

## Rehabilitation in a Rural Setting of a Young Quadriplegic Accident Victim

INTEGRATIVE CLINICOPATHOLOGICAL CONFERENCE:  
MEDICAL, PSYCHOSOCIAL, ECONOMIC, PREVENTIVE, AND  
ETHICAL DIMENSIONS OF A CASE STUDY

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Problems encountered by a young, unmarried woman who, as a result of a spinal injury in an automobile accident, loses use of all four limbs and requires complex home health care services delivered by a network of health and social service agencies in a rural area of Kentucky. Economic, psychosocial, ethical, preventive, and medical aspects of health care are discussed.

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JOHN S. THOMPSON, M.D. (*Chairman, Department of Medicine, Moderator*): Today's conference considers a 22-year-old, unmarried woman who sustained a spinal injury in an automobile accident three years ago. The case will be presented by Dr. Flanigan.

ROBERT C. FLANIGAN, M.D. (*Associate Professor, Department of Surgery*): I will present a brief summary of this patient's medical history for the three years following her accident. This 19-year-old woman was driving alone on a state highway near her home in a rural area of Kentucky when she lost control of the car and was thrown from the vehicle when it left the road. She never lost consciousness and became immediately aware that she could not move her arms or legs. She was transferred to the emergency room of a local hospital reporting pain in the back of her head and neck, and inability to move her extremities.

Her injuries were initially diagnosed as a subluxation of the C4-5, C5-6 vertebrae with the compression fracture of a lumbar vertebra 4-5. She was transferred to the neurosurgery service at the University of Kentucky Medical Center. Upon admission to the neurosurgical intensive care unit, the primary problem of hypotension, which was felt to be secondary to her loss of sympathetic tone, was treated by volume expansion with isoproterenol hydrochloride infusion. Her condition stabilized after a

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period of several hours. Polytomographic X-rays of the spine confirmed the earlier diagnosis of spinal injury. A cervical fusion was then performed because of the suspicion that her cervical injuries were unstable. Urinary tract and pulmonary problems were treated during her two-month stay at the University of Kentucky hospital. She was managed with constant gravity urinary drainage by Foley catheter. Several urinary infections were resolved with antibiotic therapy. She developed pneumonia and required a tracheostomy on her twenty-seventh day of hospitalization.

Two months after the injury she was transferred to another hospital for more intensive rehabilitation. There she learned sterile intermittent catheterization and undertook more strenuous physical therapy. About two weeks after admission to this hospital (2½ months after her injury) the transition from the shock phase of spinal injury was marked by the onset of spasms in her lower extremities and bladder. She was treated with skeletal muscle relaxants, baclofen, and valium. Six months after her injury there was an episode of sepsis secondary to *E. coli* urinary tract infection, which was effectively treated with gentamycin. About a month later she experienced symptoms of headache, bladder spasms, and urinary incontinence. These symptoms suggested the possibility of autonomic dysreflexia, but further tests at the University of Kentucky could find no evidence to support this diagnosis. Approximately eight months after her injury she was again admitted to the rehabilitation hospital for training in the use of an electric wheelchair.

At the present time, three years after her accident, she is periodically seen in our neurosurgery and urology outpatient clinics. From a medical point of view she is doing quite well, though she has had two documented urinary tract infections during this period. From the point of view of rehabilitation she is able to move herself around in her electric wheelchair and is very proud of this and other accomplishments.

It is worth noting that about 10,000 spinal injuries are sustained in the United States each year. About half of these injuries result in quadriplegia, and half in paraplegia [1, 2]. These injuries result in enormous costs to the involved families and to our society.

DR. THOMPSON: The home environment from which this patient came, and psychosocial aspects of this case, will be discussed by Ms. Betty Lewis.

MS. BETTY R. LEWIS (*Northern Kentucky Home Health Agency*): The patient was referred to our agency by the rehabilitation hospital four months after the accident, when she was about to be returned to her family for a short Christmas holiday visit. The agency provided a hospital bed for the visit and made preliminary assessments of future equipment and supply needs. Final discharge from the rehabilitation hospital occurred three months later.

At the time of the accident Cathy was 19 years old and lived with her family: mother, age 37, a homemaker; her father, age 41; two brothers age 18 and 20; two sisters, one age 12 and the other 17. The father was a construction worker, and the patient worked part-time in a neighboring town. The family owned their two-room house, located 25 yards up a steep bank just off a highway. The front door of the house opened into a living room/kitchen, with the sleeping area for the parents partitioned off by a curtain at one end. The back room was also divided by a curtain with the girls sleeping on one side and the boys sleeping on the other. The house had no plumbing except cold water piped directly from a spring to an automatic washing machine

located in the boys' sleeping area, and to an outside spigot. A gas stove provided heat, and there was an electric stove for cooking. There was an outside toilet.

The individuals in this close-knit family unit were attractive, well-groomed, soft-spoken, rather guarded in their response to inquiries. Though tense, anxious, and uncertain, they were unified in their commitment to Cathy; the father resigned his job in order to assist with her care.

The accident and disablement of this young woman touched the community, and many fund-raising activities were organized. There were donations by church groups, community organizations, individuals, bake sales, candy sales, and a special benefit gospel sing which was well attended.

The patient received approval for supplemental security income on disability criteria. She responded well to the rehabilitation and excelled in typing using a pencil fastened to a splint. The plan was for the patient to do bookkeeping in her home in order to become financially independent. The Bureau of Rehabilitation Services provided caretaker services for six weeks, and ordered an electric wheelchair, a hospital bed, a shower chair, a Hoyer lift, boxes of supplies, an office desk, several office machines, and a telephone recording system with loudspeaker. These supplies were placed in the living room/kitchen area of the small, already crowded home. There was an immediate need for more space. A driveway to the house was also desperately needed to allow the patient to be moved up and down the steep bank.

The community was mobilized to build a driveway, install a septic tank, plumb the house, and build another room. The labor was free, much material was donated, and the family paid for some of the supplies.

Cathy's first months at home required difficult adjustments for everyone. Lexington physicians encouraged local physician follow-up, but the patient and family lacked confidence in local services and made repeated trips to the Medical Center emergency room for urinary tract infections, autonomic dysreflexia episodes, and fevers. Any change would precipitate panic and a trip to Lexington.

Symptoms of family dysfunction began to appear before long. Financial difficulties increased as rehabilitation coverage for caretaker, special telephone, and medicine ended. At the same time the patient became more demanding, angry, resentful, and difficult to please. As coping strengths weakened, a home health aide was assigned to assist with daily personal care. A small allowance for caretaker services was approved by Medical Assistance to hire a caretaker for a few hours a day, two days a week, to give the family short periods of rest.

Serious conflict arose between the family and a sister, the senior in high school. She had turned 18 and was in need of nurturing through her identity crisis at a time when all of the family's emotional energies were invested in the disabled family member. She moved to her maternal aunt's house, thereby estranging herself from the family. She graduated from high school without her immediate family in attendance. The aunt helped her enroll in a vocational program, but she did not stay, got heavily involved in drugs, disappeared for a time, and was hospitalized after a drug overdose. She is now back under medication with her aunt but unable to function in any meaningful way. The family does not like her name mentioned and has removed her pictures. She has made several attempts at reconciliations but everyone except the mother rejects her.

A familial pattern of blaming has emerged. The patient claims that there was a bad place in the road which caused the accident, and that the state repaired it before a law

suit could be filed. The father complains that employers treat him unfairly. The sister, the family says, never could get along with them and is "no good." Many of the patient's physical difficulties are attributed to unskilled medical personnel. Cathy said recently, "They let me lay in a mess at the hospital and now I've come home with an infection." The family tends to be defensive, often providing barely enough information to enable service renderers to identify specific needs. All this alienates helpers.

Still, there have been significant, constructive changes. The client with all her equipment is in her own room, a room with its own entrance. There is a solid gravel driveway to the front door. Indoor plumbing, septic tank, bathroom facilities, hot water heater, air conditioner, and dishwasher have been installed. The other rooms are partitioned now. New windows, doors, ceilings, roof and siding have been installed. A bathtub was recently installed.

Cathy is enrolled in a physical therapy program at the local hospital, to which she is transported once a week by a volunteer, and twice a week by the family. At home, with the help of the part-time caretaker, she utilizes her office equipment to keep household accounts in order. For the first time since the accident, Cathy is willing to involve herself with the community. The family has become actively involved in a church. They all attend local ball games together and have even gone to a public swimming pool.

There are still, however, problems tentatively recognized but not faced. Cathy needs to focus more on the needs of individuals around her. Cathy's primary caregiver, her mother, is exhausted most of the time, yet Cathy will not allow anyone else to do personal tasks like catheterization and bowel care. The younger brother, now age 21, remains in attendance on her at all times. He makes no progress in accomplishing developmental tasks such as dating, finding a mate, having outside social relationships, and developing vocational skills. He is attached to Cathy, washes her hair, takes her places. The younger sister had difficulties the first year of high school. With a decline in grades and much absenteeism, she is at risk. The father seems somewhat passive but there is solid strength in the consistent alliance which exists between him and the patient. There is still the estrangement with the aunt and sister. We hope, with the gains over the past few months, we can begin to deal with these potentially explosive issues.

DR. THOMPSON: I would like to ask how this patient compares to other paraplegic or quadriplegic cases with which you may have had experience in this kind of family setting.

MS. LEWIS: On the positive side, her nuclear family is remarkably supportive, though there is a lack of extrafamilial support. On the negative side, Cathy has greater than usual problems resolving issues of dependence and independence. She needs more opportunity for outside social experiences.

QUESTION FROM AUDIENCE: Have social work interventions been able to help with the other children?

MS. LEWIS: Alas, no.

DR. THOMPSON: Dr. Neill, is this situation likely to be destructive to the family?

JOHN R. NEILL, M.D. (*Department of Psychiatry*): I worry about the youngest child. I see Cathy as a kind of giant power sink that is draining the whole family. That can't go on forever.

DR. THOMPSON: Ms. Lewis, would you comment on the rural health network that supports these types of patients.

JOYCE A. LEWIS, R.N. (*Coordinator, Northern Kentucky Home Health Services*): The integration of services in this patient's care worked well because of the close cooperation between the Medical Center and our agency, and in particular to the effective discharge planning: planning for what needs to be done when the patient arrives at home. I can give a negative example: a diabetic patient with a gastrostomy and a J-tube who arrived a few months ago from another hospital. The patient did not know what to do with the tubes and could not administer insulin to himself because he was blind. He called on us to help but it took 48 hours to obtain the information needed to help him. When communication in the health network fails, the patient suffers; care is delayed.

DR. THOMPSON: One thing that seems readily apparent is that this patient's medical care has been and probably will remain expensive. To address this issue, we have invited Professor Glenn Blomquist to provide an economic analysis of the case.

GLENN C. BLOMQUIST (*Associate Professor, Department of Economics, College of Business and Economics*): My analysis focuses on the financial consequences of quadriplegia. I will identify the types of cost, who incurred these costs and the dollar amounts. A more complete economic analysis of quadriplegia would include certain costs that are not easily measured and which are not available to us at this time. It is prudent to remember that the costs I will address are only part of a whole which would include the psychosocial costs of the case.

I have chosen to classify costs into two categories: (1) cost within the health care system and (2) cost outside the health care system. The sum of costs within and outside the health care system then is the total social cost. I have chosen to classify the sources of payment into three categories: private (including insurance), philanthropic, and public.

First let us consider the costs within the health care system incurred during hospitalization and rehabilitation after the automobile accident. (We are indebted to Julia Costich and Carolyn Bacdayan for assembling the economic data reported in this case.) These costs were available for the first 29 months of care following the accident and are shown in Table 1. Included are Medical Center hospitalization costs, physician's fees, and charges from the rehabilitation hospital and the Home Health Agency. Of the known costs within the health care system, approximately \$81,000, 49 percent were financed by the Bureau of Rehabilitation Services and Medicaid, 44 percent were financed by Blue Cross/Blue Shield, and 7 percent were financed by philanthropic sources.

I would now like to discuss future costs and the concept of present value. Present value takes into account the opportunity to invest at some interest rate. It follows that a dollar in hand now is worth more than a dollar to be received sometime in the future. Conversely, a future dollar is worth less and must be discounted back to the present. Of future costs for this case of quadriplegia, home health care costs would be a major portion. Based on home health care expenditures in the first 29 months, I assume that the average annual cost would be about \$8,000. With a discount (interest) rate of 10 percent, the discounted present value of future home health care costs would be approximately \$80,000; that is to say, if \$80,000 were invested with an interest rate of 10 percent, the interest would provide the annual \$8,000 needed. Adding this cost to

TABLE 1  
Costs Within the Health Care System  
First 29 Months of Care for a Case of Quadriplegia, 1980-82

Provider Total (\$)	Source of Payment (\$)		
	Public	Private	Philanthropic
Medical Center (28,117)	—	28,048	69
Physicians Foundation (4,305)	2,963	1,342	—
Rehabilitation Hospital (32,182)	20,451	6,170	5,561
Home Health Agency (16,763)	16,763	—	—
Total ( <u>\$81,367</u> )	<u>\$40,177</u>	<u>\$35,560</u>	<u>\$5,630</u>

the \$81,000 which has already been incurred, we estimate \$161,000 as the total cost of past and future health care cost related to the accident.

A major cost beyond health care is the present value to the individual of income forgone due to quadriplegia. Judging from the patient's background, I have assumed that she might have been employed as a bookkeeper or secretary and might have had a \$10,000 per year gross income. Most of the loss of this income constitutes the private part of income loss. There is, however, a public component of lost income. Based on 1982 tax rates, the public forgoes \$2,700 per year in federal income tax, Kentucky income tax, and social security taxes. The discounted present value of the future annual net income loss is \$73,000 and the present value of the lost taxes is \$27,000. The public, therefore, bears 27 percent of costs incurred outside the health delivery system. Table 2 shows the social cost of this case of quadriplegia by type and by source of payment. The total social cost then is approximately \$261,000, the sum of the cost within the health care system (\$161,000) and the cost outside the system (\$100,000). Of these total costs, 56 percent is borne by the public, 42 percent by the patient, and 2 percent by philanthropic sources.

These figures are point estimates, and there are several sources of uncertainty that should be discussed. There are other potentially large costs outside the health care system that I have not included. A factor which would increase private cost is the psychic cost to the individual. Expected forgone earnings tend to undervalue psychic costs, especially if the expected length of life decreases with quadriplegia [3]. Philanthropic cost would include community fund-raising efforts, such as church bake sales. Public costs would include expenditures for food stamps and additional public assistance to family members due to the patient's quadriplegia. Another source of uncertainty which would reduce private cost is the possibility that rehabilitation might enable the patient to gain employment in the future. An accurate estimate of costs would consider each of these factors.

In summary, the total social cost of quadriplegia for this patient is estimated at \$260,000. Of this total, 62 percent are costs within the health care system and 38 percent are costs outside the health care system. Of the total cost, 56 percent (\$148,000) are borne by the public through Medicaid, public rehabilitation services,

TABLE 2  
Total Social Cost of a Case of Quadriplegia  
(Net Present Value in 1982 Dollars)

Type of Cost	Source of Payment			Total
	Public	Private	Philanthropic	
Health care system:				
First 29 months	40,177	35,560	5,630	81,367
Future home care:				
\$8,000 per year and discounted at 10%	80,000	—	—	80,000
Forgone income:				
\$10,000 per year and discounted at 10%	26,980	73,020	—	100,000
Total social cost	\$147,157	\$108,580	\$5,630	\$261,367

home health care, and forgone tax revenue. If this case is representative of the approximately 5,000 new cases of quadriplegia each year in the United States, then about \$750 million is borne by the public annually [4,5]. This estimate may approximately answer the question about the public resources devoted to quadriplegia, but it only raises more fundamental questions about prevention, quality of life, and the best allocation of the health dollar.

DR. THOMPSON: Thank you, Dr. Blomquist. I would like Dr. Tempkin of our new Department of Rehabilitation to comment on this case.

ALAN R. TEMPKIN, M.D. (*Department of Rehabilitation*): Quadriplegics with adequate caretakers require an average of four hours a day of care [6]. Since the mother was a full-time homemaker and both sisters were in school, someone was available to provide a large part of the necessary care. It was unnecessary for the father to quit his job.

It should be pointed out that this patient is now receiving income from Social Security and Medicaid, which may be significant compared to the family income prior to the accident. This is not a prosperous family. This girl, by virtue of her accident, may be contributing significant financial resources to the family, even though she draws on their emotional and physical resources. I may be overstating this, but if she draws a lot of attention, it may well be because she is bringing in a lot of money. I find it difficult to give credence to the idea that the attention given to this young girl is wrecking the family. Certainly families affected by disabled family members do report disruption of normal family functioning [7]. At the time of the injury, the patient's brother was 19 and the sisters were 17 and 12 years of age. It is unlikely that the attention given the patient was the primary factor in the drug abuse and subsequent deterioration of one sister. In families with many more resources, children become drug abusers.

In terms of medical management, the choice of an every-four-hour bladder catheterization program causes an enormous jump in the time and resources committed to this patient's care. Many female patients are better served with an indwelling Foley catheter. In fact, about 50 percent of female patients with neurogenic bladders are treated with a Foley catheter and long-term studies have indicated that the outcome is not much different than those treated with intermittent catheterization, insofar as renal function is concerned [8]. Her recurrent autonomic dysreflexia seemed

to bring on panic visits to Lexington emergency rooms and bound her closely to the health care system. Ditropan medication might have alleviated some of this complication.

Some aspects of the medical management might have contributed to the family's increased stress, time, and expense. This might have led to an increased dependence on medical care and medical expertise. Certainly the amount of care that she took depleted family resources. This is a problem, not just with quadriplegic patients, but also with people who are elderly, people who have congestive heart failure, or anyone who has an illness that renders them disabled. It may be pointed out, 10 percent of complete quadriplegics have returned to work within three years of injury. The best predictor anyone has found for return to work after spinal cord injury is the pre-injury work history. The people who worked before injury are generally the people who worked afterward. Forty-nine percent of all spinal cord injured patients are employed, students, or homemakers within three years of injury [9]. Unfortunately, there are powerful financial disincentives for a return to work. If the patient goes back to work, his social security pension is dramatically reduced, and since so many of these patients are young and have less than a high school education, there is no financial incentive to go back to a low-paying job.

DR. THOMPSON: Thank you for your comments. This should engender some response.

MS. LEWIS: The indwelling catheter is Cathy's choice. The intermittent procedure gives her more normal feelings about herself. It is hard on her mother—a six-hour procedure each day, and severe consequences occur if the bladder gets too full.

DR. THOMPSON: Dr. Flanigan, what are the options in managing the reflex neurogenic bladder?

DR. FLANIGAN: Dr. Tempkin's points are well taken. We might have a bit of a disagreement in terms of our philosophies on catheterization procedures, however. For those who are unfamiliar with autonomic dysreflexia, very briefly, reflex neuronal arcs exist between the viscera and the spinal cord. For example, the bladder, when stimulated, causes a reflex impulse which is carried to the spinal cord. The reflex stimuli normally can make their way up the spinal cord and are centrally controlled in the brain and brain stem. If a person suffers a spinal cord lesion about the level of the sympathetic nervous system—paraspinal at (T<sub>10</sub>–L<sub>1</sub> level)—these impulses may be blocked from normal central propagation and therefore may result in uncontrolled sympathetic release. During bladder filling, e.g., in the course of a cystogram or cystoscopy, or upon rectal stimulation, these patients may have tremendous elevation in blood pressure, flushing, and tachycardia with reflex bradycardia. In some cases this can be lethal. So, as Dr. Tempkin suggests, one thing which may reduce this possibility is making the bladder more of a reservoir using an antiparasympathomimetic agent. This woman was on ditropan for a time, so some precautions were taken as regards her autonomic dysreflexia.

I don't feel quite as strongly as Dr. Tempkin does about the relative usefulness of indwelling catheters as opposed to intermittent catheterization. There is conflicting information in this area and there are proponents of both approaches.

When the cord is functionally severed above the sacral spinal segments and the viability of the distal cord persists, voluntary control over detrusor and sphincter muscles is lost. In addition, bladder sensations of filling and distension become non-functional. Because the spinal reflex arcs associated with micturition are intact,



reflex contraction of the bladder occurs, but in an uncontrolled and variably efficient manner. Under these conditions factors influencing spinal reflex emptying of the bladder include the inherent detrusor tone, the duration of motor impulses, urethral resistance, and detrusor-sphincter reflex coordination [10].

During the interval of spinal shock, intermittent catheterization is the preferred treatment for the areflexic bladder. After the onset of reflex detrusor activity, various treatment modalities are possible, although, in my opinion, none is ideal. These modalities are voluntary triggering of the detrusor emptying reflex, clean intermittent catheterization, sphincterotomy, percutaneous or surgical rhizotomy, chronic suprapubic or urethral catheterization, vesicostomy, and urinary diversion.

Voluntary triggering of detrusor reflex emptying can usually be accomplished by forceful blows to the suprapubic area. This maneuver is obviously unsatisfactory for quadriplegic patients or other patients who cannot move their upper extremities. As reflex stimulation also provokes stimulation of the urethral sphincter, bladder emptying may be incomplete (requiring sphincterotomy) or may be provoked by motion (change of the patient's position), which would therefore require condom-catheterization devices.

Clean intermittent catheterization is often not feasible because of the high-pressure, low-volume bladder with early, uncontrolled, involuntary contractions characteristic of the problem under discussion, though bladder volume and an increase in the chance of dryness between catheterizations might be increased by means of anticholinergic agents (especially ditropan or probanthine). (Self-catheterization is of course not possible in patients who have complete upper-extremity paralysis.)

Sphincterotomy is the surgical interruption of the urethral-sphincter mechanisms and can be accomplished transurethrally. This converts the bladder from a "storage" organ to a "conduit" and requires condom catheterization. As such, it is unacceptable for female patients.

Rhizotomy may be accomplished percutaneously or surgically and allows for conversion of the reflex bladder and urethra to an areflexic situation. Intermittent catheterization is then required for the achievement of some degree of continence.

Chronic catheterization via the suprapubic or urethral routes is possible, but chronic infection, calculus formation, and consequent vesicoureteral reflux, pyelonephritis, and sepsis are important complications associated with the maintenance of the foreign body in the urinary tract.

Vesicostomy is easily accomplished surgically, but the position of the stoma in the lower midline of the abdomen does not allow for the application of collection devices in most patients, especially in those who must spend significant periods of time sitting in their wheelchairs, and so on.

Finally, some patients will require urinary diversion for the protection of their upper urinary tracts, the preservation of renal function, or the circumvention of unmanageable incontinence.

Because none of the above measures is satisfactory for all patients who have quadriplegia and display various degrees of associated dysfunction of the upper extremities, or anatomic variations secondary to patient sex, or associated injuries, the treatment of the quadriplegic patient's urinary dysfunction must be designed on an individual basis.

In the case of our patient, Cathy's experiences with chronic catheterization were poor while at this institution. She had four or five major urinary tract infections over a

two-month period with sepsis and a complicating lung process. With intermittent catheterization she has had only two documented infections over 2½ years.

QUESTION: If there were no family support, what would be the comparative cost if care had to be entirely provided by an institution?

DR. BLOMQUIST: If the patient were placed in a nursing home instead, the costs would probably double.

QUESTION: What is the life expectancy of this patient?

DR. FLANIGAN: Over the past 10 or 15 years there have been dramatic advances in the care of these patients, which include intermittent catheterization, improved rehabilitation, and physical therapy. I would guess that 15–20 years ago the life expectancy of spinal cord injury patients like Cathy would have been 15–20 years after their injury. Today it might be closer to what would normally be expected for Cathy if she had not had the accident.

*Dr. Marcus J. Fuhrer was invited to comment on this case. He kindly agreed to do so, and we attach his remarks.*

MARCUS J. FUHRER, Ph.D. (*Baylor Medical School, Houston, Texas*): This multi-dimensional portrayal of Cathy highlights the enormous strides that have been made in providing effective care for the person with quadriplegia. It is now possible to forestall or reverse the progression of physiological, psychological, and social problems that only a few years ago condemned most of these persons to lives of dependency and despair. Pronounced deficiencies remain, however, in the knowledge base underlying current rehabilitation services and in the manner of organizing these services. I want to highlight three shortcomings dealing with insufficient emphasis on services for families, the uneven availability of independent living services, and the need for better evidence of the cost-effectiveness of a systems approach to service delivery.

Current reimbursement practices encourage a concentration of services on the patient as an individual and not on the person's family unit. Families represent a paramount resource for helping patients to achieve their rehabilitation goals, but only if the other family members receive needed assistance in adjusting to the disability. Additional services for Cathy's family might have included vocational retraining and job placement for her father, vocational counseling for her brother, and intensive personal counseling with her younger sister. The expected benefits of such services would be a better and more sustained rehabilitation outcome for Cathy, enhanced normalization of the lives of the other family members, and consequently less likelihood that the destructive psychological effects of Cathy's disability would be transmitted to future generations.

Cathy apparently did not receive services from an "independent living program." Managed for the most part by persons with disabilities, the objectives of these community-based programs are to assist persons with disabilities to have more control over their own lives and to be less dependent on others. Independent living programs serve as referral sources or as direct providers of a variety of services which may include peer counseling, assistance in the recruitment, training, and provision of personal attendants, help with equipment selection and repair, information about goods and services relevant to independent living, advocacy or political action, social-recreational services, and assistance with transportation.

An independent living program would not likely be found in Cathy's vicinity.

According to a survey conducted by the Independent Living Research Utilization Project of The Institute for Rehabilitation and Research, only six of 120 independent living programs in this country are located in rural areas. This maldistribution of resources underscores the importance of recently initiated efforts to demonstrate how existing outreach networks in rural areas can be exploited to provide independent living services.

Dr. Blomquist has carefully summarized the cost implications of Cathy's past, present, and future circumstances. His analysis could be importantly augmented by a multi-year study of the actual costs experienced by Cathy and her family as well as by public and philanthropic sources of support. Such data are conspicuously lacking for representative groups of persons with spinal cord injury who have received different patterns of service.

One approach to service delivery is provided by the model "regional spinal cord injury systems" supported by the National Institute of Handicapped Research. These regional systems—there are now 20 of them—provide comprehensive, multi-disciplinary services, beginning with the retrieval of the patient from the accident scene, continuing throughout the acute and restorative medical phases of care, and extending to independent living and medical follow-up services. The present systems are capable of caring for no more than 20 percent of the persons who incur spinal cord injury each year. Before the network of systems is expanded, it would be crucial to demonstrate that they are more cost-effective than less organized approaches to care. Systematic cost data of the kind provided by Dr. Blomquist will be a key component of the requisite studies.

DR. THOMPSON: To summarize, we have reviewed the case of a 19-year-old girl from rural Kentucky who became quadriplegic because of injury to the cervical spine and cord suffered in a single car accident. In the course of the three years since that event she has been hospitalized on numerous occasions for urinary tract infections, pneumonia, severe muscle cramps, and rehabilitation.

Although there have been recurrent medical problems, she has responded reasonably well from a physical point of view. On the other hand, the emotional impact on the patient and her family has been enormous. As a consequence of the financial support and guidance from the state and civic agencies, the patient has literally become the focal center of all family activities. The financial assistance to date is considerable; thus, she has become the principal "bread earner" for the family. One consequence is major improvements to the home, which include internal plumbing, a dishwasher, an air conditioner, and a driveway.

In many ways the family has become as dependent upon the patient as she is upon them, creating a strong disincentive for patient and family members to turn to productive occupations. Whether or not the patient and her family will ever become more self-reliant is unknown at this time. The supportive medical and rehabilitative care has provided her with the potential for self-reliance, but the money and attentions so provided may now be the indirect cause of the failure to continue to make progress toward this goal. Dr. Fuhrer has reviewed this case and points out that new approaches to reimbursement and "independent living programs" are becoming available in some regions of the country to create greater incentives to independence. At this time these programs are not available to our patient, and we may be witnessing the middle stages of the dissolution of a formerly low-income but independent rural family.

## REFERENCES

1. Gehrig R, Michaelis LS: Statistics of acute paraplegia and tetraplegia on a national scale. *Paraplegia* 6:93, 1968
2. Krus JF: Epidemiologic features of head and spinal cord injury. *Adv in Neurol* 19:261, 1978
3. Blomquist G: Estimating the Value of Life and Safety: Recent Developments. In *The Value of Life and Safety*. By MW Jones-Lee. New York, North Holland Publishing Co, 1982
4. Kalsbeek WD, et al: The National Head and Spinal Cord Injury Survey: Major Findings. *J Neurosurgery* 53:S30, 1980
5. Hamilton BB, et al: A Basic Evaluation Framework for Spinal Cord Injury Care Systems. *Paraplegia* 14(1): 87-94, 1976
6. Young JS, et al: Experience of the regional spinal cord injury systems. *Spinal cord injury statistics*. Good Samaritan Medical Center, Phoenix, Arizona, August 1982, p 49
7. Trieschmann RB: *Spinal cord injuries: psychological, social, and vocational adjustment*. Elmsford, New York, Pergamon Press, 1980, p 30
8. Price M, et al: Renal function in patients with spinal cord injury. *Arch Phys Med Rehab* 56:76-79, 1975
9. Young JS: Spinal cord injury statistics. *Arch Phys Med Rehab* 56:57, 1975
10. Lapides J: *Neurogenic Bladder: principles of treatment*. *Urol Clin North America*. Edited by J Lapides. Philadelphia, WB Saunders, 1974, pp 81-114