Public Health Practice

Care for chronically ill adolescents

U. Brook, A. Rapaport, & M. Heim

Too little is known about the nature and extent of physical impairment suffered by adolescents. A recent study in Israel points the way towards more systematic data gathering and analysis, so that the necessary care can be provided.

The prevalence of chronic conditions which cause mild or severe disability among children and adolescents has been found to vary from 5% to 20% and is increasing. Chronic disorders include diseases, malformation, genetic syndromes, injuries, and other conditions which inhibit bodily functions for at least several weeks. Three levels of limitation resulting from these disorders are recognized: impairment, disability, and handicap. The most obvious impact of a disability is to decrease one’s physical activities in daily life.

It is known that 25% of the handicapped suffer from several pathological disorders at the same time. The severity of the disability cannot be deduced from the diagnosis.

Disabilities often involve dependence on orthopaedic, visual, auditory, and other aids. Most of the chronically ill in this age group also suffer from reactive emotional disturbances. They receive three times as much medical care as healthy adolescents do, and miss four times as much school or work. All these factors cause considerable socioeconomic difficulties for the patients and their families.

They also place a heavy burden on the health care system, especially when they are not clearly assessed. The aim of the present study was to develop techniques for determining the relative prevalence of chronic pathologies among 16–18-year-olds in Israel.

Definitions and procedures

Chronic disease is defined as a physical condition which has disturbed the regular function of an organ or system in the body for three weeks or more during the preceding year. Daily limitation is measured with an index of functional disability, and persons falling into this category are registered with the National Insurance Institute after being examined by designated professionals. The consecutive files of 200 adolescents up to the age of 16½ were reviewed. Primary psychiatric disorders were excluded, and the pathological entities were grouped according to their systematic anatomical and physiological status.

This survey was conducted during the second half of 1990, and one of the authors interviewed and examined all 200 adolescents in

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Dr Brook is in the Department of Paediatrics, Wolfson Medical Center, Holon, 58100, Israel, and Dr Rapaport is in the Department of Neurology at the same centre.

Dr Heim is in the Department of Rehabilitation, Sheba Medical Center, Tel-Hashomer. Correspondence should be sent to Dr Brook.
the sample. Most of them (85%) were high school or professional school students, the rest had left school and were working. Those with primary behavioural problems were not included in the study.

**Findings and their implications**

The 200 individuals represented a wide variety of disorders, only six of which occurred in 3% or more of the sample (see table). The sex distribution was 56% male and 44% female.

As the information used for this study came from the National Insurance Institute, it reflects the situation in the country as a whole, rather than a certain area in which local endemic or cultural factors may prevail. However, our sample represents only a small fraction of the thousands of adolescents registered with this organization.

In some studies the same chronic disorders are featured, but with different prevalences, while in others the main disorders themselves are different. This reflects the varying genetic and environmental factors involved. A major obstacle in this research at present is the lack of common definitions and criteria, which makes it impossible to compare findings internationally. A common language is needed, with specific objective criteria, such as spirometric measurements in asthmatics or electroencephalographic data in the convulsive group. The arbitrary division into mild, moderate and severe disability is open to such wide interpretation that no scientifically valid findings can be based on it.

The male predominance is striking, and was found by other investigators. In certain conditions, however, such as spina bifida, microcephaly and rheumatoid arthritis, there is a distinct female predominance; in the present study this was found only in the case of chronic bowel disease, but it concerned only eight people (five girls and three boys).

**Response of the health care system**

Early diagnosis makes it possible to place those with chronic disorders in the hands of a comprehensive rehabilitation team which can provide ways of mitigating their disabilities. The American Medical Association draws attention to the role of the paediatrician in counselling the parents of handicapped children, and the obligation of the national health authority to help them gain as much functional independence as possible. The ultimate aim is to enable them to be fully participating and contributing members of society. To this end, handicapped children should be placed in an educational programme that is appropriate for their cognitive, social and personal abilities.

The main rehabilitation services available in Israel for the conditions featured in this study are set out below.

**Relative prevalence of chronic conditions**

<table>
<thead>
<tr>
<th>Condition</th>
<th>No. of patients</th>
<th>Percentage of sample</th>
<th>Proportion of males to females (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Convulsive disorders</td>
<td>14</td>
<td>7</td>
<td>57 : 43</td>
</tr>
<tr>
<td>Morbid obesity</td>
<td>13</td>
<td>6.5</td>
<td>62 : 38</td>
</tr>
<tr>
<td>Hearing impairment</td>
<td>10</td>
<td>5</td>
<td>50 : 50</td>
</tr>
<tr>
<td>Insulin-dependent diabetes</td>
<td>8</td>
<td>4.5</td>
<td>62.5 : 37.5</td>
</tr>
<tr>
<td>Chronic bowel disease</td>
<td>8</td>
<td>4</td>
<td>37.5 : 62.5</td>
</tr>
<tr>
<td>Severe bronchial asthma</td>
<td>6</td>
<td>3</td>
<td>67 : 33</td>
</tr>
</tbody>
</table>
For convulsive disorders. Anti-convulsive medication with 60% remission. These young people study in regular classes (unless they are mentally handicapped). On completion of their education, they can enter any profession except those involving high altitudes or the use of dangerous equipment. They can obtain a driving licence if they are in remission for at least two years.

For morbid obesity. They begin with a gradual diet change under the supervision of a dietician, have group therapy once or twice a week, and are encouraged to take regular physical exercise at least twice a week. Surgical intervention is reserved for intractable cases and includes intestinal bypass and bowel shortening.

For hearing impairment. Hearing devices are recommended for those with conductive hearing loss. They study in regular classes and belong to a public support society.

For insulin-dependent diabetes. Self-administered insulin injections twice a day, after checking blood glucose with a glucometer. Diabetics regularly attend an endocrine centre, where they are supervised by a dietician. Their diet includes 55% carbohydrates, 30% lipids, and 15% proteins. There is no limitation on their physical activity except the need for additional carbohydrate before taking exercise.

For inflammatory bowel disease. For Crohn disease and ulcerative colitis, medication, a special diet and vitamin supplements are prescribed. Surgical treatment is recommended for intractable cases if they involve perforation, haemorrhage or intestinal obstruction. Coeliac patients have to stay on a prolonged gluten-free diet. None of these patients are limited in their physical activities, and they participate in supportive group therapy.

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For severe bronchial asthma. Patients receive anti-asthmatic medication (bronchodilators) and preventive treatment (cromoglicic acid, beclometasone, and budesonide). They are encouraged to take physical exercise, including relaxation exercises, at least twice a week. Asthmatics are encouraged to participate in gymnastics at school. From 10 years of age onwards they are advised to bring their inhalers to school with them. They are advised not to participate in competitive sports. Young asthmatics and their parents participate in supportive group therapy at respiratory centres in the main cities. They also attend talks given by physicians, nurses, physiotherapists, psychologists and social workers.

Services of this kind can only be provided adequately when each country reviews its chronically ill population, takes responsibility for rehabilitating the disabled, and provides the resources for the necessary programmes. All national health budgets are limited, but in the long run early rehabilitation saves money for the health services and hence for the country.