

Information-seeking and decision-making preferences among adult orthodontic patients: an elective health care model

James R. Miller¹, Brent E. Larson¹, David Satin² and Lindsay Schuster³

¹Division of Orthodontics, University of Minnesota, Minneapolis, MN, USA,

²Department of Family Medicine and

Community Health, University of

Minnesota, Minneapolis, MN, USA, ³Private

Practice, Boston, MA, USA

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Abstract – Objectives: When it comes to their own health care, adult patients traditionally demonstrate strong information-seeking desire but a somewhat lower desire to make their own treatment decisions in nonelective situations. Little is known about these desires in patients facing elective health care situations. We used the well-tested Autonomy Preferences Index (API) as a base to construct and test our elective Autonomy Preferences Index (eAPI) for both information-seeking and decision-making and analyzed demographic variables on both. **Methods:** The eAPI was constructed to mirror the API but uses elective scenarios rather than the API's nonelective scenarios. It was validated using cognitive interviews to determine item intent and comprehension and by Cronbach's alpha. Both the API and eAPI were distributed to 188 active-treatment patients at the Division of Orthodontics, University of Minnesota. API and eAPI items were scored using a 1 (low) to 5 (high) Likert scale of desire. **Results:** Mean information-seeking desire was universally high (>4 , $P < 0.001$) for both API and eAPI instruments. Mean decision-making (DM) desire was universally low to moderate: API-DM = 2.84 and eAPI-DM = 2.6. Decision-making preferences for nonelective items (API-DM) decreased as the condition severity presented in the vignettes increased: mild = 2.88, moderate = 2.67 and severe = 2.21. Conversely, elective decision-making preferences (eAPI-DM) increased with increasing condition severity: mild = 2.51, moderate = 2.79 and severe = 3.18 ($P < 0.001$). **Conclusions:** Adult patients have universally high information-seeking preferences and moderate to low decision-making preferences regardless of the elective or nonelective nature of their condition. However, as vignette condition severity increases, patients facing nonelective scenarios display progressively less desire for decision-making, whereas patients facing elective scenarios show progressively more decision-making desire.

Key words: adults; clinical decision making; elective; information-seeking; preferences

James Miller, Division of Orthodontics, University of Minnesota, 6-320 Moos Tower, 515 Delaware St. SE, Minneapolis, MN 55455, USA

Tel.: 612 626 3735

Fax: 612 626 2571

e-mail: mill0201@umn.edu

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Studies routinely demonstrate adult patients' strong desire for information regarding treatment for nonelective (1–6) and elective (7, 8) medical or dental conditions. Alternatively, they show low to moderate desire for making treatment decisions related to their own care (1, 4, 6, 9–14). Notably,

as condition severity of nonelective conditions increases, patient desire for decision-making decreases (1, 15). There is a large gap in the current understanding of patient preferences during elective medical or dental treatments (7, 8). Elective health care treatments are those undertaken with

the objective of improving the long-term quality of life for a given patient and not necessarily stemming from a health crisis or event. Our elective health care model is orthodontics. Orthodontics is unique among health care settings in that (i) it is largely elective, (ii) active doctor–patient relationships remain intact for two or more years of treatment, and (iii) financial contracts are routinely established prior to care delivery (decisions are no longer based on future costs). These characteristics make orthodontics an excellent model to study elective procedures in general.

A valid and well-tested instrument, the Autonomy Preferences Index (API), was developed by Ende et al. (1) to measure adult patient desires for both information-seeking (desire was relatively high) and decision-making (desire was relatively low) using medical nonelective hypothetical situations and questions. The original instrument (API) consisted of two subscales: an eight-item general information-seeking scale and a 15-item decision-making scale. The latter included six general items and nine items related to three clinical vignettes. These vignettes represented conditions of different severity. Upper respiratory tract infection (URI) represented a mild condition; high blood pressure (HBP) represented a moderate condition; and myocardial infarction (MI) represented a severe condition (See appendix). Each vignette was followed by three consecutive decision-making questions.

The specific aims of our current study were to (i) modify the nonelective (API) medical instrument into a valid elective (eAPI) orthodontic instrument, (ii) repeat Ende’s API and test the new eAPI in an adult orthodontic outpatient population, and (iii) compare results and measure influences of patient demographics on both.

Materials and methods

Our first goal was to construct and validate an instrument that could test adult patient information-seeking and decision-making preferences in elective medical situations. Because Ende’s API successfully established adult patient preferences in nonelective situations, we chose to modify and reword items for elective orthodontic situations. Our elective API (eAPI) retained the same inherent structure as the API. For the eAPI’s vignette severity items, the mild condition was represented by minor crowding (MC, mild); the moderate condition was represented by moderate crowding

and a posterior crossbite (CB, mod); the severe condition was represented as being treatable only through corrective jaw surgery (CJS, sev). To validate our eAPI, cognitive interviews were conducted with five adult orthodontic outpatients who were not included in the experiment, to evaluate the comprehensibility of our modifications. Cognitive interviews were structured as ‘concurrent think alouds’ in which the respondent described their own item interpretation. These interviews were used either to identify problems associated with the meaning of a given item or to identify problems associated with the words/phrases/response categories. Interviews were conducted using the API and eAPI to match intent. As problems were identified with the eAPI, changes were made through clarification, rewording, and retesting. Additional cognitive interviews ensured that the survey was well understood by the study population and allowed study participants to accurately and fully express their preferences for rewording the survey items. This process was repeated until respondent’s interpretation closely matched our item intent; there were five interviews in total. Extreme care was taken to adapt the API for elective orthodontic scenarios without changing the intent of questions or the overall survey. For each question in the API, there was a corollary question (with similar intent) on the eAPI. To accurately match the intent of certain items from the API, we felt it necessary to include additional questions to our eAPI: one additional decision-making general item and two additional information-seeking items. Therefore, although the API had 23 general items, the eAPI contains 26 general items. These additions were based solely on outcomes of the cognitive interviews for ‘intent-matching’ purposes. For example, item six on the decision-making scale of the API reads, ‘You should decide how frequently you need a checkup’. This is matched with the elective question, ‘Your orthodontist should decide how frequently your visits are (provided you do not have a schedule conflict)’. Likewise, an information-seeking question from the API reads, ‘Your doctor should explain the purpose of your laboratory tests’. This is matched from the eAPI with ‘Your orthodontist should explain the purpose of each X-ray and picture’. Some items did not change from the API to the eAPI. For example, the item, ‘you should be given information only when you ask for it’, was left unchanged. Once we were satisfied with the intent and wording of our eAPI survey questions, we were ready to distribute the survey.

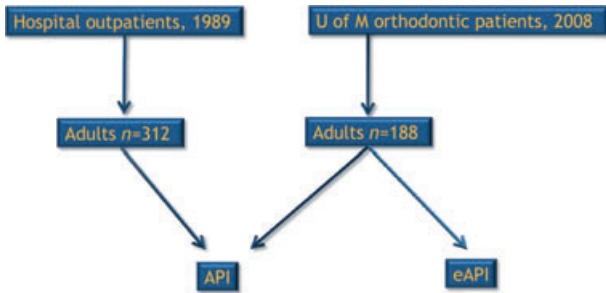


Fig. 1. Flowchart.

Our next goal was to test eAPI and API on our adult orthodontic population. Institutional Review Board (IRB) approval and patient consent were obtained. After active orthodontic treatment commenced, the combined survey was administered in person to a total of 224 orthodontic outpatient volunteers at the University of Minnesota, Division of Orthodontics (Fig. 1). The combined survey contained three parts: (i) the original API of Ende, (ii) the eAPI, and (iii) a demographic questionnaire.

Patients were excluded from participating in this study if they were under the age of 18, did not speak English, had not commenced active orthodontic treatment, or if they worked in the dental profession. The survey was distributed to 224 subjects during active orthodontic treatment. Of these, six people declined to participate in the study without offering a reason. Ten people cited lack of time, and 22 people accepted the survey with the intent of returning it at a later date. Four of these 22 people returned the survey in the recommended timeframe, one participant returned the survey after the deadline, and the other 17 did not return the survey. Additionally, two patients handed in blank surveys – these were obviously excluded. A total of 188 surveys were analyzed. Time to complete the survey was approximately 15–20 min. A nominal \$5 monetary incentive was used for study participation (16). IRB regulations which includes the maintenance of patient privacy were strictly followed. Surveys were sent to Northwest Keypunch Services for tally and incorporation into spreadsheet format. Spreadsheets were analyzed at the University of Minnesota Biostatistics, Design, and Analysis Center, (BDAC).

The following hypotheses were tested:

- Patients will exhibit high preferences for information-seeking regardless of the elective (eAPI) or nonelective (API) nature of the treatment.

- Patients faced with elective medical treatments (eAPI) will exhibit lower decision-making preferences than those facing nonelective orthodontic treatments (API).
- As elective (eAPI) or nonelective (API) conditions progress from mild to moderate to severe, patients' desire for decision-making will decrease.
- Patients taking the API in 2008 will have higher decision-making preferences than those taking the API in 1989.
- Patient demographics will have a minimal impact on information-seeking or decision-making preferences as measured by the API and eAPI.

The statistical analysis involved one-sample directional t-tests for hypotheses 1 and 2, a two-sample directional t-test for hypothesis 4, one-way ANOVAs with Tukey multiple comparisons for hypothesis 3, and equivalence tests for hypothesis 5. Our analysis used Cronbach's alpha to measure and verify the internal consistency for each of the subscales (information-seeking and decision-making) in the API and eAPI. It was determined that if the scales demonstrated an alpha of 0.70 or above, it could be concluded that the adjustments to the instrument had not significantly altered the underlying psychometric properties of the API.

Comparing our results to Ende's required a conversion formula. Ende's data were reported on either a 0-100 or 0-10 scale where 0 refers to a complete lack of desire and the upper value indicates the highest possible desire. Our study employs a 1-5 scale. We chose this 1-5 scale to simplify the statistics and for more easily comprehensible output. Additionally, this is the way Ende originally collected his data. If Y is equal to the scale score in our current project and X = Ende's scale score, the conversion becomes $Y = f(X)$, or $Y = 1 + 0.04 \times X$ (for 0-100 scale) and $Y = 1 + 0.4X$ (for 0-10 scale). For example, if Ende's results happened to be 79.5 for information-seeking, this score conversion becomes $1 + 0.04(79) = 4.18$. When describing Ende's work, all following values in this study have been converted to a 1-5 scale, and the words 'desires' and 'preferences' are used interchangeably.

When describing the data for either information-seeking or decision-making, we arbitrarily chose to call any desire score greater than 4.0 as 'high' and any score <2.0 as 'low'. These values represent the upper and lower 1/5 of the scale, respectively. Any

scores in the middle zone (2.0–4.0) will be referred to as either ‘moderate’, ‘collaborative’ or ‘shared’, depending on context.

Results

The cronbach’s alpha value for eAPI information-seeking was 0.805, and eAPI decision-making was 0.840. The cronbach’s alpha value for the 2008 API information-seeking subscale was 0.790 and 0.754 for the decision-making subscale.

One hundred and eighty-eight adult orthodontic outpatients completed the questionnaire. The 1989 Ende study tested the API on 312 adult hospital outpatients. Ende’s converted mean information-seeking API (API-IS) score was 4.18. The 2008 (orthodontic outpatients) mean API-IS was 4.63 (SD 0.47). The elective mean eAPI-IS score was 4.50 (SD = 0.51). A mean information-seeking (IS) preference score of >4 was considered ‘high’ by us. A one-directional *t*-test for a mean of >4 indicates *P* values < 0.0001 for both API-IS and eAPI-IS, thus supporting hypothesis #1 (See Fig. 2).

Ende’s 1989 API reported mean API-DM = 2.33. The 2008 mean API-DM = 2.82. This difference between API-DM (1989) and API-DM (2008) supports hypothesis #4. The elective mean eAPI-DM = 2.60 (SD 0.54) (See Fig. 3). This indicates a statistical difference between the mean 2008 API-

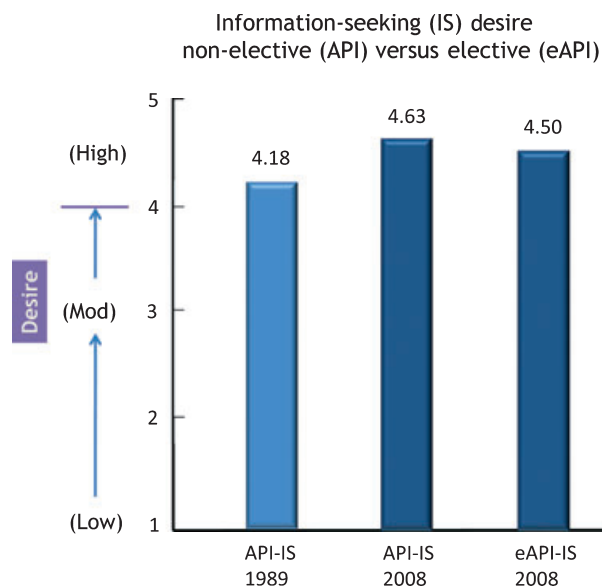


Fig. 2. Patients exhibit high preferences for information-seeking regardless of the elective (eAPI) or nonelective (API) nature of the survey.

Decision-making (DM) desire non-elective (API) versus elective (eAPI)

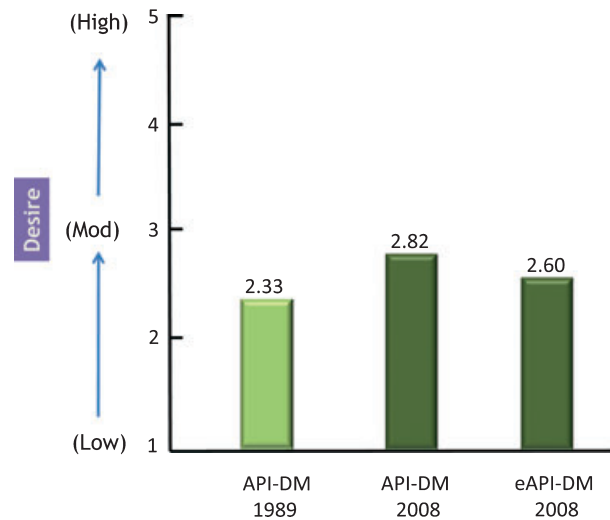


Fig. 3. Patients exhibit low to moderate desire for decision-making regardless of the elective (eAPI) or non-elective (API) nature of the survey.

DM and mean eAPI-DM ($P < 0.00001$), thus supporting hypothesis #2.

Decision-making preference mean scores were calculated for each of the vignettes. A repeated measures ANOVA test confirmed that there was a statistically significant difference between the means of the various groups. There was a difference between groups for both API ($P < 0.0001$, *F* value = 72.53,) and eAPI ($P < 0.0001$, *F* value = 87.85.). A Tukey multiple comparison test was used to differentiate between the groups. This pairwise comparison showed differences between each of the mild, moderate, and severe items in both the API and eAPI as follows. Ende found that URI (mild) = 2.6, HBP (moderate) = 1.84, and MI (severe) = 1.72 (See Fig. 4). Our study (2008 data) reproduced a similar progressive decrease in decision-making desire for nonelective (API) items: URI = 2.88, HBP = 2.67 and MI = 2.21. Conversely, we found that elective decision-making (DM) desire (eAPI-DM) increased with increasing condition severity: MC = 2.51 (mild), CB = 2.79 (moderate), and CJS = 3.18 (severe), thus refuting hypothesis #3.

All reported differences in demographics below are at 95% confidence ($P < 0.05$) and have been adjusted using the Tukey method for multiple comparisons (Table 1). For groups tested with the 2008 API, females had higher information-seeking desire than males. Additional demographic differences were noted in information-seeking desire

DM preferences by condition severity
non-elective (API) versus elective (eAPI)

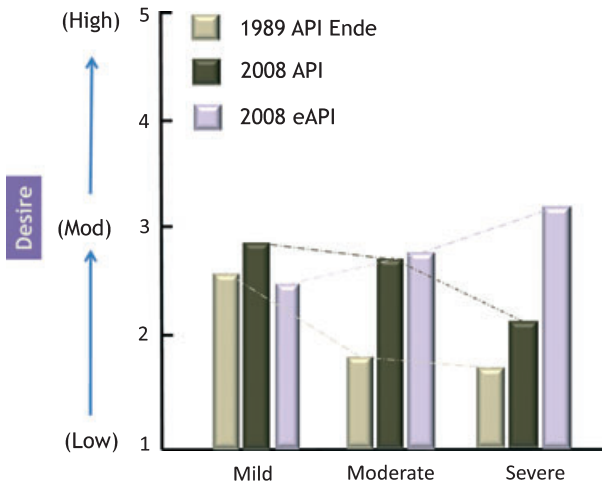


Fig. 4. As condition severity increases, patients facing nonelective scenarios display progressively decreasing decision-making desire, whereas patients facing elective scenarios show progressively increasing decision-making desire.

such that Caucasians had greater desire when compared with African Americans, and 51–65-year-old patients had greater desire when compared to those 18–25. African Americans had higher decision-making desire than did Hispanics and the ethnic group categorized as ‘other’. For groups tested with the eAPI, 51–65-year-old patients had greater information-seeking desire than patients 18–25. Likewise, patients aged 26–50 had greater information-seeking desire than those 18–25. African Americans had higher decision-making desire than did Hispanics and the group categorized as ‘other’. These statistically significant differences are

also reported in Table 2 below. Patients tested with the eAPI who actually received CJS (as opposed to imagining the surgery described in the vignette) had higher decision-making desire than patients whose actual orthodontic treatment was less complex.

Discussion

Information-seeking

These results clearly show that patients have a high desire for information-seeking (IS) about health care treatments in both nonelective and elective scenarios. Furthermore, there was excellent internal consistency of both the API (alpha = 0.790) and eAPI (alpha = 0.805) information-seeking subscales. Hospital outpatients tested with the API in 1989 scored 4.18 for nonelective-IS (Fig. 2) while orthodontic outpatients tested with the API in 2008 scored 4.63 for nonelective-IS. Although our study populations were different, it is this author’s belief that the modest increase over the 1989 data likely reflects society’s shift toward more patient autonomy and less doctor paternalism in health care. We live in an ‘information age’ where access to information is easier and more available than at any other time in history. It is becoming engrained in the collective mindset that information should be available and immediate (3). Orthodontic outpatients tested with the eAPI (elective) in 2008 scored a 4.50 for elective-IS. This expectedly shows a very strong desire for elective-IS. Numerous studies demonstrate that patients want more information from their doctors (1–8). A study by McKeague and Windsor (8) demonstrates that

Table 1. Table showing age, gender and ethnicity distribution, desire means, and standard deviation for Autonomy Preferences Index (API) and eAPI

Category	n	Percent	Information-seeking means (SD)			Decision-making means (SD)		
			API	eAPI	P	API	eAPI	P
<i>Age</i>								
18–25	93	51.38	4.53 (0.55)	4.38 (0.59)	1.00	2.81 (0.51)	2.59 (0.57)	1.00
26–50	77	42.54	4.70 (0.34)	4.60 (0.41)	0.99	2.81 (0.51)	2.60 (0.51)	1.00
51–65	11	6.08	4.98 (0.05)	4.84 (0.18)	0.99	3.05 (0.39)	2.68 (0.49)	0.99
<i>Gender</i>								
Male	77	42.31	4.51 (0.55)	4.42 (0.62)	0.97	2.80 (0.53)	2.59 (0.60)	1.00
Female	105	57.69	4.71 (0.39)	4.55 (0.42)	1.00	2.83 (0.49)	2.60 (0.50)	1.00
<i>Ethnicity</i>								
White	115	64.97	4.69 (0.36)	4.49 (0.50)	1.00	2.82 (0.49)	2.61 (0.55)	1.00
Black	22	12.43	4.38 (0.75)	4.35 (0.85)	0.65	3.09 (0.52)	2.88 (0.50)	0.98
Hispanic	9	5.08	4.49 (0.48)	4.46 (0.24)	0.55	2.55 (0.36)	2.33 (0.33)	0.99
Other	31	17.51	4.65 (0.31)	4.57 (0.29)	0.91	2.70 (0.50)	2.42 (0.50)	0.75

Table 2. P-values of significance for ethnicity, gender, and age for both Autonomy Preferences Index (API) and eAPI instruments

API	White	Black	Male	18–25
<i>Decision-making</i>				
<i>Ethnicity</i>				
Hispanic		0.03		
Other		0.02		
<i>Information-seeking</i>				
<i>Ethnicity</i>				
Black	0.01			
<i>Gender</i>				
Female			0.01	
<i>Age</i>				
51–65				0.01
<hr/>				
<i>Decision-making</i>				
<i>Ethnicity</i>				
Hispanic		0.04		
Other		0.01		
<i>Information-seeking</i>				
<i>Age</i>				
26–50				0.01
51–65				0.01

51% of surgical patients were less than ‘totally satisfied’ with the type and quantity of information they were given before their surgery. Only 47% believed they had received ‘enough’ information about risks and complications of the proposed operation, and 48% could not recall a single risk of the operation itself. To increase patient satisfaction, these authors recommend that doctors provide specific information followed by a verbal confirmation that the patient understands and is fully satisfied with the information in a pressure-free environment. Furthermore, a study of 187 low income women waiting to receive obstetric or gynecological elective procedures shows that these women desire information on every potential risk (large or small) and they will generally consider this information to be germane to their decision-making process (7). Nevertheless, Mortenson and colleagues demonstrate that when informed consent is completed thoroughly, patients are often poor at retaining this information (17). Because patients seeking elective care need not incur the risks, it has been argued it is legally more important for healthcare providers to better inform our patients(18).

Decision-making

Studies routinely show that patients want to delegate much of the decision-making to their doctor (2–6, 10–12, 15, 19). Our results along with

Ende’s (1) confirm that patients have a low to moderate decision-making (DM) desire for both nonelective and elective treatments. Furthermore, there was excellent internal consistency of both the API (alpha = 0.754) and eAPI (alpha = 0.840) information-seeking subscales. On the same 1-5 scale previously described, hospital outpatients tested in 1989 scored a 2.33 for nonelective API-DM while orthodontic outpatients tested in 2008 scored 2.82 for nonelective API-DM, and scored 2.60 for elective eAPI-DM (Fig. 3). Again, there is a modest increase in nonelective decision-making desire from 1989 to 2008. Like the information-seeking scores, the decision-making score increases are likely because of an increase in the collective autonomy desires of the public (time variable). This result was also expected. Indeed, data from two cross-sectional studies (1987 and 2001) showed that patient’s desire for involvement in decision-making has increased over time (3).

Numerous studies show a low to moderate desire for decision-making (1, 2, 4, 5, 7, 15). This preference has resulted in what authors describe as ‘shared’, ‘collaborative’, and even ‘passive’ decision-making (4, 9, 10). Two studies (1, 15), clearly demonstrate an inverse relationship between desire for decision-making and condition severity. That is, faced with nonelective treatments, patients’ desire for decision-making decreases as condition severity increases. No previous studies have been found regarding patient desire for decision-making when facing elective treatments of varying severity.

The most interesting and unexpected aspect of this study is the elective vignette data. To review, vignettes were designed to measure decision-making desire based on condition severity in the following fashion: 1 signified the patient wanted no involvement, 3 signified the patient wanted involvement equal to the physician’s, and 5 indicated that the patient wanted complete control. In the case of the nonelective API, vignette #1 asked questions based on upper respiratory infection (mild condition), vignette #2 questions were based on hypertension (moderate condition), and vignette #3 questions were based on MI (severe condition). Our elective eAPI’s vignette #1 asked questions based on mild crowding (mild condition), vignette #2 questions based on crossbite with the possibility of extractions (moderate condition), and vignette #3 questions were based on CJS (severe condition).

1989 API nonelective data demonstrated desire scores of 2.1 (mild), 1.8 (moderate), and 1.72

(severe). Similarly our 2008 API nonelective results were 2.88 (mild), 2.67 (moderate), and 2.21 (severe). This shows a similar and statistically significant downward trend but with the expected inflated scores across the board when compared to the 1989 data. However, our 2008 eAPI elective data show the opposite trend: as severity of the elective condition progresses from mild to moderate to severe, so does the overall decision-making desire: eAPI mild = 2.51, moderate = 2.79, and severe = 3.18 (Fig. 3).

Contrary to our original hypothesis #3, as the severity of a condition increases, patients exhibit opposite decision-making preferences regarding elective and nonelective treatments. We hypothesize that deferring more severe, nonelective decisions to the doctor may reflect the notion that such decisions are perceived by patients as not being 'preference sensitive'. For example, the vast majority of patients may reason that surviving a MI is simply a necessary outcome, and decisions about how to achieve this outcome are exclusively a matter of trusting their doctor's technical expertise (14). Conversely, the very nature of elective treatment is 'preference sensitive' as the outcome is by definition not necessary. It becomes apparent then to patients that such treatment decisions, even in severe cases, are not simply a matter of technical expertise (14).

It should be noted that our new rationale stems from this new data and is very different from our original hypothesis. We initially reasoned that serious interventions like jaw surgery would cause patients to perceive the decision as one of technical expertise, deferring decision-making to the doctor just as with the treatment of MI. This new data suggest to us that patients facing more severe elective treatments such as jaw surgery do not lose sight of the notion that such treatments are still elective, and their decisions are still by definition 'preference sensitive'.

Our findings from both the API and eAPI show that patients want information about their care to a much greater extent than they want to make treatment decisions about their own care. Indeed, there was a distinct discrepancy between the desire subscale means for information-seeking (4.18–4.63 = high) and decision-making (2.33–2.82 = moderate) for both elective and nonelective instruments. It is not until the decision-making vignette condition severity data are compared (API versus eAPI) that fundamental differences are realized (Fig. 4).

Demographics

As expected, there were minor differences in group demographics (See Table 1). Significant differences between demographic groups are reported in Table 2. It is interesting to note that patients tested with the eAPI who actually received CJS (as opposed to imagining the surgery described in the vignette) had *higher* decision-making desire than patients whose actual orthodontic treatment was less complex. It suggests that this subset (eight total patients) having a complex orthodontic history is special: when it comes to making treatment decisions, their desires suggest a more 'preference sensitive' approach to the decision-making subscale items. This statistically significant finding supports our vignette data (Fig. 4) and is further evidence to refute hypothesis 3.

Future direction and limitations

The main limitation with this research is that it utilized hypothetical health care scenarios. Additionally, we were unable to separate out which differences resulted from repeating the study 20 years after Ende's original study and which resulted from repeating the study on a different type of patient population (University-based orthodontic clinic outpatients versus hospital-based medical clinic outpatients). Finally, although we grounded our eAPI's relative terms like 'high' and 'low' information-seeking and decision-making preferences in the existing literature by reproducing Ende's study, the original API does not ground these relative terms in clinically significant measures such as patient satisfaction. An important direction for future studies will therefore be to develop and test an instrument, which measures and links the level of satisfaction patients feel regarding information-seeking and decision-making from variations of an actual informed consent and treatment planning interaction prior to care delivery.

Conclusion and implications

- Adult patients have universally high information-seeking desire but moderate to low decision-making desire regardless of the elective or nonelective nature of their condition.
- For adults facing nonelective scenarios: Increasing vignette condition severity decreases decision-making desire.

- For adults facing elective scenarios: Increasing vignette condition severity increases decision-making desire.

The present study has successfully reproduced Ende's API findings with respect to information-seeking and decision-making preference subscales in an orthodontic outpatient population today. Furthermore, it is the first to provide empirical evidence that there may be a distinct difference in the decision-making desires of patients contemplating nonelective versus elective treatment.

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