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POLIOMYELITIS

PROBLEMS OF REHABILITATION REGARDING CHILDREN HANDICAPPED BY POLIOMYELITIS

by

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1. INTRODUCTION

The child handicapped by poliomyelitis belongs to the group of handicapped children who are prevented by their physical condition from participating fully in childhood activities of a social, recreational, educational or vocational nature(1). Although the rehabilitation of this whole group is based on the same guiding principles and practices, regardless of the nature of the particular handicap, specific types of handicapping conditions deserve special consideration - among them poliomyelitis.

The epidemic nature of poliomyelitis sets it apart from other causes of disability. The impact of the disease is unpredictable in a given locality and year(2). Owing to its erratic epidemic character communities as a rule are not prepared to cope with the rehabilitation problems which a major outbreak will put on their facilities. This is especially true for countries with a warm or sub-tropical climate and populations that live under primitive conditions such as most of the Mediterranean countries. There, the disease displays mostly endemic characteristics, but it may all of a sudden turn, in a very dramatic way, into a real outbreak of epidemic proportions. These outbreaks, then, are almost exclusively confined to children under five years of age and will leave those children with moderate to marked involvment in need of rehabilitation for a period of many years.

Such a transition from an endemic to an epidemic disease occurred in 1950 in Israel, and left us with the problem of rehabilitating about 2000 children aged half to three and a half years, with almost non-existent

rehabilitation facilities at the onset of the epidemic.

In the following the philosophy of a rehabilitation programme for children will be described, the approach and the methods which will have to be employed in order to put such a programme into practice will be discussed, and the complexity of problems which may be encountered, will be pointed out.

In this discussion we shall draw on the experience gained in Israel during the years 1950-59.

2. THE PHILOSOPHY UNDERLYING A CHILD REHABILITATION PROGRAMME

The aims of such a programme are:

(a) To overcome, as far as possible, the total handicapping condition.

(b) To assist the child with his physical limitations and to guide his physical, social and mental development in ways which would provide the greatest satisfaction to him as a child and, later, as an adult.

(c) To assist the parents to understand, accept and adjust to the child's condition and to accept responsibility for carrying out, in the home, such rehabilitation processes as are possible.

(d) To offer training opportunities to members of various professions concerned with rehabilitation.

(e) To educate the community to accept the handicapped child and to help in a constructive way towards his rehabilitation and integration with society.

3. THE DEVELOPMENT OF THE PROGRAMME

The important steps towards carrying out the task of comprehensive rehabilitation may be listed as follows:

(1) Case Finding

Ideally, the local Health Department should maintain a register of the handicapped children, so as to be sure that each child has been brought under care and that recommendations made for such care are duly carried out. But even the mandatory reporting of the acute disease and the almost hundred per cent hospitalisation of these cases, does not ensure the completeness of such registers, as experience has shown, and this for the following reasons:

(a) Hospital and physician reporting to the Health Department on residual paralysis and the recommendation of care has been unsatisfactory.

(b) Parents did not recognise the need of further medical attention for their children.

(c) Regular visits to treatment centres were difficult for reasons of long distance, burden on accompanying parents, loss of working hours, expensive fares.

(d) Parents refused care and neglected their children.

(e) Whole areas were lacking facilities for care.

Experience has taught that the case-finding efforts would be best integrated into the overall Public Health programme, and the Public Health Nurse, in her day-to-day contact with the families in the community, should be called upon to find the neglected child, the child with interrupted and unsatisfactory care, and bring these children to the knowledge of the District Health Office for registration and further action. Social workers, physicians and parent groups should be approached to assist in the case-finding process. Easily available clinical diagnostic facilities proved also an effective method to learn about extent and nature of problem.

(2) Prevention

Secondary prevention, based on the principle of early diagnosis, early treatment and rehabilitation, has been in the past the only measure to minimise the paralytic effects of poliomyelitis. With the development of the Salk vaccine, primary prevention in the form of immunisation could be introduced to prevent the initial occurrence of the disease. The immunisation programme in Israel started in 1956 as a campaign, conducted by special immunisation teams, but the need for smooth integration of this immunisation with the general health programme for children showed itself after one year's experience as imperative for the most effective accomplishment of the objective.

(3) The Provision of Health Services

(a) Outpatient Services

Early diagnostic evaluation of the handicapping conditions followed by individual plans for medical treatment and rehabilitation will help to avoid serious disablement.

In most countries an epidemic outbreak of the disease will find services for diagnosis and treatment only in the big cities. Smaller towns and rural areas will be without facilities or will lack specialised workers of adequate qualifications.

Facilities will have to be organised according to the local conditions, and will be of various types: specialised clinics functioning in big urban health centres, special clinic services in out-patient departments of

the hospitals, itinerant clinics in rural areas connected with hospital centres.

Israel, faced with the necessity of developing clinical services all over the country, especially for remote rural areas, was helped by a few hospital centres from whom specialists were drawn for the conducting of clinic sessions.

(b) Hospital Centres

The complicated nature of rehabilitation demands a full range of specialists which only a well-equipped and well-staffed hospital with attached rehabilitation out-patient department can provide. Such hospital centres are designed for short-term rehabilitation and offer diagnosis, evaluation and treatment services by a multiprofessional team. The comprehensive character of such centres in medical, psychological, social and vocational areas, make them an important supplement to other more modest hospital centres from which they may accept, by suitable arrangement, the more complicated cases.

Because of the high costs of such centres and the shortage of well-trained personnel, we in Israel could afford to establish only one centre of such a type for children.

In a programme for children handicapped by poliomyelitis there will also be the need for institutional care other than treatment in a hospital. Such institutions are intended for children disabled to such a degree that they cannot be cared for at home. They provide medical supervision, education and vocational training on a long-term basis.

In countries in the stage of development one will find only few institutions of this type. In Israel, a voluntary Welfare Organization established such an institution and runs it on high grants received from the Health Department for maintenance.

(c) Rehabilitation Teams

To carry out the complex process of rehabilitation a variety of trained specialists is needed, such as paediatricians, orthopaedic surgeons, specialists in physical medicine, nurses, psychologists, physiotherapists, occupational therapists, social workers and brace-makers.

In starting a rehabilitation project the necessary technicians will not always be available to the full extent. Therefore the training of certain specialists such as physical or occupational therapists will have to be built up as soon as possible.

In Israel, for instance, in order to overcome the shortage of physiotherapists, in 1953 a School of Physiotherapy was opened with the help of an expert on behalf of the World Health Organization, who stayed with the School for two years and prepared her successor in order to guarantee continuity in the development of the School.

The backbone of a rehabilitation programme is team-work, and without it no programme could succeed. The question of who should be the leader of a rehabilitation team for the very young handicapped children will always arise. We decided on the paediatrician as the leader, who will have to combine with his understanding of the child's unique personality and of his aspects of growth and development, the qualities of a coordinator and an administrator, with the task of creating team spirit.

(d) Medical Rehabilitation

Apart from physiotherapy and the use of braces in the primary acute stage, in the stage of neuromuscular recovery, and in the stage of readaptation, reconstructive surgery will have to play a major rôle, chiefly concerned with the prevention or correction of contractions in the first two stages of the disease and the restoration of functional capacity in the later stage, by such measures as tendotomy, muscle transplantation or arthodesis(4). Attention should be drawn to the fact that the results of reconstructive operations carried out at an age when growth is still proceeding may be altered by growth and deformities may thus recur. On the other hand, early reconstructive procedures allow for full use of the extraordinary adaptive faculties of the young, and this may afford the patient maximum benefit. Reconstructive procedures may therefore be very carefully chosen. Right spacing during school years may make it possible to complete the physical rehabilitation by the end of primary school and no further interruption of the vocational training of the patient will have to occur(5).

(e) Provision of Braces

Provision of suitable braces may enable the handicapped child to become mobile and independent. Ways will have to be found of assisting families in the purchasing of these braces by covering part of their cost via Governmental or voluntary agencies, as this is done in Israel. In order to improve the quality of braces, programmes for the training and certification of bracemakers should be started with the technical assistance of the United Nations.

(4) The Follow-up

Information regarding the services performed for the child should be passed on from one agency having served the child to the next one taking over. This flow of information is especially important when dealing with children in need of long-term care. The Public Health nurse should become the co-ordinator in linking the hospital, the local clinic, the family, the kindergarten, the school and all the community agencies involved in the help of the child. Children failing to keep appointments may have to be visited and the importance of continuity of care, and the need of repeated evaluation may have to be explained to the parents.

4. EMOTIONAL ADJUSTMENT

(1) The Child

Disability exposes the child to the danger of emotional problems resulting from a sense of deprivation and frustration. Hospitalization is a frightening and anxiety-provoking experience for the very young child. Aspects of treatment are painful, and the world around him may be interpreted by the child as a cruel and hostile one.

The obvious gross incapacity affects the feeling of the child towards himself. The physical limitation at such an early stage causes the child also psychological limitations, because movement at a very young age means growth in the psychological as well as the physiological sense. The unfulfilled need and the desire to move cause the child a great deal of frustration and this may be the cause of behaviour problems and regression as well as the great impoverishment of his experience and development(6).

(2) The Family

The presence of a handicapped child threatens the basic parent-child relationship. Parents may react with a number of unconscious conflicts and emotions; they may respond with guilt feelings; they may feel personally injured by a child in whom they cannot take pride and whom they therefore reject. These feelings are usually covered up, since in the western world one is expected to feel sympathy for a handicapped person irrespective of the ambivalent feelings towards the handicapped. Throughout Middle Eastern cultures, the handicapped is given little special consideration. As a result, Oriental parents are not weighed down by guilt and are capable of expression of hostility feelings. We have had the possibility of observing various expressions of such rejection in different ethnic groups.

(3) The Tasks of the Rehabilitation Team

The workers will have to be trained towards an increased understanding of the mental health needs of the children with whom they are dealing. They have to develop a high degree of insight into the emotional effects of disability on the child's growth and development. They have to see the threat to the parent-child relationship and to learn how to build it up and how to maintain it.

The presence of a psychologist or a psychiatric social worker on the staff, is here of major importance, and the social anthropologist can also contribute a great deal.

5. EDUCATION AND VOCATIONAL GUIDANCE

The handicapped child has the same right to education as other children, and should receive an education as much like, and together with, other children as possible. Only severe disability should be the reason for attending special classes at special schools. Transportation to these schools may be a vital problem and should be provided free of charge by the Education Authority or by voluntary effort.

Vocational guidance should be planned on the basis of optimal physical fitness.

6. COMMUNITY PARTICIPATION

There is a wide field of social service in which voluntary action may offer a unique contribution by securing help for rehabilitation projects and for the individual child, by urging legislation in favour of the handicapped, and by inspiring existing efforts with warm humanity. In order to avoid overlapping and duplication of work, co-operation between voluntary and Government action has to be achieved and efforts have to be made in this direction.

CONCLUSION

The development of vaccination has made the outlook for the reduction of the influence of poliomyelitis, a realisable goal for the near future. Public Health efforts will have now to concentrate on the polio victims who unfortunately have already been crippled by the disease, both before and during the introduction of the Salk vaccine, and who will have to be rehabilitated over the years to come.

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