

Defining chronic diseases and health conditions in childhood (0–18 years of age): national consensus in the Netherlands

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The Dutch National Consensus Committee “Chronic Diseases and Health Conditions in Childhood”

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Abstract A national consensus procedure was organised to define chronic diseases and health conditions in childhood. Based on (1) a systematic literature search on the definitions of chronic conditions in childhood and (2) a theoretical framework of determinants and indicators of health conditions, a definition of chronic conditions in childhood was proposed. This proposal was subsequently modified according to the comments received from 21 Dutch experts (clinicians, researchers and representatives of patient organisations) in two written consultation rounds

and one national meeting, until consensus was reached. Consensus was attained on a definition consisting of four criteria: a disease or condition is considered to be a chronic condition in childhood if: (1) it occurs in children aged 0 up to 18 years; (2) the diagnosis is based on medical scientific knowledge and can be established using reproducible and valid methods or instruments according to professional standards; (3) it is not (yet) curable or, for mental health conditions, if it is highly resistant to treatment and (4) it has been present for longer than three months or it will, very probably, last longer than three months, or it has occurred three times or more during the past year and will probably reoccur. This definition was operationalised using the ICD-10 classification of the World Health Organisation (WHO; International Statistical Classification of Diseases and Related Health Problems [ICD], 10th revision, Geneva, Switzerland, 1992). By this systematic and thorough procedure, national consensus on a comprehensive definition of chronic conditions in children which can be used for epidemiological research was reached.

The names of the members of the Dutch National Consensus Committee are listed in Appendix 2.

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Introduction

Improvements in therapeutic possibilities in developed countries in the last few decades have led to increasing numbers of children and young adults who have survived congenital, perinatal or other severe medical conditions. For example, nowadays, 75% of children diagnosed with childhood cancer survive [25].

The downside of this success, as we have come to know, is that many survivors of serious and acute childhood

diseases are not without symptoms, and mortality has often been replaced by lifelong morbidity. For example, children with end-stage renal disease survive because of better dialysis and transplantation modalities, but they experience a host of morbidities [11]. Survival in more common congenital disorders, such as Down's syndrome [21] or cystic fibrosis [7], has increased considerably, but without a genuine cure, the morbidity and health care needs have certainly not decreased. And, thus, as a result of this success, the prevalence of chronic conditions in children and young adults is increasing. This can be the result of either the improved survival of children with a particular condition, such as end-stage renal disease or of the survival of a previously fatal condition, at the cost of long-term sequelae. An example of the latter is a child with cerebral palsy as a consequence of severe respiratory distress after premature birth. It is expected that the increase of the prevalence of chronic conditions in children and young adults due to improved survival will continue in the coming decades.

Valid estimations of the current and future number of children and adolescents with chronic diseases and health conditions (chronic conditions) are necessary for the planning of health care and social facilities. For this purpose, consensus on a definition of chronic conditions in childhood is a *sine qua non*. The term "childhood" is not well defined. In line with most of the literature on chronic conditions in childhood, we use this comprehensive term to designate all infants, children and adolescents in the age range of 0–18 years.

In the literature, several definitions of chronic conditions in childhood can be found. Many definitions are based on a combination of criteria, such as the duration of symptoms, limitations in the activities of daily living and the need for special health care or other requirements [3, 8, 18, 26, 30]. Some definitions consist of a measure of duration only [13, 17].

As part of a project to investigate the extent and consequences of chronic conditions in childhood in the Netherlands, we aimed to estimate the number of children with chronic conditions, based on reports of epidemiological studies performed in the Netherlands. A clear definition was indispensable to decide on the diseases and conditions for which studies had to be collected. Most of the definitions that were found in the literature focussed on consequences of chronic conditions in terms of functional limitations or health care needs [15, 18, 20, 26]. Since the information available to us consisted of diagnoses, these existing definitions could not be used. Several authors used various lists of specific conditions without clear justification of these diagnosis lists [6, 9, 10, 16, 19].

Therefore, we undertook a national consensus-based procedure to formulate a definition of chronic conditions

in childhood. In this paper, we describe the methods we used for this national consensus procedure and the result of this exercise, i.e. a consensus-based definition of chronic diseases and health conditions (chronic conditions) in childhood in the Netherlands.

Methods

Based on (1) a systematic search of the literature on definitions of chronic conditions in childhood and (2) a theoretical framework of determinants and indicators of the health status of a population, which is described below, we proposed a definition of chronic conditions in childhood. This proposal was sent to experts and was subsequently adapted to their comments (3). The final definition was operationalised using the ICD-10 classification [31].

Systematic review

The first step in the consensus procedure was the performance of a systematic literature review. Details of this systematic review are described elsewhere [28]. A wide range of definitions were in use, of which, four were cited by many other authors [15, 18, 20, 26]. Pless and Douglas proposed a definition for children with any chronic physical disorder for use in epidemiological surveys [20]. They described chronic illness as "a physical, usually non-fatal condition which lasted longer than 3 months in a given year, or necessitated a period of continuous hospitalisation of more than one month; of sufficient severity to interfere with the child's ordinary activities in some degree." Perrin et al. presented some recommendations for formulating a comprehensive, generic and flexible definition of chronic conditions in childhood [18]. They recommended two levels: duration and impact. First, "a condition is considered chronic if it has lasted or is expected to last more than 3 months." And a second specification is "to take into account the impact of the condition on the child. For example, the level of functional impairment or the use of medical attention greater than that expected for a child of the same age might be considered." Stein et al. defined "children with ongoing health conditions" as children having disorders that: (1) have a biological, psychological or cognitive basis; (2) have lasted or are virtually certain to last for at least 1 year and (3) produce one or more sequelae, such as: (a) limitations of function, activities or social role in comparison with healthy peers in the general areas of physical, cognitive, emotional and social growth and development; (b) dependency of medication, special diet, medical technology, assistive devices or personal assistance to compensate for or minimise the limitations of function, activities or social role or (c) the need for

medical care or related services, psychological services or educational services over and above the usual for the child's age, or for special ongoing treatments, interventions or accommodation at home or in school [26]. McPherson et al. defined a slightly different concept, namely "children with special health care needs" [15]. They described these children as "those who have or are at increased risk for a chronic physical, developmental, behavioural, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally." Apart from these four often cited definitions, several different definitions were found, some of which were based on a list of diagnoses and others were based on the duration and consequences of the condition of the child, the so-called non-categorical definitions. However, the clarity and theoretical basis of these definitions varied considerably [28].

Theoretical model

The theoretical model that was used in the process of formulating the draft definition is a model of determinants and indicators of public health status [23]. It was derived from the Dutch Public Health Status and Forecasts Report, which contains a large amount of up-to date information about Dutch public health status, prevention and health care, and includes international and regional comparisons [29]. Four indicators of the population state of health are distinguished (see Fig. 1): (1) diseases and health conditions, (2) functioning and quality of life, (3) mortality, (4) health and life expectancy. The last three indicators are consequences of diseases and health conditions. Determinants, also called risk factors, aetiological factors or prognostic factors, are causally related to the presence or the course of a (disease or chronic) condition [5]. These determinants can be internal, such as a genetic predisposition, or external factors, such as environmental pollution. Some chronic conditions can also be a risk factor for

another chronic condition; for example, diabetes mellitus is a risk factor for cardiovascular disease.

It was our aim to develop a new definition of chronic conditions that can be used in large epidemiological studies. Therefore, based on the theoretical framework, we decided to develop a definition based on medical diagnoses, and not on the consequences of the disease, such as functional limitations or special health care needs. This is in line with most of the available epidemiological studies in the Netherlands, which are diagnosis-based.

Next, the definition must be comprehensive, i.e. not only encompassing the most prevalent conditions, but all possible conditions, however uncommon, somatic as well as psychiatric. Furthermore, it was stated in advance that the definition is explicitly not intended to be used for the legal justification of rights or duties of individuals; for example, for gaining social or financial support.

Consensus procedure

The consensus procedure consisted of two written consultation rounds and one meeting, in which the draft definition was discussed. The first draft definition to be discussed in the consensus procedure was based on the definitions that came closest to our prerequisites, i.e. "objective" and "comprehensive," and on the theoretical model shown in Fig. 1. In the first consultation round, several questions were asked in order to obtain insight into the experts' ideas about the proposed concept. A second round was evaluated and adapted to the experts' comments in a similar way, and a third proposal was discussed in a consensus meeting to which all experts were invited.

Twenty-seven national clinical and research experts, including a representative of a comprehensive patient and parent organisation, were approached to join the consensus procedure. They were selected either because of their expertise on the subject as a researcher and as a representative of one of the eight academic paediatric departments in the Netherlands, or as a representative of a national institute or organisation that is involved in the research or the care for children with chronic conditions, such as the Dutch Pediatric Association (NVK), Dutch Youth Health Care, the National Institute for Public Health and the Environment (RIVM), the Netherlands Institute for Health Services Research (NIVEL), the Dutch College of General Practitioners (NHG), the Dutch Genetic Alliance (VSOP) and TNO Quality of Life Work and Employment and TNO Quality of Life Prevention and Health.

After reaching consensus about the definition, it was operationalised by three paediatricians, who were not involved in the consensus procedure, and who reviewed all diagnoses listed in ICD-10 together during an informal process [31].

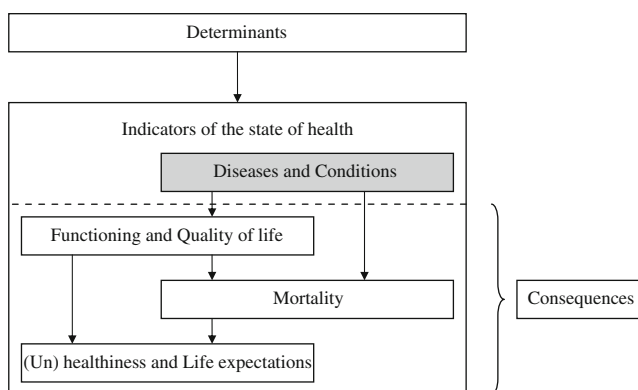


Fig. 1 Model of determinants and indicators of the public health status [23]

Results

Twenty-one of the 27 experts who had been contacted cooperated in at least one round. Three experts (11%) did not respond to our repeated requests without explanation, and three others (11%) could not co-operate due to the lack of time. Consensus on the definition was reached during the consensus meeting with 13 experts who were present, and with six other experts afterwards. These six experts, who could not attend the consensus meeting, had submitted their statements prior to the meeting and were contacted afterwards; no one disagreed with the final definition.

The definition of chronic conditions in childhood which was formulated during the consensus meeting consists of four criteria. All four criteria must be met. A disease or condition is considered a chronic condition in childhood if:

1. It occurs in children aged 0 up to 18 years, and
2. The diagnosis is based on medical scientific knowledge and can be established using reproducible and valid methods or instruments according to professional standards, and
3. It is not (yet) curable or, for mental health conditions, if it is highly resistant to treatment, and
4. It has been present for longer than three months or if it will, very probably, last longer than three months, or if it has occurred three times or more during the past year and will probably recur again

Ad (1): 0 to 18 years To define “infants, children and adolescents,” the cut-off point for age was chosen at 18 years inclusively, corresponding to the same age cut-off point used in Dutch Youth Health Care [1].

Ad (2): based on medical scientific knowledge and can be diagnosed using reproducible and valid methods or instruments During the consensus meeting, the discussion concentrated on the difference between “has been diagnosed” and “can be diagnosed.” In the first case, a child with a medically stated diagnosis is defined. In the second case, only the diagnosis is defined. The second option was chosen because it was decided to operationalise the definition using the ICD-10, which classifies conditions and health-related problems, not persons with specific diagnoses. Next, “reproducible and valid methods or instruments” do not only include objective measurements, such as laboratory investigations like haemoglobin concentration of blood, but they also comprise diagnoses made by a professional based on more subjective information, such as patient history consideration. However, there should be consensus in the group of professionals about which aspects in the history should be met before a diagnosis can be made.

Ad (3): not (yet) curable The curability of a condition may differ over time. In the 1980s, HIV/AIDS was fatal within months, whereas nowadays in Western countries, it has become a chronic disease. Therefore, it was considered appropriate to take account of the present health care facilities in the Netherlands. This criterion results in the distinction between longer-lasting conditions that are curable, such as a complicated bone fracture, and long-term conditions that may be treatable, but are not curable at this time, such as diabetes mellitus and asthma. This distinction between long-lasting curable conditions and long-term (at this time) non-curable conditions is important, because the course and the impact of both types of conditions differ considerably. In mental health care, the terms “curable” or “not curable” are inconvenient. Therefore, it is suggested to replace this criterion by “highly resistant to treatment” when applied to mental health conditions.

The framework in Fig. 2 shows the distinction between chronic conditions and other conditions. Diseases and health conditions can be divided into short-term and long-term diseases and conditions. The term “acute conditions” has not been used in this framework, since the acuteness refers to the start of a disease episode. Long-term conditions may or may not have an acute start. Short-term conditions either resolve completely or are fatal within a short time-period. In some cases, a short-term condition can lead to (another) long-term condition; for example, the short-term condition meningitis, which can be cured or may be fatal, but sometimes leads to long-lasting sequelae, such as a hearing deficit.

Long-term conditions can be divided into curable and non-curable conditions. An example of a long-term curable condition is a bone fracture. This may take more than three months to heal, but is considered to be completely curable. Long-term non-curable conditions are the focus of the

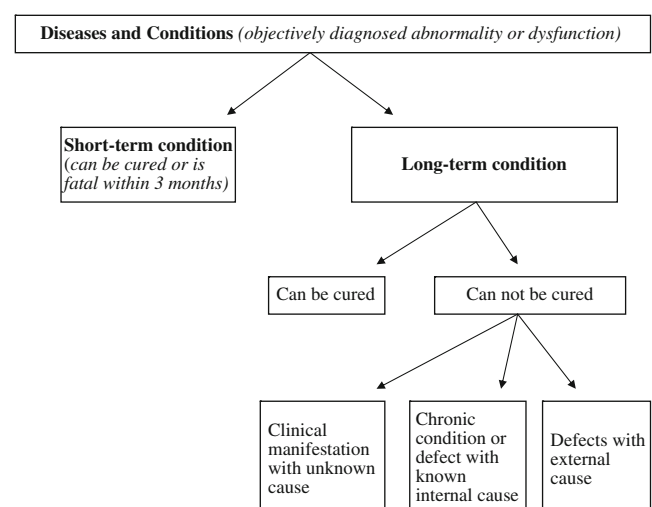


Fig. 2 Model of short-term and long-term conditions

definition. These can be divided into: (1) clinical manifestations with an unknown cause, such as epilepsy; (2) conditions of which the underlying pathology is known but cannot be cured, such as diabetes mellitus or a chromosomal defect or (3) defects resulting from an external cause, such as scars of burns, intoxications or injuries.

Ad (4): duration The most common criterion found in the literature for chronicity was “duration.” Mostly, a period of three months was proposed for somatic conditions [3, 12, 14, 18, 20, 30], and sometimes a period of 12 months [8, 22, 26]. Recurrent conditions were considered chronic if they occur three times or more in a year [13]. In the case of mental conditions, the same period was chosen. In adult patients, a period of two years is used for defining “chronic mental conditions” [24]. However, all experts agreed that this would be far too long a period to be considered in this age group.

After reaching consensus about the definition, it was operationalised using the ICD-10 classification [31]. Three paediatricians reviewed all diagnoses listed in ICD-10 together during an informal process. Except for diagnoses in the categories “other” or “unspecified,” each diagnosis was rated using all four criteria of the consensus definition to determine whether it denoted (+) a chronic condition occurring in childhood, (–) a condition that is either not chronic or does not occur in childhood or (+ –) a condition that is chronic in only a proportion of the affected patients. This resulted in 285 diagnoses or clusters of diagnoses which denote conditions that are chronic in all patients or in a proportion of patients with these conditions (see Appendix 1).

Discussion

National consensus was reached in the Netherlands with the representatives of all children’s hospitals in the Netherlands and the representatives of several Dutch research institutes and organisations. By this thorough procedure, a comprehensive definition of chronic conditions in children was obtained, which can be used as a framework for epidemiological research.

This definition is in line with the definition of chronic conditions developed for scientific research and health policy for the older population with chronic conditions [2, 27].

Additional aspects of the definition of chronic conditions in childhood that were found in the literature included limitations in daily activities [18, 20, 26], special/increased requirements of (a type or amount beyond usual) care [15, 18, 26] or social security or financial aspects [4]. These

aspects were discussed but were deliberately left out of the definition, since they were concerned with consequences of chronic conditions for the child, the parents and family or society. The comparison of prevalence rates between countries or within a country over time must be based on a clear definition, which leads to robust and reproducible prevalence data when operationalised. Definitions based on the consequences of health conditions will not yield this type of data, because the evaluation of the consequences of a chronic condition in terms of care needs or functional limitations varies according to cultural, educational and financial circumstances, and the availability of treatment and care. Obviously, the measurement of the prevalence rates of chronic conditions depends on the access to health care services. If access is limited, a number of patients will remain undiagnosed. However, this is a problem of ascertainment; it does not mean that these people do not fit the definition of having a chronic condition. The severity of disease was also not included in the definition, because this was seen as an additional aspect of chronic conditions, which may or may not be used to denote a subgroup of all children with chronic conditions. It was not seen as an essential aspect that defines chronic conditions. Other aspects of having a chronic condition, such as the unpredictability of the course of the condition, the invisibility of symptoms for other people and the insecurity arising from having a chronic disease, have been discussed in the consensus group, but have been excluded from the definition for the same reason.

Our definition states that the diagnosis is based on medical scientific knowledge using reproducible and valid methods and instruments according to the professionals. It should be specified by the professional community itself when a method or instrument is reproducible and valid. This may give the impression of not being objective. However, there will always be some subjectivity in a subset of all medical diagnoses, especially in the diagnosis of mental health conditions. This problem should be dealt with by the professional community.

There is a wide variability in the terminology and concepts in this field [28]. In our first draft definition, the term “chronic disease” was used. However, it became clear that this would mean that some chronic conditions, such as obesity, ADHD, epilepsy etc., would not be included. Since our aim was to formulate a comprehensive definition, the term was changed to “chronic diseases and health conditions.”

The procedure used to operationalise the definition was a first attempt to compile a comprehensive and useful list of diagnoses. For this purpose, we used the ICD-10 classification. Since this classification was not primarily made for the paediatric setting nor for mental health conditions, it may not be the most appropriate. We did not distinguish

between different developmental stages. It may be appropriate for specific research questions to operationalise the definition for infants, children and adolescents separately. We emphasise that the list of ICD-10 diagnoses in Appendix 1 is not considered to be final, and we welcome comments from other researchers.

Conclusion

National consensus was obtained on a comprehensive definition of chronic conditions in children, which can be used as a framework for epidemiological research. A disease or condition is considered to be a chronic condition in childhood if: (1) it occurs in children aged 0 up to 18 years; (2) its diagnosis is based on medical scientific knowledge and can be established using reproducible and valid methods and instruments according to the professionals; (3) it is not (yet) curable or, for mental health conditions, if it is highly resistant to treatment and (4) it has been present for longer than three months, if it will, very probably, last longer than three months or if it has occurred three times or more during the past year and will probably recur again. Based on this definition, a list of 285 diagnoses or clusters of diagnoses was made, which denote conditions that are chronic in all patients or in a proportion of patients with these conditions.

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