DOCUMENT RESUME

ED 214 632 PS 012 714

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TITLE Chronic Diseases in the Pediatric Age Group. Matrix No. 7.
INSTITUTION Administration for Children, Youth, and Families (DHHS), Washington, D.C.
PUB DATE Jan 82
NOTE 7p.; Paper presented at the Research Forum on Children and Youth (Washington, DC, May 18-19, 1981). For related documents, see ED 213 518-526, PS 012 713-715, PS 012 717-718, and PS 012 722-725.
AVAILABLE FROM Administration for Children, Youth, and Families, P.O. Box 1182, Washington, DC 20013 (no price quoted).

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Behavior Patterns; *Children; Congenital Impairments; *Diseases; Premature Infants; *Research Needs; *Youth

ABSTRACT

This paper briefly outlines current problems associated with chronic diseases in children and youth and provides indications for the types of future research and analysis needed to facilitate the development of solutions. In general, these problems are associated with the following: malignancies, hereditary anemias, cystic fibrosis, other chronic lung diseases, congenital anomalies, prematurely born and "small for dates" infants, injuries, and changes in the social patterns of life. The impact of chronic diseases on families is briefly discussed. (Author/MP)

MATRIX NO. 7

CHRONIC DISEASES IN THE PEDIATRIC AGE GROUP

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PAPERS PRESENTED AT THE RESEARCH FORUM ON CHILDREN AND YOUTH

May 18-19, 1981

Convened in Washington, D.C.

Sponsored by

Federal Interagency Panel on Early Childhood Research and Development

Federal Interagency Panel for Research and Development on Adolescence

Publication Date: January 1982

Research, Demonstration and Evaluation Division
Administration for Children, Youth and Families
Office of Human Development Services
U.S. Department of Health and Human Services

Papers available from: ACYF
P.O. Box 1182
Washington, DC 20013

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On superficial consideration, chronic diseases and pediatrics seem incompatible. The traditional view of the pediatrician as a caretaker of healthy, growing organisms casts an image that may be contrasted with that of the internist, whose job it is to cuddle the infirm and to stave death. Yet, through the very success of acute pediatric care and through the advances of science and technology, pediatricians have created a large constituency of the chronically ill, consisting of those whose diseases in the past had been incompatible with life. Moreover, a comprehensive view of health care of children and youth now — in contrast to the past tradition — also takes into account a variety of social ailments that appropriately fall into the province of chronic diseases.

Although infants, children, and youth are the most uniformly healthy members of our society, there are among them groups of indolently disabled, the drama of whose disability is the greater for their being so young.

One measure of the impact of chronic illness on the young people is an estimate of disability. This is not easy to derive, because there is no general agreement about the indicators of disability. It is possible to get some insight by determining the number of days lost from school among the 6- to 17-year olds and days lost from work among those over 17 years. In 1975, days lost from school amounted to 217,102,000; days lost from work, to 430,152,000.

Not only is morbidity a serious issue, but mortality caused by chronic diseases has a significant impact. Among the 10 leading causes of death for ages 5 through 24 years, six fit the definition of chronic diseases (malignancy, congenital anomalies, cardiovascular disease, suicide, diabetes mellitus, and hereditary anemias.)

Gathering data relevant to the impact of chronic disease of children is difficult, because the various compendia do not address the issue directly. For example, there is no single index of handicaps that affect children and youth. It, in fact, may be better to add the term "impairment" to the analysis, because it is likely to include a number of chronic conditions, not otherwise classified. Many of the statistics that are available tend to lump young adults with the children. Therefore, culling out of pertinent data is difficult. Nevertheless, it is possible to infer that nearly eight million people under age 19 years are victims of some handicap. This estimate misses certain subtleties, such as minor learning disabilities, minor-to-moderate emotional problems, and social maladjustments. These statistics are flawed even more seriously by the fact that they are based on information about persons *receiving* help; there are no reliable data about those who *need* help. With respect to nonphysical disabilities, the National Institute of Mental Health estimates that only 10% of those in need is being helped.

The problems of chronic diseases — in general — fall into the following categories:

1. *Malignancies.* Chemotherapy and radiotherapy and other modalities have rendered leukemia and lymphoma curable diseases. Today, life expectancy of a child with acute lymphoblastic leukemia can be considered *normal* in 20% of the entire

group at the time of the diagnosis. This proportion reaches 50% in those with the best prognostic signs. Nevertheless, even those in the category of *cure* will continue to have to receive special attention in the process of follow up, and it must be assumed that they and their families will live for a long time under a sword of Damocles, which surely qualifies them as being chronically ill.

The success of therapy is most gratifying, because it does not merely palliate, but rather, it renders the child well enough to resume normal activities, such as attending school and playing. Moreover, these children have relatively normal physical growth and development. What lies hidden behind these facts is the effort of management, as an economic toll and social and psychological price paid by the families.

It is of interest that these achievements – remarkable as they are – have been quantitative rather than qualitative. They have been extensions of the principles of chemotherapy and radiotherapy and not developments of new methods. The fundamental cause remains undiscovered, and thus, management is gross, indirect, and untargeted. There is no reason to expect that this will change in the next decade.

Management of solid tumors has been less hopeful and can be expected to continue to depend on a combination of surgery, chemotherapy and radiation. Thus, a highly expensive and labor intensive effort is required and will continue to be required.

2. *Hereditary Anemias.* Both the thalassemias and sickle cell disease now can be managed clinically very well, so that iatrogenic complications can be kept at a minimum. The diseases themselves, however, remain unaffected.

In the case of the thalassemias, clinical management does provide a basis for an approximation of normal existence. This can be accomplished through chelation and provision of young red blood cells for transfusion.

Sickle cell disease is by far less effectively handled and its victims are always under the handicap of an impending attack and requirement for hospitalization.

The available technology of molecular biology offers hope for a fundamental cure of these genetic defects. This may be achieved through intensified research. There is every reason to hope that the next decade will bring this about. In spite of its costliness, this effort is of paramount importance.

3. *Cystic Fibrosis.* There have been great strides in the management of this chronic disease, in the main, through better treatment of symptoms. This has resulted from a more rational use of antimicrobial agents and from the development of more effective drugs. In addition, more sophisticated management of respiratory function and close attention to minor failures has improved not only longevity in this disease, but also the quality of life of the survivors.

Intravenous hyperalimentation is just beginning to be used in these patients and its potential benefits can only be evaluated in the future.

Some recent developments in antenatal diagnosis may lead to prevention of this disease through therapeutic abortion. Nevertheless, what we lack is the understanding of the fundamental enzymatic defect and a reasonable hypothesis about the pathogenic mechanisms. There is no reason to expect that this will change during the next decade.

4. *Other Chronic Lung Diseases.* Evidence is now accumulating that some adult lung diseases have their origins in childhood. The consequence of continual injury to the lung in episodes of acute respiratory illness of childhood may be chronic disease of adults. Methods that will prevent such acute episodes have yet to be worked out. Many of these episodes are caused by viral infections with agents not likely to be prevented by immunization. It is possible that better symptomatic management will tend to ameliorate chronic injury. Such management is helped by advances in the assessment of lung function that allow monitoring of the acute illness. Asthma, and to a broader extent, the larger problem of individuals with hyperactive airways, are included in the same category. It is likely that the forthcoming decade will see substantial advances in symptomatic management of these problems with the likely consequence of prevention of subsequent chronic disease.

5. *Congenital Anomalies.* Some anomalies are potentially preventable. Those caused by intrauterine infections, e.g., cytomegalovirus and toxoplasma, are likely to be prevented by immunization and meticulous perinatal care. Others — such as Downs syndrome — can be prevented by antenatal diagnosis and therapeutic abortion. Others, however, are both undetectable and nonpreventable in our current state of knowledge. Among them, the neurological, musculoskeletal, and cardiac anomalies predominate. Many of these are subject to correction, but the cost of correction can be staggering. Perhaps the most dramatic examples involve congenital heart disease. Some individuals are subject to total correction and, thus, they can return to a normal, healthy life. Others are surgically palliated and must continue life monitored and in a state of variable disability.

Congenital heart disease raises many questions. The concepts of what constitutes palliation and correction are not altogether clear. An anatomically bizarre surgical rearrangement of the cardiovascular system that was incompatible with life to one that is physiologically acceptable, can be considered a correction. More important is the question of how well the patient can adjust to life.

Many surgical strides already have been made in the management of congenital heart disease, and the next decade will see more attention paid to pharmacological management. One might call this trend "a step beyond digitalis." New drugs are being developed to control arrhythmia and to improve inotropic function of the heart by antagonizing calcium metabolism. Some of these drugs, already in use in adults, have not been applied to children, because current regulations limit the use of experimental drugs in children.

6. *Prematurely Born and Small for Dates Infants.* The past decade has seen a remarkable improvement in the survivorship of newborns weighing less than 1000 grams. The data of survival vary among the best institutions, and this issue needs clarification to determine whether there are significant differences and, if so, to what they can be attributed. Even more important, however, is the outcome among the survivors. What proportion of them will be considered *normal*? What proportion will be defective in some major way that will handicap them?

Although causes of prematurity are not fully understood, diagnosis, monitoring, and management of problematic pregnancies have been vastly improved during the pre-

ceding decade. It can be expected that improvements in these categories will continue during the next decade and that wider application of management methods will be possible and will include hospitals throughout this country.

7. *Injuries.* Severe injuries leave children permanently disabled and even maimed. Little has been done to study causes and prevention of such injuries in children. This is a major need to be addressed during the next decade.

8. *Changes in Social Patterns of Life.* Violence and substance abuse are both chronic problems. Many of these problems begin during the transition from primary to secondary school. There is insufficient knowledge about their antecedents and, therefore, means for preventing them.

Child neglect and abuse also must be considered chronic problems, particularly, because they are *hereditary*, in that children, neglected and abused, become abusing parents.

9. *Behavior Patterns Relative to Chronic Diseases.* The impact of chronic diseases on families requires special attention. As the number of surviving, chronically ill children increases, it is of importance to address the question of stress that the presence of a chronically ill child imposes on the family. Such children often require a disproportionate amount of the family's time, emotional energy, budget, and other resources. They are sometimes subject to sudden crises; e.g., a drug reaction, collapse, convulsions, etc., and they may have a predictably shortened life span. Chronic disease is sometimes stigmatizing, and the stigma extends to the family. Thus, chronic illness has the potential for induction of chronic social disquiet.

These problems require much research and analysis for our better understanding and ingenuity for the development of solutions.

Conclusion

Chronic diseases have assumed a major importance in pediatrics. The future decade will demand of us even greater efforts to solve the problems of management and care of patients in this category. This will require intensification of research and development of appropriate methods of care. Both will demand financial resources beyond anything thus far provided for this purpose. The forecast budgetary restrictions do not encourage any hope that we shall be able to address the problems of chronic diseases adequately.