

Medical Decision-Making and the Patient Understanding Preference Patterns for Growth Hormone Therapy Using Conjoint Analysis

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OBJECTIVES. This study examines two questions that relate to patients' role in medical decision making: (1) Do patients utilize multiple attributes in evaluating different treatment options?, and (2) Do patient treatment preferences evidence heterogeneity and disparate patterns? Although research has examined these questions by using either individual- or aggregate-level approaches, the authors demonstrate an intermediate level approach (ie, relating to patient subgroups).

METHODS. The authors utilize growth augmentation therapy (GAT) as a context for analyzing these questions because GAT reflects a class of nonemergency treatments that (1) are based on genetic technology, (2) aim to improve the quality (rather than quantity) of life, and (3) offer useful insights for the patient's role in medical decision making. Using conjoint analysis, a methodology especially suited for the study of patient-consumer preferences but largely unexplored in the medical field, data were obtained from 154 parents for their decision to pursue GAT for their child.

RESULTS. In all, six attributes were utilized to study GAT, including risk of long-term side effects (1:10,000 or 1:100,000), certainty of effect (50% or 100% of cases), amount of effect

(1-2 inches or 4-5 inches in adult height), out-of-pocket cost (\$100, \$2,000, or \$10,000/year) and child's attitude (likes or not likes therapy). An experimental design using conjoint analysis procedures revealed five preference patterns that reflect clear disparities in the importance that parents attach to the different attributes of growth therapy. These preference patterns are (1) child-focused (23%), (2) risk-conscious (36%), (3) balanced (23%), (4) cost-conscious (14%), and (5) ease-of-use (4%) oriented. Additional tests provided evidence for the validity of these preference patterns. Finally, this preference heterogeneity related systematically to parental characteristics (eg, demographic, psychologic).

CONCLUSIONS. The study results offer additional insights into medical decision making with the consumer as the focal point and extend previous work that has tended to emphasize either an individual- or aggregate-based analysis. Implications for researchers and health care delivery in general and growth hormone management in particular are provided.

Key words: patient decision-making; conjoint; growth hormone. (Med Care 1998;36:AS31-AS45)

Shared medical decisions^{1,2} between physicians and patients have been shown to result in greater compliance,³ satisfaction, and conformance to the principle of informed consent.⁴ Understanding patient preferences that lead to medical decisions is particularly important when

the therapeutic endpoint is potentially related to quality of life. Examples of such elective or non-emergency therapies include growth hormone, in vitro fertilization, estrogen replacement, anti-aging potency, and alternative medicine. Often, the value and desirability of such treatments nec-

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essarily involve explicit consideration of tradeoffs and priorities by both the patient and physician.* In this sense, the patient is analogous to a consumer who actively interacts with his/her physician to consider treatment choices.

Despite the recognized importance of patients' input into medical decision making, little is known about how their preferences can be analyzed and tapped to optimally implement shared decisions. Previous studies have approached this question either by examining aggregate-level responses from patient samples concerning decision factors utilized⁵ or eliciting choice probabilities from each patient. Both approaches have limitations, especially in the case of nonemergency therapies. For instance, aggregate preferences risk overgeneralizations that obfuscate underlying differences. Likewise, studies that focus on preferences for individuals patient may run the risk of oversensitivity to local variations and are likely to overwhelm policy efforts to systematically incorporate patient preferences in therapy recommendations.

Few, if any, studies operate at an intermediate-level by examining key preference factors to delineate a few distinct patterns of preferences across broad patient samples. However, if patient preferences are to have practical application in and impact on physician-patient interactions and medical policy, it is necessary to understand whether different subgroups of patients (1) utilize different decision factors, (2) evidence distinct preference patterns, and (3) translate their underlying motivations and goals into tradeoffs or preference combinations for different treatment choices.

In the context of nonemergency therapies, the preceding issues assume even greater significance for three reasons. First, treatments such as growth hormone, in vitro fertilization, and estrogen replacement are to some extent elective, and physician recommendations often are significantly influenced by patient wants and desires (not just needs). Consequently, patient preferences are likely to play a more central role in such treatments. Second, the effectiveness of such treat-

ments is linked largely to the perceptions of and psychologic benefits for the patient. Thus, an understanding of patient preferences in this context is likely to require techniques that offer insights into patient perceptions and payoffs for different treatment choices. Third, because such treatments evidence rapid evolution in their characteristics (eg, delivery options, composition, side effects data), descriptive studies that focus on factors that influence current patient choices are likely to prove less useful for understanding future patient choices. Instead, approaches that allow modeling of plausible treatment choices (eg, those that are likely to be available in the future) and yield valid data are likely to be more beneficial.

The purpose of our study is to fill the preceding gaps in the literature, keeping in mind the unique characteristics of nonemergency treatments. Specifically, two questions guided our research:

1. Do patients utilize multiple, distinct treatment characteristics in arriving at medical decisions?
2. Do patient preferences evidence heterogeneity among different subgroups of patients?

Before we discuss the study context, it is useful to examine the broad rationale underlying these research questions. The first question seeks to examine the characteristics patients evoke for evaluating different treatment options. If this evoked set is empty or contains few, marginal attributes, it is less likely that patients can act as active and informed participants in medical decisions. In other words, in accord with consumer decision-making research,⁶ a multiattribute evoked set is a necessary condition for patient involvement in medical decision making. The second question seeks to determine if patients' preferences are heterogeneous and reveal distinct patterns. This notion of heterogeneity is based on the premise that different patients, with similar physiologic characteristics, have different needs and wants and consequently will utilize different tradeoffs. Thus, a homogeneous preference structure common to all patients undermines the notion of shared decision making. However, the notion of patterns is based on the idea that empirically the number of unique preference combinations (ie, tradeoffs among treatment attributes) are not as numerous as the number of patients. Rather, there are only a few unique preference combinations such that each combination reflects common tradeoffs employed

*Recently, in the popular press, some of these issues have achieved a center-stage status because of the birth of the McCaughey septuplets and highlighted the point that the issues raised in these treatments go far beyond physiologic/medical considerations that are common to many traditional treatments.

by a subgroup of patients. This intermediate analysis is between the two extremes of either individual- or aggregate-level analysis. In addition, we utilize a methodology (conjoint analysis) that has received little attention in the medical literature but appears to hold potential in, and is suited to the understanding of, patient preferences for nonemergency treatments (eg, see Wigton et al⁷ and Dawson et al⁵ for some notable applications).^{8,9}

If the intermediate approach is supported, the search for key determinants of the obtained patterns of patient preferences may provide insights. These determinants are likely to include demographic, physiologic, and psychologic characteristics of patients, among other factors. Although it is not a specific aim of this study, we provide an exploratory analysis of this search for key determinants to provide directions for future research. We begin by discussing the study context and design.

The Study: Context and Design

For several reasons, our choice of medical context—growth hormone therapy (GHT) for short stature children—offers an excellent model for the study of the patient's role in decisions to use medical technologies that address nonemergency situations.

- It is one of the first major therapies based on genetic engineering.¹⁰
- The medical condition addressed (ie, short stature) does not affect the length of life. It may, and often does, affect the quality of life (however, it is unclear what degree of short stature is dysfunctional in terms of psychologic, social, and behavioral effects).¹⁰⁻¹²
- Although GHT initially was designed and approved for overcoming growth hormone (GH) deficiency,¹³ today, this therapy is available for children who are short but not necessarily GH deficient. The GHT represents a fast-growing segment, with a market of more than \$375 million.¹⁴
- There is significant uncertainty about GHT effectiveness for short stature not due to classic GH deficiency. Consensus is lacking about whether GHT has a predictable, significant effect on adult height, es-

pecially for children who are not GH deficient, and whether it allows estimable probabilities of long-term down side risks.¹⁵⁻¹⁷

- Growth hormone therapy is expensive (~\$15,000/year), protracted (several years), and inconvenient (daily injections).
- Growth hormone therapy has received significant media attention, both positive and negative,¹⁸⁻²⁰ because of its mix of genetic engineering and societal implications of treatment.

We reason that, if patients' preferences favor shared decision making for GHT given its preceding characteristics, it is likely that this approach also is useful for other related medical therapies. Next, we turn to the methodologic approach utilized to understand patient preferences for elective treatments.

Conjoint Analysis Methodology

Conjoint analysis dates to Luce and Tukey's work⁸ and is a multivariate technique that is based on three interrelated concepts: (1) each product/service (eg, treatment) is a bundle of potential attributes, (2) each individual has a unique utility or value for each attribute level (referred to as "partworth" utilities), and (3) combining the different utilities for different attributes provides an individual's overall utility or preference for the specific product/service. However, a unique aspect of conjoint analysis is that individuals are not asked to directly provide their utilities for each attribute level. Rather, each individual is asked to perform a rather realistic task: choose among several hypothetical products/services for which each option is based on a different combination of its attributes.

On the basis of these choices, individual-level partworth utilities are extracted via regression based procedures. More importantly, conjoint analysis allows the inclusion of plausible attributes (eg, those that are at the design stage but not yet available) and the utilities are determined for each potential combination of attributes. Thus, conjoint analysis is useful in helping design products/services that are consistent with consumer preferences. Finally, for the preceding reasons, conjoint analysis has become widely recognized as a rigorous and valid method for understanding consumer preferences. In fact, Carroll and Green⁹ note that, "[c]urrently conjoint analysis . . . repre-

sents the most widely applied methodologies for measuring and analyzing consumer preferences." We highlight this potential of conjoint analysis within a medical context. However, because we focus at an intermediate (not individual) level of analysis, we extend the conjoint analysis approach to obtain insights at this level. Specifically, we initially utilize conjoint analysis to structure the research task and obtain individual-level utilities and thereafter utilize appropriate multivariate procedures (eg, cluster analysis) to identify subgroups of patients with similar preference patterns. Such approaches are referred to as hybrid conjoint analysis.

Research Methodology

Research Setting and Sampling

A large Midwestern metropolitan area was selected as the research site. With a total population of approximately 2 million people, this area includes three major medical centers. All three centers participated in the study, as did most of the pediatric endocrinologists in the selected metropolitan area. Because pediatric endocrinologists are the major prescribers of GHT, they served as the key sources of data and sampling units for this study. During a 15-month period, each site identified parents of children who were between 4 and 15 years of age who were scheduled to see a pediatric endocrinologist for short stature, but were not receiving GHT.

In all, 233 cases were identified, 190 of which were judged eligible for this study. Finally, 159 of 190 potential subjects were interviewed. Thus, the consent rate for this study was 83.7%. The participation rates did not differ significantly across the research sites (chi-square = 0.268; $df = 2$; $P < 0.10$). The study, including procedures for identification of eligible parents, was approved by the institutional review boards of all participating medical centers. Informed consent was obtained from all participants before the study.

Research Instrumentation

Growth Treatment Attributes. Initially, we identified the salient attributes of growth therapy as perceived by eligible parents using three focus groups of six to eight parents. Parents

mentioned several factors that were important in their consideration of growth augmentation therapy (GAT),[†] including anticipated height, child's behavior/attitude about being short, spousal opinion, time period of treatment, and side effects. Via content analysis, we ranked the various factors by their "frequency of mention," aggregated the data across the focus groups, and selected the more frequently mentioned attributes for additional analysis. The selected attributes were discussed with parents to refine and clarify their criteria.

The attributes finally selected included (1) amount or magnitude of effect; (2) odds or certainty of effect; (3) route of treatment; (4) out-of-pocket cost; (5) long-term side effects; and (6) target child's attitude toward therapy.[‡] The amount of effect captures the expected increase in adult height attributable to the treatment, whereas odds of effect is concerned with the probability of obtaining an increase in height. The route of treatment and out-of-pocket cost indicate the method for administering the therapy and the annual cost (net after insurance) of treatment, respectively. The long-term side effects assesses the probability of long-term risks and dysfunctional (side) effects arising from treatment. Finally, child's attitude measures the target child's attitude toward GAT.

Although physician's recommendation was considered an important attribute, it was not included because no parent was willing or, more importantly, able to put his or her child on a GAT regimen without such a recommendation. Thus, the physician's recommendation is a necessary, but not sufficient, condition for GAT. In addition, given the range of uncertainty among physicians,¹⁵ it is possible that parents can obtain physician recommendation, if desired, with a fairly low search cost and the assistance of their primary

[†]Hereafter, we distinguish between growth augmentation (GAT) and growth hormone therapies (GHT). Although the former refers to hypothetical treatments for growth, the latter is a specific on hormone therapy.

[‡]We considered interviewing the focal child because we reasoned that, as the affected consumer, he/she is likely to provide perspective and relevant data that may not be easily or accurately obtained from other family members. However, upon discussion with physicians and parents, we realized that such interviews would put vulnerable children in the uncomfortable position of focusing on their own short stature; consequently, we decided not to interview children.

care physician. Consequently, we focused on factors other than physician recommendation.

Interview Questionnaire. The final questionnaire was grouped into several sections, reflecting distinct content areas. First, we probed the sources of information that parents found useful in learning about growth in children, particularly about short stature and its possible treatments. Second, we assessed parents' perceptions about how short men and women are viewed in our society. Third, we sought parents' opinions about their child's reactions to his/her height. Fourth, we asked parents to provide us with demographic and background information. Finally, we asked parents to provide self-report importance ratings of GAT attributes.

Pretesting. The interviewers were carefully selected and trained. The training procedures included scripts, mock interviews, and feedback discussions. The entire protocol, including conjoint profile evaluations and questionnaire, was pretested with a small group of parents. In general, the parents involved in the pretest thought the interview was understandable and had little or no trouble with task comprehension.

Conjoint Analysis Task

A conjoint analysis usually involves three tasks before data can be collected: (1) model specification, (2) stimuli generation, and (3) preference measurement. Each is discussed here.

Model Specification. A conjoint analysis model specifies the relationship between an individual's overall or total utility for a specific treatment and the unique or partworth utilities for each treatment attribute. The higher an individual's utility for a treatment (relative to other treatments), the greater its desirability or preference. A typical utility formulation based on conjoint analysis is a linear, additive model that can be specified as follows:

$$TU_i = \sum PU_j \quad (1)$$

where TU_i is the total utility or worth for the i th treatment option, PU is the partworth utility, and j refers to the treatment attributes and equals six for growth therapy (as noted). Note that Equation 1 parallels a multiple regression model and specifies that the total utility of a treatment option is the sum of the partworth utilities of the particular attribute levels or values that define that treatment. To operational-

ize this model, it is necessary to identify the levels or values that the individual growth therapy attributes can assume. Based on current pricing and reimbursement patterns, understanding of efficacy and route of treatment, and physician practice patterns, we developed levels for each of the six attributes as follows: out-of-pocket cost (\$100; \$2,000; \$10,000 per year), certainty of effect (adult height increases in 50% or 100% of treatment recipients), amount of effect (the therapy increases adult height by 1–2 inches or 4–5 inches), route of treatment (daily injections or daily nasal spray), target child's attitude (would or would not like therapy), and risk of long-term side effects such as diabetes, leukemia, and early atherosclerosis (1 in 10,000 or 1 in 100,000 treatment recipients). As such, one attribute (ie, price) has three levels and the remaining five attributes have two levels each.

Stimuli Generation. The conjoint stimuli are the information provided to the respondents to elicit their preferences. Two methods of stimuli generation are common: (1) trade-off method and (2) full-profile method. A trade-off method presents two attributes at a time and asks respondents to indicate their preferences by evaluating each two attribute combinations. In contrast, the full-profile method presents all attributes together such that each option is described by a specific choice of each attribute level, and the respondent is asked to evaluate the different options presented. Because a full-profile approach is more realistic (ie, includes all attributes), it was utilized in our study.

Readers will note that given the six GAT attributes and their chosen levels, the number of feasible options is 96 (ie, 3×2^5). Clearly, it is unrealistic to have parents review 96 different growth therapy options and evaluate them in order of their preference. However, because conjoint analysis is closely related to experimental designs, it is possible to simplify the conjoint task without having to reduce the number of growth therapy attributes. Specifically, using the principle of orthogonal array in fractional experimental designs, 16 hypothetical growth therapy full-profile options were developed that systematically varied the levels of six GAT attributes.

Preference Measurement. There typically are two methods for measuring individual preferences: either the individual can be asked to rate each option (eg, using a Likert scale) or rank all options from the "most preferred" to "least preferred." In general, the ranking task is thought to be more reliable; however, the disadvantage is that it yields only ordinal

data. Because of its reliability, we chose the ranking approach for preference measurement and utilized a nonmetric conjoint analysis software.

Method of Analysis

A detailed schematic diagram for the method of analysis is displayed in Figure 1. Briefly, first parental preference patterns were analyzed to obtain partworth utilities and relative importance weights for individual GAT attributes. Because the conjoint model requires assumptions for the preference ordering among categorical variables (ie, the factor levels), the number of preference ordering reversals was used to judge the appropriateness of conjoint data. We used three reversals as the cutoff criterion. Thus, reversals exceeding two were indicative of inconsistent/careless respondents. Second, to determine the reliability of the conjoint data, a small set of respondents ($n = 10$) were randomly selected and asked to do a second, follow-up interview approximately 7 to 12 months later. The index of association between these two interviews was utilized to judge the reliability of the conjoint analysis. Third, cluster analysis procedures

were used to develop parental groupings that were based on differences in relative importance weights of different attributes. A multistep data analysis approach was utilized to ensure the stability and validity of cluster solutions.^{21,22} Initially, we aimed at determining the optimal number of cluster by using Ward's method to assess the range for the appropriate number of clusters and obtain initial centroid seeds. All of the data were randomly split into two subsamples and input for K-means cluster analysis. Based on the comparison between constrained and unconstrained solutions (ie, after cross-validation), an optimal number of clusters was selected to maximize Kappa—the chance corrected coefficient of agreement. Fourth, the optimal number of clusters was subjected to external validation. For external validation, relative importance scores of individual attributes for each individual cluster group were compared with those of self-report questionnaire data. Finally, discriminant analysis was utilized to identify demographic and psychographic characteristics that differ across the n cluster groups.

Results

Demographic Characteristics

The respondents were predominantly female (87%), married (86%), and white (90%). Of the respondents, 38% were homemakers and 54% were professionals. Overall, 49% reported incomes of more than \$50,000, 36% earned between \$25,000 and \$49,999, and 15% had family income of less than \$25,000. The focal children were mostly boys (70%), and were perceived by most parents (97%) to be significantly small. Finally, the children's average age was 10.34 years (standard deviation, ± 3.48 years).

Aggregate Parental Preference Structure

Initially, we examined the ordering assumption of conjoint analysis. More than 96% of 159 cases had less than three reversals (0 reversals = 44.65%; 1 reversal = 40.25%; 2 reversals = 11.95%). As such, five respondents with three or more reversals were excluded. Next, the conjoint model of Equation 1 was estimated. The results show that our model fits the data fairly well, resulting in an adjusted R^2 of 0.89 (standard error of 0.02). A vector model was used for out-of-pocket cost, whereas a partworth model was utilized for

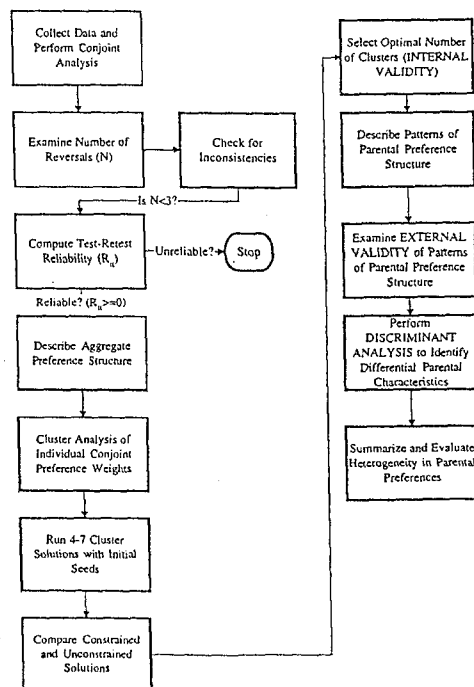


FIG. 1. Method of analysis used to examine preference patterns for subgroups of patients using conjoint analysis.

the remaining factors because of their categorical nature. Table 1 summarizes the results.

At the aggregate level, Table 1 shows that long-term side effects (risk) appear to be by far the most important attribute. This is because it accounts for the highest weight in the group relative importance score (ie, 30.15%). This attribute is followed by child's attitude and out-of-pocket cost, which appear equally important and account for approximately 20% each on the relative importance scale. Together, the preceding three factors constitute roughly 70% of the total relative importance scores. Thus, parental preference toward growth-promoting therapy appears to be critically dependent on its potential side effects, the attitude of the child toward the treatment, and the cost involved. Surprisingly, issues concerning the efficacy of the treatment (eg, odds and amount of increased height) were deemed less important by parents. Considering the purpose of GAT and the significance of these factors in phy-

sician decision making for GHT,¹⁵ this finding is both interesting and counterintuitive. At the other extreme, route/method of treatment proved to be the least important factor.

Table 1 provides the estimated aggregate partworth utilities (vector scores for out-of-pocket cost) for each level of the six treatment attributes. Note that desirable or valued attribute levels are associated with positive utilities, whereas undesirable levels have negative utility. Thus, for instance, all three levels of out-of-pocket cost are estimated to have negative vector scores because cost is nearly always undesirable. However, note that vector scores increase monotonically with the amount of out-of-pocket cost such that the utility for \$10,000/year is 100 times lower (or negative) than that for a treatment that costs only \$100/year. In addition, the coefficients of partworth utilities are directly proportional to the relative importance of the attribute. Consequently, at an aggregate level, parents see greater

TABLE 1. Aggregate Results of Parental Preference Structure From Conjoint Analysis ($n = 154$)

| Treatment Attribute* | Level [†] | Partworth Utilities [‡] | Relative Importance [§] |
|------------------------|---|----------------------------------|----------------------------------|
| Amount of effect | Adult height increases by 1–2 inches | -0.84 | |
| | Adult height increases by 4–5 inches | 0.84 | 10.42 |
| Certainty of effect | Adult height increases in 50% of recipients | -1.02 | |
| | Adult height increases in 100% of recipients | 1.02 | 12.56 |
| Route of treatment | Daily injections | -0.60 | |
| | Nasal spray | 0.60 | 7.34 |
| Out-of-pocket cost | \$100/year | -0.03 | |
| | \$2,000/year | -0.67 | |
| | \$10,000/year | -3.34 | 20.14 |
| Long-term side effects | Risk of adverse effects is 1:10,000 recipients | -2.42 | |
| | Risk of adverse effects is 1:100,000 recipients | 2.42 | 30.15 |
| Child's attitude | Child does not like GAT | -1.57 | |
| | Child likes GAT | 1.57 | 19.38 |

GAT, growth augmentation therapy.

*These attributes were identified as salient factors considered by parents in evaluating growth augmentation therapy.

[†]A full profile method was used to present hypothetical growth augmentation therapies to patients by selecting different combinations of the attribute levels. In all, 16 hypothetical treatments were developed.

[‡]These are aggregate coefficients estimated from nonmetric conjoint analysis with rankings as the dependent variable.

[§]The relative importance scores sum to 100.

utility in reduced risks of adverse long-term side effects than from any other attribute.

Reliability of Preference Structure

In all, 10 parents were randomly selected for a test-retest experiment, with a gap of at least 7 months from the initial test participation. The retest timing was selected to ensure that (1) sufficient time had elapsed to reduce test-retest consistency and (2) no major change had occurred in the state of the child's treatment. For instance, if a child began GHT after the first interview, that parent was excluded.

Separate conjoint analysis was performed to estimate both the partworth utilities and relative importance scores. The results from the retest experiment were correlated with those of the initial test experiment, resulting in correlations of 0.70 for partworth utilities and 0.66 for relative importance scores. Nunnally²³ has indicated that test-retest correlations of 0.6 or higher are indicative of reasonably reliable processes. Thus, the conjoint data appear to be reliable with significant systematic variance.

Patterns of Parental Preference Structure

The relative importance scores for each respondent were used as input for cluster analysis. The relative importance indicates how much each factor contributed to the respondent's overall evaluation. This procedure revealed that the five-cluster solution was the most compelling (Kappa coefficients were 0.97, 0.98, 0.96 for four- to six-cluster solutions). Figure 2 summarizes the preference patterns.

The five patterns are referred to as child-focused, risk-conscious, balanced, cost-conscious, and ease-of-use oriented groups. A brief description of these groups follows.

Risk Conscious. This group is the largest (36% of respondents) and appears driven by evaluation of long-term side effects. Apparently, this group is concerned about the downside risk and weighs it heavily in their decision (>47% in relative importance score). Other factors, including cost, efficacy, and child's attitude, are given significantly less importance; however, among themselves they appear equally important to parents (all scores approximately 10–13%). The route of treatment is the least important factor.

Child-focused. Constituting approximately 23% of all respondents, this group's pattern is dominated by their concern for the child's attitude toward GAT (>47% in relative importance score). Although the possibility of long-term side effects is moderately important (20%), this group appears relatively less concerned about the remaining four factors (all ≤10%).

Balanced. Consisting of approximately 23% of all respondents, this group evidences a balanced evaluation of multiple factors to arrive at a decision to undertake GAT. Specifically, long-term side effects, cost of treatment, odds of height augmentation, and the amount of height increase are jointly considered and given roughly equal weight (ranging from 16% to 25%). Somewhat surprisingly, this group places less importance on child's attitude (12%) and route of treatment (7%).

Cost-conscious. This group consists of 14% of all respondents and is predominantly concerned about out-of-pocket expenses, which alone counts for more than 51% in their relative importance scores. Of the remaining factors, none dominates such that the parents appear to give roughly equal weight to each (ranging from 6% for route of treatment to 14% for long-term side effects).

Ease-of-use Oriented. This is by far the smallest group, accounting for just 4% of respondents. The preference structure is dominated by two factors, with route of treatment accounting for 42% of weight and long-term side effects accounting for an additional 19% in weight. None of the remaining factors is critical. Thus, this group appears highly sensitive to the inconvenience of daily injections but less influenced by the child's attitude toward growth therapy.

The preceding groups differ substantively and significantly, suggesting that the aggregate analysis of preference structure (ie, Table 1) obfuscates important individual differences. Before we performed additional analysis of these groups, we sought to validate the five distinct preference patterns.

Validity of Parental Preference Patterns

The validity of preference patterns was examined by comparing importance scores from conjoint analysis with those obtained via self-report attribute ratings. The self-report data are based on asking respondents to rate the importance of each GAT attribute on a 10-point scale. These ratings were provided routinely by each participant before the conjoint analysis task. Our hypotheses

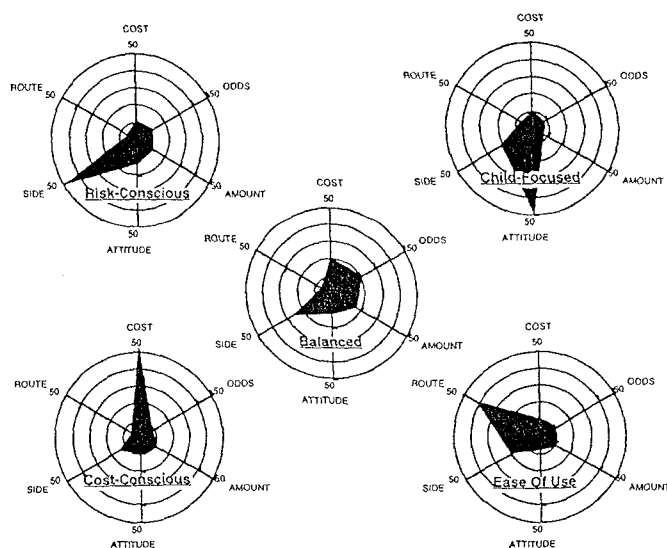


FIG. 2. Distinct patterns of parental preferences obtained from conjoint analysis of GAT data.

| MEAN RELATIVE IMPORTANCE SCORES FOR TREATMENT ATTRIBUTES | | | | | | |
|--|-------|-------|--------|----------|--------------|-------|
| Preference Patterns | COST | ODDS | AMOUNT | ATTITUDE | SIDE EFFECTS | ROUTE |
| Risk-Conscious | 10.69 | 11.50 | 11.70 | 12.92 | 47.71 | 5.48 |
| Child-Focused | 10.05 | 7.77 | 7.08 | 47.80 | 20.13 | 7.18 |
| Balanced | 20.42 | 19.85 | 16.23 | 11.57 | 25.23 | 6.71 |
| Cost-Conscious | 51.25 | 9.36 | 11.22 | 8.75 | 13.83 | 5.59 |
| Ease-of-Use | 10.94 | 10.37 | 10.29 | 7.80 | 19.08 | 41.53 |

were that the self-report attribute importance ratings for (1) long-term side effects would be significantly higher for the risk conscious group, (2) child's attitude would be significantly higher for the child-focused group, (3) out-of-pocket cost would be significantly higher for the cost-conscious group, and (4) route of treatment would be significantly higher for the ease-of-use group. No hypothesis was posited for the balanced group.

The results from the test of preceding hypotheses offer support for the validity of the conjoint data (see Table 2). For instance, the self-report ratings of child's attitude are significantly higher ($F = 2.9, df = 4, 147, P < 0.05$) for the child-focused group ($\bar{X} = 9.46$) relative to all other groups ($\bar{X} \leq 8.67$). Likewise, long-term side effects for the risk-conscious group are significantly higher ($F = 2.8, df = 4, 147, P <$

$0.05; \bar{X} = 9.82$) relative to all other groups ($\bar{X} \leq 9.47$). Moreover, out-of-pocket cost is rated significantly higher ($F = 5.0, df = 4, 147, P < 0.05$) by the cost-conscious group ($\bar{X} = 7.41$) relative to all other groups ($\bar{X} \leq 6.0$). Finally, the ratings of route of treatment are significantly higher ($F = 7.96, df = 8, 147, P < 0.05$) for the ease-of-use group ($\bar{X} = 9.50$) relative to all other groups ($\bar{X} \leq 6.84$). Taken together, we have enough evidence to conclude that the parents' preferences reflect five distinct, meaningful, and valid patterns.

Exploratory Analysis of Differentiating Factors for Parental Preference Patterns

Although recognizing patterns of patient preferences is critical to shared decision making, it is of limited value in understanding why patients

TABLE 2. Consistency Analysis Based on Preference Patterns From Conjoint Analysis and Self-Report Importance Ratings

| Self-Report Importance Ratings | Parental Preference Patterns [‡] | | | | |
|--------------------------------|---|--------------------------------|---------------------------|---------------------------------|-----------------------------|
| | Risk-conscious <i>n</i> = 55 | Child-focused <i>n</i> = 35 | Balanced <i>n</i> = 36 | Cost-conscious <i>n</i> = 22 | Ease-of-use <i>n</i> = 6 |
| Cost [†] | 4.65 | 5.03 | 5.86 | 7.41 | 6.00 |
| Odds [†] | 7.93 | 7.34 | 8.19 | 7.64 | 7.67 |
| Amount [†] | 7.76 | 7.00 | 7.33 | 7.18 | 6.67 |
| Attitude [†] | 8.53 | 9.46 | 8.50 | 7.50 | 8.67 |
| Side [†] | 9.82 | 9.43 | 9.47 | 8.64 | 8.50 |
| Route [†] | 6.84 | 6.77 | 6.56 | 6.23 | 9.50 |

*The self-importance ratings were obtained on a 10-point scale where 1 = least important and 10 = most important.

[†]Cost, Odds, Amount, Attitude, Side, and Route denote, respectively, (1) out-of-pocket cost, (2) odds of height increase, (3) amount of height increase, (4) child's attitude, (5) long-term side effects, and (6) route of treatment.

[‡]For convergent validity, mean comparisons for each self-report importance rating were conducted across the five preference patterns (read across each row). For instance, the mean value of self-report importance rating of "cost" factor was compared for the "cost-conscious" group compared to all of the other four groups (see data row-wise in Table). If this comparison is significant, it suggests evidence of convergent validity. Significant mean values from this comparison are in bold.

exhibit the preferences they do. Because different preferences lead to different tradeoffs, understanding preference determinants provides insight into motivating factors and dispositions that drive patients to seek specific tradeoffs. This understanding can be important from medical policy and practice perspectives (eg, in patient-directed education programs, predicting utilization patterns). Previous research has failed to address this issue. Typically, determinant factors for GAT may include demographic (eg, socioeconomic), psychologic (attitudes), and physiologic factors (eg, perceptions of disabling height). We provide an exploratory investigation of these linkages.

Specifically, discriminant analysis was conducted to explore the demographic, physiologic, and psychologic factors that differ across the five preference subgroups. The demographic variables included gender, race, marital status, education, (household) income, occupation, and the child's gender, height, and age. The physiologic variable included disabling height—that is, the actual height (in inches) for man and woman below which the respondent thought that an adult would face considerable difficulties (eg, in social/work settings). The psychologic variables included respondent's perceptions for the consequences of child's short stature in different

situations, including (1) personal attitudes and compensating activities (five items); (2) relationships with opposite sex and social settings (four items); (3) attitudes of others at school (eg, teachers, other kids) (six items); and (4) parental attitudes (four items).

Overall, the discriminant model produced the following statistics: Wilks' lambda = 0.61; $\chi^2 = 69.31$; $df = 28$; $P < 0.001$. The I^2 was 33.5%.²⁴ Similarly, 39.6% classification accuracy was obtained and almost twofold improvement over the expected percentage of correct assignments of 20% (Huberty's one-tailed $z = 5.924$; $P < 0.01$). In addition, 24.5% fewer errors were likely to be made in classification (Huberty's $I = 0.245$). Taken together, this suggests that reasonable discrimination was achieved among the five clusters. The psychologic variables contributed 18.9% explained variance in the discrimination function, whereas the effect of physiologic variable was marginal ($\Delta I^2 = 0.5$) and demographic variables were moderately significant discriminators ($\Delta I^2 = 14.1$). However, it is recognized that only a single physiologic variable (disabling height) was utilized, and other omitted physiologic variables may have significant influence.

In addition, we interpreted the significant discriminant functions. Each function describes a

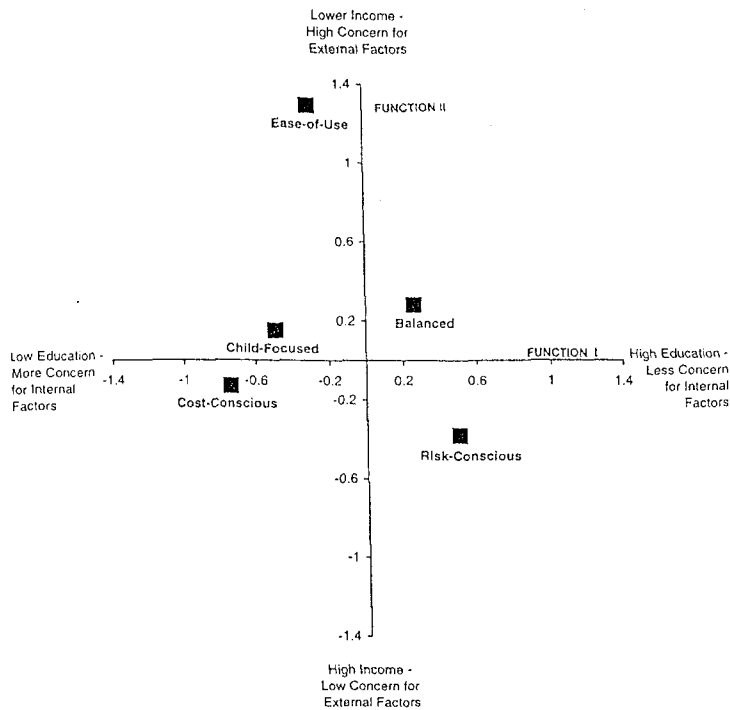


FIG. 3. Exploratory analysis of differentiating factors: a plot of the parental preference groups in a two-function discriminant space. The five parental groups are plotted as points or centroids in the discriminant space defined by Function I and Function II (see Table 3). The figure may be interpreted as follows: For instance, the ease-of-use group is characterized by high values of Function II (lower income, high concern due to external factors), implying that this group has lower income and expresses greater concern for psychologic dysfunction caused by factors external to the individual (relative to other groups); and mid-level values of Function I (education, concern for internal factors), implying that they are somewhat educated and express some concern for psychologic dysfunction attributable to factors internal to the individual.

linear composite of the explanatory variables that provides the greatest amount of discrimination among the dependent groups. In our case, the dependent groups represent the five preference patterns. Only the first two discriminant functions were significant at a level of $P < 0.05$. To aid interpretation, the two functions were varimax rotated, discriminating variables were standardized, and the resultant functions along with the five patient groups were plotted (Fig. 3, Table 3). An examination of Table 3 reveals that the fast function is composed of high levels of education (coefficient = 0.72), and a lack of concern about psychologic dysfunction because short stature is not considered unattractive (coefficient = -0.57). Note that the psychologic variable dominating Function I pertains to internal factors—that is, self-attributions of attractiveness or unattractiveness because of short stature.

Although it is difficult to provide a simple characterization of this complex dimension, for the sake of discussion we refer to the first function as a "high education, less concerned (about psychologic dysfunction) due to internal factors" dimension. The second function is indicative of a high income effect (coefficient = -0.76), although

the negative sign on the coefficient suggests that high values on this dimension indicate low income. In addition, education has a moderate effect on this dimension (coefficient = 0.59) but a much stronger effect of psychological dysfunction, indicating a high level of concern that, in comparison to their peers, short stature compels individuals to engage in compensating activities, such as sports (coefficient = 0.85), and influences teachers to not take them seriously (coefficient = 0.30). Note, that these psychologic variables relate to external factors—that is, how one reacts toward others (as in sports) and how others react toward oneself on account of short stature. We refer to this function as the "low income, high concern due to external factors" dimension.

An inspection of Figure 3 provides additional insights into parental preference patterns vis-à-vis the preceding functions. First, note that the balanced and risk conscious groups are much farther along the "high education, less concerned due to internal factors" dimension (Function I in Figure 3) than are the remaining three groups. It appears that the first function differentiates between the risk-conscious/balanced and all other preference patterns. Thus, parents with risk-con-

TABLE 3. Rotated Standardized Discriminant Function Coefficients for Differentiating Among Parental Preference Patterns

| Variable | Varimax Rotated Standardized Coefficients* | |
|---|--|--------------------|
| | Function 1 | Function 2 |
| Demographics | | |
| Education | 0.72 [†] | 0.59 [†] |
| Income | 0.06 | -0.76 [†] |
| Physiological | | |
| Disabling height [‡] | 0.18 | -0.23 |
| Psychological | | |
| Unattractiveness [§] | -0.57 [†] | 0.03 |
| Compensating activities [§] | 0.02 | 0.85 [†] |
| Teachers' attitude [§] | 0.07 | 0.30 [†] |
| Interpersonal difficulty | -0.28 | 0.16 |
| Group centroids for preference patterns | | |
| Child-focused | -0.49 | 0.15 |
| Risk-conscious | 0.50 | -0.38 |
| Balanced | 0.26 | 0.28 |
| Cost-conscious | -0.74 | -0.13 |
| Ease of use | -0.30 | 1.29 |

*Only the first two discriminant functions achieved significance at $P < 0.05$ level. Thus, the coefficients are reported only for the first two functions. Varimax rotation was implemented with only two functions.

[†]Coefficients >0.30 .

[‡]This question was operationalized as the actual height (in inches) below which an adult would face considerable difficulties in social and work settings. Separate measurements were obtained for a male and female adult. Only the male disabling height was systems in discriminant analysis.

[§]These variables were measured on a 4-point frequency scale ranging from "never" to "always." The specific items were as follows: (1) Unattractiveness: "Because of my height, I felt unattractive" (2) Compensating activities: "Because of my height, I found it necessary to prove myself in sports." (3) Teacher's attitude: "Because of my height, my teachers tended not to take me seriously."

^{||}This last set of psychological variables concerning social settings was measured on a 5-point Likert scale ranging from "strongly disagree" or "strongly agree." The operational item for "interpersonal difficulty" was: "Short men have difficulty interacting with women in social situations."

scious or balanced patterns tend to be highly educated and feel significantly less threatened by the self-impact of short stature than do parents with

any of the other three patterns. Second, note that along the "low income, high concern due to external factors" dimension (Function II in Figure 3), the preference patterns are separated in the following manner: (1) the ease-of-use group is the farthest from all of other groups and is placed at the high end of this function, (2) the child-focused and balanced groups are placed slightly above the midpoint and (3) the risk- and cost-conscious groups are located at the low end of this function. Thus, the parents with an ease-of-use preference pattern are most concerned, whereas the risk-conscious parents appear to be the least concerned about compensating behaviors of short children and teachers' attitude toward them. The remaining three groups lie somewhere in between these extremes. Figure 3 vividly shows the differences among the preference groups.

Discussion

Several limitations of our research must be considered while interpreting the key findings. Our study is based on a sample drawn from a single metropolitan area. Although this area has considerable diversity (eg, race and income mix of parents), is sufficiently large (population of more than 2 million), and care was taken to include most endocrinologists operating within this area, the possibility of sampling bias exists because of the restrictive geographical area. Replications in other areas are needed to sort out the possible effects of this bias. In addition, our study focused on growth therapy decisions. Not unlike other elective treatments (eg, in vitro fertilization), growth therapy is a high-involvement decision with significant quality-of-life implications, so our results may have less relevance for low-involvement decisions. In addition, the data were obtained in one sitting, although a variety of forms of data collection were utilized (eg, personal interview, self-report, card sorting). Consistency and other method biases may be present. However, it is highly unlikely that consistency bias, which argues for high correlations, accounts for the disparate parent preferences obtained. Finally, note that preference patterns are dynamic and are likely to change with changing informational environment and availability of newer medical options. Thus, it is important to replicate at regular time intervals our study for growth therapy in particular and preference

studies in general to better understand the dynamic nature of preferences.

This study focused on two questions: do patients (a) utilize multiple attributes to evaluate therapy decisions, and (b) reveal heterogeneity in treatment preferences. The results reported here support each of the two propositions. Our results confirm that parents utilize multiple criteria in evaluating growth therapy for their child. In all, six attributes were identified that appeared salient in parents' verbal reports. More importantly, the attributes considered range from efficacy (eg, magnitude and certainty of effect) to cost factors (eg, out-of-pocket cost) and include factors that reflect social considerations (eg, child's attitude) and medical tradeoffs (eg, long-term side effects). This breadth of GAT attributes verbalized by focal parents in unaided, free elicitation is compelling. This suggests that parents' evoked set of attributes is rich in content and multifaceted in range. Interestingly, these attributes differ from the factors that are thought to influence pediatric endocrinologists' decisions to prescribe GHT. For instance, in a national survey of pediatric endocrinologists, Cuttler et al^{15,25} found that salient decision attributes included clinical (eg, child's growth rate, height) and medical (eg, efficacy of GHT) factors. Because factors such as amount and odds of increased height were not evaluated as highly important by any parental subgroup, it is reasonable to conclude that involving parents in GAT decisions is beneficial because they utilize factors that are cognitively rich and not typically considered by physicians.

More significantly, our study reveals distinct heterogeneity in parental preferences for GAT. This heterogeneity is characterized by five disparate patterns, each reflecting a unique structure of tradeoffs that drive overall preference. Labeled as child-focused, risk-conscious, balanced, cost-conscious and ease-of-use oriented, these patterns characterize the importance parents attach to different GAT attributes. For instance, the child-focused group attaches greater importance to the child's attitude and places less importance on long-term side effects, out-of-pocket cost, the certainty of effect, route of treatment and magnitude of effect (in order of importance). Likewise, the cost-conscious group views out-of-pocket cost as the single most important factor in GAT decisions. As such, it is apparent that patients have the ability to cognitively process the multiple (and somewhat complex) attributes of

GAT to arrive at coherent decisions that reflect their distinctive preferences. Thus, it appears appropriate to hold that patients are capable of dealing with (complex) medical data concerning potential therapies or evidence disparate preferences driven by common concerns and extrinsic factors.

The delineation of patient subgroups with distinct preference patterns has implications for public policy and GHT demand. In terms of the latter, it is apparent that, given the sensitivity of the cost-conscious group (14%) to price, GHT demand may be influenced by greater insurance coverage or lower prices that lead to a reduction in out-of-pocket cost. With increasing market competition,¹³ pressure on prices is likely. In addition, thus far the pharmaceutical firms producing GHT have ventured into the consumer market rather gingerly, relying primarily on limited distribution via pediatric endocrinologists. Under the pressure of competition, it is easy to speculate that many new avenues of stimulating demand will be explored. The resulting increase in parental pressure on both referring primary care physicians and prescribing pediatric specialists is almost certain to influence GHT utilization patterns.

In terms of public policy, distinct subgroups of disparate parent preferences may be of considerable importance in understanding current GHT utilization and predicting future trends. For instance, the fact that 23% of respondents were primarily child-focused appears consistent with efforts of manufacturers to identify short children through height screening efforts in schools.¹⁹ This in turn raises issues of medical ethics (eg, is deliberate identification of short stature an ethical medical practice?) and demonstrable impairment (eg, when is short stature an impairment that needs treatment?). Likewise, the risk-conscious group (36%) indicates the importance of information provision that shapes parents' perception of GAT risk. The information environment for GHT is characterized by ambiguity (eg, lack of consensus on side effects), ad hoc reports (eg, uncontrolled studies and case reports), and inconsistency (eg, varying guidelines for GHT use). However, the sizable risk-conscious subgroup suggests the vulnerability of GAT demand to its information environment. This underscores the significance of tackling information organization and dissemination issues for patients.

Our exploratory analysis shows that the preference patterns relate systematically to demographic and psychologic characteristics of par-

ents. For instance, the cost-conscious group is characterized by lower income and education relative to other groups, whereas high income and education are associated with parents who fall into risk-conscious or balanced groups. Notably, the child-focused group generally is described by parents with moderate levels of income and education. In addition, the cost-conscious and balanced groups appear most motivated by the perceived difficulty in interpersonal relationships caused by short stature. Likewise, the cost-conscious and child-focused groups are more likely to view short stature as an unattractive attribute. Interestingly, the risk-conscious group appears least concerned (relatively) about the dysfunctional effects of short stature; this probably explains why this group is likely to consider GAT only if the downside risks are minimal. As such, heterogeneity in parental preferences cannot be attributed easily to idiosyncratic and random factors; rather, it appears to be rooted in the psychologic beliefs and dispositions and relate systematically to the demographic resources (eg, age, income). Because of its power to illuminate patients' perspective in medical decision making, unraveling the determinants of preference heterogeneity demands additional study and elaboration.

Overall, our study supports the notion that an intermediate level of patient preference analysis for nonemergency treatments is both feasible and insightful. The intermediate approach is based on the use of conjoint analysis to reveal the tradeoffs inherent in patient preferences using hypothetical levels of GAT attributes to capture future trends. Our results show that this analytical approach produces valid data and may be useful, especially in instances in which a post-hoc analysis of past decisions may not be informative about future decisions. In addition, the intermediate approach offers other advantages over the extreme positions of either aggregate- or individual-level of analysis. Specifically, it posits that, in most cases, it is possible to uncover patient subgroups with distinct preference patterns that are more parsimonious than individual patient analysis but are not highly susceptible to aggregation biases. Such parsimony is highly advantageous for several reasons. First, physicians and medical policy makers can develop informed consensual prescriptive guidelines for discussing treatment options with subgroups of patients. As such, this parsimony can help in setting broad national guidelines (such as for use of GHI). Second, in practice, pediatric en-

docrinologists may find the obtained preference patterns useful in interacting with patients. Clearly, satisfaction and compliance levels would be higher if care responds to revealed utility preferences. We urge medical researchers to use these approaches for other nonemergency treatments both to obtain more data on its validity and to help realize the benefits of shared decision making.

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