
Family Practice Grand Rounds

Rehabilitation of a Young Quadriplegic: A Team Approach

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DR. GLENYS WILLIAMS (*Assistant Professor, Department of Family Practice*): In Grand Rounds today, we will present to you the story of a young man with spinal cord injury, who had been living in nursing homes for ten years. Participating in the discussion will be members of our family practice multidisciplinary nursing home team: Dr. Michael Alexander, clinical pharmacist; Dr. William Clements, assistant professor of family practice and pastoral counselor; and Varick Olson, associate, Department of Physical Therapy. Members of the nursing home staff here today are Ms. Sally Simpson, supervisor of nursing, and Ms. Catherine Boyce, consultant social worker. We are also glad to welcome Mr. Steven Meyer, state vocational rehabilitation counselor.

The first step we took as a team was the positive decision to make an all-out effort to rehabilitate this young man. Today, we will present the prob-

lems that faced us, and tell you how we tackled them. Then we will show an interview with the patient on videotape.

On April 21, 1967, when Bob was 20, he was driving to work in a car with a friend. They hit a truck and his friend was killed; Bob had lacerations of his face and head, severe pain in his neck, and he was confused. His fifth cervical vertebra had been broken into two fragments; it was displaced posteriorly in relation to the sixth cervical vertebra.

He had become a quadriplegic with irreparable spinal cord damage. For days in the Intensive Care Unit he was critically ill. Because he had a high sympathectomy and increased vagal tone, he had very low blood pressure and slow pulse. He had hypovolemia, and his urine output was drastically reduced. Tidal drainage was used to control his bladder. On the third day he developed a stress ulcer, which bled. He had attacks of hyperventilation, apnea, and laryngeal spasms; a tracheostomy was done. He developed pneumonia, and atelectasis, and he was not doing well at all. He was losing considerable weight. All this time he had Crutchfield tongs attached to the skull with

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weights of 35 lbs to keep his neck in alignment. After a month it was decided to do a fusion of his spinal column with a bone graft from the right iliac crest.

Since then he has had many complications related to his injury. The urine became infected, uncontrollably, and a permanent suprapubic cystostomy was created. Stones formed in the bladder and kidney, which had to be removed. On one occasion there was such uncontrollable hemorrhage that the hypogastric artery had to be ligated.

Later he developed multiple decubitus ulcers which necessitated debridement, excision of necrotic ischium, and skin grafts. Because of continual fecal soiling the ischial tuberosity would not heal, so a permanent transverse colostomy was formed. Not surprisingly, Bob was depressed. He had been in University Hospital for over a year, and after discharge had repeated readmissions. He went to a rehabilitation center, and then to live in a succession of nursing homes.

Finally, he went to the Care Center, and this was where we met him, 11 years after the accident, at age 31. He lay in bed, doing practically nothing, frequently with the sheet pulled over his face. He had marked flexion contractures. There was a part-time social worker, no physical therapy, regular visits to the Department of Urology, and his condition was deteriorating.

MR. VARICK OLSON (*Associate, Department of Physical Therapy*): I worked with Bob in 1968, when he was in the rehabilitation ward here. He had severe problems with blood pressure, and could not tolerate an upright position; even though we used a tilt table, he could not stand on it for more than 10 to 15 minutes at a time. He also had severe extensor spasticity and would arch over the back of his wheelchair, so it was decided to get him a reclining back chair, which has a taller back than most conventional chairs. Range of motion exercises were administered daily. When he left to go home, he had no severe contractures but he could not help transfer himself, or dress himself, and it also seemed as though he did not really want to help in dressing. He could propel his wheelchair once he was in it, but he could not sit for a long period of time.

I did not see Bob again until 1972, while I was visiting the nursing home where he lived. He still did not have very much independence. He could propel his old 1968 wheelchair to some degree

around the nursing home but not as well as before, since a left elbow contracture was developing.

By March 1977, when I saw him next, his left elbow was so severely contracted that he could not propel his wheelchair. He also had an essentially immobile left hand, both feet were contracted in plantar flexion; he had pressure sores on the malleoli of both feet; and he had not been out of bed for three months for fear that he would have a breakdown over one of the old pressure sore areas. His old wheelchair was so dilapidated it was difficult even for anyone with normal strength to propel the chair, and he did not have an adequate cushion.

Obviously, we really missed the boat over follow-up care, both when Bob left the original rehabilitation center and each time he moved. There was no communication from one staff to the next, and I am sure that this has influenced his mood and his attitudes.

MS. SALLY SIMPSON (*Director of Nursing, Care Center*): We received Bob in February 1974. He was more of a hermit than he is now. His main interests were sleeping, watching television, and some reading. We tried many, many times to get him to sit up for long periods of time, but we had much difficulty because of frequent decubiti either on his ankles or his buttocks. The permanent colostomy helped considerably in his care. We still had the same problems with the skin, and turning him was a big problem. We tried to get him to sit up for at least an hour or two a day, and then tried increasing this. Just when we would get him up to about five hours a day, we would have another break.

He came to the Care Center from a nursing home where he had a girlfriend, also a quadriplegic, to whom he was very attached; he was very upset about leaving that home. They were in hopes that both of them could be brought to the same Care Center. So again, he had met another disappointment in his life. He had found somebody who was similar to him, somebody he could communicate with about the same problems, but now he was cut off from her also. He became very dependent on the staff.

We tried to encourage him about doing some things through the community college, but he was not interested in furthering his education. We had various people who were in situations similar to his talk to him about going on to school, but could

not get him interested until family practice came. He has since become interested in going out to play bingo; a lot of the staff members have taken him out to movies and he has become a member of the Jaycees.

I think the biggest problem we have encountered with Bob is probably that, as a Care Center primarily for the elderly, we have found it very difficult to do the things for him that we would like to do. We are not staffed or equipped to rehabilitate him as we would like to.

DR. WILLIAM CLEMENTS (*Pastoral Counselor, Department of Family Practice*): My goal in the time that I have with you is to try to make comprehensible what is essentially incomprehensible, and to do it in just a few minutes. I think the injury received by the patient here constitutes a close approximation of the ultimate insult to personality, to self-definition. It occurred to him right at the point of young adulthood.

I want to point out a few things that appear obvious, but I think bear our attention. Not only did Bob lose physical functioning, not only did he lose his ability to perform ordinary self-care activities that we take for granted; he also apparently lost the ability to define himself as a worthwhile person in the process of these other losses. In the process he lost the ability to establish goals and to participate in activities in which he experienced significant personal investment. Essentially, I saw Bob as a person who was left with only a kernel or a core of selfhood as his sole possession. The one thing that he did not lose throughout this experience was his capacity for awareness, for self-conscious reflection. He did not lose the ability to perceive; he did not lose the ability to emote; he did not lose the ability to think; and he was self-consciously reflective. I think only the most mature person imaginable could accept this core of consciousness as the basis of selfhood. Bob was 20 years old when this accident happened; he was not a reflective, mature person. He did not start off way up there as a self-actualized person and then deal with this loss. He had never really thought seriously about his identity or many other important issues.

I think the decade-long process that you are seeing and hearing about this evening involves Bob's experience of being stripped involuntarily of his identity—he lost his identity as a person who could actively do things. We see him initially as a

person who has restructured his identity around a helpless, hopeless role, a person who did not have the hope that he could do something for himself.

DR. WILLIAMS: After Bob's case had been presented twice at team staff meetings, and it had become obvious that his mental and physical condition were gradually deteriorating, a unanimous decision was made to seek rehabilitation for Bob. His own attitude was initially unenthusiastic, since he had had so many disappointments and his original rehabilitation had been less than successful. But he had matured, and as the team went ahead with plans, he gradually became enthusiastic. Finally he went to the Spinal Injuries Rehabilitation Center where he spent four months.

DR. MICHAEL M. ALEXANDER (*Clinical Pharmacist, Family Practice Center*): The medications which Bob received prior to his time at the center, and upon subsequent return to the nursing home were similar. Bob's adjunctive antispasmodic medications were switched from dantrolene sodium 25 mg twice a day and diazepam 5 mg three times a day, to baclofen 20 mg three times a day and diazepam 5 mg twice a day and 10 mg twice a day on an alternating schedule.

The alteration in Bob's antispasmodic medications, used to facilitate physical therapy and training, may have been the result of the rehabilitation center's preference or previous clinical experience. Both dantrolene sodium and baclofen may be indicated for the symptomatic control of flexor spasm and hypertonia associated with spinal cord injury in nonambulatory patients. There is a lack of literature comparing the efficacy of baclofen and dantrolene sodium and the concurrent use of diazepam with baclofen in the symptomatic treatment of spinal cord lesion sequelae. Dantrolene sodium administered concurrently with diazepam has been associated with a synergistic effect and a possible decreased dosage of each agent.¹

Dantrolene sodium is a hydantoin derivative which appears to act on the contractile mechanism of skeletal muscle to decrease the force of contraction. A decrease in the amount of calcium released from the sarcoplasmic reticulum is the proposed mechanism of action. The small intestine and colon accounts for most of the 25 percent absorption of an oral dose. The drug is 80 percent liver metabolized and has a reported half-life of eight to nine hours.^{2,3}

Baclofen is structurally similar to gamma

aminobutyric acid. In addition to flexor spasm and hypertonia, baclofen may be a useful adjunct in bladder spasms and treatment of voiding difficulty.⁴ The mechanism of action has not been fully elucidated. Baclofen appears to act within the spinal cord to increase the flexor reflex threshold by reducing monosynaptic reflex arc excitability.⁵⁻⁸

Baclofen is well absorbed with peak blood concentrations occurring two hours after a dose. The drug is 30 percent protein bound with a half-life of three to four hours, and 85 percent of a dose is excreted unchanged in the urine.^{7,8} Decreased absorption in dosages above 20 mg may result in disproportionately smaller increases in baclofen concentrations.

Baclofen should be used cautiously in patients with peptic ulcer disease, psychiatric disturbances, predisposition to seizure disorders, and in patients receiving antihypertensive therapy. The most common side effects for which we are monitoring include: nausea, vomiting, drowsiness, postural hypotension, rashes, pruritus, sleep disorders, and leg edema. These unwanted effects may be minimized by gradually increasing the daily baclofen dose. Other side effects such as confusion, euphoria, and depression may limit individual dosing. Hallucinations, increased muscle weakness, and a possible rebound have been observed upon sudden baclofen withdrawal.^{5,9-11} In contrast to dantrolene sodium, baclofen has not been associated with hepatotoxicity.

In summary, Bob's antispasmodic therapy appears to be decreasing his flexor spasticity and hypertonia. This medication program may have reduced the spasticity which often interferes with therapeutic exercise programs, transfer maneuvers, posture, and activities associated with adult daily living.

MR. STEVEN MEYER (*State Vocational Rehabilitation Counselor*): Once we had made the decision to send Bob to the Spinal Injuries Center for evaluation, we had to overcome all the financial barriers associated with this evaluation.

The first people we contacted were at Medicaid, as Bob had been a SSDI recipient for over ten years and they were the ones who were covering most of his expenses at the Care Center. They agreed to pay for the hospitalization and doctors' fees at the Spinal Injuries Center, which obviously took care of the major expenses. This left us with many minor expenses, since they would not pay

for his transportation out there, nor for any prosthetic devices purchased for Bob while he was there; and they would also not pay for his room at the Care Center while he was away.

The transportation out became somewhat complicated in that the airlines required Bob to have an attendant both going out and coming back. Since Medicaid would not pay for this, and Bob did not have the funds himself, we went to Social Services in the county, which at first refused, saying they did not have the money for this. This was later reversed by their county board of supervisors. Once we got funds for the transportation, we still had the immediate problem of transporting Bob from the Care Center to the airport, which was somewhat difficult due to the time of year. We were concerned about his sitting up too long, and his ulcer breaking down. There was much concern about liability in transferring him in the middle of a blizzard, so we decided to transport him by ambulance and the family did pay for this part of the cost.

We felt that the room at the Care Center should be reserved for him in order to have a place to return to. We contacted the local Jaycees, and they agreed to take this on as a special project and cover his room costs.

This left only the matter of the prosthetic devices, which my agency (State Vocational Rehabilitation) was able to cover. Of the devices that the Spinal Injuries Center recommended for purchase, probably the least expensive and the most critical, was an item called the Roho cushion. This allowed Bob to sit up almost immediately six hours at a time. Previously, he was only able to sit up for 30 minutes to two hours before having difficulties. The other items we were able to purchase included an electric wheelchair, and a manual wheelchair, which we felt were very important. The electric wheelchair is useful but cumbersome; it cannot be put in a car, nor used to get into a restaurant; the manual wheelchair will give him great flexibility. In addition to this we were able to purchase a shower chair and a pair of Amboots. The boots were deerskin lined in order to limit pressure which could cause sores on his feet.

I have figured out what everything cost because I was concerned and interested. The air transportation was \$500; the ambulance was \$100; reserving the nursing home room, \$2,400; prosthetic devices, \$3,500; and the total Spinal Injuries Center

bill, \$25,000. This whole program of about three months ended up costing around \$32,000, which is quite a substantial cost, especially when you take an individual who has no income whatsoever. The point I am trying to make is that, even with that amount of cost, although it was difficult, it was something that could be done.

Finally, I feel this is really just the beginning for Bob. He is going to another facility in a couple of months, to Camp Courage in Minneapolis, and we hope that he will eventually be in a situation where he will be able to work, possibly in a sheltered activity, and live in a semi-independent living situation. So I look at this as more of a beginning for him than anything else that has happened up to now.

MS. SIMPSON: He has come a long way; I think he still has a long way to go. His mental attitude has changed considerably. He seems to have a little more fight now, and I think this is one of the main things that we have to work with.

DR. CLEMENTS: In the gradual growth in the past year, an identity has developed of a person with ideas, with abilities which can be utilized for purposeful activity, for goal directed activity.

I have not seen Bob since he has returned, but I assume an element which must be very crucial in his development is a renewed capacity to focus on what he can do instead of what he cannot do. We could talk for hours about what Bob cannot do, but apparently he has developed the capacity to think about what he can do and to develop that capacity. This means he can set goals for himself, he can experience himself as making progress. This means that the life process can become meaningful for him; he can move toward achieving something that he has defined for himself.

MS. CATHERINE BOYCE (*Consultant social worker*): Being the member of our team designated to accompany Bob to Denver, I was able to spend several days touring Craig Hospital. Today, I would like to present a comparison of the services that were available to Bob at Craig Hospital with those that are available at the nursing home, and to emphasize the extreme importance of careful selection and re-evaluation of all services available to physically disabled individuals.

As the panel has pointed out, a person who becomes physically disabled must learn to cope with many changes in his life, and must make numerous emotional adjustments. When hospital discharge is

near, his worries are greatly increased. "Where do I go from here?" "Would further therapy help me?" "How will I get further help?" Professionals assisting the client at that time must be able to present all available rehabilitative services and, when needed, alternative residential settings.

Usually, referrals are made to rehabilitation centers immediately following the initial hospital discharge. However, if rehabilitation is not completely successful, as in Bob's case, two options are available. Either the patient returns to his home, receiving assistance from family or friends, or placement is sought in a nursing facility. In both environments the availability of further rehabilitation services is usually minimal. A unique atmosphere is required for successful rehabilitation of the spinal injured patient. Caring for just the physical needs is not enough; an ideal setting must include provisions for mental as well as physical stimulation.

When initially discussing his possible transfer to Craig, Bob asked some very pertinent questions: "Why do I have to go all the way to Denver to get the services I need? Couldn't you get the services to come here to the nursing home?" The answers to these questions emphasize the difference in available care in residential settings. Nursing care facilities are not equipped to provide for more than the patient's physical needs. Special spinal injury centers provide both nursing care and rehabilitation services. The staff/resident ratio greatly influences the amount of care that can be provided, and most nursing centers have limited staff. The Care Center follows state regulations, having a ratio of one aide for each 10 residents and one nurse for 63 residents. While the Care Center does have physical and occupational therapists, and a social worker on the staff, our hours are very limited. Craig Hospital, on the other hand, has optimal conditions. With a population of 70 residents, the care ratio is one aide for five residents, one nurse for ten residents, and one physician for 14 residents. Each resident has an assigned physical therapist, occupational therapist, and counselor, and residents receive therapy continually throughout the day.

Motivation towards rehabilitation of the patient is greatly affected by the stimulation he receives in his environment. At the nursing home he was surrounded by a population of individuals over 70 years of age and the activities were mainly de-

signed for the elderly. Most of the residents considered their placement to be permanent. At Craig Hospital, the entire population was under 35 years old, all having disabilities similar to Bob's, and all activities were designed for a young population. He was able to witness improvement and see others return home, which provided him with a great source of motivation.

When you are assessing a spinal injured client's potential for rehabilitation and presenting supportive services, a thorough examination of all alternatives is vital. Follow-up on his status must be continuous. If initial rehabilitation is not successful, wait awhile and reassess. Do not let your patient vegetate. As with Bob, sometimes potential for rehabilitation is hidden and must be encouraged.

DR. DENNIS BACKSTROM (*Second year family practice resident*): Why could this not have been done ten years ago? Surely there were many rehabilitation units where war wounded were treated?

DR. WILLIAMS: Bob's initial rehabilitation was at a unit attached to a general hospital and by a staff who dealt with few quadriplegics. Experience worldwide has shown that by far the best care for the spinal injured patient is in a special spinal injuries center by a team of specialists headed by a paraplegist.¹²⁻¹⁴ These have been set up all over the United States since World War II.*

To close we will show you a videotape of a recent conversation between Bob and myself.

DR. WILLIAMS: I want to ask you a few questions about how things seem to you now. How has life changed since you went to the Rehabilitation Center?

*Spain Rehabilitation Center
 Birmingham, Alabama
 Good Samaritan Hospital and
 St. Joseph's Hospital, Phoenix, Arizona
 Santa Clara Valley Medical Center
 San Jose, California
 Rancho Los Amigos Hospital, Downey, California
 Craig Rehabilitation Hospital
 Englewood, Colorado
 Northwestern Memorial Hospital and
 Rehabilitation Institute of Chicago
 Chicago, Illinois
 University of Minnesota, Minneapolis
 Institute of Rehabilitation Medicine, New York, New York
 Texas Institute for Rehabilitation and Research
 Houston
 Woodrow Wilson Rehabilitation Center
 Fishersville, Virginia
 Department of Rehabilitation Medicine
 University of Washington, Seattle

BOB: Before, I was getting up about a half hour a day because of the bed sores and I hardly ever dressed. Now I get up right around 6:00, dress, and usually I'm up 10 to 15 hours a day.

DR. WILLIAMS: I hear you learned a lot. Can you tell me what new skills you have learned?

BOB: I can brush my teeth, brush my hair, and shave myself.

DR. WILLIAMS: Could you shave yourself before?

BOB: I used to let them shave me.

DR. WILLIAMS: What was the most difficult thing about leaving the Care Center and going to the Rehabilitation Center?

BOB: Being away from my family. I got pretty homesick, but I was around a lot of younger people and that helped.

DR. WILLIAMS: Did it help seeing other people who had the same difficulties you have?

BOB: It helped me to realize that there are people worse off than I am, and I didn't feel sorry for myself, as I did before.

DR. WILLIAMS: What has been the most difficult thing about coming back? I don't imagine it has been very easy.

BOB: Going back to the nursing home, I guess. I like it at the nursing home; it's a good place, and I like the people there, but they are all old people.

DR. WILLIAMS: Did you have any goals before you went to the Rehabilitation Center, or any plans for your future? Do you remember when you said you more or less gave up?

BOB: I did give up. I just let everybody do everything for me. I didn't even push my own wheelchair; they were doing all my dressing and everything. About the only thing I was doing for myself was feeding myself and using the remote control on the television. Otherwise I was letting everybody else do everything for me.

DR. WILLIAMS: How do you feel now that you are doing more for yourself?

BOB: I feel more independent and I want to be more independent. Otherwise I'm afraid I'll go backwards instead of forward.

DR. WILLIAMS: Is there anything that you would like to say to the people who are looking after a person like yourself that you think would help?

BOB: Tell a person "You try it, do the best you can, and if you are unable to do it I'll give you a hand." My mom would say, "I can put your shirts

on better than you can, easier and faster." Never tell a person that. Let the person do what they can for themselves first and if they can't do it, then help them. Once you take the independence away from a person, the reason for living really goes way down.

DR. WILLIAMS: Do you have a reason for living now?

BOB: I doubt that I will get married, but I think I can help other people.

DR. WILLIAMS: That's great, Bob, thank you.

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