Definitions and Measurement of Chronic Health Conditions in Childhood

A Systematic Review

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Context Changes in the prevalence of chronic health conditions in childhood have considerable societal consequences for health care planning and for employment. To obtain valid and reliable estimates of the prevalence of chronic health conditions, a clear definition is needed.

Objective To present an overview of all definitions and operationalizations that have been applied to measure the prevalence of chronic health conditions in childhood.

Data Sources PubMed and the Web of Science were searched for articles published up to December 2006. Also, references were searched by hand for related articles.

Study Selection Non–English- and non–Dutch-language articles were excluded. Of 7252 articles found, 64 articles that stated a conceptual definition and/or operationalization of chronic health conditions in children (aged 0-18 years) were included.

Data Extraction Data on the (1) definition; (2) operationalization in terms of source of information, method of information retrieval, and study population; and (3) resulting prevalence rate were extracted by 2 independent reviewers.

Data Synthesis A large range of definitions were in use, of which 4 were cited by many authors. Various operationalizations of the concepts that were measured were identified. Chronic health conditions in childhood prevalence estimates ranged from 0.22% to 44%, depending on these operationalizations.

Conclusions The wide variability in reported prevalence rates of chronic health conditions in childhood can be explained by considerable diversity in the concepts and operationalizations used. International consensus about the conceptual definition of chronic health conditions in childhood is needed.

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As a result of improved efficacy of treatments and care for life-threatening pediatric conditions, the survival of children with serious congenital or acquired diseases in developed countries has increased during the last decades.[1,2] Yet, many of these children have not been cured (eg, those with cystic fibrosis) or they have disabling sequelae of their disease (eg, cerebral palsy and juvenile rheumatoid arthritis) or its treatment (eg, retinopathy of prematurity). The incidences of some other conditions, such as asthma and obesity, are rising. Therefore, the prevalence of chronic diseases in children and in young adults, which is a function of incidence and duration, has increased since the 1980s and will likely increase further.[3-6]

In addition to the added disease burden of children and their families, this increase in prevalence has considerable financial and organizational consequences for health care planning and for employment. To enhance the societal participation of these children as they approach adulthood and to be able to plan for sufficient and adequate facilities, policy makers and politicians need to rely on valid prevalence data. Such prevalence data on chronic conditions in children and young adults are not only useful for planning for health care and provisions for the welfare of young adults with chronic conditions, they can also be considered, in addition to mortality statistics, as an outcome measure in comparisons of determinants of youth health between countries and over time.[5] So far, many different approaches have been used to measure the prevalence and consequences of chronic diseases and health conditions in children, resulting in a wide variability of prevalence estimates that cannot be readily com-

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pared. Research on prevalence of chronic diseases in children is often focused on 1 or more specific diagnoses.[7] An unequivocal definition of the concept of chronic health conditions in childhood has been lacking, and, as a consequence, operationalizations to measure the prevalence are diverse.

The aim of this article is to provide a systematic overview of all definitions and operationalizations that have been used to measure the prevalence of chronic health conditions in childhood. By *operationalization*, we mean all aspects of the methods of a prevalence study, including (1) the source of the information (eg, parents, medical files, or insurance data); (2) the instrument used to obtain the information (eg, questionnaire, interview, list of diagnosis codes, or computer query); and (3) the study population (eg, a representative sample of all noninstitutionalized children aged 0-18 years or all children registered in a hospital database).

METHODS

Two literature searches were performed in MEDLINE using PubMed (complete database through December 2006) on the topic of definitions of chronic conditions in children, and 1 in Web of Science (1988 through December 2006). The search strategy is available from the corresponding author. In addition, we searched references by hand for related articles.

Articles that fulfilled the following inclusion criteria were included: (1) the main focus of the article was on chil-

Table 1. Most Frequently Cited Definitions of Chronic Health Conditions in Childhood

Source	Location	Concept	Proposed Definition	Operationalization	Prevalence
Pless and Douglas, 1971[8]	England, Wales, and Scotland	Chronic illness	A physical, usually nonfatal condition that has lasted longer than 3 mo in a given year or necessitated a period of continuous hospitalization of more than 1 mo; of sufficient severity to interfere with the child's ordinary activities to some degree	National Child Development Study, a longitudinal survey of all children born in 1 week in England, Scotland, and Wales	11% aged <16 y
Perrin et al,[9] 1993	United States	Chronic health conditions	A condition is considered chronic if (1) it has lasted or is expected to last more than 3 mo and (2) the definition takes into account the impact of the condition on the child, eg, level of functional impairment or medical need greater than expected for a child of that age	NHIS, 1989	31% aged <18 y; added: 5.3%; unable to conduct major activity: 0.6%
Stein et al,[10] 1993	United States	Chronic health conditions	Conditions must have a biological, psychological, or cognitive basis; have lasted or are virtually certain to last for 1 y; and produce ≥1 of the following sequelae: (1) limitations of function, activities, or social role in comparison with healthy age peers in the general areas of physical, cognitive, emotional, and social growth and development; (2) dependency on 1 of the following to compensate for or minimize limitations of function, activities or social role: medications, special diet, medical technology, assistive device, or personal assistance; and (3) need for medical care or related services, psychological services, or educational services above the usual for the child's age or for special ongoing treatments, interventions, or accommodations at home or in school	NA	NA
Stein and Silver,[11] 1999	United States	Chronic health conditions	Same as for Stein et al[10]	NHIS household telephone interview, 1994	14.8% aged <18 y
McPherson et al,[12] 1998	United States	Children with special health care needs	Children who have or are at increased risk of a chronic physical, developmental, behavioral, or emotional condition and who also require health care and related services of a type or amount beyond that required by children generally	NA	NA
Newacheck et al,[13] 1998	United States	Children with special health care needs	Same as for McPherson et al[12]	NHIS-D, 1994	12% aged <18 y; additional 6% had a presumed need for health care or related services

Abbreviations: NA, not applicable; NHIS, National Health Interview Survey; NHIS-D, National Health Interview Survey on Disability.

dren (ie, aged 0-18 years); (2) the definition concerned chronic conditions, excluding articles focusing on specified chronic conditions and on disability; and (3) the aim of the article was either to present a definition or to estimate the prevalence of chronic conditions in children. We excluded non-English and non-Dutch literature. Two of the authors (J.H.L. and L.B.M.) independently performed the selection of articles based on titles and abstracts retrieved in the 3 searches. When in doubt, the complete article was screened using the same criteria. The decision to include articles in this review was reached by consensus.

Information was extracted from the articles on (1) the conceptual definition; (2) the operationalization in terms of source of information, method of information retrieval, and study population; and (3) the resulting prevalence rate. Data were collected by J.H.L. and L.B.M. Only minor differences occurred, which were solved by discussion. All definitions and operationalizations were assessed in light of our aim of contributing to the development of a definition that could be used to make comparisons of the prevalence of chronic conditions in children between countries and at different points in time. We also tried to evaluate the influence of the following possible sources of variance on the reported prevalence rates: (1) the concept of chronic disease underlying the definition; (2) the operationalization of the definition; (3) the country; and (4) the year in which the study was performed.

RESULTS

The search yielded 7252 articles, of which 64 articles were included. All of the articles were in English, from 14 countries. Articles that did not comply with at least 1 of the inclusion criteria were excluded. TABLE 1 describes the most frequently cited definitions and TABLE 2 presents the prevalence studies with the operationalizations used. TABLE 3 describes articles in which a definition is presented with a different goal than to measure prevalence.

Concepts and Definitions

Many different terms are used to denote the central concept, the most frequently used terms being *chronic conditions*, *chronic health conditions*, *chronic illness*, and (*children with*) *special health care needs* (Tables 1-3). A conceptual definition was presented in 61 of the 64 articles; the clarity and theoretical basis of these definitions varies considerably. Many authors referred to 1 of the 4 definitions presented in Table 1, which were the most frequently measured concepts.[8-10,12]

The earliest definition concerned duration of disease and its impact on daily activities.[8] The type and extent of impact of the condition on the child's functioning and health care needs is emphasized more in the later definitions of Perrin et al[9] and Stein et al,[10] while in the most recent definition of children with special health care needs, the types of conditions included are more extensive, even including "increased risk for a chronic condition," whereas the impact is limited to "requiring health and related services."[12]

An important issue for debate in the United States in the 1990s was the distinction between a conceptual definition based on a list of diagnoses and a noncategorical definition based on the duration and consequences of the condition of the child.[9] The *noncategorical approach* was adopted as a reaction to the diagnosis-based approaches that had been used before to assign health care facilities and financing to individual children.[10] Instead of a list of diagnoses, the basis of the noncategorical approach was the functional limitations resulting from the health condition, including dependency on medication, assistive devices, or medical care. In this way, the similarity of specific consequences of various diseases and conditions was taken into account.

Operationalization

Table 2 includes the 32 articles presenting operationalizations of the definitions (ie, the methods to measure prevalence) and the prevalence rates. The conceptual definitions vary considerably with regard to their clarity and comprehensiveness; sometimes they were not stated in the article.[16,31] In 8 of the 32 articles in Table 2, data generated by the National Health Interview Survey were presented.[11,13,18,21,23,26,30,34] The concepts and methods of the National Health Interview Survey have been adapted every 10 to 15 years since the first survey in 1957.[76] Both the noncategorical approach and lists of diagnoses were used. Information was retrieved from interviews with parents* or with the patients themselves,[36] from medical examination of children,[25,27] from claims files,[33,35,45] or from medical records.[19,20,24,32,39] Sometimes health care professionals were asked to report all designated children known to them, either based on medical records[31] or without a specified method.[14,15] One study combined prevalence data from several registries and earlier prevalence studies,[29] and in another article an overview of surveys based on school samples in several countries was presented.[42]

The study population described in each article depended on the purpose of the study. General population samples were drawn in a systematic way in studies aiming at generating prevalence data†; other samples were used to answer different questions—eg, when comparing the lifestyles of adolescents with chronic conditions with those of their healthy peers.[36]

The prevalence rates varied from 0.22% for "medically fragile children" aged 0 to 19 years, a small subset of all children with special health care needs identified from North Carolina's Medicaid paid claims database,[45] to 44% of children aged 0 to 18 years visiting an urban health center identified by a diagnosis list.[32] Restriction to the terms *chronic conditions*, *chronic*

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*References 11, 13, 16-18, 21-23, 26, 30, 32, 34, 40, 41, 44, 46.

†References 13, 17, 18, 21, 23, 26, 30, 49, 50.

Table 2. Operationalizations to Measure Prevalence of Chronic Health Conditions in Childhood

Source	Location	Concept	Definition Used	Operationalization	Prevalence
Urponen and Peltonen,[14] 1978	Finland	Chronic disease	Children whose disease is lingering either due to its mechanism of origin or to its nature or known to be such from experience	Not clear; apparently public health nurses	5.3% aged <16 y
Vuori et al,[15] 1978	Finland	Chronic illness	Children having any of 11 disease category diagnoses; illness had lasted at least 3 mo and was expected to continue further	Public health nurses reported children they were aware of	3.49% aged <16 y
Weale and Bradshaw,[16] 1980	Great Britain	Long-standing illness, disability, or infirmity	Not clear	General Household Survey, 1974	7.6% aged <16 y
Cadman et al,[17] 1986	Canada	Chronic health problems	Chronic illnesses or medical conditions as well as limitations of normal function present for at least 6 mo	Ontario Child Health Study (functional limitations scale and checklists of chronic illnesses or conditions)	19.6% (95% CI, 17.9%-21.3%) aged 4-16 y
Newacheck et al,[18] 1986	United States	Chronic conditions causing activity limitations	Some degree of limitation in school, play, or other recreational activities because of chronic conditions	NHIS, 1960-1981	1960: 2%; 1981: 3.8% aged 0-17 y
Westbom and Kornfalt,[19] 1987	Sweden	Chronic illness	Pless and Douglas[8]	Child health clinic records (attendance almost 100%) and school health records	8.4% (95% CI, 6%-10.8%) aged 0-15 y
Bendel et al,[20] 1989	Israel	Disabling conditions	Children who have special needs for health and other services in comparison with their peers, due to their health condition	List of 76 conditions; Family Health Centers files	8.9% of all 3-year-olds
Newacheck et al,[21] 1991	United States	Chronic conditions	First noticed >3 mo before interview, or type of condition that ordinarily has a duration of >3 mo	NHIS, 1988, list of conditions	31.5% of adolescents (aged 10-17 y)
Vuorinen et al,[22] 1991	Finland	Chronic diseases	Any reported chronic condition causing disability	National Health and Social Security Interview survey (interview with adult family member, preferably mother)	1987: 8.8% (95% CI, 7.3%-10.3%) aged 0-6 y; 15.0% (95% CI, 13.2%-16.9%) aged 7-14 y
Newacheck and Taylor,[23] 1992	United States	Chronic conditions	First noticed >3 mo before interview, or type of condition that ordinarily has a duration of >3 mo	NHIS, 1988	31% aged 0-17 y had ≥1 chronic conditions
Palti et al,[24] 1992	Israel	Health conditions leading to disabilities	Not clear	Diagnoses in school file records, regular schools and special education	Regular schools: 17.5% of all 7-year-olds had at least 1 condition; special education: 100%
Janson and Dawani,[25] 1994	Jordan	Chronic disease and disability	Chronic disease: a condition that appreciably affected the child's life for ≥3 mo during the preceding year; disability: International Classification of Impairments, Disabilities and Handicaps	Regular visitors to Institute of Child Health and Development; all children were examined by pediatricians	7.8% (95% CI, 6.7%-8.9%) aged 0-7 y had a disability or chronic disease
Newacheck and Stoddard,[26] 1994	United States	Chronic conditions	Type of condition that ordinarily has a duration of >3 mo	NHIS, 1988	19% aged 0-17 y had ≥1 chronic conditions; 3.5% had 2 conditions; 0.9% had >2 conditions
Jessop and Stein,[27] 1995	United States	Chronic physical conditions	Lasts ≥3 mo, necessitates a period of hospitalization of 1 mo, or is expected to be permanent (Pless and Pinkerton[28])	Health Examination Surveys, 1963-1965 and 1966-1970; comparison of history and physical examination	Aged 6-11 y: 25.2%; aged 12-17 y: 35.3%; only 4% identified by both history and physical examination
Vogel et al,[29] 1996	New Zealand	Chronic conditions	Selected conditions	Best estimates from various sources	Condition-specific data
Newacheck and Halfon,[30] 1998	United States	Disabling chronic conditions	NHIS classification of chronic conditions causing activity limitations (disabilities): duration >3 mo or specific condition from *International Classification of Diseases, Ninth Revision* list	NHIS, 1992-1994	6.5% in children aged <18 y

(continued)

health conditions, and *chronic illness* in the general population yielded a range in estimated prevalence rates from 3.49% of children younger than 16 years identified by public health nurses[15] to 35.3% of youth 12 to 17 years old identified by a combination of parental history and physical examination.[27]

Table 2. Operationalizations to Measure Prevalence of Chronic Health Conditions in Childhood (cont)

Source	Location	Concept	Definition Used	Operationalization	Prevalence
Newacheck et al,[13] 1998	United States	Children with special health care needs	McPherson et al[12]	NHIS-D, 1994	12% aged <18 y; additional 6% had presumed need for health or related services
Stein and Silver,[11] 1999	United States	Chronic conditions	Stein et al[10]	NHIS household telephone interview, 1994	14.8% in children aged <18 y
Al-Eissa,[31] 2000	Saudi Arabia	Chronic illness	Not clear	Interview of physicians from patient file or asking patient directly	18% aged 11-21 y visiting primary health care clinic
Kuhlthau et al,[32] 2002	United States	Chronic conditions	Stein et al[10]	Comparison of identification by a diagnosis list using encounter data with identification by the QuICCC	Among those aged 0-18 y visiting an urban health center, diagnosis list: 44%; QuICCC: 36%
Neff et al,[33] 2002	United States	Chronic health conditions/ special needs	Categorical clinical classification system: dominant, moderate, and minor chronic conditions	Claims files	9.5% had ≥1 chronic conditions
Stein and Silver,[34] 2002	United States	Chronic conditions	Comparison of 4 definitions based on a sample ascertained by the National Center for Health Statistics	NHIS (1994-1995), QuICCC, New England SERVE, Maternal and Child Health Bureau	NHIS, 15.3%; QuICCC, 14.6%; New England SERVE, 13.7%; Maternal and Child Health Bureau, 17.7%
Beers et al,[35] 2003	United States	Children with special health care needs	Comparison of application of 3 definitions among states	Social Security Administration Annual Statistical Report, 2000, and Title V Information System Web site	Social Security Income eligible median, 1.06% (range, 0.39%-3.23%); Title V median, 1.12% (range, 0.14%-3.33%)
Miauton et al,[36] 2003	Switzerland	Chronic conditions	Physical handicap: lesion that affects bodily integrity and limits its functioning in any way; chronic illness: lasts >6 mo and may need regular care[10,28,37,38]	Swiss Multicenter Adolescent Survey on Health, 1992, 1993	11.4% of girls and 9.6% of boys aged 15-20 y
Rolnick et al,[39] 2003	United States	Children with special health care needs	Comparison of 2 instruments for identifying children with special health care needs in health maintenance organizations (and Medicare, Medicaid, and MinnesotaCare)	QuICCC telephone interview random sample; Clinical Risk Grouper administrative data	QuICCC, 37%; Clinical Risk Grouper, 11%
Seguin et al,[40] 2003	Canada	Poor infant health in the first 5 mo	(1) Health perceived to be less than excellent; (2) chronic health problems present; (3) admitted to hospital since birth	Home interviews with representative sample of mothers	(1) 24.1% (95% CI, 22.2%-26.0%); (2) 9.2% (95% CI, 7.9%-10.5%); (3) 12.9% (95% CI, 11.3%-14.5%)
Spencer and Coe,[41] 2003	United Kingdom	Long-standing health problems	Any long-standing illness, disabilities, health problems, or handicaps (such as developmental delay or speech problems)	Coventry Cohort Study, Warwick Child Health and Morbidity Profile	10.3% (95% CI, 8.7%-12.2%) of 3-year-olds
Suris,[42] 2003	France, Switzerland, Canada, Spain	Chronic conditions	Condition that lasts more than a defined period of time (usually 3 mo) and that may limit daily activities	Surveys based on school samples (review)	France: girls, 8.3%; boys, 9.0%; Switzerland: girls, 11.3%; boys, 8.3%; British Columbia, Canada: girls, 11.0%; boys, 7.0%; Barcelona, Spain: girls, 12.6%; boys, 8.3%
Youngblade and Shenkman,[43] 2003	United States	Children with special health care needs	McPherson et al[12]	Children with special health care needs screener, telephone interview, parents and adolescents	Parents reported 17.8% among adolescents; adolescents (aged 12-17 y) reported 12.6%
McDougall et al,[44] 2004	Canada	Chronic health conditions	Long-term (at least 3-mo duration) or of a permanent nature	1994-1995 National Longitudinal Survey of Children and Youth; conditions lasting longer than 6 mo diagnosed by a health care professional	30.3% aged 6-11 y
Buescher et al,[45] 2006	United States	Medically fragile children	Children who have very serious health problems and must often depend on technology for vital functions	Medicaid paid claims database, selection of certain procedures and equipment	0.22% aged 0-19 y enrolled in Medicaid
Partington et al,[46] 2006	United States	Children with special health care needs	McPherson et al[12]	Children with special health care needs screener, computer-assisted telephone interviewing system	23.5% aged <18 y in Milwaukee, Wis

Abbreviations: CI, confidence interval; NHIS, National Health Interview Survey; NHIS-D, National Health Interview Survey on Disability; QuICCC, Questionnaire for Identifying Children With Chronic Conditions.

Table 3. Articles in Which Definitions Are Presented With a Different Goal Than to Measure Prevalence

Source	Location	Concept	Definition Used	Operationalization	Main Objective
Hobbs et al,[47] 1984	United States	Chronically ill children	Condition that interferes with daily functioning for >3 mo in a year, causes hospitalization of >1 mo in a year, or (at time of diagnosis) is likely to do so	Not applicable	Background and policy issues
Kaplan et al,[48] 1986	United States	Chronic illness	Being ill for ≥4 mo	Hospitalized patients, chart review	Investigation of life events and depressive symptoms in hospitalized adolescents and general population
Newacheck et al,[49] 1986	United States	Chronic conditions causing activity limitations	Noticed >3 mo before interview date or type of condition that ordinarily has a duration of >3 mo	NHIS, 1979-1981	Condition-specific measures of severity, including degree of activity limitation, annual totals of restricted-activity days, duration of activity limitation
Gortmaker et al,[50] 1990	United States	Chronic health conditions	Checklist; conditions that had been present for >3 mo and had not been cured; autism, mental retardation, and various other diagnoses excluded	NHIS, 1981	Investigating associations with socioeconomic variables and behavior problems
Pless et al,[51] 1993	United Kingdom	Chronic physical disorders	Pless and Douglas[8]	National Child Development Study: longitudinal survey of all children born in 1 week in England, Scotland, and Wales	Investigating long-term psychosocial sequelae of chronic physical disorders
Knafl et al,[52] 1996	United States	Chronic illness	(1) duration >3 mo; (2) stable or progressive illness course; (3) relatively normal life span despite impairment; (4) active management required to minimize serious illness consequences	Not clear how sample was drawn	Investigation of family management styles by structured and unstructured data collection techniques
Martin and Nisa,[53] 1996	Australia	Chronic illness, chronic disease	Perrin et al[9]	Literature review	Literature review
Stein et al,[37] 1997	United States	Chronic health conditions	Stein et al[10]	QuICCC	Development and validation of the QuICCC
Garwick et al,[54] 1998	United States	Chronic conditions	*ICD-9* codes; Stein et al[10]	Identified from medical records	Identifying parents' perceptions of helpful vs unhelpful types of social support received in managing care
Boekaerts and Roder,[55] 1999	Netherlands	Chronic disease	Conditions that affect children for extended periods, often for life; can be managed but cannot be cured (Eiser[56])	Not applicable	Coping and adjustment
Cooper et al,[57] 1999	United States	Chronic health conditions	List of *ICD-9* diagnoses	Discharge diagnoses	Evaluation of a health care program[9,23]
Perrin et al,[58] 1999	United States	Chronic health conditions	List of *ICD-9* diagnoses	Medicaid enrollment files and claims data, Social Security Income recipients	Estimation of changes in clinical characteristics of children enrolled in Social Security Income after changes in eligibility
Silver et al,[59] 1999	United States	Chronic physical health conditions	Pless and Douglas[8]	Hospital records	Cohort selected for a randomized controlled trial; associations between sociodemographic and condition-related characteristics and conduct problems
Feudtner et al,[60] 2000	United States	Deaths due to complex chronic conditions	Any medical condition that can be reasonably expected to last ≥12 mo (unless death intervenes) and to involve either several different organ systems or 1 organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center	Death certificates from vital statistics computer files	Service planning

(continued)

Table 3. Articles in Which Definitions Are Presented With a Different Goal Than to Measure Prevalence (cont)

Source	Location	Concept	Definition Used	Operationalization	Main Objective
Stein et al,[61] 2000	United States	Chronic conditions	Physiological, behavioral, or cognitive disorder that has lasted or is virtually certain to last for 1 y and produces $\geq$1 type of consequence: functional limitations, reliance on compensatory assistance for functioning, or increased service	QuICCC, telephone interviews (parents)	Validation of the QuICCC
Dosa et al,[62] 2001	United States	Chronic health conditions	Noncategorically defined (McPherson et al[12])	Hospital charts, unscheduled intensive care unit admissions	Comparison of acute illness in children with and without chronic conditions[9,12,13]
Feudtner et al,[63] 2001	United States	Deaths due to complex chronic conditions	List of *ICD-9* codes	Mortality data from the National Center for Health Statistics	Service planning
Spaite et al,[64] 2001	United States	Children with special health care needs	Aged $\leq$21 y, congenital or acquired condition or chronic physical or mental illness affecting physical or mental growth and development, requiring $\geq$1 of the following: assistive technology device, prolonged or frequent hospitalizations, or a specialized approach to assessment and management	Emergency medical service response patient care forms, *ICD-9* codes	Evaluation of specialized paramedic training program
Stein et al,[65] 2001	United States	Chronic health conditions	Noncategorical	QuICCC interview (parents)	Validation of shorter version of QuICCC[9,10,12]
Stein et al,[66] 2001	United States	Chronic health conditions	Stein et al[10]	NA	Policy statement and research agenda
Gallaher,[67] 2002	United States	Chronic health conditions	List of *ICD-9* diagnoses	Medicaid claims data	Comparison of children with and without diagnosis of developmental delay
Neff et al,[68] 2002	United States	Chronic conditions	National Association of Children's Hospitals and Related Institutions Classification of Chronic and Congenital Health Conditions system (1996 version)	Hospital discharges	Comparison of utilization measures between chronic and nonchronic conditions
Perrin,[69] 2002	United States	Disabilities and chronic conditions	Disabilities: inability to carry out age-appropriate daily activities as a result of a health condition or impairment Chronic conditions: health conditions that at the time of diagnosis are predicted to last $>$3 mo	Review	Health services research
Geist et al,[70] 2003	Canada	Chronic disease	Illnesses that affect a person for an extended period, often for life, and that require medical care and attention beyond the normal requirements for a child or an adolescent (American Academy of Pediatrics[71])	Review	Review of psychosocial impact of chronic disease in childhood and adolescence
McDougall and Miller,[72] 2003	Canada	Chronic health conditions distinct from disability	Chronic health conditions: based on diagnosis, at least 3-6 mo duration Disability: umbrella term for impairments, activity limitations, and participation restrictions	Review	Review of surveys in Canadian schoolchildren; coverage of chronic health conditions and domains of disability and related environmental factors
Jee et al,[73] 2006	United States	Chronic conditions	Any health problems that last a long time or come back repeatedly; 28 diagnoses	Survey, interview with (foster) parents	Investigation of factors associated with chronic conditions in children in foster care
Farooqi et al,[74] 2006	Sweden	Chronic health conditions, functional limitations, and special health care needs	Nordic Health and Family Questionnaire, QuICCC, Five to Fifteen questionnaire	Interview with parents	Comparison of children born at 23-25 wk gestational age with general population sample at age 10-12 y
Stein et al,[75] 2006	United States	Chronic conditions, special health care needs, other types of health problems	List of 14 conditions, children with special health care needs screener, hospitalization, learning disabilities, emotional or behavioral problems, etc	NHIS, 2002	Comparison between moderately low-birth-weight and normal-birth-weight children

Abbreviations: *ICD-9*, *International Classification of Diseases, Ninth Revision*; NHIS, National Health Interview Survey; QuICCC, Questionnaire for Identifying Children With Chronic Conditions.

Influence of Possible Sources of Variance

Comparison of different operationalizations in the study by Rolnick et al[39] showed variation in the resulting prevalence rates, from 11% when using the "clinical risk grouper" on administrative data to 37% when using the Questionnaire for Identifying Children With Chronic Conditions in telephone interviews in the same population. Prevalence differences due to source of information were found by Youngblade and Shenkman[43] by comparing interviews with parents (17.8%) and adolescents (12.6%). Jessop and Stein[27] found little overlap between children identified by physical examination and parental history. Not surprisingly, generally higher prevalence rates were reported in older children; eg, in the article by Vuorinen et al,[22] a prevalence rate of 8.8% in 0- to 6-year-olds and 15% in 7- to 14-year-olds. There also appeared to be a time effect indicated by higher prevalence rates in more recent studies (Table 2).

COMMENT

Our review summarizes the current definitions and operationalizations of the concept of chronic conditions in childhood. The included articles contain a wide range of concepts, from "medically fragile children" to "children with special health care needs." The large number of excluded articles (7188/7252) illustrates the difficulty of performing a specific literature search on such a broad concept as chronic health conditions in childhood. Because of the complexity of the concept and the diversity in methods used in studies on this subject, there is, at present, no such thing as a "proper way" to combine prevalence rates quantitatively. We attempted to use transparent and reproducible methods. However, a fair amount of judgment in selecting and appraising individual articles proved unavoidable because of the considerable variation in terminology, types of articles, and study designs that we found. This makes a systematic review of definitions, measurement methods, and prevalence rates of chronic health conditions in childhood less convenient than a systematic review of, for instance, randomized controlled intervention studies.

Only articles in English were included because none of the Dutch articles met all inclusion criteria. It is possible that the language restriction to English and Dutch resulted in omission of 1 or more existing definitions or operationalizations. Also, it is likely that national and international public health organizations assemble and report data based on diverse definitions that are not reported in the scientific journals indexed in MEDLINE or Web of Science. Most of the included articles (41/64) originate from the United States, raising the possibility of selection bias. Nevertheless, a clear conclusion of a current wide variability in concepts, operationalizations, and, as a consequence, prevalence rates can be drawn. This variability appeared not only due to variations in definitions (eg, whether noncategorical definitions or diagnosis lists are used) but also to diversity in operationalization of similar definitions, including the source of information (eg, parents or adolescents), whether interviews or medical records were used, the age of the study population, and the year in which a study was performed.

Newacheck et al[18] suggested several possible causes for the apparent increase in prevalence rate in the National Health Interview Survey between 1960 and 1981, including the following: (1) prior screening using a checklist of conditions in the early years, thereby ignoring conditions not listed; (2) increased survival of neonates and older children with chronic illnesses; (3) deinstitutionalization of disabled children; and (4) increased availability of medical services for children. This suggests that at least part of the increase can be ascribed to changes in the definition and operationalization of the concept of chronic conditions in childhood. Whether the prevalence rates also vary between countries is unknown, since no studies were found in which the same definition and operationalization were applied to assess prevalence rates in different countries.

One would expect that the choice between a noncategorical definition and a list of conditions or diagnoses would have consequences for the operationalization. For example, medical records, except in rehabilitation settings, do not generally contain comprehensive information on children's functional limitations. Parents are not always able to state all medical diagnoses given to their child, while they do know his/her functional limitations well. However, surprisingly, several authors who adopted a noncategorical definition report use of medical files,[62] and, vice versa, some authors use diagnosis lists in interviews.[73] However, in several studies it seemed that the concept of what was measured was dictated by the methods by which data were gathered, rather than the other way around.[18,50]

When considering the variety of studies included in this review, one can conclude that the various concepts that authors have aimed to measure cannot be denoted by a single term. However, differences or similarities among the various concepts are not always transparent. For example, it is not difficult to understand that the group "medically fragile children" is a subsample of children with special health care needs, but even authors who used similar terms presented very diverse operationalizations and results. The variety in terms and operationalizations that we found shows that there is no consensus among researchers about concepts and definitions and that, in most articles, the only source of information on what exactly was measured is the methods section concerning the operationalization.

All conceptual definitions that are summarized in Table 1 incorporate the consequences of the chronic condition in terms of functional limitations and/or the need for medical or other care services. Theoretically, this leads to a lower measured prevalence com-pared with the prevalence of all children with 1 or more conditions that last longer than a certain period of time (usually 3 or 12 months). If the prevalence is measured with the aim of establishing the need for services, this is justified. However, comparisons between countries and within a country over time are hampered because the consequences of a chronic condition in terms of care needs or functional limitations vary according to cultural, educational, and financial circumstances and availability of treatment and care. For example, behavioral problems that might have been labeled as “bad behavior” in the past may now be diagnosed as attention-deficit/hyperactivity disorder, a chronic condition needing treatment. Or a young child in rural Africa may be considered lazy, whereas he or she might be diagnosed as having sickle cell disease if his/her parents had the time and money to go to an outpatient clinic.

Differences among studies in definitions and operationalizations can in part be ascribed to different goals with which these studies were performed. However, these differences are most often obscured by the use of an unstandardized terminology. Comparable with the International Classification of Functioning, Disability and Health, researchers in this field need a comprehensive framework of terminology. The International Classification of Functioning, Disability and Health is a revision of the International Classification of Impairments, Disabilities and Handicaps under the auspices of the World Health Organization(http://www3.who.int/icf/icftemplate.cfm). In this model, the components of functioning and disability can be classified in 3 different dimensions: body structures and functions, performance of activities, and participation in communal life.[77] A comprehensive framework for chronic conditions should allow for differences in definitions related to different research goals. For instance, evaluation of the outcome of determinants of youth health, including pediatric medical care, calls for a different definition than planning for financing of social security and labor availabilities for young disabled people. The framework might consist of the following concepts:

1. The most comprehensive level: children with chronic conditions (based on a list of diagnoses of chronic conditions based on the *International Statistical Classification of Diseases, 10th Revision*); essential components of a definition at this level are, in our opinion, that the disease can be diagnosed according to professional standards, a basic requirement to ensure validity, as well as an expected duration of at least 3 months or the impossibility of cure;
2. A limitations-oriented second level, comprising a subset of the first level: children with limitations in ordinary activities due to chronic conditions;
3. A health care use–oriented third level, a subset of levels 1 and 2: children with chronic conditions in need of medical care or related services in addition to what is usual for this age;
4. The group “children with special health care needs” (who have or are at increased risk of a chronic physical, developmental, behavioral, or emotional condition and who also require health care and related services of a type or amount beyond that required by children generally) has a different background. There will be overlap with children with chronic conditions, but this definition also includes a group of children not included in any of the previous categories; ie, those who are at increased risk[5] and would occupy a separate place in the framework.

More levels can be added when addressing subsets of conditions, severity levels, or specific limitations or needs.

Many prevalence studies or registries are concerned with a single disease entity. Simply adding up these prevalence rates disregards possible biases in methods and the possibility of comorbidity, since the units are diagnoses instead of individuals. National population-based surveys are the most useful data source for health state information, including information on chronic conditions in childhood. Since 1957, the National Health Interview Survey has been performed regularly in the United States. Data about chronic conditions in children have been collected by different types of questions, often in the absence of an underlying definition, thereby causing bias in longitudinal comparisons.[14] To avoid this bias in future longitudinal and international comparisons, standardization is important, first of concepts and definitions and subsequently of operationalizations.

CONCLUSION

To evaluate the effects of determinants of child health, including perinatal and pediatric health care factors, and for the efficient planning of health care facilities and services for children and young adults with chronic conditions, valid and reliable prevalence estimates are needed. The wide variability in reported prevalence rates results from the considerable diversity in concepts and operationalizations in terms of source of information, method of information retrieval, and study population. To make valid international comparisons of this prevalence and comparisons over time, a first requirement is to achieve international consensus about the conceptual definition of chronic health conditions in childhood.

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Study concept and design: van der Lee, Mokkink, Grootenhuis, Heymans, Offringa.
Acquisition of data: van der Lee, Mokkink.
Analysis and interpretation of data: van der Lee, Mokkink.
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Critical revision of the manuscript for important intellectual content: van der Lee, Mokkink, Grootenhuis, Heymans, Offringa.
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> Whoever desires to give his hearers a perfect conviction of the truth of his principles must, first of all, know from his own experience how conviction is acquired and how not.
>
> —Hermann von Helmholtz (1821-1894)