WHO DISCUSSION PAPERS ON ADOLESCENCE

Department of Child and Adolescent Health and Development

The Adolescent with a Chronic Condition

Epidemiology, developmental issues and health care provision

Dr P.-A. Michaud Dr J. C. Suris Dr R. Viner



WHO Library Cataloguing-in-Publication Data

The adolescent with a chronic condition : epidemiology, developmental issues and health care provision / P-A. Michaud, J.C. Suris and R. Viner.

(WHO discussion papers on adolescence)

 Chronic disease – epidemiology. 2. Chronic disease – therapy. 3. Chronic disease – prevention and control. 4. Adolescent health services. 5. Delivery of health care.
 Adolescent. I. Michaud, Pierre-André. II. Suris, Joan-Carles. III.Viner, Russell. IV. Series.

ISBN 978 92 4 159570 4

(NLM classification: WT 500)

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Editing and layout by Inís - www.inis.ie

Printed in

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Acknowledgments

Dr P-A Michaud Dr JC Suris Dr R Viner

Address for correspondence: Prof P-A Michaud, MD UMSA, CHUV, 1011 Lausanne, Switzerland

Tel: (+41) 21 314 37 60 Fax: (+41) 21 314 37 69

E-mail: Pierre-Andre.Michaud@chuv.ch

Acronyms and abbreviations used in this report

CNS	central nervous system
FEV1	forced expiratory volume
HEADSSS	Home, Education, Activity, Drugs, Sexuality, Security, Suicide and self-harm
HIV	human immunodeficiency virus
IGF-1	Insulin-like Growth Factor
IQ	intelligence quotient
NHIS	National Health Interview Survey
OC	oral contraceptives
STI	sexually transmitted infection
WHO	World Health Organization

Introduction

The incidence and prevalence of chronic conditions is rising in most developed and developing countries and will constitute the main cause of death by 2020^{1,2}. Among children, and especially among adolescents, increased life expectancy due to improvements in nutrition, hygiene and control of infectious diseases are producing an epidemiological transition in which noncommunicable diseases including chronic diseases and disability are emerging as major health problems. This transition has already occurred in developed countries^{3–8}. The management of any chronic condition during adolescence, a time of rapid growth and physiological changes accompanied by important individuation and socialization processes, constitutes a major challenge for the individual, his/her family and the health-care team. The purpose of this paper is to present data related to the epidemiology of chronic diseases during adolescence, to review their impact on the bio-psychosocial processes of adolescence and to provide evidence-based suggestions on how to manage young people with chronic conditions in a comprehensive and holistic way.

Although adolescence^a has been defined by the World Health Organization (WHO) as the period between 10 and 19 years of age⁶, most of the content of this review applies to individuals from 12 to 19 years of age, that is having entered puberty. A non-categorical approach has been used, as first defined by Stein and Jessop in 1982^{9,10}. These authors suggest that there are commonalities that cross disease categories and that, while there are issues that are specific to each disease, the commonalities can be used to increase the experience of the practitioner. These cross-disease commonalities apply not only to children and adolescents, but also to their families¹¹. Finally, although this paper focuses mainly on the issue of somatic diseases, its content applies to a large extent to any chronic condition, including mental illness and chronic disability.

^a To avoid too many repetitions, we have used interchangeably the word adolescent, teenager and young people all of whom should refer to individuals aged approximately 12 to 19 years. We have attempted to use both genders (e.g. he/she or his/her) whenever possible.

1.

Epidemiology

The prevalence of chronic conditions among adolescents is difficult to assess due to the lack of quality data focusing specifically on this age group, as well as the diversity in methodology and definitions used^{12,13}. There are many issues involved in the definition of chronic health conditions, including duration, age of onset, limitation of age-appropriate activity, visibility, expected survival, mobility, physiological functioning, cognition, emotional/social impairment, sensory functioning, communication impairment, clinical course, and uncertainty about the outcome¹¹. For instance, for asthma, definitions used vary from "ever wheezing" to "ever diagnosed by a physician" with several other possibilities in between. If conditions such as mild asthma or correctable vision conditions are included, the prevalence of chronic conditions in adolescence can be as high as 15%. If the definition is narrowed, the prevalence is reduced by half¹⁴.

Table 1 shows raw data regarding the prevalence of chronic conditions among in-school adolescents according to surveys carried out by self-administered questionnaires in a number of countries. Rates seem to be higher among males, rural residents, less privileged social classes, impoverished areas within countries and adolescents living in less educated families^{12,15}. Note that the validity of these data is limited as school-based surveys may not include those with severe physical limitation who either stay at home or live in special institutions.

Tables 2 to 5 provide figures for specific conditions such as diabetes, asthma, cerebral palsy and obesity. The differences between studies quoted relate partly to differences in methodology (e.g. data from hospitals, insurance, population-based data, data from school surveys, etc.). However, even if similar methods of data-gathering are used, the prevalence of certain conditions can vary considerably between countries. For example, the incidence of type 1 diabetes in children under the age of 15 years varies worldwide, from 0.1/100 000 per year in China or Venezuela, to 36.5 in Finland or 36.8 in Sardinia, Italy¹⁶. These differences can also be seen between regions within the same country. In China, for example, the incidence rate varies between 0.1/100 000 per year in Zunyi to 4.6 in Wuhan, and in Italy incidence rate ranges from 7.2 in Lombardy to 36.8 in Sardinia¹⁶. The same variability also holds true for disability rates. For the 10–14 year age group, rates vary from 108/100 000 in Myanmar to 6726 in Canada, and for the 15–19 year age group, they range from 142.6/100 000 in Myanmar to 5099.5 in Austria¹⁷.

Globally, the incidence of childhood cancer (under 15 years of age) is estimated to be between 100 and 150 per million. Different prevalence patterns can, however, be observed. In Europe and North America, leukaemias are the most common childhood cancers, followed by central nervous system (CNS) tumours and lymphomas, while in Latin America, leukaemias, then lymphomas and CNS tumours predominate. In Africa, lymphomas largely predominate. The incidence seems to be higher for males and to differ among races and socioeconomic status¹⁸. In Europe, 5-year survival rates for childhood cancers are increasing and reach up to 94% for Hodgkin's lymphoma and 65% for leukaemias¹⁹.

The reciprocal effects of chronic condition and adolescent development

The development of the individual during this period of life can be divided into three main stages: early, middle and late adolescence, each characterized by specific biological, psychological and social steps (see Table 6). While any chronic condition can potentially affect these developmental processes, the reverse is true; that is, both physiological change and psychosocial adjustments can have an impact on chronic conditions. As a prerequisite to adequate health care for young people with chronic conditions, this section of the paper reviews these reciprocal effects of chronic conditions and adolescent maturation, as summarized in Table 7.

2.1 Effect of chronic disease on growth and puberty

Chronic illness may delay growth, puberty and the maturation of other biological systems through lack of nutrients (malabsorption in cystic fibrosis and other gastrointestinal disorders; competition for nutrients from chronic inflammation and infection; increased nutritional requirement from excess physiological work (e.g. asthma), toxin excess (e.g. renal or liver failure; hyperglycaemia in diabetes; interference with Insulin-like Growth Factor (IGF-1) generation); down-regulation of hypothalamic hormones (gonadotrophins, growth hormone) due to chronic inflammation, nutrient unavailability, low weight, hypothalamic damage (thalassemia), stress (reducing growth hormone production) and cytokine production (e.g. in juvenile chronic arthritis); stress reducing hypothalamic drive; and the side-effects of medications such as steroids^{*20a}.

Delayed growth and puberty are common to most adolescents with chronic illnesses, although more common in those where malnutrition and chronic inflammation are also a factor (e.g. bowel disorders, cystic fibrosis). This delay may be transient, with later catch-up growth producing normal adult heights, however permanent growth loss may also occur. Large birth cohort studies, such as the British 1958 birth cohort²¹ of 12 537 subjects, found that physical chronic illness of any type in childhood and adolescence made no difference to adult height, whereas children with psychosocial chronic illnesses (e.g. enuresis, mental health problems) were on average 1cm shorter as adolescents and adults, a finding which remained significant after controlling for confounders such as socioeconomic status^{***22}.

2.1.1 Asthma

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