

Elicitation of preferences for health outcomes in children

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Abstract

This paper considers some of the important issues surrounding the description, assessment and valuation of health-related quality of life of children, with a particular consideration of pre-school children. Empirical studies are reviewed to examine whether valuations for children's health states differ according to background characteristics of respondents. It is argued that a research programme is warranted which addresses whether the values of children should be included in the general public's values.

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1. Introduction

The QALY model requires that utility values, or quality of life weights, are assigned to individuals' health states. The duration of each health state is then multiplied by its utility value and these values summed sequentially over the health states experienced. Two approaches are available to define the health state of individuals. The first is through the use of a health status classification instrument and the second requires specially written vignettes of each health state. The preferred approach will depend, among other things, on the research framework for the economic evaluation. The use of health status classification instruments are only feasible if the researcher has access to a prospective sample of respondents who can be followed up over a sufficient period of time, as for example, in the context of a randomised controlled trial. There are, however, additional issues, which will influence the choice of approach, the importance of which will depend on the context in which the economic evaluation is being applied. In this paper we discuss the issues, which arise in evaluating health care interventions in the context of health care programmes for children.

Regardless of whether the health states have been defined by a classification instrument or vignettes describing each health state, the QALY model requires utility values to be assigned to the health states. A number of issues are raised in the paper when considering the appropriate methods for valuing such health states in the context of evaluating health care programmes for children.

2. Classifying or describing health state of children

We begin by discussing the issues, which need to be considered in the choice of approach to defining the health states of children.

2.1 Capturing developmental changes in children

Defining the health states of children is complicated by the fact that, unlike adults, children undergo relatively rapid developmental changes. In terms of the health state descriptions, this implies that a larger number of health states may need to be described to capture the changes over time.

In terms of a health state classification instrument, this may mean that it needs to be completed by respondents more frequently. A further implication of the developmental changes is that it is less feasible to use the same set of dimensions to describe the functional, cognitive and behavioural characteristics of children across all age groups from early infancy to late adolescence. Quality of life researchers usually refer to children “as the moving target, for whom levels of function in various dimensions- and even the dimensions themselves- change with age and developmental stage” [1].

This is reflected in the use of the Health Utility Index 2 (HUI 2), the only utility based health status classification instrument available for use in children at present [2]. The instrument uses as a reference what is regarded to be normal for a certain age. For example, in the sensation attribute, the level one is described by: ability to see, hear, and speak normally for age. Nonetheless, the partial failure of this instrument to classifying 3 years old ex-premature children cast doubts on whether the same aspects and levels of functioning are appropriate to pre-school children. It is therefore only recommended for use in children over the age of 5 years. Attempts have been made to develop a new pre-school health state classification system, the HUI-PS [3], although utility values are not available for the instrument at present (Saigal, personnel communication).

2.2 Who classifies the health states

It is usual for individuals receiving the health care to complete the classification instrument in order to describe their current level of health. If classification instruments are to be used in the evaluation of health care interventions for children, it then raises the issue as to whether

children, in particular very young children, can complete such instruments as they may lack the necessary cognitive or linguistic skills and/or be too ill to report their own health status. The alternative would be for an adult proxy to complete such an instrument on behalf of the child.

Empirical studies have shown considerable similarities as well as differences in the assessment of health status by children and proxy respondents [4]. A recent review found some limited evidence that parents are better able to judge observable aspects of health-related quality of life, such as physical functioning, than non-observable aspects such as social and emotional functioning [5]. This is illustrated by a study, which examined the outcomes of extremely low birth weight. Saigal et al. (1995) used the HUI 2 in direct interviews with adolescents, who had been extremely low birth weight babies, and their parents. The study found remarkable consistency in the health status reported by both groups but differences occurred in the cognition domain where adolescents described themselves at a higher level of functioning than their parents described them. Teenagers also reported more problems in relation to the domain of sensation than their parents [6] [1]. The finding has been confirmed by Barr and colleagues (2000) who examined health related quality of life of adolescent survivors of childhood cancer and found a high level of agreement between parents-child dyads in all attributes except cognition [7].

Nonetheless, the psychometric literature is undecided on the use of proxies for children. Some researchers are in favour of relying exclusively on parents as informants on the premise that this will facilitate assessments of children across the age range compared with multiple measures designed for child self-reports at different age levels. Others argue that this approach might result in incomplete assessments to the extent that children's perceptions on health-related quality of life might be overlooked [5]. Nevertheless, it does seem pertinent to obtain information from children themselves, particularly when parents' responses appear to be confounded by the burden of care-giving, own mental health problems and their concerns about possible future health problems of the child. It is not completely understood, however, whether and how concordance between children and proxy responses is affected by child age, gender and illness status, although some research findings suggest that parent-child agreement might be greater for groups of chronically sick children compared with healthy children [5].

2.3 *The additive assumption of the QALY model*

An issue that is of importance to both the health classification instrument and the descriptions of health states is the additive separability assumption of the QALY model. This assumes that the utility value of health state is independent of the previous or following health states such that the utility derived from an entire health profile over time is equal the sum of the duration of sequential health states each multiplied by its utility value.

In the context of health states experienced by children, this assumption is likely to be violated. The value assigned to children's health states might differ depending on whether a child has a good or bad health-related quality of life at the point of transition into adulthood. Prognosis for normal role fulfilment in later life has, for example, been found to be one of the most important factors in determining parents' preferences for quality of life dimensions in children [8]. Parents may be more willing to accept some limitations in early childhood as long as the child is enabled to attain independence in late adolescence. It also has been emphasised that HRQoL implications in children are not limited to the present. Eiser & Morse (2001) note: *Where illness limits a child's ability to participate in everyday activities, social, physical or educational, then the repercussions may be as much, if not more, for their future* (p.49) [5].

An alternative measure that does not require this restrictive assumption is the healthy-year equivalent (HYE). This approach differs from the conventional QALY model in that the respondent is asked to value the entire health profile. The valuation procedure also differs and there has been much debate about the proposed two-stage standard gamble and the extent to which this is equivalent to a one-stage time trade-off procedure [9]. It not our intention to revive the latter discussion here, instead we focus on the question of whether the use of a decomposed approach, where each health state is valued separately, is to be preferred over the use of an holistic approach, where the respondent is asked to value an entire health profile consisting on two or more health states. The latter approach will of course exclude the possibility of using a health status classification instrument.

Little empirical work has been carried out to investigate the extend to which both methods provide similar answers [10]. Those studies, which have been carried out leave us ambiguous in our conclusions. MacKeigan et al. (1999) found no significant difference between the values obtained with both approaches using the time-trade off technique value lifetime

treatment paths for type 2 diabetes [11]. Krabbe & Bonsel (1999) found the majority of respondents (67%) to be indifferent to the sequence of outcomes presented to them i.e. years spent in a good quality of life first followed by years spent in a bad quality of life and vice versa [12]. This is in contrast, however, to the findings of the studies by Kuppermann et al. (1997) and by Richardson et al. (1996) [13] [14]. Both studies concluded that individual-level preferences are not clearly separable and additive in the sense that preference scores derived from a holistic valuation were not congruent with the scores obtained by combining the valuations for the discrete health states. Violation of the additive separability assumption of the QALY model may be context specific. None of the empirical studies were conducted in the context of valuing the outcomes of child health care.

Describing a holistic health profile in the context of health outcomes in children has the potential to overcome the likely violation of the additive separability assumption of the QALY model, however it raises potential problems in terms of increasing the cognitive burden for respondents and presents potential presentation difficulties in terms of compressing the quality of life experiences over time into one vignette.

2.4 Empirical example of a holistic quality of life profile for children

In the absence of a pre-scored health status classification system for younger children and in the context of an economic evaluation conducted within a decision analytic framework, we wanted to describe the health outcomes of a neonatal screening programme for congenital heart disease which was anticipated to have a potential impact on the well-being and quality of life not only for school-aged children, but also for infants and toddlers.

Guidance on methodology for the development of such descriptions is lacking. We undertook a review of developmental scales and quality of life measures for children and identified 11 important dimensions of health-related quality of life for this age-group: feeding/eating, independent living, gross motor mobility, fine motor ability, cognitive/school performance, vision, hearing, speech and language, social interaction, emotional understanding and health care needs [5] [2]. In addition, we reviewed relevant quality of literature on congenital heart disease and descriptions of the experiences of children with this disease published by patients and their parents on the web pages of support groups. Drawing also on the experiences of clinical experts in developmental paediatrics and paediatric cardiology, we developed eight hypothetical health state descriptions or vignettes. These described the quality of life

associated with varying degrees of cardiac and neurological disability due to congenital heart disease.

Our intention was to take aspects of health-related quality of life of pre-school children into consideration as well as health-related quality of life of school-aged children. We began by investigating the relevant dimensions of HRQoL for babies (0-18 months), pre-school children (18 months- 5 years) and school children (5-16 years) and characterised the varying limitations due to congenital heart disease in these dimensions. We considered the possibility of presenting this information to respondents as separate health states for each age group, but rejected the idea due to the complexities of valuing temporary health, the number of possible health states as well as concerns over the violation of the additive separability assumption of the QALY model. A decision was, therefore, made to use health profiles. Descriptions were written in the format of the HUI2 using a bullet point and headings explicitly stating age groups. Nevertheless, because of the considerable detail of information for each age group, pilot testing revealed that respondents found it to be cognitively demanding to comprehend these descriptions. Therefore, the information presented in these descriptions was condensed as much as possible but we also made some allowances for developmental aspects relative to peers. The final descriptions are presented in the appendix of this paper. In conclusion, developing vignettes is a very time-consuming and challenging task because of the difficulties involved in reconciling the conflict between the required face and content validity of the vignettes and the potential cognitive overloading of respondents.

3. Valuing health states

The QALY model requires utility values to be assigned to health states regardless of whether these have been defined by a classification instrument or vignettes describing the health state or holistic profile. A number of issues are raised in considering the appropriated methods of valuation in the context of evaluating health care interventions applied to children.

Although the issue of whose values should be used has been much debated, it is generally recommended that for purposes of resource allocation the values of a representative sample of the general public should be used [15] [10]. Others have gone further to recommend that where the general public's values are used in the evaluation of a health programme treating or preventing a condition, sensitivity analysis should include the values of those with the condition.

Where does this leave us in the context of evaluating health care programmes for children? Even if we don't agree with the use of using patient specific values, should children be included as members of the general public, at least where interventions are directed at their care?

The extent to which children, particularly young children, have well-defined preferences over the range of alternative choices and are able to comprehend the nature of death as irreversible is questionable [16]. It is not clear that children have well-defined preferences that can be elicited using cognitively demanding instruments such as the Standard Gamble (SG), Time-Trade off (TTO) or the Visual Analogue Scale (VAS). We have found only one study that has examined the minimum skills and age required to complete the VAS and the SG and this was in children with a health condition, rather than a sample of the general population of children. Juniper and colleagues, using a sample of asthma patients aged 7-18 years, found that children younger than 8 and 12 years had considerable difficulties comprehending the VAS and SG, respectively [17].

If the values are not to be elicited from children, then the general public from whom values are to be elicited should at least be informed members of the public. Asking adults to value health states experienced by children raises a number of issues, however. The first relates to whose perspective the respondents should take when valuing the health state. Asking adult respondents to imagine themselves as a child experiencing the health state could result in very different values to asking respondents to value the health state from their own adult perspective. Moreover, adults are likely to have difficulties in imagining themselves to be children and being able to disentangle their own values from the perceptions they are required to imagine. Adults may also misinterpret children's subjective experiences and perceptions, and therefore, misrepresent their preferences.

Inconsistencies in the perspectives taken can be seen in the literature where parents have been asked to value health states experienced by children. For example, Torrance et al. (1996) in the valuation of the HUI 2 health states asked the parents of schoolchildren to imagine themselves to be 10 years of age and live in that health state for the rest of their lives. The same approach was adopted in a series of studies exploring preferences for health outcomes of extremely low birth weight infants [18] [19] [20] and in a study examining preferences for paediatric oncology treatments [21]. Saigal et al. (1998) justified their approach by stating that

this might minimise the emotive aspects involved in parents rating their own children [4]. Contrary to this approach, Kuppermann et al. (2000) asked parents, using the TTO method, how much time off their life expectancy they would be willing to trade to avoid their child's experiencing particular outcomes after different childhood vaccinations [22]. Others have not explicitly stated their chosen perspective [23] [24] [25], but appear to be assuming an adult's (parents and other adults) perspective on children's health outcomes.

The exclusion of children in the valuation of health states is only a real issue, however, if their valuations differ from the general public. Evidence that the general population may misinterpret children's values can only be gained indirectly from the literature at present to a very limited extent. In the paper that reported the results of the valuation of the HUI 2 based on the sample of parents of school-aged children in Canada, the authors asserted that their preference scores might not be significantly different from the mean scores that would be reported in a survey of the general public¹ [2]. Furthermore, Torrance and colleagues state: *It is our view that in these kind of measurement, the difference attributable to the ways in which health states are described and to the instruments used far exceed the differences due to the characteristics of the population surveyed. Nevertheless, further research to investigate this issue would be useful* (p. 720). However, we are not aware of any published study that attempted to investigate this.

There are several empirical studies, which compare the values assigned by parents of sick children with those of the general public. A study by Feeny et al. (1991) found that a sample of parents drawn from the general population tended to assign lower values to some health states describing outcomes of paediatric cancer treatments than parents of children with childhood cancer [21]. In a study examining health states after treatment for haemophilia, Naraine et al. (2002) asked three different sets of respondents and found that healthy adults with and without children consistently rated hypothetical health states statistically significant lower while parents of children with haemophilia and adults with haemophilia provided similar scores [24]. Wang et al. (2002), however, found no differences when they compared the HUI 2 scoring function obtained from a sample of parents of childhood cancer patients with parents of similarly aged schoolchildren [26].

¹ This assertion is based on an earlier valuation work of the HUI, which found valuations from the sample of the general public to be similar to those obtained from a sample of parents, but the sample size was only 32 individuals in each group [8].

It should be noted, however, that parents' values are not necessarily good proxies for the values of children. Saigal et al. (1995), for example, compared adolescents and parental ratings using the SG and VAS in a series of studies using a cohort of extremely low birth weight (ELBW) adolescents and an age and demographically matched control group of healthy adolescents [27]. Both groups of teenagers rated their own health state and four additional hypothetical health state descriptions lower than their parent ratings, indicating that both groups of parents were more generous than their children in assessing preference scores [1]. Given lower ratings by teenagers were not only apparent in the patient group, but also in the control group suggests adults generally may value health outcomes differently from children.

The values of sick children or those who have experienced illness in the past may also differ from those that are well or have not experienced illness. Saigal et al. (1995) found that extremely low birth weight survivors generally rated hypothetical health states higher than control teenagers [6].

To our knowledge, no study has been conducted to date, which compares the values of those with children with those who do not have children in the general public. In a study that was primarily intended to test for differences in preferences among health care professionals and parents, Saigal et al. (1999) found that childless health care professionals tended to assign lower values than health care professionals without children [19]. In a study we conducted which was designed to elicit preferences for health outcomes of children with congenital heart disease from the perspective of professionals working in paediatric cardiology and to compare their preferences with those obtained from parents of children with congenital heart disease in a clinical decision making context, secondary analysis of the data suggested parents with only one child rated all health states higher than parents with more than one child, suggest the hypothesis that parents values changes with their experience of other (probably relative healthy) children.

It is important to investigate whether valuations for children's health states or profiles differ according to background characteristics of respondents. Although it has been emphasised, the debate on whose valuations to use in the context of resource allocation decisions is not going to be resolved by empirical evidence; it is rather a political and philosophical issue [10].

Nevertheless, it is our view that empirical work to elicit preferences from sick/healthy children and/or their parents in comparison to the general public should be undertaken. Even if members of the general public are judged to be the most appropriate respondents, they clearly have to understand the ratings of actual patients or- in the context of child health- parents and/or children with and without experience of particular health states being evaluated [28].

What are possible implications of systematic variations of preferences between different groups of individuals- parents/children and a sample of the general public? The issue of preference subgroup analysis has been subject of a recent debate [29] [30] [31]. Nevertheless, using different sets of valuations for health outcomes could alter the decision of whether an intervention is considered to be cost-effective or not. For example, take the situation where the incremental cost-effectiveness ratio (ICER) of a certain screening strategy for congenital heart disease is acceptable on the basis of valuations for children's health outcomes from public raters; but the valuations of parents are such that their sub-group specific ICER is unacceptable. The ethical implications of such an analysis are considerable.



3. Conclusions

This paper has illustrated the difficulties in describing the health states of children in the context of economic evaluations, which arise from the developmental changes that take place in childhood. It also highlighted the lack of methodological guidance in this area. Moreover, the development of a pre-scored health classification system will not provide a solution if the additive separability assumption of the QALY is violated. Further empirical work is needed in this area.

A research programme is warranted which addresses whether the values of children should be included in the general public's values. This may be pre-determined by the fact that children do not have well-defined preferences. Others may argue that children are not representative of the tax-paying community which funds the health service, but neither are those adults who are not in work and, thus far, there has been no discussion over their exclusion. Further work is also needed on the implications of the perspective adult respondents are asked to take when valuing children's health states. Evidence is also lacking on whether the general public is

informed or whether it misinterprets children's subjective experiences and perceptions. If it does, we need to know why. We also drew attention to the need to explore whether values for children's health states vary according to background characteristics of respondents, such as whether they have children, and if they do, to examine why. The above research agenda is likely to require both quantitative and qualitative research methods.

4. References

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Appendix: Vignettes used in the empirical study mentioned in the text

Health state Pink	Health state Orange
<ul style="list-style-type: none"> • Has always eaten well • Development as a toddler has been as fast as other children • Walks and runs as well as other children of the same age • Rarely tired before end of the day • Sees and hears normally • Eats, baths, dresses and goes to toilet independently • Joins in as well as other children in the classroom • Learns normally for age • Speech and communication is normal for age • Generally happy and free from worry • Visits hospital regularly once or twice a year; takes medication only very rarely 	<ul style="list-style-type: none"> • Has always eaten well • Development as a toddler has been slower than other children • Walks and runs but a bit clumsy • Rarely tired before end of the day • Sees and hears normally • Eats, baths, dresses and goes to toilet independently but with some difficulty; occasional bedwetting • Joins in with some difficulty in the classroom • Learns a little more slowly than normal for age; gets special help at school • Speech can still be difficult to understand; usually manages to communicate own needs • Generally happy but can be angry or upset and difficult to handle • Visits hospital regularly twice a year; takes medication only very rarely
Health state Green	Health state Purple
<ul style="list-style-type: none"> • Eating has always been a struggle; needs extra feeds by stomach tube • Development as a toddler has been much slower than other children • Sits in a special chair; walks with help; uses buggy or wheelchair if outdoors • Tires quite easily • Poor vision; hears normally • Needs help to eat, bath and dress and go to toilet; uses nappies at night • Recognises carers and classmates • Learns very slowly; attends special school • Some words and some sign language; communicates own needs with difficulty • Generally settled but also periods when angry or frustrated; becomes anxious when breathless • Visits hospital regularly once or twice a year; takes some courses of medication 	<ul style="list-style-type: none"> • Eats well now but some problems as a younger child • Development as a toddler has been as fast as other children • Walks normally but a bit breathless if runs • Tires more easily than other children • Sees and hears normally • Eats, baths, dresses and goes to toilet independently • Joins in as well as other children in the classroom • Learns normally for age • Speech and communication is normal for age • Generally happy but can get upset and worried; aware of own limitations and can be anxious about own health • Visits hospital and doctor quite frequently; takes medication every day

Health state Turquoise	Health state Yellow
<ul style="list-style-type: none"> • Eats well now but some problems as a younger child • Development as a toddler has been slower than other children • Walks and runs but a bit clumsy and breathless • Tires more easily than other children of same age • Sees and hears normally • Eats, baths, dresses and goes to toilet independently with some difficulty; occasional bedwetting • Joins in with some difficulty in the classroom • Learns more slowly than normal for age; gets special help • Speech can still be difficult to understand; usually manages to communicate own needs • Generally happy but can be angry or upset and difficult to handle; can be anxious about own health • Visits hospital and doctor quite frequently; takes medication every day 	<ul style="list-style-type: none"> • Eats is still slow but more problems as a younger child • Development as a toddler has been slower than other children • Walks but becomes breathless if runs; sometimes uses buggy or wheelchair if outdoors • Often tired • Sees and hears normally • Eats, baths, dresses and goes to toilet independently • Joins in with other children in the classroom but limited by physical effort • Learns normally for age considering school absences due to health problems • Speech and communication is normal for age • Generally happy but can get upset and worried; often anxious about own health • Visits hospital and doctor frequently; takes medication every day
Health state Red	Health state Blue
<ul style="list-style-type: none"> • Eating is still a struggle; still has some mashed and pureed food • Development as a toddler has been slower than other children • Walks and runs but becomes quickly breathless; uses buggy or wheelchair if outdoors • Often tired • Sees and hears normally • Eats, baths, dresses and goes to toilet independently with some difficulty; occasional bedwetting • Joins in with some difficulty in the classroom • Learns more slowly than normal for age; gets special help • Speech can still be difficult to understand; usually manages to communicate own needs • Generally happy but can be angry or upset and difficult to handle; can be anxious about own health • Frequent hospital visits; takes medication every day 	<ul style="list-style-type: none"> • Eating is still a struggle; needs extra feeds by stomach tube • Development as a toddler has been slower than other children • Sits in special chair; stands and walks with help; uses buggy or wheelchair if outdoors • Often tired • Poor vision; hears normally • Needs help to eat, bath and dress and go to toilet; uses nappies at night • Recognises carers and classmates • Learns very slowly; attends special school • Some words and some sign language; communicates own needs with difficulty • Generally settled but also periods when angry or frustrated; becomes anxious when breathless • Frequent hospital visits; takes medication every day

