed with the pain. There was no improvement with one week of treatment with bed rest at home, so she was admitted to the hospital. Ibuprofen and bed rest were continued with the addition of muscle relaxants. Repeat lumbar spine films revealed some increased lordosis, but normal disc interspaces. She went to physical therapy and was given some exercises. With some improvement after one week of treatment in the hospital, she was dismissed with the same medications and the addition of a back brace.

Six months later in February 1981, she reinjured her back by lifting a heavy, incapacitated patient on her first night back at work. This put her back in bed at home for another week. She continued in this cycle with intermittent back difficulties until, at her request, an orthopedic consultation was obtained from Dr. S. in December 1981. Dr. S.'s second opinion was the same as Dr. B's. The diagnosis was chronic low back syndrome, and he didn't feel that further workup was needed. He switched her from ibuprofen to meclofenamate. She was told to limit her lifting to 14 pounds, which was the weight of her baby at that time. So in December 1981 with the orthopedist telling her that she couldn't return to her old job, she requested a transfer to the neonatal intensive care unit. Because there were no openings available, she was unable to go back to work at the hospital.

She eventually resigned her position at the hospital and went to work in a weight clinic in the spring of 1982. There she lost 35 pounds, to 130 pounds from about 165 pounds. In May 1982 she transferred to a job as a nurse in industry and has had no recurrence of her back pain in the last 1½ years.

Marie, first I would like you to go back over some of the treatment and tell us your reaction to seeing the chiropractor and what happened there.

MARIE: I was willing to try anything that would be quick because I knew very well that if I went to an orthopedist, he would put me in bed for a while and in traction, and I didn't want that. The chiropractor's initial diagnostic procedure, the whole spine x-ray, made me feel secure, but with all the tools he used, he really didn't have anything

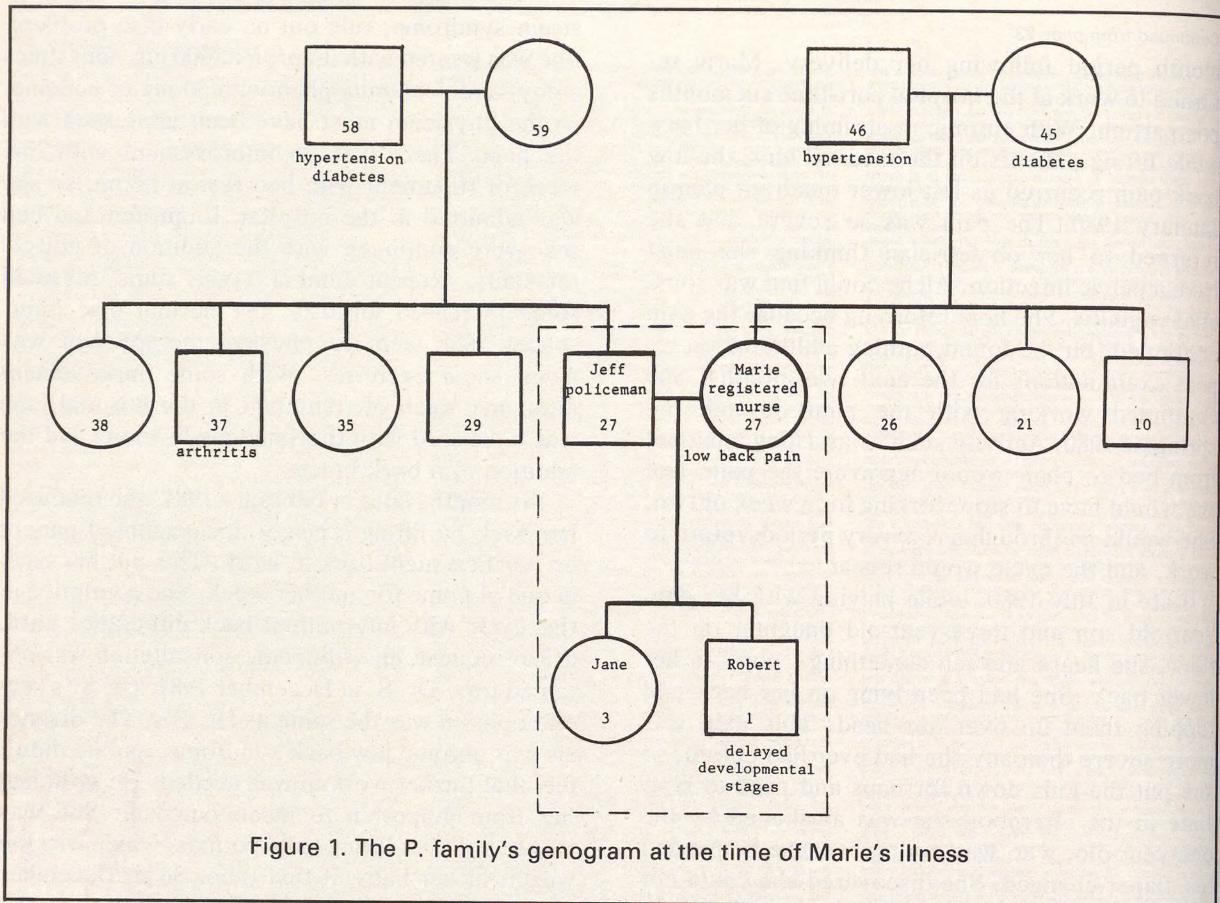

Figure 1. The P. family's genogram at the time of Marie's illness

to tell me. He performed the manipulations and said come back tomorrow. It felt as though after he did the manipulations, the swelling would pop my back right out again. I would go home and lie down on my ice pack. It wasn't fun. Going through this personally was different from seeing it from a professional point of view.

DR. WILLIAMSON: Would you tell us more about what it was like those first few weeks following the injury while you were at home?

MARIE: In some ways the first two weeks were easier because at that point everyone realized the extent of my injury. I hurt. I couldn't move and people would do things for me. As time went on, people drifted away and wanted me to become more independent more quickly. But I couldn't become independent and that put pressure on my family. They felt guilty because they had their own lives to live. When there was no one there, I just had to do it; change the kid's diapers, do this, that, whatever needed doing.

One thing that was important in the treatment was getting out of our water bed. I had to have something hard to lie on. So most of the time I was on the floor. My most comfortable position was lying on the floor with my back absolutely flat to straighten and stretch those lower back muscles. I would then bend my knees and put my lower legs on a couch or a chair and stay there until I became too uncomfortable. Then I would go to bed with as many pillows as I could get underneath my knees to try to elevate them to that same position, but it just wasn't as comfortable.

DR. WILLIAMSON: A major decision for the family physician is when to hospitalize a person with low back pain for bed rest and when home care with less time lying down will be adequate.

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Azo Gantrisin®
Each tablet contains 0.5 Gm sulfisoxazole/Roche and 50 mg phenazopyridine HCl.

Before prescribing, please consult complete product information, a summary of which follows:

INDICATIONS: Initial treatment of uncomplicated urinary tract infections caused by susceptible strains of *Escherichia coli*, *Klebsiella* species, *Enterobacter* species, *Proteus mirabilis*, *Proteus vulgaris* and *Staphylococcus aureus* when relief of pain, burning or urgency is needed during first 2 days of therapy. Azo Gantrisin treatment not to exceed 2 days. Evidence lacking that sulfisoxazole plus phenazopyridine HCl better than sulfisoxazole alone after 2 days. Treatment beyond 2 days should only be continued with Gantrisin (sulfisoxazole/Roche). (See DOSAGE AND ADMINISTRATION.) *Important Note:* Coordinate *in vitro* sulfonamide sensitivity tests with bacteriologic and clinical response. With ongoing therapy, add aminobenzoic acid to culture media. Increasing resistance of organisms may limit sulfonamide usefulness. As identical doses produce wide variations, measure blood levels in patients receiving sulfonamides for serious infections: 12 to 15 mg/100 ml is optimal; adverse reactions are more frequent above 20 mg/100 ml.

CONTRAINDICATIONS: Children under 12; known sensitivity to either component; pregnancy at term and during nursing period; in glomerulonephritis, severe hepatitis, uremia and pyelonephritis of pregnancy with gastrointestinal disturbances.

WARNINGS: Sulfonamides are bacteriostatic; organisms causing common infections are often resistant. Sulfas won't eradicate group A streptococci or prevent sequelae like rheumatic fever and glomerulonephritis. Deaths from hypersensitivity reactions, hepatocellular necrosis, agranulocytosis, aplastic anemia and other blood dyscrasias have been reported. Sore throat, fever, pallor, purpura or jaundice may be early signs of serious blood disorders. Perform blood counts and renal function tests.

PRECAUTIONS: *General:* Use with caution in patients with impaired renal or hepatic function, severe allergy, bronchial asthma. Hemolysis may occur in glucose-6-phosphate dehydrogenase-deficient individuals.
The more soluble sulfonamides are associated with fewer renal complications. Maintain adequate fluid intake to prevent crystalluria and stone formation.
Information for Patients: Maintain adequate fluid intake; urine will turn reddish-orange.
Laboratory Tests: Perform urinalysis with careful microscopic examination at least once a week and regular blood counts after 2 weeks therapy; measure blood levels in patients with serious infection (see INDICATIONS). *Drug Interactions:* Sulfonamides may displace oral anticoagulants from plasma protein binding sites, increasing anticoagulant effect. Can also displace methotrexate. *Drug Laboratory Test Interactions:* May affect liver function tests in hepatitis.
Carcinogenesis, Mutagenesis, Impairment of Fertility: Carcinogenesis: Azo Gantrisin has not undergone adequate trials relating to carcinogenicity; each component, however, has been evaluated separately. Rats appear especially susceptible to goitrogenic effects of sulfonamides; long-term administration has resulted in thyroid malignancies in this species. Long-term administration of phenazopyridine HCl has induced neoplasia in rats (large intestine) and mice (liver). No association between phenazopyridine HCl and human neoplasia reported; adequate epidemiological studies have not been conducted. *Mutagenesis:* No studies available. *Impairment of Fertility:* The components of Azo Gantrisin have been evaluated in animal reproduction studies. In rats given 800 mg/kg/day sulfisoxazole, there were no effects on mating behavior, conception rate or fertility index. Fertility was not affected in a two-litter study of rats given 50 mg/kg/day phenazopyridine.
Pregnancy: Teratogenic Effects: Pregnancy Category C. The components of Azo Gantrisin have been evaluated. At 800 mg/kg/day sulfisoxazole was nonteratogenic in rats and rabbits, with no perinatal or postnatal effects in rats. In two other studies, cleft palates developed in rats and mice after 500 to 1000 mg/kg/day sulfisoxazole. No congenital malformations developed in rats given 50 mg/kg/day phenazopyridine. As there are no satisfactory animal or human studies, it is not known whether Azo Gantrisin can cause fetal harm or affect reproduction capacity. Use during pregnancy only if the potential benefit justifies the potential risk to the fetus. *Nonteratogenic Effects, Nursing Mothers and Pediatric Use:* See CONTRAINDICATIONS.

ADVERSE REACTIONS: *Allergic:* Anaphylaxis, generalized allergic reactions, angioneurotic edema, arteritis and vasculitis, myocarditis, serum sickness, conjunctival and scleral injection, periarteritis nodosa, systemic lupus erythematosus. *Cardiovascular:* Tachycardia, palpitations, syncope, cyanosis. *Dermatologic:* Rash, urticaria, pruritus, erythema multiforme, Stevens-Johnson syndrome, toxic epidermal necrolysis, exfoliative dermatitis, photosensitivity. *Endocrine:* Goiter production, diuresis, hypoglycemia. Cross-sensitivity with some goitrogens, diuretics (acetazolamide and the thiazides) and oral hypoglycemic agents may exist. *Gastrointestinal:* Nausea, emesis, abdominal pain, anorexia, diarrhea, glossitis, stomatitis, flatulence, salivary gland enlargement, G.I. hemorrhage, pseudomembranous enterocolitis, melena, pancreatitis, hepatic dysfunction, jaundice, hepatocellular necrosis. *Genitourinary:* Crystalluria, hematuria, BUN and creatinine elevation, nephritis and toxic nephrosis with oliguria and anuria, acute renal failure, urinary retention. *Hematologic:* Leukopenia, agranulocytosis, aplastic anemia, thrombocytopenia, purpura, hemolytic anemia, anemia, eosinophilia, clotting disorders including hypoprothrombinemia and hypofibrinogenemia, sulfhemoglobinemia, methemoglobinemia. *Musculoskeletal:* Arthralgia, chest pain, myalgia. *Neurologic:* Headache, dizziness, peripheral neuritis, paresthesia, convulsions, tinnitus, vertigo, ataxia, intracranial hypertension. *Psychiatric:* Psychosis, hallucinations, disorientation, depression, anxiety. *Miscellaneous:* Edema (including periorbital), pyrexia, drowsiness, weakness, fatigue, lassitude, rigors, flushing, hearing loss, insomnia, pneumonitis.

OVERDOSAGE: *Signs:* Anorexia, colic, nausea, vomiting, dizziness, drowsiness, unconsciousness; possibly pyrexia, hematuria, crystalluria. Blood dyscrasias and jaundice may occur later. *Treatment:* Institute gastric lavage or emesis; force oral fluids; administer intravenous fluids if urine output is low with normal renal function. Monitor blood counts and appropriate blood chemistries, including electrolytes. In cyanosis, consider methemoglobinemia and treat with intravenous 1% methylene blue. Institute specific therapy for blood dyscrasias or jaundice.

DOSAGE AND ADMINISTRATION: Azo Gantrisin is intended for the acute, painful phase of urinary tract infections. The recommended dosage in adults is 4 to 6 tablets initially, followed by 2 tablets four times daily for up to 2 days. Treatment with Azo Gantrisin should not exceed 2 days. Treatment beyond 2 days should only be continued with Gantrisin (sulfisoxazole/Roche).

HOW SUPPLIED: Tablets, each containing 0.5 Gm sulfisoxazole/Roche and 50 mg phenazopyridine HCl—bottles of 100 and 500.

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As the major home support and provider, how did you feel about Marie's being at home and being in the hospital, Jeff?

JEFF: It was a real relief to me when I was able to have Marie admitted to the hospital just because I felt so insecure about everything. I didn't know how to help her because I didn't know what to do. There was a tremendous workload besides my 40-hour week at work with things to be done at home. Just to have her in the hospital where I knew she was being cared for was a real relief. Of course, I was able to shift the kids to Grandma's then, which was also a big help. There was so much anxiety not knowing how to help when she was home, or when I was doing something that might do more damage than was already done.

DR. WILLIAMSON: Tell us what happened with your family physician's treatment. You were in the hospital and you still weren't getting well; how did you react?

MARIE: Essentially my family physician said that all I needed was bed rest—give it time and I would be better. As a mother I didn't want to hear that, especially when I was off work and had two babies to care for. I didn't want to hear that I had to lie in bed and be dependent on everybody else, especially when I saw my mother and husband already worn to a frazzle from doing all my work. It put a big guilt trip on me. During one visit I had with Dr. B., he said, "Well, I went through this several years ago, and I worked right through it and eventually got better; yours will get better too." That attitude ticked me off.

DR. WILLIAMSON: Jeff, what did you know about what was going on with Marie. Did you go to her appointments with her?

JEFF: I remember going to the chiropractor with her. Part of the time I was with her at Dr. B's. In the hospital, my contact with Dr. B. was minimal. He didn't seem to notice I was there, so there was really no meaningful communication. He would talk to her in terms a nurse would understand, but I couldn't. All my knowledge came from Marie.

DR. WILLIAMSON: You didn't know how severe this was or how long it would last?

JEFF: No, not really. I don't think anybody did. Marie didn't, at least I don't think Marie did.

DR. WILLIAMSON: Despite doing everything

you knew to do, at the end of that first month nothing was getting better, and you didn't know how long it would last.

MARIE: Nothing improved and that was so frustrating.

DR. WILLIAMSON: How was that period for you, Jeff?

JEFF: Frustrating, about sums it up. Quite honestly, I don't know whether it's an emotional defense or just a bad memory, but I can't remember many specifics about that time. I was working many extra hours because of the sudden loss of income. We had just changed houses and financially were obligated more heavily than previously, so I was trying to make up the difference by working extra shifts during a factory strike. After working an 8-hour shift as a policeman, I would work an 8-hour guard duty shift over at the factory, come home to a sick wife and two kids, and then would work 16 hours the next day. I kind of withdrew from everything except my work.

DR. WILLIAMSON: That brings up another critical issue. What was happening to your marital relationship?

JEFF: It was strained. Looking back I can see now that there were other things happening at that time. I had changed to an odd shift, 8 PM to 4 AM, and didn't realize how difficult that schedule in and of itself was on our marriage. When I would get home from work, Marie was in bed asleep; when I finally woke up around noon, she was well into her day. By the time we finally got to where we could communicate, it was time for me to go to work again. Then along came her injury, the extra workload on me, and the stress of managing. It put a real strain on our marriage and began a really low point in our life, which I am glad to say we have worked through.

MARIE: But it took a while—four full years. It's better to forget it, and that's why it is hard to remember certain things.

DR. WILLIAMSON: Can you tell us what your reaction was to Jeff during that time?

MARIE: It was very mixed because I felt guilty about putting that workload on him. I felt inadequate and my self-esteem went down. When he felt that I should be doing a little more, of course I would become defensive and rebound with anger. It got to where all we knew was the anger and resentment. We still told each other that we loved each other and still had enough sense to have sexual relations. As a matter of fact, sex was something that didn't stop with the back injury. As with being eight or nine months' pregnant, we just found a way around it. We had that physical closeness, but meaningful verbal communication was gone.

DR. WILLIAMSON: What do you think happened to your parenting skills during this time?

MARIE: The disability took its toll. We very much love our kids, and they know it. But our ability to care for them properly and to meet their emotional needs was decreased. Our son is very slow in developing, and I'm sure his development has been affected by the turmoil during the first $2^1/_2$ years of his life. I breast-fed him and took care of him to keep that mother-child bond going, but I was in pain, and there were so many factors involved. My experience with him was not the way it should have been or the way I wanted it to be, and the child knows that. Our son didn't walk until he was 15 months old. I was worried.

I remember during one particularly stressful period when our daughter, who was three or four years old, came up to Jeff and asked, "What are you going to do, Daddy?" He said, "Oh, we're going to eat supper and get ready for work." She repeated, "No, Daddy, what are you going to do?"

JEFF: She specifically asked me whether I was "going away" or "going to leave." What a blow! I wonder whether we are still seeing insecurities resulting from the strain the children felt during Marie's injuries and the following breakdown of our marriage relationship.

ELIZABETH KUDSK *(Social Worker, Department of Family Practice)*: Would it have helped to have had someone to talk with about the emotional strain while you were going through all this?

MARIE: No one approached me in the hospital or at the physician's office. Maybe everyone thought that because I was a nurse I knew how to deal with what was happening.

JEFF: It wasn't until last week when Dr. Williamson asked us about this conference that we had ever sat down and talked about our experiences from beginning to end. After we did, I was wrung out. No wonder we had problems, and healing has taken as long as it has. I think it would have been beneficial for us to have worked

through this before. I don't know whether I was mature enough to do it earlier, but talking about it may very well have speeded the healing process.

MARIE: A 22-, 23-, or 24-year old thinks he or she has the world by the tail. I had to hit the pits before I was willing to admit that I needed help. Especially as a young professional, I wanted to prove to the world that I had it together. I didn't, but I didn't want to admit it to anyone.

DR. WILLIAMSON: Some basic principles encountered by this family can be generalized to other families with a member experiencing chronic disability. All family members were eventually drawn into the course of this illness, and each member was eventually affected by it as much as the ill member. This was not simply a case of a nurse with recurrent back injuries affecting her ability to work at the hospital. Her other roles as wife and mother were altered as dramatically. Approaching her as an individual in the medical model illustrates again "the illusion of the dyad in medical practice."[2] A fundamental shift from treating an individual to also treating the family system is required when the illness becomes chronic.

A trap to avoid while focusing on the treatment of a frustrating chronic problem is triangulation with the family.[2] In the case of the P. family, Marie was seeing her family physician, Dr. B., who was examining and prescribing treatment for her back. The disability caused by her low back pain was producing considerable stress in her marriage. She talked with Dr. B. about her marital problems, and he empathized with her. When Jeff later saw Dr. B. while Marie was in the hospital, the previous interaction and bond with Marie created a barrier between Jeff and Dr. B. Jeff felt that Dr. B. did not talk to him or used language Jeff could not understand. With that triangulation, Jeff was left in the position of having to ask Marie what was going on at a time when trust between them was at a low ebb. Jeff did not know whether what Marie told him about her condition was true, or whether he was being used. Their marital relationship was weakened instead of supported. Earlier inclusion of the spouse and allowing them both to express their frustrations together may have helped. The physician can moderate renegotiation of their altered relationship during the illness on an equal basis.

The sense of role loss and Marie's and Jeff's feelings of being overburdened could have been predicted.[4] An appropriate time for assembling the family to deal with the chronic illness was reached when it became apparent that these role changes would not be temporary.[3] Periodic meetings with the family to set expectations about how difficult the future will be and what the ill person can and cannot do with respect to his or her usual duties and responsibilities can be helpful in preserving the ill person's sense of being wanted and needed.[4] The destructive effect of role loss can be minimized by redefining a role that is still important and satisfying to the disabled person. The physician can bolster hope by stating his or her confidence in the family's ability to cope.

There were several times in this case when it would have been appropriate to broaden the scope of medical care given to this family. The complaints of problems in the marriage partnership, the delayed developmental stages in the son, and the loss of a career and second income were all signs of major family side effects this illness was producing. The services of a marriage counselor or family therapist could have helped bridge some of the communication problems. Family dissolution fortunately did not occur in this case, but such families are at high risk for divorce.[5] A social work referral may have helped this couple deal with the worker's compensation system, which was neglected as a potential resource. Child care was provided intermittently by the extended family, but the couple may have obtained more relief and regular support in parenting from a day-care center so that both children may have felt more secure.

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