Independent Living: Caring for the Adult With Cerebral Palsy

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DR. BARRY N. KNISHKOWY *(Family Practice Resident):* Today's Grand Rounds deals with a segment of the population that has often received insensitive and fragmented care—the physically and mentally disabled. Our presentation stems from a learning experience in patient care and resident training with which our Department of Family Practice has been involved for the past two years. We have been providing care for nine residents of the Independent Living Program (ILP), a residential facility and skills training program for disabled adults sponsored by Cleveland's United Cerebral Palsy Association. Most of these patients have cerebral palsy. All of them have multiple medical and psychosocial problems, and all are working toward independent functioning in the community. The goals of our care-giving arrangement have been to provide sensitive and comprehensive care to this medically deprived segment of the population and to teach family practice residents the principles of caring for adults with multiple disabilities.

Cerebral palsy is a relatively common disorder that may be viewed as one example of the many incurable, disabling conditions that family physicians frequently encounter. This morning's case presentation and the discussions that follow emphasize two important principles in caring for affected individuals: (1) family physicians need to appreciate the many broad biopsychosocial aspects of these conditions in order to coordinate care and interact effectively with the patient, family, medical specialists, and community agencies; and (2) physicians and other health care providers should strive to maximize the patient's functioning and to promote independence.

George is a 37-year-old man with cerebral palsy of the spastic diplegia type. He has many associated problems (Table 1), which include flexion contractures of both hips and knees, near-total subluxation of the left hip, mild mental retardation, and atypical psychosis (controlled on thioridazine).

Until the age of 35 years, George lived at home with his parents and was unable to bathe, dress, or cook for himself. He had always received fragmented medical care from multiple providers. Two years ago, in a move largely motivated by his parents' aging, George entered the Independent Living Program. The residents of this 10-bed, apartment-based facility are at least 18 years old and have entered from either an institutional setting or from home. In many cases, as in George's, the resident had never lived apart from his family.

Shortly after moving to ILP, George began to receive health services at the Family Practice Center. His health care management has included extensive coordinating efforts and a great deal of counseling. Biomedical problems, such as the decision to undergo orthopedic surgery, have involved orthopedists, a psychiatrist, physical therapists, ILP staff, and family. This particular decision also involved an assessment of many issues including patient self-image, cognitive ability to make an informed decision, motivation to continue physical therapy postoperatively, and the possibility of major psychological regression after surgery. Psychological problems requiring counseling have included sexual misconceptions and fears about having abnormal children. Social problems have included parental interference with his medical decisions and George's lack of family support in general.

I initially considered George to be a very burdensome patient. He walked and spoke terribly slowly, was a poor historian, and refused to undress himself. With time, however, his skills improved, and we became comfortable with this "different" kind of patient. During his two years of coming to the Family Practice Center, George has been expected to make his own appointments, undress himself, and make the final decisions about his treatment options—all important steps toward independence.

DR. SUNDEE L. MORRIS *(Family Practice Resident):* Today's case illustrates the neurological manifestations and other associated problems that may be encountered in cerebral palsy. Cerebral palsy is a nonprogressive state or disorder of muscular function and

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TABLE 1. SOME PROBLEMS ASSOCIATED WITH CEREBRAL PALSY

Cerebral palsy—spastic diplegia
Mild mental retardation
Near total subluxation of left hip—requires surgery
Flexion contractures of hips and knees—desires surgery
Atypical psychosis (on thioridazine)
Balanitis; desires circumcision—performed 1983
Urinary hesitancy
Tinea cruris and corporis
Poor dentition
Abnormal skin lesion, biopsied 4/83—"combined compound plus blue nevus"
Sexually naive with possible sexual dysfunction
Parental interference
Lack of family support

posture caused by damage to the upper motor neuron in the brain or brain stem during early brain growth.[1] Among the many motor patterns seen, the most common type is characterized by spasticity. The uncontrolled spinal reflexes lead to multiple orthopedic complications from contractures, dislocated hips, scoliosis, and shortened heel cords. Although cerebral palsy is primarily a motor deficit, it is frequently associated with other handicaps including mental retardation (50 to 75 percent), hearing and speech disorders (over 50 percent), visual problems (25 percent), seizure disorders (33 percent), and social, emotional, and family problems.[2]

Cerebral palsy continues to be a commonly occurring disorder, with the etiology traced to presumptive prenatal and perinatal conditions 85 percent of the time.[2] Prematurity and low birth weight are major factors in cerebral palsy, accounting for one third of the cases. According to a study from Rochester, Minn, incidence rates of all cerebral palsy syndromes changed minimally between 1950 and 1976, from 2.5 to 2.3 per 1,000 neonatal survivors.[3] Advances in monitoring labor and neonatal care have changed the types and distribution of cerebral palsy as the smaller infant with the more severe case survives. In the above study, for infants greater than 2,500 g, the mortality rate decreased from 4.6 to 1.7 per 1,000, and the incidence of cerebral palsy decreased from 1.8 to 1.1 during this 27-year period. For infants less than 2,500 g, the mortality rate decreased from 201 to 156 per 1,000, while the incidence remained constant at 12 per 1,000. Thus, the relative risk for the low birth weight (less than 2,500 g) infant increased from 6.6 to 10.9.[3] This is clinically significant because the severity of cerebral palsy is much greater in the low birth weight infant and the occurrence of seizure disorders and mental retardation parallels the severity of the motor disorder.[2]

School achievement, employability, and reintegration into society correlate with the person's level of self-care.[1] The physician's responsibility therefore involves not only medical intervention, but the promotion of maximal function regardless of the organic limitations that may exist. Family physicians must work closely with other physicians, such as orthopedists and neurologists, physical therapists, occupational therapists, nurses, and social workers to correct and help control these organic manifestations of cerebral palsy.

DR. DAVID L. STEWART *(Family Practice Resident):* Comprehensive management of cerebral palsied patients also involves psychological evaluation. In today's case, for example, addressing sexual misconceptions and fears was an important intervention. Another area of evaluation that is crucial for promoting independence is an assessment of the patient's psychological adaptation to his disabilities.

Strain's[4] suggested parameters of psychological adaption to chronic disability provide a framework for assessing patient function by the family physician. These parameters include (1) an evaluation of the patient's response to the psychological stress of disability (This stress correlates best with the patient's self-perception, not with the stage of the illness, the place of treatment, or even the nature and severity of the disability.), (2) an evaluation of the extent of psychological regression stemming from the disability (The patient's desire to remain dependent, often encouraged by caregivers, may not be warranted by his true limitations.), (3) an evaluation of the conflicts this regression may revive between the patient's desire to be passive and his age-appropriate self-condemnation of passivity (This conflict may manifest itself in various ways, including depression and harmful physical exertion.), and (4) an evaluation of the patient's self-image and of his ability to relate to others.

The physician should use broad psychological assessment to aid the patient in overcoming psychological barriers to growth and independence. It is also important to bear in mind that the chronically disabled patient's relationship with his primary care physician may be a key determinant of his self-image.

MARLEEN GROSS *(Nurse Consultant, ILP):* In making a psychological assessment, family physicians also need to be aware that disabled adults have special concerns. The following feelings are expressed by most of our clients at ILP. While those entering ILP from institutions fear institutionalization, the clients also fear independence; they deny worries about money, employment, marriage or children; most clients deny having friends; and at least 70 percent of the clients have seriously considered suicide at some point in their lives prior to ILP.

Obviously the primary care physician must address these issues openly with the patient and his family when appropriate.

DR. KNISHKOWY: In caring for the disabled patient, assessment of family function is another area of special importance. Not only may the presence of a disabled person have profound effects on other family members, but the reactions and attitudes of the family strongly influence the disabled patient's development.

Much has been written about the families of handicapped children. Frequently, the parents become so-

cially isolated, the mother gives up her job, and there is increased marital tension. Siblings are also affected by feelings of jealousy, relative neglect, and being overburdened at an early age with having to perform a parental role.[5] On the other hand, parental reactions may lead to overprotective behavior toward the handicapped child.[6] Respite care can provide the family with a badly needed vacation from the constant burden of caring for a handicapped child.

In contrast to the extensive literature on children with disabilities, very little has been written about disabled adults and their families. It is instructive to consider the normative tasks of the family life-cycle stage known as "launching children and moving on." Parental tasks include accepting their children's independence and becoming grandparents, while tasks of the offspring include moving toward independence, choosing mates, and relating to their parents for the first time on the basis of mutual adulthood.[7]

The young adult with cerebral palsy, however, may be sexually naive and have no prospect of finding a mate or of starting a traditional family of his own. He may never be able to look forward to complete independence. His parents may never consider him to be truly an adult. Achieving independence, in very concrete terms, appears to be the overwhelming issue for these young adults. This quote from an ILP patient underscores the importance of independence:

PAT: *(age 25, resident of ILP)*: I think if I had a handicapped child, I'd probably be disappointed. The first thing I'd want to do is to find out about the type of handicap, let the child do as much as he or she can by himself, and give help only if needed. The child might have a handicap, but he or she is still a human being. Parents must let these children do their own thing. If the child falls, let him get back up again. That's how they learn—fall down and get back up until you do it right.

MS. GROSS: Unfortunately, for disabled people this process of learning often begins late in life, if at all. One reason that many clients enter ILP and finally learn these skills is that parents have begun to face their own aging and question, "Who will care for my child when I am gone?" At this point the "child" may be 30 to 40 years old.

PAUL *(age 36, resident of ILP):* My mother felt that this was the right place for me to be because she's old and there's no telling when she may be in a nursing home herself.

DR. KNISHKOWY: Health care providers should educate families with disabled children about facilitating their development from an early age. At the same time, when dealing with disabled adults, it is important to identify actually who their "family" is. As with other young adults, disabled individuals need to create new families for themselves. In the case of our patients from ILP, although some have returned home because of their difficulty with separation, most of them actually visit their families of origin rather infrequently. Furthermore, many important family functions, such as personal and home care, discipline, support, and counseling on important decisions, are provided by the staff and co-residents at ILP. We have viewed ILP as a type of "transitional family" and accordingly have made "home visits" there and included its staff in "family meetings." This approach has been essential for coordinating care effectively and for promoting independence.

Unfortunately, we don't provide care to the other actual members of these patients' families. Their needs are often unmet, leaving them as "hidden patients."

MS. GROSS: Working together with both families and community agencies is indeed an important role of the primary care provider. In addition, physicians need to appreciate the very basic limitations in activities of daily living as well as the great potential of their disabled patients. For example, at the time of entering ILP, many of our clients had never performed tasks and daily routines independently, primarily because it is easier to bathe, clothe, and feed someone with limitations than it is to teach him or watch him move painfully through the process. Some had never pushed a grocery cart, let alone managed grocery shopping on a Saturday afternoon. Others had never independently ordered a meal in a restaurant or experienced dating, as relationships are often maintained by telephone or by family members.

GEORGE *(age 37, resident of ILP):* I wasn't independent at home like I am here. I was depending on my parents to do everything—mostly my mother . . . . My parents told me I could try to cook a meal when I went home the last time, but they didn't get around to showing me what to cook, so I just sat back and watched TV and tried to be out of the way until dinner time.

LAURA: When I was at home I didn't do as much as I do now. I was sitting down the whole time. I didn't go shopping and didn't wash clothes. I'm going to make a higher level than I am on now and do a lot more things that I'm not doing now.

PAUL: It's hard to do it at home because our parents want to help us so much.

MS. GROSS: During their anticipated two- to three-year stay at ILP, the clients typically receive instruction in (1) use of leisure time, (2) toileting, (3) hygiene, (4) eating skills, (5) home maintenance (eg, grocery shopping, cleaning, and laundering), (6) community skills (eg, banking, shopping, and ordering in public), (7) survival skills (eg, use of the phone, use of calendars, and crossing at traffic lights), (8) sex education and health care, and (9) self-medication. In addition to what happens at ILP, the clients are expected to attend a day program in a competitive or sheltered employment or school setting.

As the client succeeds in the tasks and establishes a greater sense of self, his family often tends to have

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difficulty accepting the change. This is not to say that the family disapproves, but it is something they never expected. The family tends to blame the professionals as the client starts to become less dependent on them.

PAT: You do your own thing in living here. When parents see you growing up and doing your own thing, they get scared. When I first came here, it was hard for my mother—she really didn't want to let me go.

MS. GROSS: The Family Practice Center has offered clients the opportunity for adult health services, as opposed to the typical pediatric services that are usually extended to disabled adults. The clients relate that they used to feel dragged from one physician to another by their parents so that they might be fixed or mended and no longer disabled. Their frustrations grew as the interactions primarily occurred between the client's parents and the physician. The family physicians see the patients as adults and expect them to perform as adults. These patients are expected to undress themselves, for example, and to make decisions regarding their treatment. The cooperative interaction between family physician and patient has facilitated the client's development of self and independence.

DR. KENNETH G. REEB *(Associate Professor, Department of Family Medicine):* These presentations on the care of adults with cerebral palsy are important for three reasons: (1) the care of patients with chronic disease and disability is assuming increasing importance for family physicians as the prevalence of these disorders increases, (2) caring for the disabled can help us better understand some of the basic family medicine principles, and (3) caring for the disabled can influence the family physician's self-understanding of the physician-patient relationship.

Chronic disease and disability are assuming increasing importance in family practice. The prevalence of disabled people is increasing because medical advances have extended their lifespan.[8] At the same time, there has been a societal move toward deinstitutionalization of the retarded and handicapped. Although this move has not been as dramatic as the deinstitutionalization of psychiatric patients, it has resulted in a 30 percent decrease of patients in public residential facilities between the 1960s and the late 1970s. These disabled persons are now living in small community-based residential facilities that do not have their own intramural medical facilities. Such patients therefore rely on community-based physicians. Access to physicians' offices is difficult as it tends to be more time-consuming.[9]

Physical disabilities in young adults highlight the biopsychosocial model of disease. These conditions have major mind-body relationships. Physicians working with such patients can gain new insights into these relationships by working with the altered bodies and altered minds of the disabled. Lidz[10] points out that the young adult's development focuses on occupation and intimacy. Physical handicaps interfere with the accomplishment of both of these major tasks. Family physicians should work to enhance the self-esteem of these patients by helping them accomplish these developmental tasks. Patterson and McCubbin[11] use the "double ABCX model of family adaptation" to help understand the impact of chronic illness on family stress and coping: the family must adapt over time and avoid overprotection, blaming, denial, and rejection of the disabled young adult. At the same time, they must encourage self-reliance. The family physician should be vigilant in watching for the "hidden patient" in these families. The person responsible as the major caretaker for the disabled person may well be at increased risk for health problems of his own. As we have seen and heard this morning, these young adults often have great difficulty in maintaining a supportive relationship with their families.

Working with the disabled can help us understand patients and our own relationship with them. The disabled patient can help us as physicians confront our own vulnerability. They make us aware that the able-bodied state is temporary for us all. They help each of us face the likelihood of our own eventual disability and inspire us with their courage in coping with their disabilities. Through their work with these young people at the Independent Living Program, perhaps our physicians and nurses have gained a better understanding of these fundamentals of living, of doctoring, and of caring for others.

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