THE FORGOTTEN PATIENT: MEDICAL MANAGEMENT OF THE MULTIPLE HANDICAPPED RETARDED

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MEDICAL TREATMENT of the mentally retarded patient is one area of mental retardation that often receives minimum attention. In recent years many reports have been published concerning etiology and diagnosis and classification of mental retardation; for example, the classic article by Wright and Tarjan (*1*) or the three-part series on subnormality by Knobloch and Pasamanick (*2*). Other reports, such as that by the Group for the Advancement of Psychiatry (*3*), have been devoted to treatment of the family and to the physician's reactions when he encounters a mentally retarded patient.

Sorely lacking in this rapidly growing volume of literature are specific references to, let alone detailed accounts of, how the physician can directly intervene in the medical problems or the continuing health care of the retarded. Perhaps the best example here is the excellent 192-page manual published by the American Association on Mental Deficiency (*4*) in which only 10 lines appear under the section titled "Medical Care and Treatment."

The physician's traditional concern for his patient seems to have been displaced by his concern for the parents and other members of the patient's family or even the community. In other words, after he makes the initial diagnosis and neatly classifies the retarded, the physician's role as it pertains to treatment becomes focused on the parents. According to the literature, the parent rather than the retardate seems to be in greatest need of treatment.

This is not to question the need or importance of counseling for the family, but rather to point out what I believe is an important area of neglect; that is, the need for the physician's interest beyond the initial diagnosis and classification and parent counseling. First, this interest is required in the prevention and correction or at least amelioration of physical handicaps to permit full achievement of whatever functional potential may exist. Second, even where no improvement in function can be foreseen, increased personal comfort for the patient and increased ease of attendant care must be considered sufficient indication for medical or surgical intervention.

It is generally acknowledged that the true capacities of children with severe physical or sensory handicaps cannot be measured by their motor abilities. Even the child with normal intelligence appears to lag in development if he is severely handicapped.

Korsch and associates (*5*), in a comparison between the "estimates" of 81 pediatricians and the results of standard psychological tests given by experienced psychologists to 242 children, noted that about two-thirds of the estimates came within 15 points of the test scores. The one group consistently misjudged and underestimated was the children with major physical illnesses. For the retarded child, the effects of additional physical handicaps on developmental function may be almost catastrophic, because of his more limited ability to compensate. Correction or amelioration of the physical defects, therefore, becomes more imperative than for the child with normal mentality.

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We superficially acknowledge the effect of multiple handicaps on the retarded, because too often we fail to make enough allowance for their total effect when we judge an individual performance. A result of this tendency has been to relegate too readily the severely handicapped retarded child to the back wards of institutions as a "custodial" or "crib case." This same attitude has been reflected, until quite recently, in the exclusion of retarded children from the crippled children's programs of some States. Yet, the Children's Bureau has reported that up to 75 percent of those children under the age of 6 years seen in mental retardation clinics, supported by State maternal and child health programs, had physical handicaps in addition to retardation (*6*).

As to the necessity for what might be considered merely palliative intervention, one example is surgical correction or release of a fixed, severe scissors deformity of the lower extremities in a bedridden, profoundly retarded person. This would make it possible to abduct the legs and make maintenance of good perineal hygiene much easier. It would also save hundreds of hours devoted to care of the patient in the course of a year. Further, with the good skin care this would make possible, fewer skin infections would occur and the patient's general health and comfort would be improved. Although this is the most limited type of condition from the standpoint of functional improvement, surgical correction is still morally and economically warranted.

Although comprising only 12 to at most 15 percent of the retarded population, the moderately, severely, and profoundly retarded certainly require far more than this proportion of the physician's time and energies. In this group, the pediatrician, the general practitioner, the surgeon, and the specialist in physical medicine can make their greatest contribution, while their role as family counselor remains no less important than in the case of the mildly retarded.

Although training, habilitation, and general supportive care must not be neglected, the primary need of the profoundly, the severely, and to some extent the moderately retarded, with their high incidence of multiple handicaps, is comprehensive high-quality medical care. This is in contradistinction to the mildly retarded whose prime need is education and training, because their medical needs, as a rule, are essentially those of the normal population.

Furthermore, with the larger numbers of the profoundly and the severely retarded and physically handicapped who are surviving infancy and having increasingly longer lifespans, we must recognize what their care represents in terms of days of attendant care. Additionally, we must become more concerned with the medical needs of the rapidly rising population of adult retarded persons of all levels.

The neglect in the area of adequate medical programing for the retarded has its greatest impact on the more severely retarded group. Difficulty in obtaining help for the child's physical handicaps compounds the parent's feelings of guilt and frustration engendered by the lack of a "cure" for the mental handicap. As Dybwad pointed out, it is just this relative lack of interest in the more severely retarded that allows the medical quack to flourish in this field (*7*).

Why has this lack of emphasis on the medical needs of the multiple handicapped retarded persisted?

Perhaps Grover Powers, more than 10 years ago in an address to the American Pediatric Society (*8*), pointed the way when he said: "When there is no cure, the doctors sometimes capitulate too easily to therapeutic defeatism, forgetting that the physician is just as responsible for alleviating as for curing; action is just less urgent, not less vital."

It is time to give more emphasis in our thinking, planning, and writing to the direct medical needs of the retarded who seem too often to be forgotten as patients. What can be accomplished when the full energies of the various medical specialties and allied professionals are brought to bear on the retarded patient just as they would be on a "normal" patient?

Specifically, in neurosurgery there is the ventricular jugular shunt using the Holter valve—one method of treatment for hydrocephalus. Heffelfinger (*9*) has reported the results of 21 operations on patients with hydrocephalus admitted to the Coldwater (Mich.) State Home and Training School. The editor of the journal which published his report had posed the ques-

tion: "Should heroic surgery be attempted if the patient will continue mentally defective?" Heffelfinger's summary gives the answer: "A number of our patients who would not have survived are alive and happy today. Some are ambulatory and able to care for themselves. There are a few who had no recovery or improvement except an arresting of the advancing size of their heads. Some of these patients would be dead or would be subjected to the care program of the large decubitus head and emaciated body, if surgery had not been done. There was definite risk with postoperative complications, but we feel that taking that risk is justified."

That this approach has not been universal is obvious: in many institutions for the retarded there are patients with operable premature closure of the cranial sutures, who are retarded and even blind from the longstanding increased intracranial pressure.

According to a personal communication from Dr. Robert Jaslow, January 1964, at the Plymouth State Home and Training School in Michigan surgeons are removing meningomyeloceles, even in children with complete paralysis of the lower extremities, thereby eliminating the hazard of meningitis and making bracing possible, so that if the child can sit balanced on the edge of a table, by means of bracing and arthrodesis of the tarsals, he can learn to walk.

In a report of his experience as orthopedic consultant in the Fort Wayne (Ind.) State school for the retarded, Brown (*10*) described procedures for correction of many of the musculoskeletal deformities seen in the severely retarded. His report begins: "Treatment by the orthopedist may be for relief of pain or it may be for correction of deformities by either conservative or surgical means. By appropriate treatment more efficient nursing care and body hygiene can be achieved for bedridden patients and for those with severe involvement. In others, the orthopedist can make an important contribution to rehabilitation. The orthopedist's ultimate goal for these patients is to promote, when possible, self-sufficiency and to restore selected ones to society and to gainful employment."

Physical medicine should play one of the most important roles both in prevention of deformities and in habilitation or rehabilitation of those with neuromuscular handicaps. However, in a survey reported by Andrews and Ebling (*11*), 60 percent of the 69 responding institutions (out of 109 sent questionnaires) indicated that they had no physical therapy program at all.

At Central Wisconsin Colony, nonambulatory patients with structural deformities that are progressive receive daily passive exercises administered by institutional aides. These aides learn the specific therapy for a specific patient from the physical therapist and carry it out under the immediate supervision of the ward nurse. These procedures could also be carried out by parents at home after minimum supervision and training by a physician or registered physical therapist. Thus the greatest single manpower resource for the care of the retarded—the parents—could be used in a way that would be therapeutic for both patient and parent.

Koch (*12*) has reported a case, seen in the Child Development Clinic of Childrens Hospital, Los Angeles, of a child with Apert's syndrome, consisting of cleft palate, coronal synostosis, beaked nose, exophthalmus, and syndactyly. She had been conceived when her mother was recovering from infectious hepatitis. The parents were ashamed of having had this child. She was first seen at 19 days of age, at which time it was felt that surgical correction of the coronal synostosis was indicated. This was accomplished without incident. Subsequently, the cleft palate was repaired and multiple plastic procedures were performed on her hands. The clinic social worker was able to help the parents to recognize and examine their feelings about having such a multiple-handicapped child, who was also regarded as mentally retarded. Before coming to the clinic, the mother had been advised by family and friends on several occasions to "forget about the child and put her away." On one occasion, a physician had refused to perform surgery, saying, "It isn't worthwhile." With the continuing help of the clinic personnel the family has made an excellent adjustment to the problem, and, at present, the child is in a special class in a public school. Her developmental and intelligence quotients have remained stable.

Conclusions

The examples I have cited point out the following needs:

1. Where possible, a clinic for retarded children should be integrated into a children's medical center where all necessary special services, medical and social, can be made available either directly or indirectly for the patient and his family.

2. Because much of the parents' discomfort, anxiety, and eventual dissatisfaction result from failure to obtain help for their child, clinics should focus on what can be done to improve the child's physical handicap.

3. Caution should be taken in making a diagnosis of retardation in a child with severe physical handicaps; when the handicaps are ameliorated, the child may be "normal," not retarded.

With the rapid strides being made in reconstructive surgery, physical medicine, and medicine in general, much more can be done now for all the physically handicapped, including the retarded. An extensive medical program can reveal the true potential for functional improvement so often hidden in the child doubly handicapped by mental retardation and physical deformity.

Particularly in the severely handicapped group, a sound medical program will provide the foundation on which to build the continuum of life services they require. Without such a foundation the entire structure of efforts for the retarded and his family may, like the house built on sand, vanish in the first flood of parental discontentment.

Summary

A review of the literature indicates a need for physicians to take a more active and responsible part in the medical care aspects of the patient with mental retardation. Correction or amelioration of associated physical or sensory handicaps is as important for the retarded child as it is for the one with normal intelligence. This is essential not only to permit the retarded child to achieve his full functional potential, but it is indicated on both moral and economic grounds, even if only to increase the patient's personal comfort or to reduce the time and effort needed for attendant care.

Particularly in dealing with moderately, severely, and profoundly retarded children, who generally have the largest number of associated physical handicaps, such a medical program is the necessary foundation on which the total program, social and educational, must be based.

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