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The Value Adults Place on Child Health and Functional Status



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ABSTRACT

Objectives: To summarize the value adults place on child health and functional status and provide a new quantitative tool that enhances our understanding of the benefits of new health technologies and illustrates the potential contributions of existing data sets for comparative effectiveness research in pediatrics. **Methods:** Respondents, ages 18 years and older, were recruited from a nationally representative panel between August 2012 and February 2013 to complete an online survey. The survey included a series of paired comparisons that asked respondents to choose between child health and functional status outcomes, which were described using the National Survey of Children with Special Health Care Needs, a 14-item descriptive system of child health outcomes. Using respondent choices regarding an unnamed 7- or 10-year-old child, generalized linear model analyses estimated the value of child health and functional status on a quality-adjusted life-year scale. **Results:** Across the domains of health and functional status, repeated or chronic physical pain, feeling anxious or

depressed, and behavioral problems (such as acting out, fighting, bullying, or arguing) were most valuable, as indicated by adult respondents' preference of other health problems to avoid outcomes along these domains. **Discussion:** These findings may inform comparative effectiveness research, health technology assessments, clinical practice guidelines, and public resource allocation decisions by enhancing understanding of the value adults place on the health and functional status of children. **Conclusions:** Improved measurement of public priorities can promote national child health by drawing attention to what adults value most and complementing conventional measures of public health surveillance. **Keywords:** National Survey of Children with Special Health Care Needs, NS-CSHCN, paired comparisons, patient-reported outcomes, QALY, quality-adjusted life-years.

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Introduction

A *quality-adjusted life-year (QALY)* is an idealized year of life with no health problems and serves as a common preference-based metric in comparative effectiveness research (CER), health technology assessment, and allocation of communal resources [1]. Health problems for a given duration may be summarized by their equivalence in lost QALYs using various methods. Although standard gamble and time trade-off (TTO) responses were commonly used in the past [1], these methods have serious limitations, including cognitive difficulty, scaling biases, and practical considerations [2–5]. A recent alternative that addresses these limitations and facilitates the measurement across a much wider domain of problems is to use preference questions on a health valuation survey, such as paired comparisons. For example, the survey might ask a participant, “Which do you prefer: a year in mild pain or a 6-month loss in life span with no health problems?” Responses to such questions help us understand the value placed on a year of pain without referencing money, which may be a less reliable and ethical metric. If, for example, half of the respondents prefer the 6-month loss in life span, this

empirical result (i.e., median respondent) suggests that a year in mild pain is worth six quality-adjusted months (i.e., 0.5 QALY). This study examined the value adults place on child health and functional status and provides a new quantitative tool that enhances our understanding of the benefits of new health technologies. Specifically, this tool applies preference weights to existing data on child health outcomes, such as the National Survey of Children with Special Health Care Needs (NS-CSHCN), summarizing these outcomes to better inform CER in pediatrics.

Faced with a wealth of evidence on child health outcomes, translation and summary of such measures into values that can be used for analysis in medical decision making (e.g., Markov models) require tools. Multiple studies have examined the value adults place on child health [6–10]; however, few studies have targeted outcomes measured by a child-specific health questionnaire or attempted to summarize value on a QALY scale. Valuation on a QALY scale requires including a description of life span or risk of death as an attribute in the alternatives, which can be difficult. An Australian study assessed adult preferences for health scenarios as described by the Child Health Utility 9D, but did not include a life span attribute, and so the study does not

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report QALYs [11]. This limits its value for formal decision analyses. More recently, a UK study assessed QALY values for the Child Health Utility 9D by eliciting adult preferences on adult outcomes (not child outcomes) [12].

To date, only two health valuation studies both 1) use a child-specific health-related quality of life (HRQOL) instrument and 2) translate instrument responses to the QALY scale. Both studies valued the Pediatric Asthma Health Outcome Measure using the standard gamble technique with samples of adults from Seattle, Washington (N = 94), and Birmingham, Alabama (N = 261) [13,14]. Furthermore, the Health Utilities Index (HUI) Mark-2 represents a noteworthy general health instrument marketed largely for adults, yet originally developed for adolescents using preferences from parents in the general population [15,16].

Our expanding technology to systematically collect real-time data can potentially advance our understanding of children's health-related experiences for CER and public health surveillance. Formally weighing evidence on child health outcomes in decision analyses informs clinical guidelines, resource allocations, and policy decisions, yet only the Pediatric Asthma Health Outcome Measure studies summarized child outcomes on a QALY scale. The passing of the 2010 US Patient Protection and Affordable Care Act and the formation of the Patient-Centered Outcomes Research Institute have strengthened the importance of HRQOL as a patient-centered outcome [17,18]. Still, tools are needed to summarize quantitatively the evidence in a manner that accounts for the priorities of stakeholders.

Because of the paucity of child health valuation studies in the literature, many comparative studies have used adult measures of HRQOL—the HUI [19] and the EuroQol five-dimensional questionnaire (EQ-5D) [9]—and applied the same values to both child health outcomes and adult outcomes as if their experiences were interchangeable. We know from other literature, however [10], that adults often express preferences about health care differently for children than for adults, especially when resources may be limited. In this study, we take the perspective of US adults and examine the values they place on child health outcomes; however, future studies may focus on the values of children, parents, caregivers, or other stakeholder populations.

The purpose of this study was to be the first to assess the value adults place on child health and functional status as described by the NS-CSHCN. The NS-CSHCN items measure the health and functional status of US children with special health care needs and gather critical information on access to quality health care, care coordination of services, access to a medical home, transition services for youth, and the impact of a chronic condition(s) on the child's family [20,21]. A multitude of studies have examined the NS-CSHCN to assess 1) the roles of medical homes [22–25], 2) medical transitioning to adult services health care [26–30], 3) impact on the family [28,31–37], and 4) health care services and disparities [24,34,36,38–42]. Moreover, the NS-CSHCN is a tool to monitor service systems for these children and their families to comply with *Healthy People 2000 and 2010* [23]. By summarizing the child health and functional status items in the NS-CSHCN on a QALY scale, this study provides a new tool that extends its use for comparative studies and public health surveillance.

Methods

Participants

To inform medical decision making and health policy, CER requires measurement and valuation [43]. Measurement typically involves surveys of health outcomes completed by patients (e.g., children) or their proxies (e.g., parents and caregivers). The currently available NS-CSHCN data are one source of such

measurement. Valuation requires surveys of preferences from the perspective of decision makers (e.g., general population). For this valuation study, we surveyed adults (instead of children) aged 18 years or older who resided in the United States because adults typically make health care decisions for children. We recruited respondents from a preexisting national panel of US adults, and to promote concordance with the 2010 US Census, we used 18 demographic quotas (all combinations of two sexes, three age groups, three race/ethnicity groups). Once filled, the survey admitted no additional respondents belonging to that quota. The survey was administered online between August 7, 2012, and February 5, 2013. The protocol, including its sampling design and survey instrument, was adapted from the PROMIS-29 valuation study (1R01CA160104) [44] and approved by the University of South Florida Institutional Review Board (USF IRB no. 8236).

Survey

After consenting, respondents completed a screener in which they reported their current US state of residence, ZIP code, date of birth, race, Hispanic ethnicity, educational attainment, and household income. After the screener, respondents proceeded to the survey, which was composed of health, paired comparisons (below), and follow-up components. The health component included the PROMIS-29, a validated measure supported by a National Institutes of Health initiative, as a measure of adult HRQOL [44]. The follow-up component asked about the respondent's experience with parenting and selected childhood health conditions and provided an open text box for opportunity to leave survey feedback.

Paired Comparisons

Because of space constraints, this section summarizes the preference elicitation task. The Appendix in Supplemental Materials found at <http://dx.doi.org/10.1016/j.jval.2015.02.012> includes a more didactic overview of paired comparisons, adjectival statements, and results of each pair as well as a more comprehensive econometric discussion.

A paired comparison is a choice-based question that asks a respondent about his or her preference between two alternatives (e.g., orange vs. apple). Responses show how choices change with different combinations of alternatives. Each respondent first completed three example paired comparison questions: “Which do you prefer?” (1: Apple or Orange); (2: Good Health or Poor Health); and (3: Bad Health or Poor Health). The “Bad Health” versus “Poor Health” question was included to prepare respondents for potentially more challenging descriptions of health and functional status problems later on in the survey. Next, respondents received a randomly assigned base scenario and completed a series of paired comparisons building from this base scenario. The base scenario described the age of an unnamed child (7 or 10 years old) and health-problem duration (1 or 2 years). Each respondent completed up to 40 paired comparisons.

Initial pairs asked respondents to choose between a health problem and a loss in life span given the assigned base scenario. For example, the paired comparison shown in Figure 1 has a base scenario for a 10-year-old child. In this task, the respondents must choose between a reduction of 3 years (i.e., loss of 3 QALYs) in the child's life span and an increase in feeling anxious and depressed for 1 year. For these initial pairs, the loss in life span occurred 10 years after the problem, which follows common practice in TTO tasks and allows for sufficient range in loss of life span [45]. Remaining pairs asked respondents to choose between two problems. All health problems were described using statements derived from the NS-CSHCN. To strengthen concordance with the 2010 US Census at the pair level, all pairs were assigned and sequenced following the 18 demographic quotas.

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