A Noncategorical Approach to Chronic Childhood Illness

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THE MOST SIGNIFICANT BREAKTHROUGHS affecting child health in the past several decades have been advances in biomedical therapies for defined disease entities. Frontiers of activity in child health now require a broader view—one that is not disease specific and that, in addition to accounting for biomedical realities, is concerned with the total life experience of children and their families. A promising conceptual framework that expands and enlarges previous approaches is a noncategorical view of child health and health problems.

In this paper we review briefly the factors leading to the need for a change in orientation, present examples of the feasibility and usefulness of a noncategorical approach in an evaluation of a home care program, and discuss the implications of this change of direction in the field of child health.

Although there is little empirical evidence to substantiate an overall increase in the number of children with chronic problems, the literature indicates that such children do represent an increasing percentage of today's population with health care needs (*1–4*). Therefore, a larger relative share of health professionals' time is being spent on patients with chronic conditions. Immunization programs and antibiotic therapy have radically altered the morbidity and mortality of the pediatric population. Biomedical research has provided tremendous advances in disease-specific therapies that allow children with a wide variety of congenital and metabolic problems to survive into adolescence and adulthood. As a result of these factors, many more professionals have and will have contacts with children who have chronic disorders, and although they may have these contacts with only a few in any one disease category, the total sum of interactions with chronically ill children will be sizable.

It also has become apparent that the technological potential of biomedical research may rapidly outstrip the ability to pay for sophisticated medical services and to deal with the related personal, social, and ethical issues entailed in giving care to these children. We have become more aware of issues of cost-benefit ratios and of society's unwillingness to underwrite constantly escalating health care expenses. There is also growing concern about the relative long- and short-term benefits of dramatic technological interventions vis-a-vis psychosocial supports and services aimed at improving adjustment and adaptation in daily life.

All of these forces appear to converge in establishing the need for some reorientation in child health. The alternative that we espouse—a noncategorical approach—is not only a revolutionary concept that seems to be an enigma to many disease-oriented health professionals but also a return to old concepts of treating the "whole child" rather than the diseased organ or system. I. Barry Pless, professor of pediatrics and epidemiology at McGill University, a primary advocate of this approach over the past several decades, has repeatedly pointed out that regardless of the specific disease, children with diverse chronic medical problems have great similarities in life experiences and in the preventive and rehabilitative aspects of their lives. According to Pless and Pinkerton (*2a*):

> the chronicity of the illness and the impact that it has on the child, his parents, and his siblings, is more significant than the specific character of the disorder, be it diabetes, cerebral palsy, hemophilia, etc. In other words there are certain problems common to all chronic illness over and above particular challenges posed by individual needs.

Thus, the essence of a noncategorical approach is that children face common life experiences and problems based on generic dimensions of their conditions rather than on idiosyncratic characteristics of any specific disease entity. The lives of children and their families are affected by whether the condition is visible or invisible; whether it is life threatening, stable,

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This paper is adapted from one presented at the annual meetings of the American Association for the Advancement of Science in Toronto, Canada, January 1981. The research was supported by the Department of Health and Human Services, Maternal and Child Health Crippled Children's Services grant, MC–R360402 (Social Security Act, Title V). Tearsheet requests to Ruth E. K. Stein, MD.

or characterized by unpredictable crises; and whether it involves mental retardation, has a cosmetic aspect, affects sensory or motor systems, or requires intrusive and demanding routines of care. A generic approach focuses on dimensions that vary across disease categories rather than on disease-specific differences. For example, the effect on children of repeated hospitalizations and days lost from school can be examined regardless of whether the hospitalization was because of crises associated with asthma or sickle cell anemia.

Workers in medical education, social services, and psychological counseling have long advocated that clinicians should be concerned with psychosocial issues and be sensitive to the individual needs of a given child. The extent to which such an approach is not only desirable but absolutely necessary is perhaps what has changed with the changing face of pediatric problems and the current state of health care delivery. A focus on the commonalities has become more central for all in the helping services who have contact with chronically ill children and their families.

For the past 5 years we have been engaged in the Pediatric Ambulatory Care Treatment Study (PACTS), a large-scale randomized trial of two modes of treatment of chronically ill children. In this field trial, we are evaluating a home care program for children with chronic conditions at the Albert Einstein College of Medicine-Bronx Municipal Hospital Center. The program has been operating for more than a decade.

The Pediatric Home Care program is designed to provide comprehensive pediatric health care and integrated medical and psychosocial services for the child and family. The staff attempts to provide coordinated care to families who get "lost" in the face of the bureaucracy and the complexity of the subspecialty systems from which their children need service. The program has been described as an ambulatory special-care unit for children who cannot be managed within the traditional ambulatory program because of (*a*) the severity or complexity of the illness or (*b*) the inability of the families to use traditional resources, or both (*5,6*). The services offered include monitoring the patient, delivering direct services, providing health education and patient advocacy, teaching the therapeutic program to the family and patient, and coordinating services such as homemaking, social services, and the subspecialties. While the program is oriented to the health of the child, it focuses on the whole family and its needs. It seeks to foster patients' independence and to maximize rehabilitation and adjustment.

The program uses an interdisciplinary Pediatric Home Care team. The core team for each patient consists of a generalist pediatrician, a pediatric nurse practitioner, and the patient's family. A social worker, consultant psychiatrist, and physical therapist are also available. The resident or referring physician and the subspecialists who are involved with the child are included in the team when necessary. Services are provided in the patient's home as needed, as well as in the traditional locations (the clinic, the wards, and the Pediatric Home Care office). Home visits are conducted to teach the patient and family in the location in which care will be given as well as to evaluate medical and psychosocial needs in the household setting and family context.

In preparing to undertake this longitudinal study, the research team found itself, on the one hand, impressed clinically by the commonalities among children with different conditions but, on the other hand, confronted by the absence of measures for defining levels of health that could be used with children having a variety of conditions. Several new measures were designed, and we selected two of these for this discussion to demonstrate the feasibility and usefulness of measures that are not disease specific. The first measure, the Clinician's Overall Burden Index, is based on the concept that all illness places a burden on a family. This index is completed by health care professionals. The second is a measure of functional status that assesses the health-related dysfunction of the child in performing socially expected roles as reported by the child's parent or caretaker.

Clinician's Overall Burden Index

The Clinician's Overall Burden Index measures generic features of illness including (*a*) medical and nursing tasks that the parents need to perform, (*b*) disruption in family routine entailed in caring for the child, (*c*) fixed deficits in the child requiring compensatory parental behavior, (*d*) dependency of a child who cannot perform age-appropriate activities of daily living, and (*e*) the psychological burden inherent in the child's prognosis. These five areas were selected for the index because they place demands on the family that are different from those entailed in the care of a well child. The principal focus of the burden concept is on the specific departures in performance which differentiate care of the ill child from that of a well child. The assumption is that such departures in performance are burdensome in and of themselves.

In conceptualizing burden in this way, we decided to separate the demands or burdens entailed in care of the child from those highly personal background characteristics and psychodynamic factors that make a particular type of stress more or less burdensome for a given family. The interest was in quantifying the demands of an illness on the family independently of the perceived or "subjective" impact of these demands. The work was modeled after that of Spitzer and associates (7) with adult psychiatric patients, in which a distinction was made between a person's subjective notion of burden and a more general group consensus about what was burdensome to a person. The group notion, viewed as "objective" or intersubjective burden, is what our instrument attempts to measure. Emphasis is on components likely to pose hardship for any family, irrespective of the individual family's potential ability to adapt to or cope with them.

An inventory of burdensome features was compiled through a review of the literature, interviews with clinicians providing care for chronically ill children, and the clinical experience of the research team. Identified components were organized into the five dimensions contained in the conceptual framework, and items were written to cover each dimension comprehensively. The list of items was then reviewed by clinicians and research consultants for completeness, comprehensiveness, clarity, relevance to the construct being measured, and appropriateness for a group of chronically ill children.

We assumed that all elements of burden are not equally important (for example it is more burdensome to have a child who is wheelchair bound than one who wears glasses). To weigh the items to reflect the relative degree of burden, a sample of more than 100 medical, nursing, social work, and rehabilitation professionals rated 81 items according to their assessment of the relative burden imposed by each item. Ratings were obtained from providers rather than parents because the raters needed to be familiar with the entire spectrum of demands placed by a large number of medical procedures. The providers, who came from five institutions, rated each item from low to high burden on a 5-point scale, using as a standard reference point a 6-year-old child on whom the procedures were required once a day (unless otherwise specified). The results indicated that items concerning major deficits, such as deafness or severe malfunction of an extremity, and those entailing considerable parental inconvenience, such as frequently leaving work for hospital appointments, were rated as most burdensome. Medical and nursing tasks were seen as less burdensome. Items regarding prognosis were rated in the expected direction.

To eliminate the possibility that several minimally burdensome items would be scored the same as a single extremely burdensome item, final weights were achieved by rounding each mean rating and squaring it. Scores on the 81 items in this sample ranged from 0 to 336.

To validate the clinical usefulness of the resulting measure, a questionnaire based on the weighted items was pretested. Scores obtained by summing the derived weights of the individual items placed children in a rank order consistent with clinical impressions regarding the burdens entailed in their care; that is, a child with quadraplegia and a tracheostomy received a score of 276 in contrast to a score of 114 for a child with stable diabetes. The scores were as follows:

Diagnosis	*Score*
Arrhythmia, fully controlled	24
Nephrotic syndrome	55
Nephrotic syndrome	57
Ventricular septal defect	58
Congenital adrenal hyperplasia	94
Diabetes mellitus, stable	114
Diabetes mellitus and learning disability	142
Prune-belly syndrome	144
Coarctation of aorta	146
Diabetes mellitus, unstable	152
Multiple endocrine insufficiency	158
Prune-belly syndrome with nephrosotomies	174
Infant with meningomyelocele and hydrocephalus with developmental delay	196
School-aged child with Down's syndrome and diabetes mellitus	209
School-aged child with nephrotic syndrome, focal segmental sclerosis, adrenal insufficiency	223
Quadriplegia and tracheostomy	276
Nonambulatory school-aged child with meningomyelocele urinary diversion and asthma	311

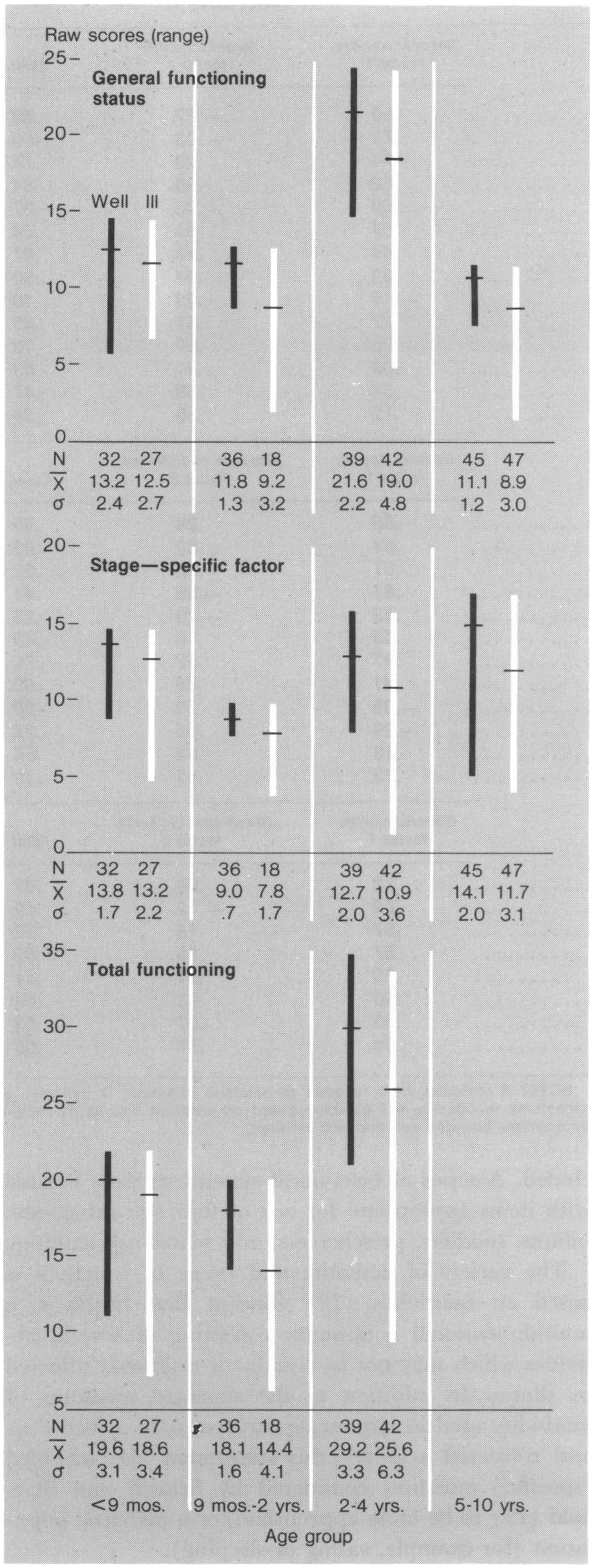
Criterion-oriented validity of the measure was tested by correlating the score derived from the Clinician's Overall Burden Index with a general rating by the respondent clinician of the burden entailed in a specific child's care. The results indicated a high correspondence (Pearson's $r = .82$, significant at the $P \leq .001$ level).

Although the instrument needs further refinement and additional items as more procedures are added to the list of tasks that families are expected to do for their chronically ill children, the Clinician's Overall Burden Index seems to be a useful beginning in an attempt to classify and quantify levels of illness across disease categories. Because the index is capable of classifying relative burden among patients across disease categories, an instrument of this type may be useful in evaluating intervention programs that deal with a large number of children with chronic conditions in a center having small numbers of children within each diagnostic category.

Functional Status

The second instrument, the Functional Status Measure, assesses impairment by measuring the behavioral

Functional status scores of chronically ill children compared with those of well children



consequences of disease for physical, psychological, and social functioning of the child. In general, such disability measures for pediatric populations present many obstacles and they are poorly developed (*8,9*). One problem is that there is much less agreement on the normal roles and functions of children at each age, both within and between social contexts, than there is for adults. By definition, children are undergoing major changes resulting from the interaction of environmental factors with biological factors. These factors alter the child's dependency and make it difficult to determine whether the failure of a child to achieve independent function in an area is part of the normal developmental process, a result of an environment that fosters dependency, or a loss of ability to function secondary to illness. The complexity of these issues has led to some skepticism about the feasibility of measuring functional status in children under 1½ or 2 years old. Moreover, typical sequences in psychological, social, and intellectual development barely have been worked out for general populations of healthy children, and there is heightened concern about whether patterns derived from healthy children are applicable to children with significant handicapping conditions whose life experiences are radically different from "normal" children (*10*).

Despite these difficulties, several groups have attempted to formulate functional status measures for children. One of the better designed measures was produced by researchers at the Rand Corporation (*11*). This instrument focuses on identifying the small fraction of children who have significant functional disability, and it appears to distinguish between children who are normal and those with significant functional disabilities. It does not, however, distinguish among children with differing degrees of impaired functioning. Therefore, while this measure is excellent for population-based studies aimed at identifying children in the community with significant handicaps, it is not sufficiently sensitive to change in chronically ill children or to the wide range of functioning among children with chronic illnesses associated with physiological impairment but not major handicap. Since only a small percentage of chronic childhood conditions produce major functional limitations (*2*), it appears that there is still a need for scales which are more sensitive to measurement in the interface between normal children and those with severe handicaps.

In our study, the majority of children were not disabled; thus, we needed an instrument that is more sensitive to minor differences than the Rand instrument. We met this need by devising a measure of

Table 1. Functional status factor analysis for subscales and total score (principal components

Item	*Factor loadings*		
40 children under 9 months old	*Responsiveness, factor 1*	*General health, factor 2*	*Total* [1]
Seem interested in what was going on around him/her	*.80*	—.07	*.68*
Babble or use other sounds	*.79*	—.03	*.69*
Seem lively and energetic	*.74*	.20	*.74*
Try to get objects that were near but beyond his/her reach	*.62*	.20	*.64*
Seem to look at things	*.60*	—.38	*.37*
Smile and coo	*.54*	.34	*.64*
Hear and turn to sound	*.44*	*.48*	*.61*
Eat well	.02	*.64*	*.30*
Occupy him/herself unattended (D)	—.15	*.60*	.13
Seem unusually difficult (R)	.22	*.57*	*.45*
Sleep only for a short time and then wake and cry (R,D)	—.05	*.50*	.18
Seem contented and cheerful	.38	*.41*	*.53*
Sleep well	.34	*.38*	*.47*
Communicate what he/she wanted	.12	.30	.23
32 children 9 months to 2 years old	*General health, factor 1*	*Absence of sickness, factor 2*	*Total* [1]
Get involved in games and other play	*.65*	.25	*.65*
Seem contented and cheerful	*.64*	.52	*.83*
Act moody or difficult (R,D)	*.61*	.10	*.52*
Seem lively and energetic	*.61*	—.05	*.41*
Sleep well	*.53*	—.20	.26
Eat well	*.53*	.13	*.48*
Seem to feel sick and tired (R)	*.47*	*.52*	*.70*
Have frequent temper tantrums (R,D)	*.41*	*.45*	*.60*
Get more help in eating than other children his/her age (R)	—.05	*.78*	*.50*
Act nervous or tense (R)	—.29	*.65*	.23
Cut down on his/her usual level of play activity (R)	.18	*.63*	*.56*
Stay in bed all or part of the day (R)	.12	*.45*	*.39*
56 children 2 to 4 years old	*General health, factor 1*	*Stage-specific tasks, factor 2*	*Total* [1]
Seem contented and cheerful	*.73*	.08	*.69*
Seem to feel sick and tired (R)	*.72*	—.12	*.60*
Get around the house without assistance	*.57*	.13	*.58*
Play with other children	*.57*	.19	*.60*
Cut down on his/her usual level of play (R)	*.53*	.31	*.64*
Get involved in games and other play	*.56*	.23	*.60*
Seem lively and energetic	*.55*	.07	*.53*
Stay in bed all or part of the day (R)	*.54*	.37	*.65*

[1] The total score represents the results of a 1-factor solution. No total score is presented for the oldest age group because too few items load on a 1-factor solution for it to be meaningful.

NOTE: R indicates item recoded to opposite direction; D indicates a trichotomy recoded to a dichotomy based on criterion that items should differentiate between well and sick children.

functional status that would be useful for children with a wide range of chronic illnesses, such as those seen in broad-based intervention programs.

In developing the Functional Status Measure, we defined child health as the capacity to perform age-appropriate roles and tasks. Behavioral responses to illness that interfere with normal social role performance constitute the domain to be measured. The elements included in the conceptual framework of this variable are communication, mobility, mood, energy, sleeping, eating, and toileting patterns. The measure assesses behavior in three sites: home, neighborhood, and school. Leisure, work, and rest activities are included. A series of behavioral statements were created with items appropriate for one of four age categories: infants, toddlers, preschoolers, and school-age children.

The variety of activities and range of functions is based on Starfield's (*12*) concept that health is a multidimensional continuum consisting of several activities which may not be equally or uniformly affected by illness. In addition to the standard measures of morbidity used in large-scale surveys (such as bed days and restricted activity) this instrument also included "specific" measures considered by Schach and Starfield (*13*) to be more appropriate for a pediatric population (for example, eating or sleeping).

analysis using varimax rotation), Pediatric Ambulatory Care Treatment Study total time-1 sample

Item	*Factor loadings*		
56 children 2 to 4 years old (continued)	*General health, factor 1*	*Stage-specific tasks, factor 2*	*Total*[1]
Act moody or difficult (R,D)	*.47*	—.24	*.32*
Sleep well	*.47*	.09	*.46*
Eat well	*.46*	—.08	.36
Get more help with eating than other children his/her age (R)	*.45*	.20	*.49*
Act nervous or tense (R)	*.40*	.11	*.41*
Have frequent temper tantrums (R,D)	*.39*	—.01	*.34*
Pick up and throw a ball (in the intended direction)	*.38*	.12	*.40*
Amuse you with things he/she did or said	*.32*	.28	*.41*
Have trouble doing things for him/herself that you thought he/she could do (R)	*.53*	*.50*	*.69*
Dress him/herself	.08	*.72*	*.38*
Wet the bed at night (R)	—.08	*.71*	.23
Care for him/herself at the toilet	—.13	*.69*	.17
Take off a piece of clothing unassisted	.18	*.53*	*.39*
Communicate with words so that others can understand	.23	*.33*	*.35*
81 children 5 to 10 years old	*Severe motor handicap, factor 1*	*General health, factor 2*	
Go up and down stairs without help	*.77*	.03	
Get outdoors without assistance	*.67*	.06	
Care for him/herself at the toilet	*.66*	.10	
Wet the bed at night (R)	*.63*	—.16	
Attend a special school or special classes (R)	*.62*	—.04	
Dress him/herself without help	*.60*	.12	
Have bowel or bladder accidents during the day (R)	.49	—.01	
Get around the house without assistance	*.45*	.20	
Participate in regular gym classes	*.46*	*.35*	
Cut down on things he/she usually does (R)	.04	*.63*	
Absent from school in past 2 weeks (R)	.12	*.61*	
Spend all or part of the day in bed in past 2 weeks (R)	—.37	*.59*	
Seem lively and energetic	—.06	*.58*	
Complain of feeling tired or sick (R,D)	.04	*.57*	
Seem contented and cheerful	—.04	*.56*	
Eat well	—.22	*.50*	
Cut down on his/her usual level of play activity (R)	.08	*.50*	
Participate in hard exercise or play	.26	*.47*	
Sleep well	.05	*.38*	
Play games by him/herself	—.02	*.31*	
Get more help with eating than other children his/her age (R)	.18	.28	
Eat foods prepared for a special diet (R)	—.14	.23	
Concentrate or pay attention for a period of time	—.27	.19	
Urinate more or less frequently than he/she should (R)	.22	—.13	

Questions can be raised about whether including such diverse and potentially encompassing ranges of function within a single measure is a form of "healthism." The threat of this ideology is of expanding the domain of health to include progressively larger areas of human experience and in turn of placing them under the control of the medical profession. In studies of adult populations (*14*) it is easier to separate the psychological and social consequences of illness from health-related dysfunction in specific tasks that are components of the adult's social roles. For children, however, the mastery of social and psychological development tasks is more intrinsically a part of their social role than it is for adults. In the broadest sense the "role" of children is healthy intellectual, psychological, and social development; therefore, these social and psychological constructs are more clearly relevant components of children's health status.

The functional status instrument was created in several stages. We based a series of items on a thorough literature review and our clinical experience. As with the Clinician's Overall Burden Index, the functional status instrument was reviewed by a panel of consultants for content, clarity, and relevance to the construct being measured. Various sources were used in building a potential item pool (*1,9,15–30*). A form was developed, pretested, and used in the randomized field trial of PACTS. It consists of a subset of items for each of 4 groups: 0–9 months, 9 months–2 years, 2–4 years, and 5–10 years. A core of overlapping items is common to more than one age group. The format of each item includes a question about what the child does and a probe about whether nonperformance is related to the child's illness.

Any measure of the functional status of children with chronic conditions must meet certain psychometric standards. It must have a conceptually plausible factor structure. The total measure and its component factors must yield reliable scores, and the structure of the measure should be invariant across samples.

Since there are four subsets of items (one for each of four age groups), a large number of cases is needed for the factor analysis. The psychometric properties of the Functional Status Measure have been investigated with three different (but overlapping) samples: (*a*) children with a chronic illness (the first 100 cases in PACTS combined with data from 40 pretest cases), (*b*) 209 time-1 cases from PACTS, and (*c*) a combined sample of the 140 children with chronic illness and 152 children without such conditions who were attending a pediatric primary care center for health care maintenance visits or treatments of minor ailments. The factor structure obtained and found to be invariant across samples is shown in table 1. At each level, there is a general functioning status factor as well as another factor specific to that level, which appears to be an age-specific measure. The tentative indications are that while the individual items are different at each level, common interpretations can be made about these factors across levels. The factors obtained are sufficiently reliable to be used to measure change (table 2).

To demonstrate the construct validity of the Functional Status Measure, children without chronic conditions must score at the upper end of the distribution of scores. Since the measure is designed to discriminate among chronically ill children and not necessarily among well children, it need not differentiate among well children. But, at the very least, well children should not score more poorly on the scale than do children with chronic conditions. Moreover, in view of the clinical observation that some children with chronic illness function normally, it would also not be unexpected if the range of function of chronically ill children was larger than and overlapped with the range of well children. It would, however, be anticipated that the range for children with chronic illness would be considerably lower than the range for well children.

Table 2. Functional status of child, reliability analysis for four age groups, Pediatric Ambulatory Care Treatment Study total time-1 sample

Factor	*Number of items*	*Alpha coefficients*
40 children under 9 months old		
Responsiveness (1)	7	.78
General health (2)	7	.62
Total score	11	.78
32 children 9 months to 2 years old		
General health (1)	8	.75
Absence of sickness (2)	6	.68
Total score	10	.76
56 children 2 to 4 years old		
General health (1)	17	.83
Stage-specific tasks (2)	6	.68
Total score	20	.83
81 children 5 to 10 years old [1]		
Severe motor handicap (1)	9	.77
General health (2)	12	.72

[1] No total score is presented for this age group because too few items load on a 1-factor solution for it to be meaningful.

The functional status scores of children with chronic medical problems and children without such conditions are compared in the chart. The scores for the well children generally cover the upper portion of the range of scores of the children with chronic conditions. The means and standard deviations for each group indicate that the well children generally score better than the children with chronic conditions and that there is less variability among the well children. The differences between the groups are significant ($P \leq .006$) for 3 of the 4 age groups (9 months–2 years, 2–4 years, and 5–10 years). The instrument as presently scored is less able to differentiate among children with and without chronic conditions who are under 9 months old.

The results presented reflect the parent's perception of whether a given pattern of behavior exists (for example, the child eats well). The mothers's report of whether the pattern of behavior is attributable to illness is not taken into account. It has been suggested that parents may have difficulty acknowledging that the lack of performance of certain tasks by the child is indeed attributable to illness (*31*), and this hypothesis will need to be explored empirically. Rescoring the responses to reflect illness-related dysfunction in each age group is planned for the future. Such rescoring has been done for the youngest age group, and it appears to improve the capability of the instrument to differentiate between children with and without chronic conditions.

In summary, factorial invariance has been demonstrated in each of the four age groups. Reliabilities obtained from the scales are satisfactory. The measure appears to differentiate between children with and without chronic health conditions.

Discussion

Some people in medicine, and particularly in biomedical research, will resist the focus on the generic dimensions of chronic illness in children. Many medical researchers have devoted much of their careers to investigating the dynamics and treatment of specific disease entities. To some of these persons, the noncategorical approach may seem to be a step in the wrong direction. Similarly, the ideologies of interest groups formed around specific disease entities often maximize the distinctiveness of each constituency, rather than the commonalities shared by large numbers of those with chronic physical illness. Politically, each of these groups may resist an approach which threatens their hegemony, despite the fact that this intergroup competition might be more productively applied to improving conditions through a collective effort.

No one will deny that a child with a chronic or handicapping condition should have the advantages of specialized treatment and technology. However, in addition to biomedical and disease-specific therapies, these children and their families have additional needs in the psychosocial, preventive, and rehabilitative aspects of their lives. These needs are shared among those with many other types of chronic conditions.

Again, all agree that an individualized treatment plan is necessary for each child. Nevertheless, because there are commonalities that cross disease categories, one can begin to understand what is necessary for the treatment of a given child with sickle cell anemia based not only on knowledge of other children with sickle cell anemia but also, for example, based on extensive experience with asthmatic or diabetic children. Undoubtedly, there are some disease-specific issues, but if one concentrates only on the disease-specific elements and neglects the commonalities, the individual practitioner is not able to generalize from past experience to children with other types of chronic conditions.

What are the advantages of a noncategorical approach? Such an approach is most helpful to generalist pediatricians, allied health professionals, and workers in public health and health service delivery. It is in service delivery and basic and applied research that immediate gains can be obtained from a noncategorical approach. When chronic illness is viewed noncategorically, it is possible to begin to learn more about characteristics, attitudes, and behaviors of the affected children in relation to the total child population in given communities. Additionally, since local communities are more likely to contain children with a range of conditions, but only a small number within each disease category, the noncategorical approach facilitates the creation and evaluation of service programs targeted to meet the needs of those with diverse conditions. The concept that there are commonalities among children with various specific diagnoses is already accepted in education and family services. In health care delivery, in pediatrics as well as adult medicine (especially in research), pressure is increasing to define levels of health irrespective of specific disease entities.

One result of defining chronic illness noncategorically is that physical differences between people are seen in a less stigmatizing way. One can begin to look at minor and major differences in health status as points along a continuum from the completely healthy to the severely ill. It is an attempt to break out of gross categorizations of people (for example, "asthmatic," "diabetic," "cystic"), which are labels intended to designate discrete groups. In terms of life chances, psychological, social, and medical variables, more variability seems to occur within each of these groups than between them. Starfield and Pless (*4a*) have suggested that:

> to describe in detail the specific manifestations of each discrete condition in a single child fails completely to describe the health of the child as a whole. Thus, regardless of the causes, summarizing measures of health that reflect the common pathways of dysfunction must be used. The use of discrete description perpetuates the insidious effects of labeling and other important social implications of systems of classification of children based on their diagnoses rather than on themselves as individuals. It is an attempt to counteract the powerful impact of the diagnostic label that we espouse the use of not one but a group of summarizing measures of derangement.

Instruments such as the Clinician's Overall Burden Index and the Functional Status Measure, although still in an embryonic stage hold the promise of allowing us to accomplish some important goals. They offer us a chance to look at children in ways other than by "pure" diagnostic categories and to begin to ask questions about social and psychological well-being. As Starfield and Pless have suggested (*4b*), such measures "would make it possible to view the children in terms of individuals rather than diseases." These instruments should permit us to measure change in an individual patient over time and to evaluate intervention programs. The reality is that most services for children with chronic conditions are not provided exclusively in categorical programs, but in health facilities, social organizations, schools, and communities that generally have little cumulative experience with any one diagnostic situation. Until there are ways of assessing the efforts of these resources, society must remain highly subjective in determining the effectiveness of intervention and in advocating the use of limited resources. Perhaps the development of a noncategorical framework will facilitate the acquisition of the empirical information on which to base rational choices.

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