THE UTILITY OF STRABISMUS IN ADULTS

BY **George R. Beauchamp MD,*** Joost Felius PhD, **David R. Stager Sr MD**, AND Cynthia L. Beauchamp MD

ABSTRACT

Purpose: To determine the utility (quality-of-life weight) associated with adult strabismus.

Methods: Time tradeoff utility values were measured in physician-conducted interviews with 140 adult patients with strabismus in a private practice setting. Patients also completed a questionnaire containing six items that rated the following aspects of disability: specific health problems, problems with tasks of daily living, problems with social interaction, self-image problems, concerns about the future, and job-related problems. Patients were characterized as presurgical or nonsurgical, and their diplopia and asthenopia were rated by the physician on a four-level scale.

Results: About 60% of all patients indicated willingness to trade part of their life expectancy in return for being rid of strabismus and its associated effects. The median utility was 0.93 (interquartile range, 0.83 to 1.0). A significantly smaller proportion (44%) of the nonsurgical patients (N = 41) appeared willing to trade time compared with surgical patients (68%; $P = .009$). Median utility in the presurgical patients was 0.90. Strong relationships were found between utility and the level of diplopia ($P < .0001$), and between utility and the level of asthenopia ($P < .0001$). Utility was correlated with all six disability ratings (all $P \leq .00062$).

Conclusion: A majority of the patients interviewed would trade a portion of their life expectancy in return for being rid of strabismus and its associated effects. These results were validated by significant associations with diplopia, asthenopia, and disability.

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INTRODUCTION

Strabismus in adults has recently become an increasing focus of attention. Although the management of adult strabismus has traditionally been regarded as difficult, good clinical and functional outcomes have been reported.[1-9] A recent report by the American Academy of Ophthalmology[10] concluded that surgical treatment of strabismus in adults is generally safe and effective. Also, several reports have shown that strabismus in adults is associated not only with functional deficits but also with psychosocial problems.[9,11-15] These results suggest that the health value inherent in the treatment of strabismus in adults may be determined by a complex equation weighing cost not only with functional benefits but also with a variety of subjective, psychosocial improvements.

In modern health care, such patient-centered outcomes are increasingly recognized as important measures in decision making and policymaking. Cost-effectiveness and cost-benefit analyses often include the effects of health management on the patients' quality of life. Although it is widely appreciated that quality of life is a multidimensional trait, it is desirable for the purpose of cost-effectiveness analysis to capture quality of life in a single number: the "quality-of-life weight" or "utility," defined on a continuous scale from 0 (corresponding to death) to 1 (corresponding to perfect health). In cost-*utility* analyses, the outcomes of interventions are thus evaluated by offsetting the cost with the utility gained. More specifically, the utility values associated with relevant health states are multiplied by the length of time that the patient spends in each health state to arrive at quality-adjusted life years (QALYs). The QALY has become the common currency for a wide variety of health outcomes and, by virtue of the numeric scale, can be used to compare outcomes not only within but also across diseases.[16] Although such comparisons are not without problems,[16,17] the use of utilities has become an accepted means of expressing quality of life for the purpose of different types of value analyses. In the field of ophthalmology, utilities have been measured for health states associated with a variety of conditions[18-22] and have been used successfully for cost-utility analyses.[23-27] Cost-utility analyses form the basis of *value-based medicine,* which takes evidence-based medicine to the next level by incorporating cost and effectiveness measures (including utility) into its analyses. For a snapshot overview of published cost-utility analyses in ophthalmology, see a recent extensive literature review by Brown and colleagues.[28]

In this study, we used a time tradeoff method [29] to assess the quality-of-life weight (utility) in adult patients with strabismus and validated the results by comparing utility values with both patient-perceived disability ratings and clinical ratings of diplopia and asthenopia.

METHODS

Consecutive adult patients with strabismus who visited our private practice setting were invited to participate. Participants were categorized as presurgical if they were scheduled (or planned to be scheduled) to undergo strabismus surgery; as postsurgical if they had recently undergone strabismus surgery; or as nonsurgical otherwise. For the analyses presented here, the results from postsurgical patients were excluded. The data in this study were obtained from 140 patients, mean age (± SD) 48 ± 17 years (range, 18 to 85 years), of whom 99 were presurgical and 41 were nonsurgical. (Five additional patients agreed to participate but declined to answer the time tradeoff question or were not able to produce a meaningful answer.)

From the Department of Ophthalmology, University of Texas Southwestern Medical Center (Dr G. Beauchamp, Dr Felius, Dr Stager, Dr C. Beauchamp), and the Retina Foundation of the Southwest (Dr Felius), Dallas, Texas.*Presenter.
Bold type indicates AOS member.

Of the 140 patients, 69 had long-standing or recurring strabismus stemming from childhood, whereas 71 patients had strabismus that was acquired after childhood. (For the purposes of this study, childhood ends when vision is assumed to have reached maturity: around age 9 years.[30]) Participants were further characterized by ratings (performed by the treating physician, G.R.B. or D.R.S.) of their level of diplopia and asthenopia, each on a four-point Likert scale. Patients signed a written informed consent form approved by the Institutional Review Board of the University of Texas Southwestern Medical Center.

Participating patients were interviewed by the physician following a scripted protocol, asking the patient to estimate his or her own life expectancy (number of life years remaining). If no useful estimate was obtained, the patient's life expectancy was estimated using gender-specific life tables[31] instead. The patient was then asked if he or she would be willing to trade in a portion of the estimated life expectancy (off the end of his or her life) in return for being rid of strabismus and all its associated effects, and if so, how many years he or she would be willing to trade under those hypothetical conditions (the time tradeoff question). Time tradeoff utility was calculated according to the following:

$$\text{Utility} = 1 - \frac{\text{Time traded}}{\text{Life expectancy}}$$

Note that this equation yields the value 1 if the number of years traded is zero: the patient is not willing to trade any portion of the life expectancy and presumably values his or her current quality of life equal to that of perfect health. The utility decreases with increasing number of years traded, eventually approaching zero if the patient should indicate willingness to trade all of his or her life expectancy.

Participating patients also completed a six-item written questionnaire (see Appendix)[32] in which they were asked to rate the severity of problems associated with their strabismus in the following aspects: specific health problems, problems with tasks of daily living, problems with social interaction, concern or doubts about the future, self-image problems, and job-related problems. All severity ratings were performed on a Likert scale from 1 (corresponding to no problems) to 10 (severe problems). In addition, gender, race, and the presence of comorbidities (defined as "other health problems that influence [the patient's] quality of life") were collected.

All data analyses were performed in STATISTICA (Statsoft, Tulsa, Oklahoma) using nonparametric statistics because of the nonnormal distribution of the utility values and the discrete nature of the rating scales for disability, diplopia, and asthenopia.

RESULTS

Overall, under the hypothesized condition outlined in the time tradeoff question, 85 patients (61%) indicated to be willing to trade in part of their life expectancy in return for being rid of strabismus and its associated effects. The distribution of time tradeoff utility values (Figure 1) had a median value of 0.93 (interquartile range, 0.83 to 1.0).

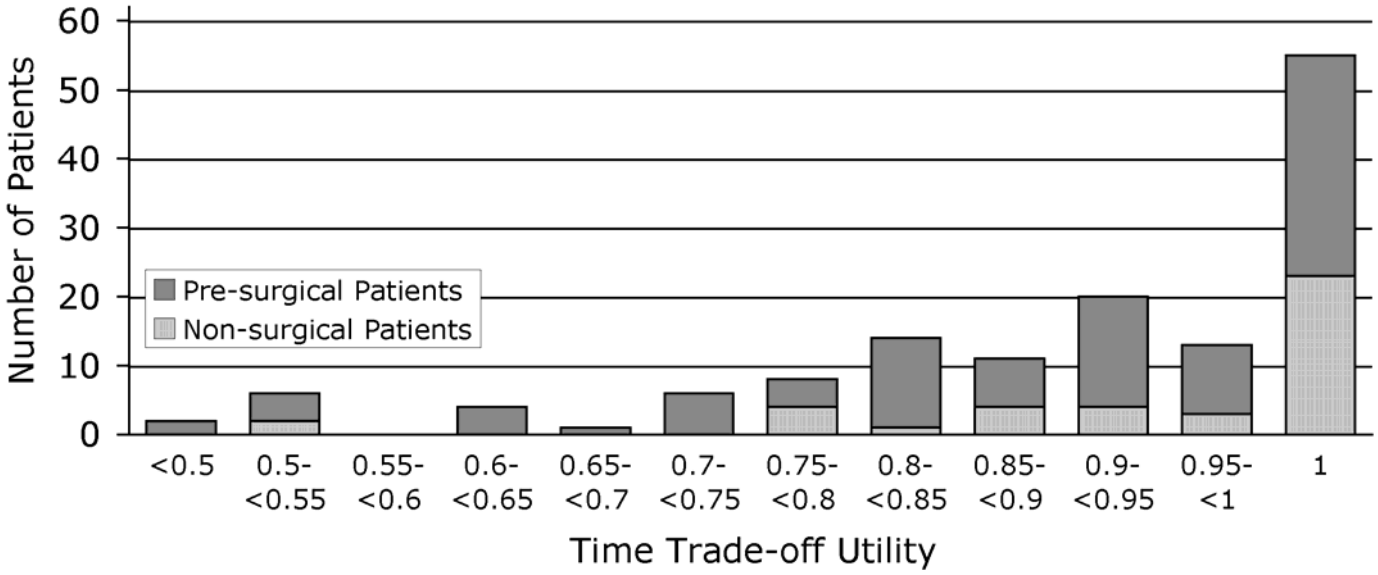

FIGURE 1

Histogram showing the overall distribution of time tradeoff utility values in 140 consecutive adults with strabismus. The median of this distribution equals 0.93 (interquartile range, 0.83 to 1.0). A total of 85 patients (61%) indicated that they would be willing to trade part of their life expectancy in return for being rid of strabismus and all its associated effects. The remaining 55 patients returned a time tradeoff utility of 1 (ie, *not* willing to trade part of their life expectancy). Dark and light portions of each bar indicate the proportion of presurgical and nonsurgical patients, respectively

When analyzed separately by subgroups of patients, a larger proportion of the surgical patients than of the nonsurgical patients appeared willing to trade in part of their life expectancy (67 patients [68%] versus 18 patients [44%], respectively; $P = .0009$, z test for proportions). Also, the utility values returned by the surgical patients were lower than those returned by the nonsurgical patients (median, 0.90 versus 1.0, respectively; $P = .013$, Mann-Whitney U test). Between subgroups of patients with long-standing or acquired strabismus, no significant differences were found in the proportions of patients willing to trade time (41 patients [58%] versus 44 patients [64%]; $P = .47$, z test) or in the utility values (0.95 versus 0.92; $P = .73$, Mann-Whitney U test). These comparisons are summarized in Table 1, which also shows that no differences were found in time tradeoff utility between patients with and without comorbidities or between male and female patients.

TABLE 1. OVERVIEW OF TIME TRADEOFF UTILITY RESULTS IN CONSECUTIVE ADULT PATIENTS WITH STRABISMUS

GROUP	N	PATIENTS (%) INDICATING WILLINGNESS TO TRADE TIME*	*P* VALUE†	MEDIAN UTILITY (INTERQUARTILE RANGE)	*P* VALUE‡
All	140	85 (61%)		0.93 (0.83–1.0)	
Surgical	99	67 (68%)	.009	0.90 (0.82–1.0)	.013
Nonsurgical	41	18 (44%)		1.0 (0.88–1.0)	
Long-standing	69	44 (64%)	.47	0.92 (0.83–1.0)	.73
Acquired	71	41 (58%)		0.95 (0.82–1.0)	
Comorbidities	58	36 (62%)	.78	0.90 (0.75–1.0)	.17
No comorbidities	82	49 (60%)		0.95 (0.87–1.0)	
Male	67	38 (57%)	.35	0.96 (0.88–1.0)	.08
Female	73	47 (64%)		0.90 (0.80–1.0)	

*Number of patients willing to trade part of their life expectancy in return for being rid of strabismus and its associated effects, under the hypothesized conditions outlined in the time tradeoff method.

†Differences between proportions were evaluated using the z test.

‡Group differences were evaluated using the Mann-Whitney U test

Figure 2 shows the relationship between utility values and the clinical ratings of the levels of diplopia and asthenopia. Significant effects of the level of diplopia ($P = .048$) and especially of the level of asthenopia ($P < .0001$) on utility were found (Kruskal-Wallis analysis of variance). Linear trend analysis confirmed that higher (worse) levels of diplopia and asthenopia were associated with lower (worse) utility values (both P values < .0001).

An overview of the severity ratings from the disability questionnaire is presented in Table 2, with specific health problems rated highest (median, 7 on the 10-point scale) and job-related problems lowest (median, 3 on the 10-point scale). The relationships between utility values and the patient-perceived disability ratings are also given in Table 2 and illustrated in Figure 3. Strong correlations were found between utility and each of the six severity ratings (r_s ranging from –0.29 to –0.42, all P values ≤. 00062; Spearman rank correlation).

TABLE 2. MEDIAN DISABILITY RATINGS FOR SIX ASPECTS OF DISABILITY AND THE ASSOCIATIONS WITH TIME TRADEOFF UTILITY IN ADULTS WITH STRABISMUS

DISABILITY (QUESTIONNAIRE ITEM)	MEDIAN SEVERITY (INTERQUARTILE RANGE)	ASSOCIATION WITH UTILITY (SPEARMAN RANK CORRELATION, R_S)
Specific health	7 (5–8)	–0.32 ($P = .00013$)
Daily tasks	6 (3–8)	–0.29 ($P = .00062$)
Social interaction	4 (1.75–7)	–0.31 ($P = .00021$)
Concerns	5 (2–8)	–0.42 ($P < .0001$)
Self-image	5 (2–8)	–0.37 ($P < .0001$)
Job	3 (1–7)	–0.31 ($P = .00017$)

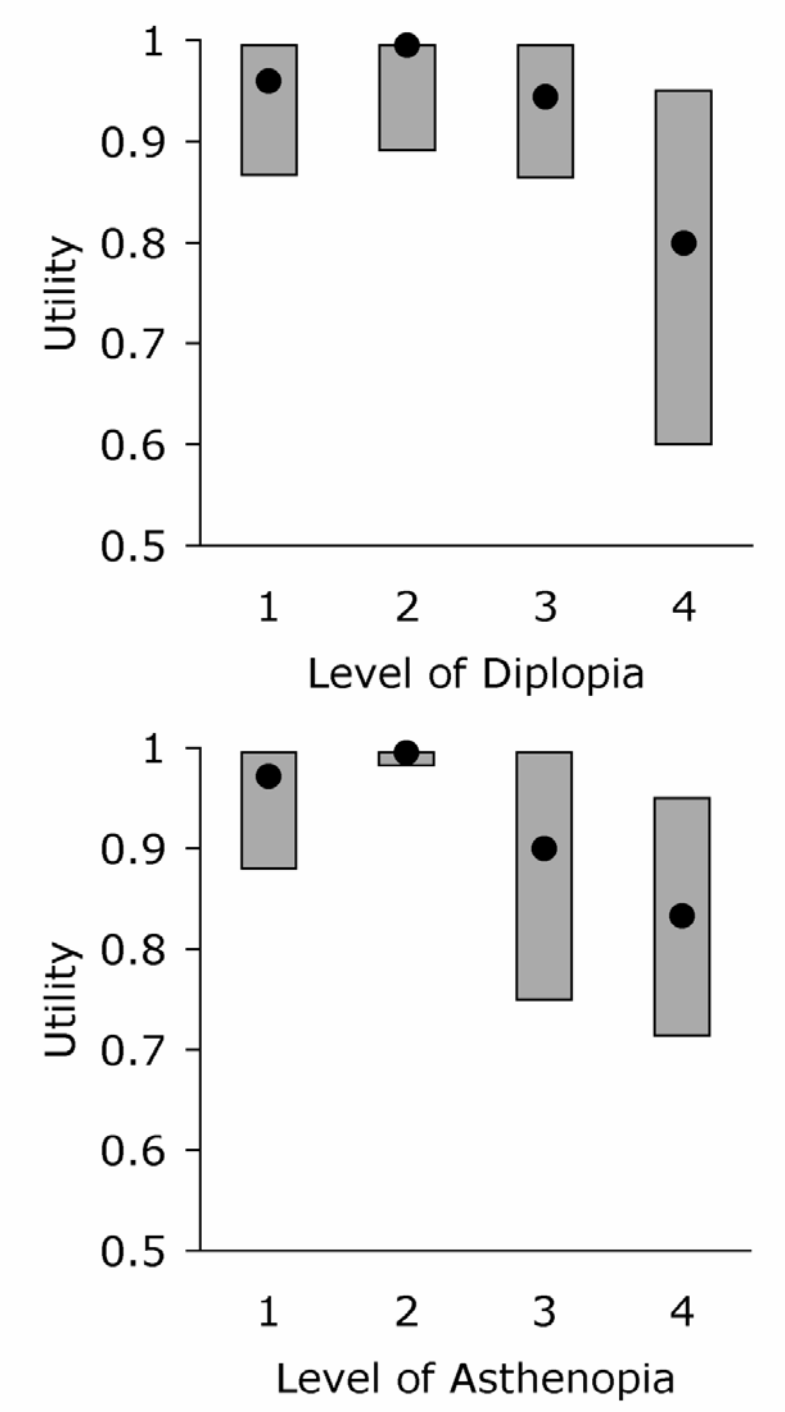

FIGURE 2

Box plots showing the relationship between time tradeoff utility in adults with strabismus and the physician ratings of each patient's level of diplopia (top: 1 = None, 2 = In side gaze and/or upgaze only, 3 = In primary gaze and/or downgaze, 4 = Constant) and asthenopia (bottom: 1 = None, 2 = With prolonged effort, 3 = With minimal effort, 4 = Constant). In each box plot, the filled circle corresponds to the median utility, and the box spans the interquartile range (25th percentile to 75th percentile).

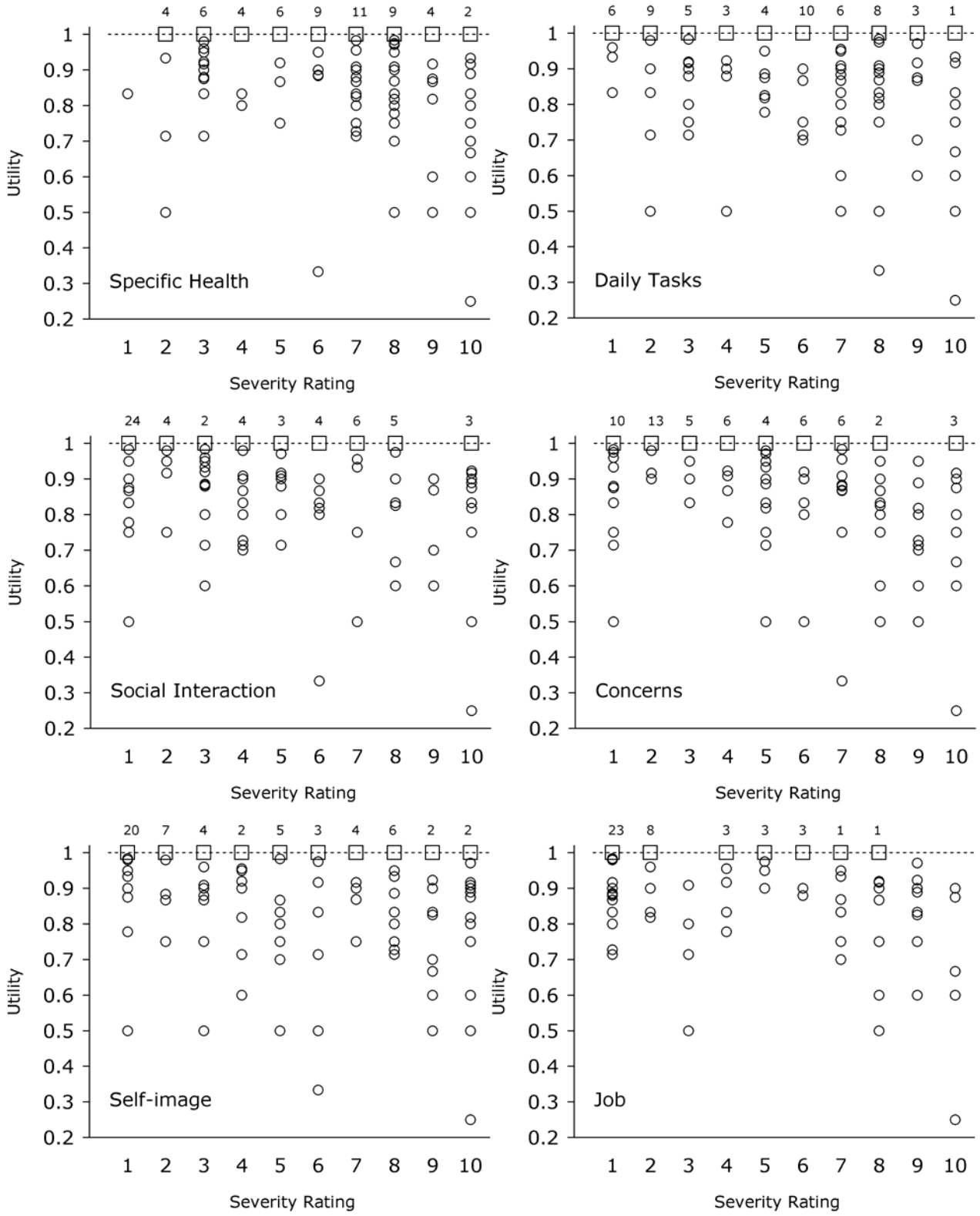

FIGURE 3

Scatter plots showing the relationships between time tradeoff utility values and each of the six severity ratings of patient-perceived disability in adults with strabismus. For clarity, multiple overlapping data points at 1.0 utility were replaced by single open squares with labels indicating the number of overlapping points in the original database. For utility values less than 1.0, open circles represent individual patients.

DISCUSSION

The utility associated with strabismus was measured in a large group of adult patients, and the results correlated strongly with both patient-perceived and clinical measures of disability. These data confirm the substantial decrement in quality of life—in terms of both disability and utility—caused by the disease strabismus. It is unknown whether these data will translate effectively to strabismus in children. A reasonable presumption may be that the quality of life decrements imposed by strabismus in children are equal to or exceed those of adults.

Results from patients who are meant to undergo surgical treatment (median utility, 0.90) are comparable to those reported in the literature for other ophthalmic conditions: The mean utility associated with untreated unilateral amblyopia (visual acuity 20/80 in the amblyopic eye, 20/20 in the sound eye) was shown to be 0.83.[26] Patients with diabetic retinopathy and visual acuity between 20/20 and 20/25 in the best-seeing eye reported utility of 0.86.[22] The same study found that age-related macular degeneration with visual acuity between 20/20 and 20/25 in the best-seeing eye corresponded to a mean utility of 0.84.[22] For a wider comparison, the compilation by Bell and coworkers[16] includes the following patient-based utilities (obtained with time tradeoff or standard gamble methods, or both) for health states associated with nonophthalmic conditions: mild stroke, 0.85; post–myocardial infarction, 0.88; angina with no chest pain symptoms, 0.87; partially controlled seizures, 0.79 (patients taking lamotrigine and having two to nine seizures per month), or 0.91 (less than two seizures per month while taking lamotrigine). (This compilation of utility data,[16] organized by categories of the *International Classification of Diseases, Ninth Revision* [*ICD-9*], and references to the original studies can be found at http://www.hsph.harvard.edu/cearegistry.)

Utility was higher among participants who were not planning to have strabismus surgery than in the presurgical patients. The fact that more than half of the nonsurgical patients indicated no willingness for trading part of their life expectancy caused the median utility in this group to equal 1.0. Nonetheless, a sizeable minority (44%) of the nonsurgical patients returned a utility less than 1 (see the light bars in the histogram of Figure 1.)

Crucial in any cost-utility analysis of a treatment strategy is the utility differential between treated and untreated health states, rather than the absolute values of the utilities associated with these health states. Therefore, in the case of adult strabismus, long-term postoperative data are necessary to evaluate the utility gain. This gain (expressed in QALYs), when offset against the cost of treatment, can then be compared with cost-effectiveness (cost-utility) analyses of other conditions and treatments. Value-based medicine may thus form the basis for calculating the economic consequences and contributions of medical interventions in the treatment of strabismus and may be compared to other medical conditions and interventions.

APPENDIX
WRITTEN DISABILITY QUESTIONNAIRE (6 ITEMS) ADMINISTERED TO CONSECUTIVE STRABISMUS PATIENTS OLDER THAN 18 YEARS OF AGE

Item	Wording	Rating
Instructions	***Please indicate on a scale from 1 to 10 the degree to which your strabismus (eye misalignment) affects your life in the ways described. For <u>each</u> of the questions, answer '1' means 'no effect,' while '10' means 'severe effect.'***	
Rating scale	**1 2 3 4 5 6 7 8 9 10** *(None)* *(Severe)*	
Specific Health	Specific health problems—including poor vision, double vision, headaches/eyestrain, decreased field of vision, decreased depth perception, etc	
Daily Tasks	Difficulty with non-work-related tasks of daily living—including walking, driving, reading, sports, etc	
Social Interaction	Social interaction problems—including inability to maintain eye contact, decreased ability to communicate, social confusion, difficulty establishing and/or sustaining relationships, etc	
Concerns	Concerns/doubts about the future—including worry about possible blindness, inability to work, read, etc	
Self-image	Problems of self-image—including diminished self-confidence, self-esteem, and feelings of self-worth	
Job	Job-related problems—including being hired, retained, and/or promoted	

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PEER DISCUSSION

DR EVELYN A. PAYSSE. Strabismus in adults has recently become a topic of increasing interest in the ophthalmic community. As our population continues to age, more and more patients with visually significant strabismus will be living amongst us. It has also now well known that there are many more benefits to strabismus surgery in adults than just the elimination of diplopia.[1-3] In addition to this important benefit are the following benefits: 1) Increased fusion; 2) increased binocular visual field (in esotropia); 3) elimination of an anomalous head posture; 4) improvement in psycho-social functioning; and 5) potential improvement in vocational and employment status

As we embark on the 21st century, steadily more pressures are being placed upon us to use evidence-based medicine, and most recently, value-based medicine in our practices. The science of value-based medicine is founded on cost-benefit analysis, or better stated, cost-utility analysis.[4] In order to arrive at a true value of a treatment for a disease entity, one first needs to assess objectively how the disease adversely affects a person's quality of life. Once this is arrived at, one can evaluate treatments and arrive at a number that can be compared across various medical fields.

Dr Beauchamp and co-authors have used an intriguing approach to analyzing the value of strabismus surgery in adults. They used a time trade-off method to assess quality of life or "utility" in adults with strabismus. They compared utility first to a patient-perceived disability score and next to a physician-derived diplopia/asthenopia rating. This prospective study included 140 patients of which 99 were pre-surgical candidates and 41 were non-surgical. The 140 patients were secondarily subdivided by time of onset of strabismus Sixty-nine patients had strabismus before visual maturation (BVM) and 71 developed strabismus after visual maturation (AVM). In the manuscript it was not delineated how many of the pre-surgical and non-surgical patients were BVM versus AVM.

Current utility was derived from the following formula:

$$\text{Utility} = 1 - \frac{\text{Time traded}}{\text{Life expectancy}}$$

The closer the utility is to "1" the less the patient is willing to trade life years and presumably the better is his/her perceived quality of life.

Dr Beauchamp and coworkers demonstrated that, indeed, strabismus in adults significantly lowers one's quality of life. Understandably, the quality of life was lower in the presurgical group with a median utility of 0.90 than the non-surgical group with a median utility of 1.00. The authors also demonstrated that as the asthenopia/diplopia level increased, the utility decreased, as would be expected. Further still and most importantly, Dr Beauchamp and coworkers demonstrated that the utility was similar to other serious ophthalmologic and systemic diseases such as age related macular degeneration, amblyopia, stroke, post myocardial infarction, and angina.

Several important questions remain unanswered from this study. First, were older patients (i.e. shorter life expectancy) less willing to trade years of remaining life than younger patients? It would not be unexpected that as a person gets closer to the end of his life, ailments may suddenly not bother him as much. Next, were patients with strabismus onset before visual maturation less bothered or disabled by their strabismus than those with strabismus acquired after visual maturation? Specifically, which areas were more bothersome to patients with strabismus before visual maturation versus after visual maturation?

Now that Dr Beauchamp has shown that indeed adult strabismus significantly decreases quality of life to a similar level as other serious health problems, the next step in the cost-utility analysis needs to be performed. A comparison of utility before and after treatment needs to be performed for both surgical and non-surgical adult strabismus groups to evaluate the effectiveness of our treatments. From this analysis, we will then be able to compare the "value" of our treatments to those of other ophthalmologic and systemic conditions.

Dr Beauchamp and his co-authors are to be commended for this excellent work. I encourage them to continue this line of research, which will result in the ability to objectively compare our treatments to other treatments in medicine. Insurance companies have historically viewed medical doctors as "cost centers." We must change this ill-conceived perception. We really are…"value givers." Dr Beauchamp is on the right track to getting us there.

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DR ALBERT W. BIGLAN. You did not really explain how you administered these surveys. If you have a population of patients with pediatric cataracts, and you wanted to survey the parents, or the child that has now become older, can you do these after the surgery have been done? Is this still a valid use of your surveys? And do such surveys have to be composed?

DR MALCOLM R. ING. Have you even received a successful application of these principles with any medical insurance companies? Or is this something we hope to achieve at a future date if we can convince our colleagues? Is there a difference in the ethnic or social background of these patients that might predispose them to making these selections? In Hawaii we have a multi-race culture with some being fairly passive about their disabilities whereas others are not. This also applies in the social realm, as well. So you might consider profiling the patients in surveys according to their ethnic and maybe even religious backgrounds. Were these patients pre-selected, in the sense that they have sought treatment? There are many patients who do not seek treatment and you might have to make some kind of accommodation for that.

DR M. EDWARD WILSON. I am interested in documenting the improvement in quality of life and function with adult strabismus as they regain some fusion, even if it's peripheral fusion. Data is accumulating that indicates more of our patients regain some binocularity than most ophthalmologists would have thought, especially when strabismus has been long-standing. It would be interesting to document, based on your methods, whether patients who regain some binocularity, as we can measure in the office, have experienced any improvement in real life, compared to patients with straight eyes with a nice return of normal appearance.

DR EDWARD L. RAAB. I think you will continue to have much difficulty convincing insurance payers about this. Unfortunately, selection bias is a fairly valid insurance industry concept. If the companies agree to start paying based on your formulations, those who sign up for the coverage will use it and then it makes payouts a lot higher. This is a problem all across the insurance industry in healthcare.

DR ZANE F. POLLARD. This desire for straight eyes starts very early in childhood. Dr Evelyn Paysse performed a study several years ago, where she placed dolls in her waiting room. Some dolls were manipulated to have crossed-eyes and some had straight eyes. She had her office staff observe the children as they came into her office – to see which dolls they would pick up and play with. Almost uniformly the children ignored all the dolls that had strabismus, preferring to play with the dolls that had straight eyes. In adults, insurance companies and the general public need to know that re-fusion is attainable. If you exclude patients that had good sensory potential – for example acquired fourth and sixth nerves and patients with Graves disease – and consider only the patients that have a long-standing strabismus with probably no pre-operative fusion, then I think that about 15 % of my adult patients do show sensory fusion. Maybe this is something that requires nationally pooled data to determine more definitively.

DR JANE D. KIVLIN. Do you have any idea how patients would answer if it were something really tangible, like how much money would you pay to get your eyes straight? Or, would you pay half your house? Because you really cannot trade one's life.

DR GEORGE R. BEAUCHAMP. The questions Dr Paysse raised are in progress on an ongoing basis. The particular question about whether older people or younger patients are willing to trade less or more is something that has captured my attention. Generally speaking, the younger people are more interested in trading some time because they are the ones who are living in the thick of their lives with the disabilities. The older persons, perhaps seeing the horizon a bit more clearly, are less likely to do so.

Does treatment affect utility? Our preliminary calculation is that strabismus surgery does substantially improve the utility. We have calculated a preliminary cost-utility analysis and, because it is so preliminary and the model is not yet refined, it would be irresponsible to say a number. Using this sort of analysis, the treatment of strabismus is a very cost-effective intervention.

With regard to the testing of the utility for a patient with a pediatric cataract, this will be very difficult to get any surrogate to trade away, for example, their child's life, by participating in this pretend game. I do not think that is going to be a realistic strategy. But you can use the surrogate markers that Drs Brown and Sharma have created in their database on visual acuity, which is the principle driver of utility in these conditions. If you wanted to have a reference point, probably acuity would be the best for such analysis.

What is its application to insurance companies? This has not yet been presented to any insurance company and I expect that it will be a tough sell.

The evaluation of ethnic and social backgrounds is part of the ongoing study. This is a pre-selected group of patients because these are the patients that showed up in a consecutive way in our office. The study will sort this out over time.

Does documenting the improvement when patients regain fusion matter? Probably yes. We will know more about that when we have that portion of the data analyzed.

Dr Pollard, I agree with your comment about the desire for straight eyes being almost an essential component of human nature. Eyes are important communicating devices. Throughout history and poetry this is well documented. Is sensory fusion attainable? Yes. Each of us who worked in this area has had that experience. We are accumulating a series of cases that are demonstrating that such is the case. Would national pooling of data help on this? I think there will be a proposal for that in the future.

"How much money would you pay for this?" There are three strategies in the methods of measuring utility. There's the so-called standard gamble, "How much risk of dying would you take for the intervention?" Then there is the time trade-off utility, which is probably the most common standard that is being used today. There is also the "What would you pay?" scenario. The problem with the latter is that not everybody earns the same amount of money making it difficult to equate that across a broad range of income.

We have to go through some mindset changes ourselves. As we relate to these various kinds of analyses, the payers, in particular, view us as cost centers. To a degree, we bought into that and, to a degree; it has been forced upon us. My counsel to all of us is, "Don't think of yourself as a cost center." You can never win in that position. Think of yourself as a value production center. But that puts a burden on us to measure what that value is, and how we deliver it.