

## Pediatricians and Special Educators Collaborators in the Rehabilitation and Education of Children with Chronic Illnesses

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Willa Cather, the famous American novelist once said that writers, performers, and physicians have the experience that is «unique and marvelous of entering the very skin of another human being.» May I humbly add «teachers» to the list. Entering the «skin» of a child with a chronic illness and entering the «skin» of his or her parents sets the foundation for caring and treating these children and their family members. In our individual and our collaborative efforts, this professional privilege and special empathy and must always shape and direct our professional practice.

This paper explores the principal elements essential to the effective collaboration of pediatricians and special educators as they cooperatively strive to improve the comprehensive development, adjustment, and life functioning of children with chronic illnesses. The first part of the paper explores the shared role both of these professionals play in assisting parents and other family members in dealing with their response to the child, in arriving at acceptance, and in facilitating their performance as critical team members in the collaborative rehabilitative and educational process.

### The Role of the Teacher

Before exploring effective collaboration between pediatricians and special educators, it should prove beneficial to begin by describing the role that teachers should play in the identification, management, and treatment of children with chronic illnesses. Teachers, because of their continual contact with students in a variety of teacher-student interactions, can play a key role in the early identification of chronic medical conditions. This special role is to be alert to the possible existence of a medical problem while, at the same time, avoiding any temptation to engage in specific diagnoses or prognoses.

Teachers are ideally situated to observe the behavior of children, to make judgments about the possible existence of a chronic medical condition, and are less likely than parents,

family members, and other caregivers to engage in the denial process. The defense mechanism of denial, while it can be a protective stage in a parent's evolving emotional responses to his or her child with disabilities, unfortunately, may interfere both with early identification and the remediation of its subsequent problems. Parents who are in denial, as we know, will fail either to seek medical help or to follow the recommendations of physicians (McLoughlin, 1993).

Teachers, if they are to play a role in the identification and remediation of chronic illnesses, must be concerned not only about those conditions that are likely to affect a child's learning or behavior. They also must be alert to those conditions, especially when they are *subtle* deviations from normal, that require the attention of physicians and those other health care professionals who provide specialized therapeutic interventions (Kirk, Gallagher & Anastasiow, 1993). In most cases, when a medical problem is a severe one, it will be diagnosed by physicians and by parents early in the life of the child (Valletutti, 1984). Oftentimes, this recognition occurs at birth or shortly after birth, when a physical abnormality is obviously present, as in the cases of Down's syndrome and various cranial anomalies, including anencephaly (Anastasiow, Frankenberg, & Fandall, 1982; Batshaw & Perret, 1992; Haslam & Valletutti, 1995). More subtle problems, however, are more likely to go undetected.

- Mild mental retardation, for example, is typically not identified prior to the school years and is first recognized by teachers when the student fails to meet academic demands (Drew, Logan, & Hardman, 1992; Thomas & Patton, 1990).
- Mild orthopedic problems that do not interfere substantially with gross and fine motor performance required by school-related motor tasks are likely to go undetected (Kirk, Gallagher, & Anastasiow, 1993).
- The early stages of the Duchenne form of muscular dystrophy in a young student whose gradually progressive motor disability has escaped the attention of any adult in his life. That is, the child may be beginning to fall in class when he had seldom done so previously. Then, imperceptively over time, he may begin to fall more frequently while still being able to lift himself up with little difficulty. Sometime later, the deterioration in motor

function, invariably leads to his experiencing great difficulty in getting up after falling, at which time the deterioration in performance becomes obvious, even to unsophisticated observers (Cross, 1993). These gradual changes, after a pattern of normal development, in the early stages of this disease process, unfortunately, may escape the attention of most parents, teachers, and even, on occasion, some physicians and other medically-related personnel.

In the early stages of any newly acquired or newly emerging disease process, minor changes in a child's appearance or performance may easily be overlooked by parents and other adult observers. Often, parents, family members, and other caregivers are so involved with the multitude of issues affecting their own lives and those affecting the child's life, that slight changes are either overlooked or denied. When subtle changes or subtle deviations from normal performance occur, a sophisticated lay observer, whether parent or teacher, can prove to be a most valuable participant and collaborator in both assessment and treatment processes.

- For example, children who have a mild-to-moderate high frequency loss of hearing will appear to a casual observer to have normal hearing because they have sufficient hearing to respond to environmental and speech sounds (Bloodstein, 1984; Davis & Silverman, 1978; Martin 1986 and 1990). Hewett and Forness (1984) point out that a loss of 30 or 40 decibels often goes unnoticed while, unfortunately, the behavior problems that often develop may be viewed by teachers as being a symptom of underlying emotional problems or restricted intelligence rather than as a result of the confusion caused by the auditory impairment.
- A further example are those children who earlier in their lives suffered a traumatic brain injury with no apparent residual damage. These children may give no indication that a problem exists until learning disabilities and concomitant behavioral problems are demonstrated in school (Accouloumre & Caldwell, 1991; Mira, Tucker, & Tyler, 1992).

Teachers, therefore, in their day-to-day observations and their more formal evaluations, must be alert to the possibility that specific behaviors may be a sign of some untoward medical condition and be especially alert to the more subtle signs that a problem exists or is emerging.

Teachers must be particularly concerned about auditory and visual impairments because of the powerful impact on learning and behavior. It is obvious that the longer a student is sensorially disabled and does not receive appropriate treatment, the more difficult it will be to remediate resultant learning problems and to facilitate new learning (Hatlen & Curry, 1987). Children with deficits in visual or auditory acuity are likely to experience difficulty (depending on type, degree, and age of onset) in acquiring key academic skills. Therefore, teachers must be especially alert to behaviors that suggest that a sensory deficit may exist. For example, an individual with a moderate sensorineural loss of hearing (with its typical high frequency

loss) reacts to sounds, including noises and voices, as though he or she has normal hearing, thus escaping the attention of unsuspecting and unsophisticated observers. A student who has an undetected congenital loss of hearing in the mild-to-moderate range and has never experienced normal hearing cannot easily engage in the self-diagnosis process in which he or she recognizes that a discrepancy exists. Since this student has never experienced normal hearing, he or she is usually not aware that an acuity problem exists in the absence of a normal frame of reference. Mild-to-moderate visual impairments will often lead to behaviors such as: shifting or covering one eye; stumbling or tripping over small objects; abnormal positioning and distance spacing of the student's head vis-a-vis reading material; squinting and frequent blinking; excessive sensitivity to light; complaints of poor vision; frequent rubbing of the eyes; and faulty or peculiar eye movements (Hewett & Forness, 1984; Hoy & Gregg, 1994). Students with visual impairments are likely to develop problems in perception, sensorimotor, social and academic areas, especially those that require intact visual functioning (Warren, 1977). Many display emotional concomitants such as irritability and reduced ontask behavior.

As most individuals with disabilities, especially those whose disabilities are severe, have multiple impairments, it is especially important for teachers to develop a heightened awareness of chronic medical problems because it is very easy to overlook coexisting problems that are not as dramatically or obviously manifested as the primary disability. Additionally, teachers must be conversant with the possible effects of chronic illnesses on student learning and behavior whether it is a direct result of the condition itself or is a function of the treatment regimen, e.g., adverse responses to medication. Increased awareness of the effects on learning and behavior of diverse chronic illnesses is essential as teachers engage in the mandated processes of developing and implementing individual education plans (Strickland & Turnbull, 1990), individual family service plans (IFTPs) for young children with disabilities and their families (McGonigel, Kaufmann, & Johnson, 1991), and individualized transition plans (ITPs) for adolescents and young adults with disabilities (West, Corbey, Boyer-Stephens, Jones, & Sarkees-Wircenski, 1992).

An awareness of medical problems as they may exist in the children they teach is prerequisite to making judicious decisions about, among other things:

- the need for medical and/or medically-oriented diagnosis and/or treatment,
- appropriate referral sources and procedures,
- effective consultation and communication with medical and medically-oriented practitioners.

Moreover, teachers must not only be sensitive to the possible existence of a chronic illness in a child, they must play a critical role in collaborating with pediatricians, other physicians, and medically-related specialists, such as occupational and physical therapists, in efforts to prevent secondary and tertiary physical and mental disabilities. What is then needed is an increased sensitivity to those patterns or constellations of behavior that suggest the presence of a chronic illness, especially when that problem can be ameliorated or

reversed. Early identification is especially important in planning patterns of intervention and interaction with the child and, of equal importance, with his or her parents and other family members. Because teachers have prolonged contact with students, they have the opportunity to prevent secondary and tertiary physical and mental disabilities by assisting children in obtaining, as early as possible, pertinent medical and other health-related therapeutic services, in carrying out specific interventions recommended by physicians, and in monitoring the results of medical treatment regimens. In this way, secondary disabilities, arising from the primary condition, may be prevented or lessened while tertiary disabilities may be realized by decreasing the condition's severity through appropriate treatment modalities. The early identification of medical problems, whether acute or chronic, can be an invaluable contribution to preventive medicine when it leads to prompt treatment and management. This is true whether the treatment directly affects learning or whether it corrects a medical problem that has no direct impact on the student's learning.

Whenever prompt remediation and care is secured, there is the greater likelihood that further physical deterioration and, perhaps, permanent damage to the involved organs or systems will be avoided. Untreated metabolic diseases (such as phenylketanuria) and drug abuse, as examples, can lead to irreversible brain damage with resulting mental retardation and/or psychosis. Early correction of physical problems will likely minimize the effects of a pathological condition on learning. «Early identification of a handicapping conditions is highly important. First of all, in certain cases the ultimate impact of a handicapping condition can be reduced substantially with early treatment or intervention. Certain handicaps may even be prevented if action is taken soon enough» (Drew, Logan, & Hardman, (1992, p. 117). *It is axiomatic that the earlier the identification of a disability, the more likely it will be reversed or its debilitating defects minimized.*

This axiom is especially relevant when one considers that the age of entry into day care and preschool programs in the United States continues downward (Jordon, Gallagher, Hutinger, & Karnes, 1988), as mandated by both federal and state laws in the case of special education and as increasingly required by working parents. As a result of this downward trend in the age of schoolage, the teacher's role in identifying behaviors that signal both acute and chronic problems increases not only in magnitude but, also, in difficulty. Teachers (as, incidentally, do pediatricians) must be skilled enough to differentiate among behaviors that represent normal variations in development during this period of rapid growth from those behaviors that are symptomatic of an existing or emerging chronic medical condition. As a case in point, teachers should attempt to determine whether a child's difficulty in fine or gross motor coordination is merely a benign developmental variation or suggests a possible neurological or orthopedic disorder that requires the immediate attention of a physician. Furthermore, pediatricians, as well, need to differentiate between variations in developmental patterns that are within normal limits and those that require immediate and intensive study. It should be remembered that, for example, children do not always outgrow their speech and language problems, and parents should not be comforted by the physician's words, «he will outgrow the problem!» when

insufficient time has been devoted to analyzing the child's behavior and physical status. Recently, it has become clear from medical research that attention deficit hyperactivity disorder (ADHD), which was long thought to be a disorder of childhood, persists into adulthood in upwards of 30% of ADHD children. «It may lead to a variety of consequences and comorbidities, ranging from poor occupational and social functioning to depression, bipolar disorder, substance abuse, and antisocial traits» (Haupt, 1995, p. 34).

Teachers, also, must familiarize themselves with a wide range of assistive devices, including wheelchairs, canes, crutches, and walkers as well as voice synthesizers, braces, artificial limbs, catheters, hearing aids, and a host of other specialized equipment often required by students with chronic medical problems (Blackhurst & Berdine, 1993). «The growth of scientific technology, electronics, and computerized equipment has done much to assist the severely physically handicapped population. In the past few years, space age prosthetics, electronic sensory devices, specially equipped vans, and audiovisual equipment have been designed to augment the program needs of such students» (Smith, 1984, pp. 89-90).

Teachers, as do pediatricians and other physicians, must analyze their own feelings toward students chronic illnesses. For example, teachers of students who experience seizures first must examine their own feelings about seizures and epilepsy before spending class time helping classmates understand and deal with their fears and feelings toward a peer with a convulsive disorder. School systems need to adopt comprehensive health and safety education programs, in collaboration with pediatricians and other physicians, through which knowledge of and sensitization to the needs of people with chronic illnesses is included. Teachers who participate in programs such as these, hopefully, will then possess the skills needed, for example, in preparing the child and his or her classmates before the seizure occurs, during its occurrence, and when carrying out the required procedures after the seizure has ended (Smith, 1984). With epilepsy, as with other disabling conditions, it is important to direct the attention of peers to the needs of the student with medical problems and to describe the condition to them realistically so that the mystery, mythology, and stigma may be reduced.

When a student with a chronic health problem has a terminal illness, teachers and pediatricians must examine and resolve their own feelings and attitudes toward death and deal with both the student's and his or her classmates' fears and concerns about death and dying (Hardman, Drew, & Egan, 1984). At the same time, teachers must provide a school program that takes into consideration reduced energy, strength, motivation, and various emotional responses to the illness. Teachers may have to be particularly alert to changes in the progression of illness, being especially responsive to crisis and exacerbations.

Teachers need to become increasingly cognizant of medical intervention strategies so that their effects on learning and behavior may be anticipated. Of special interest to teachers is the use of drug therapy to control the behavior of students who have been diagnosed as having (ADHD). Medications used to treat this disorder fall into one of two groups: stimulants such as ritalin, Cylert, and Dexedrine and stimulating antidepressants, such as Norpramin, Wellbutrin, and, perhaps, Prozac (Haupt, 1995).

There are a number of concerns that have been voiced by teachers related to the use of drug therapy with children with ADHD with accompanying learning disabilities, they include:

- The paucity of studies that show a positive change in learning.
- The lack of consensus that there is a reduction in inappropriate behavior.
- The danger of adverse physiologic side effects.
- The perils of adverse psychological side effects.
- The neglect of alternative and more humanistic behavioral management strategies.
- The absence of legitimate student-oriented goals, i.e., the underlying purpose is for the teacher's convenience (Marsh, Price, & Smith, 1983).

Teachers face a number of problems when they are expected to aid in dispensing medication to students. There are still unresolved legal as well as professional/ethical ramifications that must be thoroughly evaluated before agreeing to participate in such a program. Schools need to establish written policies relevant to the administration of prescribed medications as well as the overall relationship between medical treatment and instructional programs (Mercer, 1992). Specific policies are critical not only for legal reasons but also to provide a framework for improving teacher feedback to the prescribing physician. Releases to administer drugs should include data, submitted by the physician, on expected changes in behavior, possible adverse side effects, symptoms of toxic reactions or inadequate dosage, and dates of therapy initiation and review (Marsh, Price, & Smith, 1983). Caution is especially pertinent when dealing with students who have been classified as hyperactive and are receiving stimulants. Since hyperactivity is a subjective phenomenon, teachers may be in diagnostic disagreement with psychologists and physicians, if they view the behavior of a student as within normal limits. The use of drugs as a management strategy may conflict with a teacher's approach to behavior modification. If a student is on a drug regimen, does this prevent a teacher from dealing with emotional controls and self-regulation? Does this interference by a medical intervention technique interfere with a teacher's professional responsibilities? Does the use of medication reduce student activity and, thus, inhibit learning?

Whenever students are placed on special diets by a physician because of endocrine problems (such as diabetes mellitus), convulsive disorders, or allergies, it is essential that teachers assist these students in meeting the constraints imposed by their special diet. In the typical classroom, this may be a difficult task, since serving junk food snacks and at class parties is a school tradition in the United States. Teachers need input from pediatricians, other medical specialists, and nutritionists to assist them in planning menus for class parties and for dealing with students who are frustrated and angry at their dietary restrictions.

### **Pediatricians and Special Educators: Collaborative Team Members**

Historically, collaboration among the many professionals involved in treating and teaching children with chronic illnesses can be characterized as the «expert model of consultation»

which involved a unidirectional channel of communication, that is, from the top down, metaphorically speaking from Mount Olympus to the masses below (Pugach & Johnson, 1995). It was soon recognized, however, by most professionals, including many reluctant physicians in the United States, that this model, epitomized by a professional pecking order, was, in reality, a non-collaboration model. The need for greater parity among participants in professional interactions has led to the emergence of a new model «collaborative consultation» which has become the generally accepted model of professional interaction in which specialists work as equal partners. The current model, which is proving to be effective, in supportive of the basic tenets of collaboration, that is, equals with different kinds of expertise come together to solve problems and that their joint efforts are more powerful than the efforts of any one in isolation (Pugach & Johnson, 1995). Collaborative consultation depends upon effective communication. Teachers and pediatricians in their efforts to communicate with each other must overcome the barriers to communication arising from differing perceptions of status, undue concern for territory, confusing terminology and jargon, and disparate goals and their treatment priorities. In addition, Pugach and Johnson (1995) warn collaborators about the way advice is given, «Perhaps the most common error that someone can make is a collaborative effort is to give advice too quickly... If it is pressed too strongly, giving advice can negate the professionalism of our colleague by dictating a specific course of action... we was be treating our colleagues not as equal professionals but instead as individuals who do not have the capacity to act on their own» (p. 90).

The nature of pediatrics has evolved and expanded as the nature of its challenges has changed and proliferated. Initially, pediatrics was mainly concerned with and narrowly focused on maintaining life and function against the deleterious effects of malnutrition and infectious diseases. Pediatrics has progressed in several directions: specialization of efforts, concerns for mental as well physical growth and development, and increasing involvement in the holistic care of young children with chronic illnesses and their families. The role has also expanded into fostering the psychological and emotional health and development of well children and children with acute illnesses. In addition to providing acute health care, pediatricians have become increasingly involved in long-term developmental concerns for both normal and chronically-ill children. *Pediatricians, as do educators, must no longer focus myopically on the here-and-now but most adopt a long-term view of the child. They must project their young clients into the future and envision them as adults and, then, provide them with a treatment regimen that will lead to their successful adaptation to a quality adult life in the cultural mainstream.* This basic principle must shape all collaborative efforts as teachers and pediatricians work together to ensure the successful functioning of the client in his/her childhood, adolescence, and adulthood.

Traditionally, the thrust of pediatric services has been directed toward prevention, diagnosis, and treatment. Better nutrition, immunizations, early parental care, removal of environmental poisons, and effective counseling are examples of preventive measures. The pediatrician, in his or her diagnostic mode, is concerned with identifying the underlying condition(s) that is affecting a patient's life for the purpose of establishing

a treatment regimen. The pediatrician, in the not too distant past was trained to practice under the disease-oriented model which holds up in general, but in a large number of cases, it has its weaknesses, particularly when involved with those interventions having to do with the child with a chronic disability. For example, therapeutic trials may be necessary before etiology and specific diagnoses can be established. In fact, the nature of the response to therapy may often aid in establishing a diagnosis (for example, in ADHD). The medical model seeks cures and the removal of disease. Teachers, on the other hand, must look first at the person with a disability and at his or her abilities and interests. This should be done before exploring the impact of the disability on behavior and learning (Valletutti & Salpino, 1979). Teachers, therefore, must shun the disability model which focuses on an individual's «diseased» parts or systems rather than on the total individual with his or her distinct profile of abilities and disabilities. Disabilities must be approached, by the teacher, from the vantage point of demonstrated abilities so that previous knowledge and experiences as well as acquired skills can serve as the basis for remedial and developmental programming. So, too, must the pediatrician look at the whole child in all his or her dimensions and aspects – as an individual, as a member of a family unit, and as a member of the different communities with which he or she interacts.

The cure-oriented pediatrician will be extremely frustrated in the field of chronic illnesses. The traditional treatment paradigm has undergone significant modification as chronic diseases become a greater part of the management problems confronting pediatricians and other caregivers. Whereas previously, disease was the focus of treatment, the emphasis is now on health information and maintenance and the prevention of secondary and tertiary disabilities. Emphasis is away from pathophysiology and disease and now incorporates function, physiology, quality of life, successful adaptation, and well-being. Restoration of function and adaptation to disability is the new goal of pediatricians and other human service professionals because of the rising incidence of chronic and debilitating illnesses. When the role of treatment is to ameliorate and habilitate, the efforts of all team members take on more significance, and the roles and contributions of each discipline can be better appreciated. Interdisciplinary communication and collaboration is essential in identifying goals for clients and in describing treatment priorities, sequences, strategies, implementations processes, materials, and evaluation strategies. Sharing interdisciplinary information is a prerequisite to providing a mechanism through which the collective wisdom of the individual collaborators may be marshalled for the purpose of arriving at the most logical, productive, and efficient means possible to remedy those problems that are subject to correction, for preventing secondary and tertiary disabilities, for designing a management program that minimizes the physiological and psychological effects of a chronic illness on both the person so disabled and his or her parents and other family members.

In the absence of collaborative efforts, fear of encroachment on one another's territory, may result in needless and esoteric tests and treatment procedures that adversely affect the child and his or her progress. To make any significant area of human endeavor the exclusive domain of any one discipline negates the advantages inherent in several disciplines working toward

common objectives. A further benefit of collaborative approaches is that discussions may generate more creative approaches and a higher professional commitment to keeping abreast of developments in the various related fields. With increasing professional contact and support, the problems of professional isolation, coupled with the possible consequences of insensitivity are reduced in both frequency and intensity. With team discussions and continuous professional stimulation from peers, marked improvement in morale and performance are more likely to occur.

Because teachers are the recipients of interdisciplinary attention in school settings, they are expected to:

1. Identify the most propitious time for remediation of problems.
2. Interpret information and suggestions coming from professional resources.
3. Implement suggestions from professional resources in the classroom.
4. Infer programmatic implications from suggestions and information coming from professional resources.
5. Evaluate the intervention effects so that helpful feedback and modification of programming may occur.

In order to more effectively carry out these tasks, teachers urge collaborating professionals such as pediatricians to avoid the following behaviors. *DO NOT*

1. Write reports that are incomprehensible to those reading them.
2. Make recommendations that are far removed from any possibility of implementation.
3. Advise others to use materials and skills that are not available to them.
4. Analyze problems by examining only one component of the problem, e.g., psychological assessments, and ignoring broad-based dimensions of the problem.
5. Rely exclusively on indirect communications.
6. Assume that teachers are merely the recipients of advice and information.
7. Ignore teacher observations and insights, teacher expectations for students, and the pressures on teachers from the outside.

Referral to a pediatrician of a child who is suspected of having a medical problem is an important task of a teacher and the school system. Whenever teachers refer a student for diagnosis and possible treatment, they must compile sufficient data that justify the referral. The best type of documentation is an anecdotal report in which pertinent behaviors of the student are described in sufficient detail and in behavioral terms. Included in this anecdotal report should be the conditions under which the pertinent behaviors have occurred, the frequency and duration of these behaviors, and their consistency over time. The referral should also request both feedback and the specific details of future access to the physician or other allied health professional who conduct the evaluation or treatment to facilitate shared understandings and effective collaboration when a treatment regimen is pursued. Teachers should ensure that

provisions are made to have the results of professional consultations communicated quickly and directly, except when it might constitute an invasion of privacy. Teachers must assist in establishing mechanisms through which they receive feedback from professionals who are involved in the diagnosis and treatment of children with chronic illness and that allow them to provide feedback to these professionals relevant to the results of their intervention regimens on the student.

Pediatricians and teachers have not paid enough attention to the stress placed on clients/students by treatment regimens that fail to consider fatigue factors or appreciate the pervasive pressures from having a disability. Further, in chronic medical problems such as peptic ulcers, asthma, migraine and tension headaches, and epilepsy, the reduction of stress may need to be an integral part of the total management regime. Teachers and pediatricians must be especially aware of the social and psychological problems that arise from being different. The legendary cruelty of children to those who are clearly different must be dealt with in a direct and forceful manner. This is necessary if the unkind barbs and taunts of peers, through appropriate units of instruction and sensitivity training and other special learning activities, are to be replaced by empathy, support, and companionship. Pediatricians must help to educate the child and his or her family about the nature of his or her chronic illness in general and how it affects him or her specifically in order to foster coping mechanisms and to increase his or her ability to effect changes in his or her daily life. Educators must assist in this critical process and must also program to prevent avoidance reactions in others and must assist students with disabilities in developing the social competencies required for interaction with their peers and adults, disabled as well as nondisabled. Furthermore, whenever, children with chronic illnesses have to be hospitalized as part of their treatment program, pediatricians and teachers must consider the tremendous stress that results from their separation from home and family and from apprehension about the hospital environment and its personnel as well as its strange and frightening equipment. Curriculum experience need to be directed toward helping students understand the nature of medical settings as well as medical and medically-related personnel and equipment. Pediatricians and teachers should assist clients in understanding their medical condition, the nature of their specific medical interventions, and the role they must play in the management of the condition. Discussions should be pursued that facilitate acceptance of their condition and that help them deal with the ignorance, fear, and anxiety of others while dealing with their own fear, anger, and need for positive attention.

### **Meeting the Diverse Needs of Parents and Other Family Members: Making Parents Part of the Collaborative Team**

In the United States the basic family unit has changed drastically over the last several decades. The divorce rate has more than doubled and the number of children of divorced parents has more than tripled (Office of Policy and Planning, 1992). «Since 1970 there has been a 30% decrease in families made up of a married couple and children. During the same time period there has been a 97% increase in single parent

families... with 57% of these families living below the poverty level... (while) in 1990 74% of married women worked outside the home» (Pugach & Johnson, 1995, p. 225). Obviously, these sobering figures, coupled with the fact that many families have lost the support of the extended family who, in the past, have been a major source of emotional strength and comfort, have made the physician's and teacher's task of working with families much more complex and demanding.

The holistic model of rehabilitation requires that the needs of the family members of a patient/client must be met as well as those of the child if more beneficial treatment and management outcomes are to be realized. Just as the child with a chronic illness needs to become acquainted with the nature of his or her medical condition, so must family members be similarly educated. Just as the child with a chronic illness needs a variety of counseling and psychotherapeutic interventions, so do family members.

In recent years, there has been an increasing awareness among patients, family members, and the general public of the relationship between genetic factors and chronic illness. This awareness has led to a rising interest in and demand for genetic counseling. Therefore, the aims of these seeking genetic counseling as well as the data requirements and its specific techniques must be understood by physicians before engaging in the process. Pediatricians, when dealing with parents of family members of children with chronic illness, in addition to providing or arranging for any needed therapeutic counseling, may have to provide or arrange for genetic counseling and education. Issues such as: the risk of recurrence in specified relatives (recessive and dominant transmission patterns as, for example, in cystic fibrosis and Treacher-Collins respectively and chromosomal aberrations as, for example, in Down's syndrome), the options for dealing with the risk of recurrence, the alternatives involved in choosing the course of action which seems appropriate to them in view of the risk and its interaction with family goals and value system, and the approach to be taken in arriving at the best possible adjustment to the disorder and its risk of recurrence. The stages of genetic counseling include: 1) diagnosis, 2) compilation of the family history, 3) estimation of risk of recurrence, 4) education of the counselee relevant to the risk of recurrence, 5) formation of a plan of action, and 6) establishment of follow-up procedures (Talbot, Hales, & Yudofsky, 1988).

Special attention, also, must be paid by pediatricians and other human service professionals to the parents of a dying child, who have to cope with tremendous agony. These parents, therefore, require an extraordinary level of support. Many parents find support from other parents who are experiencing or have experienced the same circumstances. Others find great support in their religion. Parents of children with chronic illnesses need a continuing and supportive relationship with their pediatrician so that they may help him or her provide the medical care necessary for meeting the child's physical and emotional needs. Many adaptive mechanisms enable humans to cope with extreme distress. Denial, for example, can protect parents to some extent from overwhelming pain and extreme disorganization. Intellectualism is yet another mechanism that leads parents to seek as much knowledge as possible about the specific chronic illness and its particular manifestation in their child. Some

parents of children with disabilities experience periods of anxiety, depression, grief, anger, and guilt while others seek magical cures. This magical thinking engaged in by some parents has a special impact on the role of the pediatrician who must avoid contributing to unrealistic optimism while, at the same time, helping parents maintain a positive, yet realistic, perspective.

In addressing the diverse needs of family and child, one needs to appreciate that individual family systems may be composed of several subsystems, namely: marital, parental, sibling, and extrafamilial (which includes the family members in interaction with friends and the extended family) (Turnbull, Summers, & Brotherson, 1984) all of which must be addressed when assisting the family of a child with a chronic illness.

The holistic model of treatment and rehabilitation is an offshoot of the family movement which arose, in part, because of the frustration experienced with the rigidities of the child-centered guidance model. This former model placed heavy, if not exclusive, emphasis on the child which, invariably, resulted in the exclusion of the family's needs and the negation of the positive role the family can play in promoting the child's mental and physical health or the negative role it can play in creating dysfunction in a child, whether the child is disabled or not. The holistic model of treatment requires that physicians, teachers, and other human service professionals assist family members in meeting their various needs and in obtaining their assistance in helping the child with a chronic illness to cope with the effects of the illness and to benefit as much as possible from the treatment regimen.

Of special concern, in the United States, is the fact that child abuse is growing at an alarming rate with the highest rates found among children with chronic diseases (Haslam & Valletutti, 1995). Given this disturbing fact, pediatricians and teachers must be especially alert to the possibility that child abuse may be occurring. For physical abuse the nature of the injury itself may raise suspicion while one should be particularly concerned if differing explanations by family members are offered, if the history was discrepant with direct observation of the injury, and if the injuries are multiple and in varying stages of healing. Delay in seeking or refusal to accept treatment and a history of previous injuries are other helpful clues. Suspicion may be aroused if the child has frequent absences from school, is fearful of going home after school, and refuses to undress for physical education. Child sex abuse may be suspected when there are such obvious signs as offensive odor or other evidence of sexually-transmitted diseases, and pain or evidence of trauma in erogenous areas. There may be excessive fear of being left alone with adults and fear of closed doors, bathrooms, or showers. Unusual interest in sexual matters may be expressed in a number of ways, including art products, unusually seductive behavior, refusal to undress, fear of going home, and frequent absences. Teenage pregnancies, which are almost at epidemic proportions in the United States, also contribute to the incidence of disturbance in children, not only because of the teenager's own problems but because their offspring contribute heavily and steadily to the increasing population of children with chronic illnesses and other disabilities.

The holistic treatment model not only recognizes that the attention of physicians and other human service professionals

must be directed toward the needs of parents and family members as well as the child in the family unit. It also recognizes that intervention programs must be multidisciplinary and collaborative and that parents and family members must play a vital role in the treatment and management process. Parents can assist the child in structuring and regulating his or her life, in meeting treatment goals and objectives, in coping with his or her disability, in managing stress, in acquiring knowledge and insights, in fostering a positive self-concept, in living safely and with optimum health, and in practicing acquired and emerging functional skills both in the home and community. As co-equal members of the collaborative team, parents can help the professional team members acquire essential insights into the child that they cannot easily acquire because of their limited exposure to the way the child performs in the myriad daily tasks expected or required of him or her. Parents can assist in identifying treatment goals and help to place them in a priority order. In the United States, the collaborative role of parents is formalized in both federal and state education law as epitomized in P.L. 101-476, The Individuals with Disabilities Education Act.

### **The Impact of a Chronic Illness on a Child: Physiological Factors That Shape the Habilitative/Rehabilitative Process**

When one examines the physiological factors that affect the habilitative and educational processes, obviously, the principal elements to be considered are specific to the individual chronic illness and to its idiosyncratic manifestation in the individual child. While it is not this paper's purpose to review specific chronic illnesses, there are several physiological factors common to a number of chronic illnesses that should be addressed by pediatricians and other physicians in their treatment of the affected child and his or family members. These general concerns include: the management of pain, the reduction of fatigue, the avoidance of adverse side and interaction effects of specific medications, the impact of dietary restrictions, and the consequences of physical limitations on mobility and autonomy in the activities of daily living and in the various roles children expect and are expected to perform in their lives.

**Pain Management**-When one treats a child with a chronic illness, attention must be directed to the effects of pain on the quality of the child's life. Pain in children with chronic illnesses is a result not only of the physiological expression of the specific illness but the psychological (including depression) and social concomitants of the illness as well. Physicians must explore specific medical, surgical, and medically-oriented procedures that are likely to be successful in symptom control and relief. Pediatricians must provide support for both the child and his or her family members; provide or arrange for individual and family therapy, as indicated; prescribe appropriate medication; collaborate with teachers and other professionals in the development of coping mechanisms and social skills; and join with other human service professionals in the total habilitation process (Blackwell, Merskey, & Kellner, 1989).

Methods of symptom relief and control include: traditional psychotherapy, the use of pain and psychotropic medications, physical therapy, cognitive therapy, relaxation therapy, hypnosis,

sensory stimulation, nerve blocks, and surgical procedures. The enhancement of healthy behavior must also be a professional concern if chronic pain is not to lead to pervasive depression, to interfere with educational and habilitative efforts, to seriously diminish the child's social and eventual vocational adjustment, or do profound damage the child's quality of life (Blackwell, Merskey, & Kellner, 1989).

**Fatigue Reduction-**Whenever one is treating a child with a chronic illness, attention must be directed to the effects of fatigue and its accompanying depression on the quality of the child's life. Abnormal fatigue is the loss of energy which is out of proportion to effort or tiredness that is not relieved by rest. Many medical conditions may be associated with fatigue, they include: neoplasms, infections (bacterial, fungal, parasitic and viral), toxins, and environmental agents such as solvents, pesticides, and heavy metals (lead).

Pediatricians must be especially concerned about fatigue factors when encountering children with specific chronic illnesses such as:

- 1) autoimmune diseases (rheumatic heart disease);
- 2) metabolic diseases (diabetes mellitus, Type I, hypothyroidism, and hypoadrenalism);
- 3) neurologic impairments (cerebral palsy, dystonia muscularum deformans, Werdnig-Hoffmann syndrome and Kugelberg-Welander syndrome both forms of amyotrophic lateral sclerosis which manifest in childhood and adolescence, respectively, and the Duchenne form of muscular dystrophy);
- 4) orthopedic disabilities (spina bifida and juvenile arthritides);
- 5) chronic health impairments such as cardiac, pulmonary, and renal diseases and hemologic disorders (Dugdale & Eisenberg, 1992; Hoffman, (1992).

**Adversive Side and Interaction Effects of Medication-**Many adverse effects occur when dosages are inappropriate to the patient's age, size, and physiologic status. Salicylates are one of the most commonly used drugs for minor pain control. Salicylates, however, may cause gastric intolerance, resulting in gastritis and peptic ulcer disease. Additionally, aspirin sensitivity, in particular, can result in bronchospasms, rhinosinuosities, and urticaria (Ramsey & Larson, 1993). Tinnitus, also, can occur with high dosages of aspirin. Reye's syndrome can occur in children and teenagers with viral infections such as influenza and varicella.

Interactions among drugs can occur. Salicylates, as an example, have significant interaction effects with warfarin. Patients treated with both these drugs will have prolonged prothrombin time, possibly leading to bleeding or hemorrhage. This in addition, the synergistic effects of drugs given in conjunction with each other may potentiate the effect. A case in point, is the use in convulsive disorders of phenobarbital with any of the anticonvulsive agents (dilantin, tegretol, mysoline, and depakene). These are examples of adverse interactions and synergistic effect that can occur with frequently used drugs. It is imperative that a pediatrician or other physician be alert to the adverse effects of any medication he or she plans to prescribe.

**Dietary Restrictions-**Whenever the holistic treatment of a child with a metabolic or other chronic condition requires dietary restrictions, attention must be directed to the effects of these dietary restrictions on the nutritional needs and health of the child and to the impact of these restrictions on the quality of the child's life. Dietary manipulations are pertinent when dealing with children who have medical conditions such as phenylketonuria, diabetes mellitus, some forms of epilepsy, and obesity which should be viewed and treated as a chronic illness. The holistic nature of treatment, when dietary restrictions are placed on a child, is especially vivid when dealing with the above identified chronic illnesses. The pervasive psychological impact of the condition, the cosmetic differences that may be present, and the differences that occur in the behavior of the individual so affected vis-a-vis food and the social institution of eating and dining can result in profound psychological damage. The obese child, as a case in point, is usually an object of scorn and ridicule by childhood and adolescent peers and a person who is often rejected by others as potential mates and a potential employer. In recognition of the impact of obesity on employment and promotions, the recently-enacted civil rights legislation, the Americans with Disabilities Act, and its regulations include obesity as a covered disability.

**Physical Limitations-**Whenever one is treating a child with orthopedic, neuromuscular, and some chronic health impairments, attention must be directed to the effects of physical restrictions on the quality of the child's life. Physical limitations must be considered when dealing with children who have: 1) orthopedic conditions such as juvenile arthritis, scoliosis, spondylosis, torticollis, kyphosis, slipped capital femoral epiphysis, the orthopedic anomalies of dwarfism, common sports injuries, and the residua of accidents; 2) neuromuscular conditions such as cerebral palsy, muscular dystrophy, and spina bifida; and 3) chronic health impairments such as cystic fibrosis, asthma, congenital heart defects, and chronic renal disease. The holistic nature of treatment, when a child has physical limitations or restrictions, is especially clear when seeking improvements in motor functioning with the above identified chronic illnesses. The pervasive psychological impact of the condition itself, the devastation of any cosmetic differences that are present, and the influence on the performance of fine and motor tasks, on mobility, on participation in leisure and other social activities, and on the world of work must all be considered when managing and facilitating the physical skills and performance of children with certain chronic illnesses.

### **The Impact of a Chronic Illness on a Child: Psychological Factors That Shape the Habilitative/Rehabilitative Process**

A student with a chronic health problem, usually, requires help from teachers and physicians in developing a positive self-concept and in increasing his or her ego strength. Frequent negative reactions to a disabling condition, invariably, results in lowered self-esteem and hostility toward others. People with disabling conditions invariably develop a negative world view. Therefore, they must be helped to view both themselves and others in a more positive light.



The greatest obstacle to the successful adjustment of a child with a chronic illness faces is depression which results from the ridicule and rejection of others, from internalized standards of normal appearance and functioning, and from diminished self-esteem and ego strength. While depression is a normal emotion that is an expected component of normal experiences and is transitory, more lasting symptoms of depression are highly prevalent among patients with diverse medical, neurological, and psychiatric disorders. For example, a child with epilepsy may have difficulty not only adjusting to his or her physical and neurological symptoms but may experience greater trauma from the reactions and attitudes of others toward epilepsy and persons with a seizure disorder.

When considering childhood depression, it must be recognized that one is dealing with a variable entity that «...differs with the cognitive and social abilities of the child as he proceeds through the various levels of ontogenesis. The treatment of depression thus depends on the age of the child, his cognitive and social sophistication, and the amount of internalization of views of the self and others that has occurred... (therefore) intervention must be stage-appropriate» (Bemporad, 1989, p. 1952). Therefore, eliminating or diminishing must be assiduously pursued when treating children with chronic illnesses. Among the short-term therapeutic interventions designed to treat depression are: cognitive-behavior therapy, interpersonal psychotherapy, and behavior therapy. Among the psychopharmacologic treatments employed with children are: monoamine oxidase inhibitors, and tricyclic derivatives. In severe cases of depression, ritalin and amphetamines have been used in the past.

In conclusion, the role and dimensions pediatricians and all physicians, of teachers, and of the other human service professionals who work within the interdisciplinary model of treatment and habilitation has changed and expanded with the marked and continuing increase in children with chronic illnesses. Collaboration of team members and of the patient and his or her family members is essential if symptoms are to be controlled, if treatment regimens are to be more successful, and if secondary and tertiary disabilities are to be avoided or, at least, minimized.

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