General Health and Life Satisfaction in Children With Chronic Illness

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OBJECTIVES: To investigate children's general health and life satisfaction in the context of chronic illness.

METHODS: Caregivers (*n* = 1113) from 3 concurrent cohort studies completed the Patient-Reported Outcomes Measurement Information System Parent-Proxy Global Health measure, which is used to assess a child's overall physical, mental, and social health, as well as the Patient-Reported Outcomes Measurement Information System Parent-Proxy Life Satisfaction measure between March 2017 and December 2017 for 1253 children aged 5 to 9 years. We harmonized demographic factors and family environmental stressors (single parent, maternal mental health, and income) to common metrics across the cohorts. To examine associations between chronic illness and children's general health and life satisfaction, we fit linear regression models with cohort fixed effects and accounted for the multilevel data structure of multiple children nested within the same family (ie, twins and other siblings) with generalized estimating equations.

RESULTS: Children with chronic illness had worse general health than those without illness (adjusted β = −1.20; 95% confidence interval: −2.49 to 0.09). By contrast, children with chronic illness had similar levels of life satisfaction (adjusted β = −.19; 95% confidence interval: −1.25 to 0.87). Additionally, children's psychological stress had the strongest negative association with both outcomes, even after adjusting for demographics and family environmental stressors.

CONCLUSIONS: Although children with chronic illness have lower parent-reported general health, their life satisfaction appears comparable with that of peers without chronic illness. With this study, we provide evidence that chronic illnesses do not preclude children from leading happy and satisfying lives.

abstract

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WHAT'S KNOWN ON THIS SUBJECT: Associations between chronic illness and negative health outcomes are well established. Less is known about the relation between chronic illness and positive health outcomes, such as life satisfaction, particularly in pediatric populations.

WHAT THIS STUDY ADDS: In this large multicohort study, we use innovative measures to evaluate positive aspects of child health beyond the absence of problems and provide novel evidence that children with chronic illness have similar levels of life satisfaction as their peers.

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ARTICLE

The prevalence of childhood chronic illness in the United States continues to rise, and ~1 in 5 children have a chronic illness that affects their daily function.[1,2] With major advancements in medicine and health care, many once-fatal conditions are now treatable, which leads to longer life expectancies but also more years living with disease. Providing high-quality disease management for children living with chronic illness is paramount, but traditional care models are often limited in scope. Although more holistic perspectives look beyond health as the absence of disease,[3–5] current measurement strategies primarily assess negative outcomes and risks. Although research suggests associations between chronic illness and negative outcomes,[6] interpretation of findings is conditional on the deficit perspective from which these constructs are most often measured.

Alternatively, a positive-health approach characterizes health as a function of positive and negative resources. Positive assets strengthen one's capabilities to adapt to environmental challenges, satisfy needs, and attain goals, which enable well-being; negative challenges (eg, disease, illness, and impairment) limit or interfere with one's general health and functioning (for an overview of positive health, see ref 5). This perspective moves beyond the traditional health care focus of alleviating problems to one that acknowledges and promotes positive assets, even in the presence of challenges. As such, children with chronic illnesses, physical limitations, or developmental delays can also have positive health assets that help them adapt to such challenges and live happy and satisfying lives.[5]

Life satisfaction is a key component of positive health and part of the multidimensional construct of well-being.[7] Defined as an individual's evaluation of his or her life as good and satisfying, life satisfaction provides a measurable and momentary assessment of children's positive health status.[7–10] However, there is a noticeable absence of research on children's life satisfaction in general and in the context of chronic illness, especially for younger children.

Recent advances in measurement development offer new ways to address these knowledge gaps, including a suite of recently validated positive-health parent-proxy measures developed as part of the National Institutes of Health's (NIH) Patient-Reported Outcomes Measurement Information System (PROMIS).[11–13] All PROMIS measures undergo a rigorous mixed-methods development process, which results in brief, non–disease-specific instruments that achieve greater precision and broader measurement ranges than most traditional measures; such characteristics decrease participant burden, lead to lower floor and ceiling effects, and increase power without requiring larger samples.[14,15]

The new state-of-the-science PROMIS parent-proxy measures enable investigation of younger children's general health and life satisfaction on a large scale without losing scientific rigor. Such measures also offer the opportunity to build foundational empirical evidence in the emerging field of positive health. Although child self-report is the criterion standard, parent-proxy reports provide valuable and well-accepted alternatives for children who cannot provide reliable and valid self-reports.[16,17] Using these novel measures, we hypothesized that (1) chronic illness is negatively associated with general heath and (2) chronic illness is not associated with life satisfaction. We also evaluated effect modification by cohort, child demographics, family environmental stressors, and child stress.

METHODS

In this large multicohort study, we combine data from 3 concurrent pediatric cohort studies (Supplemental Table 4) within the NIH-funded Environmental influences on Child Health Outcomes (ECHO) research program. ECHO has 5 primary child health outcomes: pre-, peri-, and postnatal outcomes; airways (eg, asthma); obesity; neurodevelopment (eg, autism spectrum disorder [ASD] and attention-deficit/hyperactivity disorder [ADHD]); and positive health (eg, life satisfaction, meaning, and purpose). A primary goal of ECHO is leveraging existing cohorts through harmonization of extant data and standardization of newly collected data to investigate a range of exposure effects (eg, biological, social, and chemical) on children's health. The current study represents the first multicohort ECHO initiative to fulfill this goal.

As part of ongoing data collection, 3 ECHO cohorts voluntarily administered the PROMIS Parent-Proxy Global Health, Life Satisfaction, and Psychological Stress Experiences measures between March 2017 and December 2017. We did not impose specific inclusion and exclusion criteria on the basis of chronic illness status such that data represented both children who were chronically ill and children who were not ill. Cohorts shared extant covariate data for child demographics, chronic illness status, and family environmental stressors. Northwestern University and each cohort's home institutional review board approved data collection and sharing.

Participants

In total, 1113 caregivers completed the PROMIS measures for 1253 children aged 5 to 9 years (mean: 6.5; SD: 1.3). One-fifth (20%) of children had at least 1 chronic illness, with 8.5% having ≥2 chronic illnesses. Half of children were male (53%), the majority was white (79%), and 10% were Hispanic. Children were evenly

TABLE 1 Descriptive Statistics of the 3 Cohorts Based on Parent Report

	Cohort A	Cohort B	Cohort C	Total or Average	P
No. children	198	967	88	1253	—
No. caregivers	196	829	88	1113	—
Chronic illness, %	46	12	55	20	<.001
Age, mean (SD), y	5.5 (0.06)	6.7 (1.4)	6.3 (0.6)	6.5 (1.3)	<.001
Range	5.5–6.1	5.0–9.0	5.0–7.5	5.0–9.0	—
Sex (male = 1), %	57	51	59	53	.08
Race, %					<.001
White	67	84	46	79	—
African American	29	0	23	6	—
Other race	5	16	32	16	—
Hispanic origin, %	26	5	35	10	<.001
Annual family income, %					<.001
≤$20 000	20	22	16	21	—
$20 000–$40 000	18	19	12	18	—
$40 000–$60 000	12	41	10	34	—
≥$60 000	50	19	62	26	—
Single parent, %	20	7	31	11	<.001
Maternal mental health, %	10	32	41	30	<.001
Child stress, %					<.001
Low	64	30	36	36	—
Moderate	16	31	39	29	—
High	20	40	25	35	—
General health, mean (SD)[a]	50.62 (9.14)	53.09 (7.89)	53.61 (9.73)	52.74 (8.23)	<.001
Range	29.44–66.10	27.56–66.10	30.47–61.10	27.56–66.10	—
Life satisfaction, mean (SD)[a]	55.28 (6.65)	52.40 (7.39)	54.50 (5.91)	53.00 (7.27)	<.001
Range	34.28–59.20	30.86–59.20	38.16–59.20	30.86–59.20	—

—, not applicable.

[a] General health and life satisfaction were assessed with the PROMIS Pediatric Parent-Proxy Global Health and Life Satisfaction measures, which are scored on the PROMIS T-metric (mean = 50; SD = 10). Norm-referenced percentile ranks are derived from nationally representative samples through calibration and centering such that the 50th percentile represents an average PROMIS T-score of 49.88 (range: 14.70–66.10) for global health and 55.32 (range: 20.20–59.20) for life satisfaction.

distributed across income levels, 10% came from single-parent households, and 30% had mothers with mental health issues (see Table 1 for descriptive statistics).

Measures

Outcomes

Child general health was measured by the PROMIS Parent-Proxy Global Health 7, which provides an overall evaluation of a child's physical, mental, and social health.[12,18] Caregivers rated 4 omnibus items (eg, "In general, how would you rate your child's physical health?") on a 5-point Likert scale from poor to excellent and 3 social-emotional items (eg, "My child had fun with friends") on a 5-point Likert scale from never to always.

Child life satisfaction was measured by the PROMIS Parent-Proxy Life Satisfaction Short Form 4a, which is used to assess children's global (ie, not context specific) life satisfaction (eg, "My child was happy with his/her life") on a 5-point Likert scale from not at all to very much.[15]

Primary Independent Variable

Chronic illness was used to describe whether the child had at least 1 chronic illness. For this study, we focused on illnesses representative of the primary ECHO child outcome areas and available in the cohorts' extant data. Illnesses included the following: low birth weight (LBW) (<2500 g), preterm birth (<37 weeks after the last menstrual period), asthma, hay fever or respiratory allergies, eczema, obesity (BMI ≥ 95%), digestive problems (eg, colic and inflammatory bowel disease), ADHD, ASD, behavior problems, anxiety, depression, and epilepsy (see Supplemental Table 5 for

frequencies). We recognize that LBW and preterm birth are not chronic illnesses in and of themselves but serve as proxies for illnesses in childhood (eg, retinopathy of prematurity and respiratory problems). We included them to maximize our sample size and ran sensitivity analyses to check whether inclusion of these conditions influenced results.

Variation in specific chronic illnesses evaluated across the 3 cohorts limited investigation of specific illnesses or illness types (ie, perinatal [eg, LBW and preterm birth], physical [eg, asthma and obesity], and mental [eg, anxiety and ASD]), as did the low prevalence rate (<11%) of any particular illness in the overall sample. Additionally, cohorts used various metrics for identifying chronic illnesses (eg, condition checklists and medical records). Thus, we created a dichotomous indicator for chronic illness (1 = at least 1 chronic illness). Previous work supports this methodologic approach on the basis of the notion that similar psychosocial impacts result across illnesses.[19–21]

Covariates

Child demographics included age in years (continuous from 5 to 9 years); sex (male = 1); Hispanic origin (yes = 1); and race, categorized as white (reference), African American, and "other race," which included all other racial categories that could not be assessed individually because of small sample sizes (ie, American Indian or Alaskan native, Asian American, native Hawaiian or other Pacific Islander, and mixed or >1 race).

Family environmental stressors included a categorical indicator of annual family income (≤$20 000 [reference], $20 000–$40 000, $40 000–$60 000, and ≥$60 000), a dichotomous variable for single-parent household (single parent = 1), and a dichotomous variable for maternal mental health problems

(yes = 1) that represented whether the mother ever had a mental health problem (eg, depression or anxiety).

Child stress was measured by the PROMIS Pediatric Parent-Proxy Psychological Stress Experiences Short Form 4a, which is used to assess children's stress (eg, "My child felt overwhelmed") on a 5-point Likert scale from never to always[11]; caregivers completed this measure at the same time as the PROMIS outcome measures.

Analytic Strategy

PROMIS Scoring

We followed standard scoring techniques for PROMIS instruments[22] using FireStar version 1.2.2, an R-based simulation software,[23] to estimate scale scores by using Bayesian expected a posteriori estimation.[24] Expected a posteriori scoring uses an individual's pattern of responses and the model's parameters to estimate an individual's score, called θ, which is set to a mean of 0 with an SD of 1. We linearly transformed θ scores to T-scores by multiplying by 10 and adding 50. A score of 50 represents the average global health, life satisfaction, or psychological stress level for children on the basis of the national samples used for calibration and centering of scores[11–13]; a score of 40, for example, is 1 SD below the national average. Because of the skewed distribution of stress scores, we converted scores to a categorical variable that was based on national norms: low stress represented the bottom 50th percentile, moderate stress represented the 50th to 74th percentile, and high stress represented the top 25th percentile of national reference norms.

Exploratory Analyses

Preliminary Pearson's χ^2 and analysis of variance analyses revealed cohort-level differences for all variables except child sex (Table 1). Such differences reflected the unique makeup of individual cohorts and confirmed the need for cohort fixed effects. To determine the appropriateness of combining samples, we computed cohort-level unadjusted and multivariable regressions with generalized estimating equations (GEEs) to account for nested data (ie, caregivers who completed PROMIS measures separately for multiple children). Models revealed negative associations between chronic illness and general health and null associations between chronic illness and life satisfaction for each cohort (Table 2).

Primary Analyses

On the basis of cohort-level exploratory models, we used an individual patient data (IPD) meta-analysis approach and conducted GEE-based linear regressions with the cohort fixed effects to control for unobservable cohort-level differences. We conducted additional sensitivity analyses using random effects. We tested effect modification of chronic illness by demographics, family stressors, and child stress for global health and life satisfaction outcomes to examine robustness of findings across subgroups. We considered IPD meta-analysis superior to single-study replication or meta-analysis given the availability of individual-level raw data for all cohorts, including identical outcome measures and comparable covariate data. Advantages include a larger combined sample size to improve statistical power and model stability and increased heterogeneity due to between-study sample variation.[25] We selected fixed-effect models because of the small sample of cohorts, making it infeasible to characterize a 3-level random-effects hierarchical model.[26]

RESULTS

General Health

On average, parents reported their children's general health as 52.74 (SD = 8.23), equating to the 59th percentile of nationally normed data.[12] Results from GEE-based regressions with cohort fixed effects revealed that children with chronic illness had worse general health compared with children without illness (adjusted β = −1.20; 95% confidence interval [CI]: −2.49 to 0.09). Boys (adjusted β = −.87; 95% CI: −1.69 to −0.05) and Hispanic children (adjusted β = −2.15; 95% CI: −3.91 to −0.39) had worse health, as did children from single-parent households (adjusted β = −1.96, 95% CI: −3.73 to −0.18). Children with moderate (adjusted β = −2.51; 95% CI: −3.63 to −1.40) and high stress (adjusted β = −6.70; 95% CI: −7.78 to −5.61) also had worse health compared with children with low stress levels. Alternatively, children from higher-income families (adjusted β = 3.48; 95% CI: 1.86 to 5.19) had better general health. We found no significant effect modification (Table 3). Random-effects models produced similar results (Supplemental Table 6), as did models that excluded perinatal

TABLE 2 Chronic Illness β Coefficients and P Values for Unadjusted and Multivariable Models by Cohort

	Cohort A		Cohort B		Cohort C	
	β	P	β	P	β	P
General health						
Unadjusted model	−5.51	<.001	−.38	.67	−3.43	.1
Multivariable model	−3.39	.02	.17	.83	−4.37	.05
Life satisfaction						
Unadjusted model	−2.41	.01	−.49	.54	.87	.5
Multivariable model	−1.15	.29	−.03	.97	−.22	.88

Multivariable models include child age in years, sex (male = 1), race (white [reference], African American, and other race), ethnicity (Hispanic = 1), single-parent household, maternal mental health, annual family income, and child stress.

TABLE 3 Multivariable Regression Models Based on GEEs With Cohort Fixed Effects Regressing Child Chronic Illness, Demographics, Family Environmental Stressors, and Child Stress on General Health and Life Satisfaction

	General Health			Life Satisfaction		
	β	95% CI	P	β	95% CI	P
Chronic illness	−1.20	−2.49 to 0.09	.07	−.19	−1.25 to 0.87	.72
Age	−.17	−0.49 to 0.14	.28	−.03	−0.31 to 0.26	.85
Sex (male = 1)	−.87	−1.69 to −0.05	.04	−.44	−1.17 to 0.29	.23
Race						
African American	−2.03	−4.70 to 0.63	.14	.48	−1.55 to 2.50	.65
Other race	.98	−0.40 to 2.36	.16	.80	−0.46 to 2.05	.21
Hispanic origin	−2.15	−3.91 to −0.39	.02	.29	−1.12 to 1.69	.69
Single parent	−1.96	−3.73 to −0.18	.03	−.49	−1.91 to 0.92	.49
Maternal mental health	−.54	−1.56 to 0.48	.30	.01	−0.86 to 0.89	.98
Income						
$20 000–$40 000	.78	−0.77 to 2.33	.32	1.22	−0.14 to 2.57	.08
$40 000–$60 000	1.78	0.38 to 3.18	.01	1.43	0.22 to 2.64	.02
≥ $60 000	3.48	1.86 to 5.10	<.001	2.65	1.29 to 4.01	<.001
Child stress						
Moderate	−2.51	−3.63 to −1.40	<.001	−2.03	−2.93 to −1.13	<.001
High	−6.70	−7.78 to −5.61	<.001	−6.73	−7.70 to −5.77	<.001
Cohort B	3.31	1.57 to 5.06	<.001	−.94	−2.27 to 0.38	.16
Cohort C	3.73	1.36 to 6.10	<.01	−.90	−2.71 to 0.91	.33

General health and life satisfaction outcomes are scored on the PROMIS T-score metric (mean = 50; SD = 10).

chronic illnesses (Supplemental Table 7).

Life Satisfaction

On average, parents reported their children's life satisfaction as 53.00 (SD = 7.27), equating to the 44th percentile of nationally normed data.[13] Results from GEE-based regressions with cohort fixed effects suggested that children with chronic illness had similar levels of parent-reported life satisfaction as peers without illness (adjusted β = −.19; 95% CI: −1.25 to 0.87). Children with moderate (adjusted β = −2.03; 95% CI: −2.93 to −1.13) and high stress (adjusted β = −6.73; 95% CI: −7.70 to −5.77) had lower life satisfaction, whereas children from higher-income families had higher life satisfaction (adjusted β = 2.65; 95% CI: 1.29 to 4.01). We found no effect modification (Table 3). Random-effects models (Supplemental Table 6) and those that excluded perinatal chronic illnesses (Supplemental Table 7) revealed similar results.

DISCUSSION

In this study, drawing on data from 3 ECHO pediatric cohorts, we investigated associations between chronic illness and parent reports of children's general health and life satisfaction. Results confirm previous work revealing that children with chronic illness have worse parent-reported general health than their counterparts without illnesss,[12] and results are robust across demographics, family environmental stressors, and child stress. Such findings extend research in which the PROMIS Global Health measure was used in illness-specific samples[18,27] by providing a broader evaluation of children's general health across various common childhood chronic illnesses.

The null association between having a chronic illness and life satisfaction supports the positive-health perspective because children with a health challenge (in this case, chronic illness) exemplified similar levels of well-being as their peers. These findings extend a burgeoning area of research primarily focused on older youth and adults that reveals that children 8 years and older have positive life satisfaction despite reports of lower physical, social, and/ or cognitive quality of life.[28–32] Additionally, a longitudinal evaluation of chronic illness status at age 7 revealed negative associations with self-reported health in adolescence but no associations with life satisfaction,[33] suggesting long-term, positive health outcomes despite early illness onset.

The dearth of work on life satisfaction for children age <8 years is partially due to the lack of measurement strategies for this age group.[17,33] Although measures to evaluate younger children's well-being exist,[17,34,35] they are framed from a deficit perspective, measuring the absence of problems versus the presence of well-being.[36] Additionally, the few studies specifically used to investigate life satisfaction outcomes for younger children are not focused on health-related factors[33] or differences by chronic illness status[13]; in other studies, life satisfaction is conflated with related constructs (eg, positive affect).[37] Although the authors of 1 novel study elicited qualitative reports of life satisfaction from children as young as 5 years through a board-game format,[38] such methods are not feasible for population-level assessment. Thus, with the current study, we provide the first cross-cohort quantitative analysis assessing

younger children's life satisfaction in the context of chronic illness.

The lack of effect modification supports the robustness of results across subgroups. Given that environmental assets (eg, high income and positive maternal mental health) did not modify the observed associations, we speculate that internal positive health assets may contribute to the null association between chronic illness and life satisfaction. Additionally, although stress did not modify this relationship, high stress had the strongest associations with both general health and life satisfaction compared with other covariates. Future work should investigate the factors that influence children's stress as well as examine associations between stress and specific chronic illnesses. Complementary work used to examine health assets, such as adaptability and positive coping strategies, could provide additional insight into the dynamic interplay of health resources in the context of chronic illness.

This study has several limitations. These data are not nationally representative, but the sample represents geographically, racially, and financially diverse children across a broad age range, providing the basis for future research with nationally representative samples. Additionally, findings are drawn from parent-proxy reports rather than children's self-report. Previous work suggests low to moderate associations between the 2, and when responses do vary, parents tend to underestimate their children's life satisfaction compared with children themselves[6,17,39–41]; thus, results from the current study may be downwardly biased. However, given the state-of-the-science methods used to develop and validate all PROMIS parent-proxy measures, we believe the results are sound. Using parent-proxy reports is a common and, indeed, necessary strategy for evaluating young children[7,15] and can provide valuable insight (eg, parental perceptions of their children's health and well-being often drive health care use[17]).

The IPD meta-analysis required harmonization of covariate data to common metrics, resulting in data reduction for some covariates. For example, the highest annual income category for 1 cohort was ≥$60 000 such that we had to collapse higher income categories available in other data sets. Harmonization was necessary because cohorts collected such data previously for cohort-specific aims and not specifically for this study.

Additionally, cohorts measured different types of chronic illnesses and used diverse measurement strategies to do so. This left large samples of participants (and in some cases, entire cohorts) with missing data. Although the current data included many prevalent childhood chronic illnesses, some chronic illnesses had low incidence or were not present. This may partially be due to low incidence in the general population (eg, the 2016/2017 National Survey of Child Health revealed that only 0.7% of children between the ages of 6 and 11 years have epilepsy, whereas even fewer [0.2%] have diabetes[42]). We could not, therefore, examine associations between specific illnesses or between illness severity and children's general health and life satisfaction. Nevertheless, the current study provides a solid foundation for future investigations of illness-specific associations with children's life satisfaction, particularly in large research consortia in which incidence rates of specific illnesses may be amplified through pooled analyses with large, heterogeneous samples.

CONCLUSIONS

Traditional health care models are focused on evaluating health problems and do not capture the full spectrum of health resources that, when assessed, can provide insight into children's lived experience with chronic illness. The current study suggests that having a chronic illness is certainly a health challenge (evidenced by lower parent-reported general health) but does not preclude these children from having happy and satisfying lives that are comparable with those of peers without illness. Such findings support the positive-health approach and provide a basis for additional research with nationally representative samples and for specific chronic illnesses. Overall, this work highlights clinical opportunities to broaden the perspective of health beyond the absence of disease to one in which all children, regardless of illness or impairment, can have well-being.

ABBREVIATIONS

ADHD: attention-deficit/ hyperactivity disorder
ASD: autism spectrum disorder
CI: confidence interval
ECHO: Environmental influences on Child Health Outcomes
GEE: generalized estimating equation
IPD: individual patient data
LBW: low birth weight
NIH: National Institutes of Health
PROMIS: Patient-Reported Outcomes Measurement Information System

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