Effects of Treatment Perception, Misconceptions, and Outcome Uncertainty on Dental Patients’ Decisions

BY

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THESIS
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<td>International Patient Decision Aid Standards</td>
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SUMMARY

Evidence that strategies to strengthen patient engagement in decision making are effective is substantial. This study hypothesized that some unfavorable consented dental treatment decisions are based on patient uncertainties and misconceptions that dental care providers might not be aware of. The objective of the study was to identify factors that potentially influenced dental patients’ decision at the point of choosing between saving and extracting restorable teeth by exploring underlying motivations, beliefs, attitudes, and emotional feelings and by measuring the extent to which dental practitioners involve patients in the decision making process using the OPTION Scale. For this research study, a purposive sample of 16 subjects was recruited from patients who presented and registered in the study site as “Urgent Care” patients for urgent and palliative treatment. Subjects were sampled from two groups; one group included eight patients who decided to save a restorable tooth and the other group included eight patients who decided to extract a restorable tooth. Data were collected by conducting semi-structured interviews with the subjects and by administering a structured Likert scale questionnaire (Observing Patient Involvement [OPTION] Scale). The study identified various factors that can interact and influence dental patients’ decisions, including past dental treatment experience, knowledge about dental treatment, treatment uncertainty, dental fear, financial constraints, and tooth value. This investigator concluded that the patient’s decision making could be a complex interaction between personal views and experiences that the dental provider might not be aware of and he suggested proposing decision aid frameworks in the dental field that can guide patients and clinicians through the process of shared decision making.
1. INTRODUCTION

Decision support has been a major concern in the medical field. Decision support frameworks and decision aids have been developed to help patients and to screen for decisional conflicts (1). The “Ottawa decision support framework” (ODSF) is one of the tools developed in the medical field that guide clinicians through the process of shared decision making (2, 3). The concept of shared decision making (SDM) was introduced to the clinical medical field but has received less attention in the dental field (4). The study upon which this paper was based hypothesized that some dental treatment decisions are based on patient uncertainties and misconceptions that dental care providers might not be aware of.

A systemic review of SDM programs indicated that, in comparison to usual care or simple educational material, these programs performed better in terms of disseminating more information, encouraging patients to have more realistic expectations, lowering decisional conflicts, increasing the proportion of people active in decision making, reducing the proportion of people remaining undecided and fostering greater agreement between values and choice of therapy (5).

Evaluation of decision aids distinguished between improved decision making and improved outcomes. In other words, good decisions can still result in unfavorable outcomes. Therefore, a good decision is one that is informed, consistent with personal values, and acted on and in which participants express satisfaction with decision making (6). For example, the desirable higher level of patient participation in decision making might possibly direct the decision of the patient toward the extraction of a restorable tooth (unfavorable outcome).

Studies of clinical decision analysis in dentistry have noted some uncertainty in the process of clinical decision making with respect to diagnosis, treatment, and prognosis. For
example, in restorative dentistry, restorations of teeth need to be replaced over the years, resulting in larger restorations. There is, however, a paucity of data on dental restorations’ longevity (7). With the paucity of longevity data, treatment strategies, based on lifetime costs on the patient, might not be straightforward ones (8), and when this uncertainty is perceived by dental patients, it can lead to decisional conflicts. Decisional conflict is a state of uncertainty about the course of action to take, which is likely when making choices involving risk or uncertainty of outcomes (1).

Patients might have misconceptions and negative experiences towards dental treatments based on their perception of the treatment outcomes (9). The purpose of one study (10) in endodontic literature was to assess patients’ perceptions of their endodontic treatment (root canal therapy) outcomes during a one-year follow-up period relative to any long-term problems that may have developed. The study reported a high frequency of perceived problems in the year following endodontic therapy. Most of the patients that experienced problems did not revisit their endodontist to seek treatment. Most of the problems were related to inappropriate restorative management and follow-up following the endodontic treatment. Despite the high success rate and survival rate of endodontic therapy reported in literature, 94% and 97%, respectively, in 4- to 6-year follow-ups (11), coronal bacterial microleakage can occur in a short time through restorations of endodontically treated teeth and potentially cause endodontic treatment failure (12, 13). Restoration of an endodontically treated tooth is a key predictor of the treatment’s ultimate success (14, 15). Therefore, the problems might be perceived to be an “Endodontic therapy problem” although the real problem could be inappropriate restorative management or follow-up.
The limited work that has been conducted in the dental field about SDM included a randomized controlled trial study in a dental endodontic specialty clinic that tested a chairside visual aid for shared decision making using an “Endodontic Decision Board.” The results showed that the Endodontic decision board improved patient knowledge of treatment options (4). Most frameworks for patient decision making, like the Endodontic decision board used in this study, structure decisions according to options, costs, outcomes, and probabilities of outcomes so that patients are better able to judge the value of the benefits versus the risks.

It was also important to assess the level of patients’ participation in the decision making process. Patients can be active in treatment decision making on some occasions and rely on the dentist’s expertise on others. However, it is a responsibility of the dentist to attempt to engage the patient in the decision-making process (16). A study about factors influencing decision making revealed that only 33% of the dentists considered patient factors (including patient preference and costs) important in choosing alternative therapies. The results suggested that patients may have little influence on decision making among experienced general dentists (17). Studies have shown significant associations between stable patient characteristics, such as age, gender, race/ethnicity, and education, and patient participation preferences. Also, preferences for involvement can increase with time and knowledge and can be influenced by the health care provider behavior (18). Arora and McHorney (19) examined data from 2,197 patients in the Medical Outcomes Study and found that the odds for preferring an active role significantly decreased with age (patients aged 35 to 44 years were 6.9 times, 95% CI [3.95, 11.86] more likely to prefer an active role than those 75 years or older) and increased with education (patients with college degree or more were 3.5 times, [2.35, 5.09] more likely to prefer active roles than those with fewer than 12 years of education).
The OPTION (observing patient involvement) scale is a measurement scale that was also developed and validated in the UK. It is a twelve-item, 5-point scale that assesses and measures the extent to which practitioners involve patients in the decision making process. Elwyn and colleagues (20) designed a study in which the OPTION scale was used by two independent raters to assess primary care consultations in order to evaluate its psychometric qualities, reliability, and validity. The OPTION scale provided reliable scores and the authors concluded that the scale provided a validated outcome measure for future empirical studies.

The aim of the present study was to determine factors that potentially influence dental patients’ decision at the point of choosing between saving (also called restoration throughout this thesis) and extraction of restorable teeth. It used the OPTION scale to explore underlying motivations, beliefs, attitudes, and emotional feelings and to measure the extent to which dental practitioners involve patients in the decision making process.
2. METHODS

The case scenario selected for decision analysis was “saving versus extraction of restorable teeth,” which is a decision that can have remarkable consequences with regard to oral health due to the impact of edentulism and missing teeth on the quality of life. Both systemic health and quality of life are compromised when edentulism or poorly fitting dentures affect eating and food choices. Missing teeth can be associated with feelings of withdrawal, embarrassment, and anxiety (21). Although the decision making process in this scenario was critical because of the irreversible consequences of losing a tooth, guidelines were lacking to assist clinicians and patients in making an informed, evidenced-based decision (22).

For the present study, 16 dental patients who made treatment decisions participated in individual in-depth interviews that explored their values, beliefs, and underlying motivations toward the selected treatment. Having such information can raise dentists’ awareness and help design better decision aids to provide broad access to patients’ cognitive processes. Improved decision aids can provide insights to assess patients’ values, ask about patients’ preferred role in decision making, screen for decisional conflicts, identify and assess support or undue pressure on patients, and increase patients’ involvement in decision making (23). Utilizing qualitative methods through the interview component offered a unique insight into people’s personal perspectives, provided an understanding of their beliefs, knowledge, and attitudes, and offered greater depth and methodological flexibility than quantitative research methods (24).

2.1 Study Sample/Setting and Recruitment

The University of Illinois at Chicago Institutional Review Board examined and approved the research protocol (IRB#2011-0589, Appendix A), the recruiting material (Appendix B), the informed consent form (Appendix C), the interview questions (Appendix D), and the OPTION
scale questionnaire (Appendix E). A purposive sample was recruited from patients who presented and registered in the study site as “Urgent Care” patients for urgent and palliative treatment. This investigator targeted a sample of two groups of patients. One group included patients who decided on extraction of a tooth that had been deemed restorable by the dental provider (after getting necessary consults when needed); the other group included patients who decided to save the tooth that was deemed restorable. In both groups, the tooth of interest was diagnosed with irreversible nerve damage that required root canal treatment (RCT) prior to restoration. This researcher recruited subjects from patients of dental student providers who diagnose and provide treatment options for urgent care patients in the undergraduate clinics at the study site. He verified the student dental providers’ clinical findings and diagnoses through clinical exams and diagnostic dialogues. Student dental providers did not know about the research and its objectives before their patients decided on a treatment choice. The investigator communicated directly with the eligible patients about the study enrollment immediately after they made their decisions and before “treatment delivery,” “referral,” or “no treatment.” Eligible participants were between 18 and 65 years of age and spoke English.

Patients that needed immediate treatment (such as draining an abscess) or patients in extreme pain (9 or 10 on a pain scale from 1 to 10) were excluded from study enrollment. The objective in the study was to interview subjects until data saturation was reached (25).

2.2 Data Collection and Analysis

Interviews were audio recorded and fully transcribed in a written form, then analyzed using thematic content analysis. This was performed using a deductive approach (26) that involved listing the factors that can potentially influence dental patients’ decisions, including: past experience with dental restorations and their longevity, knowledge about dental treatment,
dental fear, desire to avoid multiple visits, complexity of the restorative treatment required, and the effects of family and friends on patients’ decisions. The researcher then examined the interviews to determine the occurrence of those factors and their influence on patient subjects. He read and re-read the data, generating initial codes in a systematic fashion across the entire data set and collating data relevant to each code. Next, he sorted codes into potential themes, collating the relevant coded data extracts within the identified themes (27).

Each participant completed the OPTION instrument following the interview. OPTION responses were scored by taking the sum of the responses to each item; the summed score, represented the level of patient involvement in decision making. It had a range from 12 (least involved patient) to 60 (most involved patient). Individual items that were frequent indicators of lack of patient involvement were also noted (28).
3. RESULTS

3.1 Participants

A total of 16 subjects were recruited. Eight decided to have their tooth extracted and eight decided to save their tooth. The characteristics of the groups are shown in Table I.

3.2 Interview Questionnaire

Various influencing factors were identified after examining the interviews. Themes were generated and refined to more clear and defined themes. A thematic map was developed to illustrate the generated final themes and their categories (Figure 1). The following section presents the identified themes in the interview questionnaire data and compares the participants in the two groups of patients based on their responses.

3.2.1 Past Experience with Dental Treatment

All study participants had a history of dental fillings placed in their teeth except for one (SB-5-ext). Participants in the “saving group” mostly had positive experiences with dental

| TABLE I |
|-----------------|-----------------|
| PATIENT CHARACTERISTICS | Extraction Group (n = 8) | Restoration Group (n = 8) |
| Gender (% Female) | 87.5% | 75% |
| Age in Years Range | 25–58 | 18–56 |
| Median (IQR) | 35 (29.25–52.00) | 41.50 (31.25–54.50) |
| Pain Level (1–10) Range | 5–8 | 1–8 |
| Median (IQR) | 7.50 (6.25–8.00) | 6.00 (4.00–7.00) |
fillings and thought that their fillings have been lasting for a long time. One patient had a negative experience with a filling and an RCT that ended with teeth extractions that made her not interested in going through the RCT again and leaning initially toward extraction. She then decided to save her tooth after the provider explained the consequences of teeth loss:

I came with a tooth that was said it’s worth saving [referring to today’s dental provider] but I was the one suggesting to get it out, but my provider talked about consequences that might happen to my top tooth that opposes it so I thought for minutes and changed my mind and decided to save it. (SB-4-sav)

Another patient also had a negative experience with a filling that failed in less than a year but mentioned that her previous dental provider was in a rush:

I went to a dentist before and he was so rushed in doing my fillings. (SB-6-sav)
Patient SB-8-sav had a negative experience with an RCT that ended with a fractured tooth; however, the patient mentioned that it was his fault because he never went back for a crown:

I knew my root canal was intact but I never went back for a crown as advised by the dentist. (SB-8-sav)

Subjects in the “Extraction group” all had some negative experiences with dental work they received except for SB-5-ext, who never had dental restorations in the past but mentioned that his wife had negative experiences with fillings and ended up getting extractions. Patient SB-2-ext also didn’t have negative experiences but her sister did:

My sister got many root canal treatments and had some negative experience, some of her teeth ended up being removed. (SB-2-ext)

Two patients had a history of root canal-treated teeth that ended up being extracted. They both mentioned that this negative outcome made them lean towards the extraction decision this time:

I did have a root canal before but went for two visits and never continued, it was a painful experience and I ended up getting this tooth removed. (SB-1-ext)

I did have a root canal treatment done before. I actually ended up having the tooth pulled. I think this affected my decision today in getting my tooth extracted as opposed to getting a root canal. (SB-3-ext)

One patient mentioned that she was told by the dental provider that one of her previously root canal-treated teeth had a cyst, which was not understandable and disappointed her:

I was told that one of my root canal-treated teeth has a cyst or a lesion. I don’t understand how could this happen when the nerve is dead. That disappointed me and affected my decision today. (SB-8-ext)
3.2.2 **Knowledge about Dental Treatment**

A study on perceptions of dental patients regarding barriers to restorative care concluded that “no advice received from dentist” and “lack of knowledge on restorative care” were the two major barriers to restorative care (29).

Patients in the present study relied mostly on the dental provider as the source of their knowledge about dental treatment except for one patient in the “Saving group” who mentioned that his knowledge is mostly self-gained by Internet-based search:

I use the Internet to get information about dentistry. Before I came in, I saw the operation video [referring to an RCT procedure] on the Internet. Most of the explanation about the procedure, I got by myself, I was never explained that much by the dentist about dental procedures. Today, I was explained how the process is and how procedures are but nothing about risks was explained. (SB-5-sav)

Patients SB-2-sav, SB-4-sav, SB-6-sav, and SB-3-ext, SB-4-ext, and SB-5-ext had very limited knowledge about RCT with respect to procedure and risks. One patient seemed to have no distinction between “RCT procedure” and “crowning the tooth”:

I always thought that a root canal is just a deeper cleaning, I did not know that it’s also a crown. (SB-3-ext)

Five of the “Extraction group” subjects and three of the “Saving group” subjects were presented the possible need for a “crown lengthening surgery” procedure as part of the treatment option to save the tooth. Among those patients, SB-2-sav and SB-3-sav and SB-3-ext, SB-4-ext, SB-5-ext, and SB-8-ext felt uninformed about what the procedure involved. Larsson et al. (1) found greater difficulty making surgical decisions among patients who felt uninformed about the nature, consequences, and extent of surgical procedures.

I was told that I might possibly need crown lengthening surgery. I didn’t really understand what kind of surgery is that. I would really rethink about saving my tooth at the point they tell me I would really need it. (SB-2-sav)
I was told something about crown lengthening that I might need. I don’t know what it involves. We didn’t really get into this. Having a surgical component as part of the treatment influenced my decision. (SB-4-ext)

3.2.3 Treatment Uncertainty

All study subjects in both groups were not provided any information about longevity of treatments presented to save their tooth. Some patients mentioned that they were not sure if RCTs would really last long, referring to stories they heard from family members or friends.

Patient SB-2-sav mentioned that her dad thought it was not worth it to get a root canal done but she preferred to get it done because she previously had one that relieved her from pain and was still working fine:

My dad was talking to me about that it’s not really worth it doing root canals and told me “just get it out.” He thought, Why should you spend your time and money on root canal treatments. (SB-2-sav)

Patient SB-4-sav said that her mom and friends at work told her it was not worth it to get root canals, which influenced her decision and made her lean toward extraction, especially after she had had a bad painful experience with a root canal before. However, the dental provider redirected her decision to save her tooth:

My friend at work today and my mom told me “just get this tooth out, don’t go through all this work for a root canal.” My dad encouraged me to do a root canal when I did it the first time; my dental provider today spoke about the consequences of extraction so I decided to try to save it. (SB-4-sav)

Patient SB-6-sav asked her aunt about her previous RCT. Her aunt told her that although it is a painful procedure it relieves your pain:

My aunt had a negative experience during her root canal procedure. She said, “It was painful,” but she also said it’s a real pain relief later. That’s why I went for a root canal today. (SB-6-sav)

Patient SB-7-sav mentioned that although her friends told her not to go for root canals, she decided to get it done because of her personal positive experience with root canals:
Every one used to tell me that root canals are “horrible,” “don’t do them” but my personal experience proved to me that they work and are not horrible. (SB-7-sav)

Patient SB-3-ext spoke to her mom about her tooth pain. Her mom recommended not to go for root canals because they are painful and not worth the money:

My mom had a root canal treatment before, she told me they are a lot of money, very painful and it’s not worth it. (SB-3-ext)

Patient SB-7-ext was avoiding RCTs based on his family’s and friends’ negative experiences:

I heard from family and friends that root canals are painful, time consuming and that caps can fall off on you. This definitely had an impact on my decision. (SB-7-ext)

### 3.2.4 Dental Visit Fear and Avoidance Behavior

Dental fear is a remarkably severe and stable condition with a long duration (30). In epidemiological studies on dental anxiety and its effects on oral health, it was reported that dental anxiety results in avoidance behavior (31, 32, 33).

In the “Saving group” only one patient claimed that she had fears from the dental visit and that her fear was associated with avoidance behavior:

I do fear from going to the dentist. One of my first visits was a very painful procedure. I do avoid going to the dentist because of that and that’s why I’m here today with pain. (SB-3-sav)

In the “Extraction group” five patients had fear from the dental visit and tended to avoid going to the dentist. Among the five patients, four mentioned that they preferred to get a tooth extraction to avoid coming for the multiple dental visits that are required to save their tooth:

Having to come multiple times for a dental visit is not fun. I wish I was offered a one-day treatment to save my tooth. (SB-4-ext)

Dental fear is what makes me avoid multiple visits. I don’t like pain. I have to do a lot to get prepared to come here. (SB-8-ext)
Patients SB-7-ext and SB-8-ext were concerned by hearing surgical terms such as “cutting” or “surgery” mentioned by the provider while presenting their treatment options:

I was explained the need for crown lengthening that involves cutting into my gums and then my jaw bone to save my tooth. I got scared from the word “cutting.” I don’t want this done. (SB-7-ext)

The crown lengthening surgery being part of the treatment just freaked me out. They explained the need for it. This made me more towards extracting the tooth. (SB-8-ext)

3.2.5 Financial Constraints

Alternative treatments presented for a patient usually vary in complexity and cost (34). The cost of dental treatment is an influencing factor on the patient’s treatment choice (17, 35). Patients SB-2-sav, SB-3-sav, and SB-7-sav and SB-2-ext, SB-3-ext, SB-5-ext, and SB-6-ext thought that the tooth saving option was expensive. One patient mentioned that finances was the only reason she decided to get her tooth extracted:

Even though I don’t like root canal procedures, I would like to save my tooth. It’s just the finances. (SB-6-ext)

3.2.6 Value of the Tooth

Two patients in the “Saving group” rendered their decision to save the tooth to their perception of the tooth’s value:

I was the one suggesting to get my tooth out, but my provider talked about consequences that might happen to my top tooth that opposes it so I thought for minutes and changed my mind and decided to save it. (SB-4-sav)

When I came in today I was thinking about extraction of my tooth, especially that I don’t have dental insurance and worried about expenses to save the tooth, but I’m concerned about my “looks” [referring to cosmetic aspect]. It might be visible when I smile, so I decided to save my tooth. (SB-5-sav)

3.3 Likert Scale Questionnaire (OPTION Scale)

Figures 2 and 3 illustrate the level of participation of patients in the “saving” and “extraction” groups on a scale from 12 (least involvement) to 60 (most involvement). The two
least involved patients (with scores of 42) were both in the “saving group.” Of the two most involved patients (with scores of 60), one was from the “saving group” and one was from the “extraction group.”

Figure 2. Comparison of OPTION scores for extraction and restoration patients. Boxes indicate interquartile range with the median marked by the bold horizontal line. Whiskers extend 1.5 times the height of the boxes.

Figure 2. Comparison of OPTION scores for extraction and restoration patients. Boxes indicate interquartile range with the median marked by the bold horizontal line. Whiskers extend 1.5 times the height of the boxes.
Figure 3. Histogram of OPTION scores for extraction and restoration groups.

Among the individual OPTION items, two received low responses (less than 4) from at least five subjects. Five subjects did not agree that their provider had presented the pros and cons of options; six did not agree that the provider provided an opportunity for deferring the decision.
4. DISCUSSION

Patient decision making can be a complex interaction between personal views and experiences that the dental provider might not be aware of. This researcher conducted in-depth interviews to offer insight into patients’ personal perspectives relative to their decision making.

Patients who decided not to save their tooth—even though they knew that it was restorable—gave various reasons for their decision: personal past experience with negative treatment outcomes, financial constraints, being uncertain about the treatment outcome and its longevity, and fear from the dental visit associated with avoidance of multiple dental visits. Limited knowledge about treatment procedures was also noted.

Uncertainty was due to lack of knowledge about outcome longevity or stories heard from friends or family members about their negative experiences with dental treatment outcomes. Fear and avoidance behavior was due to fear from pain that could be associated with the RCT procedure and therefore avoidance of the multiple visits required for that treatment. Fear and avoidance behavior by some subjects was due to presenting “crown lengthening surgery” as part of the treatment option to save their tooth. Some of those patients were not aware of the type and extent of the surgical procedure.

Several reasons were mentioned by patients who decided to save their tooth. They included the following: valuing their tooth, their personal positive experiences with dental treatment, knowledge about consequences of the tooth extraction from the dental provider, and positive influence from friends or family members who received the same treatment.

Different interactions between the influencing factors were observed throughout the study. In the “Saving group,” one patient had a negative past experience with a filling and an RCT that resulted in dental extractions, but when the consequences of extracting the tooth were
explained to the patient, the “Value of the tooth” factor had a stronger influence on the patient’s decision than the “past negative experience.” This was also the case with another patient in the “Saving group” when the “Value of the tooth” (from a cosmetic aspect) was a stronger influencing factor on the decision than “financial constraints” with no dental insurance to cover the expenses involved to save the tooth. Interaction between “Treatment uncertainty” and “Past treatment experience” was also observed in the “Saving group”; one patient was advised by her friends to avoid RCTs because they don’t work, which might have raised the level of the patient’s uncertainty about the outcome of root canals; however, the patient’s personal past positive experience with a root canal was the stronger influencing factor on the decision.

Patients in the “Saving” and “Extraction” groups differed in their perception of similar influencing factors. When “Past negative experiences” had an influence on the decisions of the “Extraction group” subjects, they were perceived differently by “Saving group” subjects. One patient in the “Saving group” was not influenced by the past negative experience because she thought that her previous dental provider was in a rush when he was performing her dental treatment procedures. Another patient thought that his past negative experience with an RCT—it had resulted in a tooth fracture—was his fault because he did not follow up to get a crown as advised by the dental provider, and therefore his decision was not influenced by that experience.

Treatment decisions involve making value trade-offs between benefits and harms that should depend on informed patient choice (36). In the present study, the OPTION scale questionnaire, which was used to measure the level of patients’ participation in decision making, revealed that five study subjects thought that the dental provider did not explain the pros and cons of options. It also revealed that six study subjects were not offered the opportunity to defer their decision.
There is substantial evidence that strategies to strengthen patient engagement are effective (37). Therefore developing decision aid frameworks in the dental field to guide patients through the process of shared decision making is essential. For example, the ODSF tool developed in the medical field was structured to assess patients’ value, to ask about patients’ preferred role in decision making, screen for decisional conflicts, assess support or undue pressure on patients, and increase patients’ involvement in decision making (22). If utilized in the dental field, the ODSF tool could reduce treatment uncertainty and misconceptions through its structure as well as increase patient involvement in the decision making process.

In this study, the OPTION instrument that was used as a tool to measure the extent of patients’ participation in the decision making process, showed close levels between the “Saving group” and the “Extraction group.” Comparing this result to the variations observed between the two groups in the interview questionnaire responses with regard to their perceptions and the factors influencing their decisions, the OPTION instrument was not a reliable tool in demonstrating how the two different decisions were related to the level of involvement.

Efforts have been made to develop criteria that can evaluate decision aids and their capability of supporting patients in decision making. An international collaboration reported a set of criteria for judging a good decision aid known as the International Patient Decision Aid Standards (IPDAS). In the IPDAS publication, Elwyn and colleagues (38) reported research and consensus-based standards for recommended content and development processes for decision aids to support informed choices about screening and treatment options. The IPDAS criteria are in the form of a checklist of questions that assess the ability and strength of the decision aid in influencing the decision making. The IPDAS criteria can be a helpful guide in constructing decision aids in the dental field.
The study had its limitations. Subjects were recruited from patients presenting for treatment at the study site. It offered dental treatment at a lower cost than private practices and is affordable for middle-class and low-income patients. This sample might not be representative of dental patients from various socioeconomic groups. Also, the dental providers were dental students, who might not be representative of dental providers due to their having relatively less experience in dental practice.

The study included only three males (two in the “Saving group” and one in the “extraction group”), so interviewing more male subjects might reveal different attitudes that would provide more information about gender in relation to decision making. Even though patients who decided on extraction of their tooth had various reasons for their decision, financial constraints might have had a strong influence on their decision to avoid the relatively higher cost of treatment to save the tooth. Despite the slight difference noted (Table I) in pain level between the two groups, the slightly higher pain levels in the “Extraction group” might have led to a tendency towards the extraction decision.

There was some inconsistency between the interview responses and the responses to some items in the OPTION scale structured questionnaire for some study subjects. For example, SB-3-ext and SB-5-ext both mentioned during the interview that they had limited or no understanding of the RCT procedure that was presented to them as an option; however, they responded to item #8 in the Likert scale questionnaire with a “4” and “5” score, respectively, reflecting that the provider checked their understanding to the information presented. This inconsistency can highlight the advantage of qualitative research (through utilizing in-depth interviews) in offering a deeper insight into patients’ perspectives compared to quantitative structured questionnaires.
The study used a deductive approach to analyze the qualitative data, which involved using a structure and predetermined framework to analyze the data due to the awareness of the investigator of probable participant responses. Even though it is a quick and easy approach, it can potentially bias the analysis process as the coding framework is predetermined, which can limit theme and theory development (39).

Moreover, the qualitative analysis was conducted by a single investigator, and member checking was not performed. Triangulation was limited to comparisons with the OPTION responses discussed above.
5. CONCLUSIONS

This study showed the complexity of the process of dental patients’ decision making and identified various factors that can interact and influence dental patients’ decisions. Identified factors included past dental treatment experience, knowledge about dental treatment, treatment uncertainty, dental fear, financial constraints, and tooth value. The results indicated that the patient’s decision making could be a complex interaction between personal views and experiences that the dental provider might not be aware of. Decision aid frameworks should be developed and validated in the dental field to guide patients and clinicians through the process of shared decision making to increase patients’ involvement in treatment decisions and to guide the dental providers in assessing patients’ values and screening for decisional conflicts.

The study also demonstrated the importance of qualitative approaches in dental research. They offer greater depth in assessing people’s personal perspectives, providing an understanding of their beliefs, knowledge, and attitudes as well as enriching the results of quantitative structured questionnaires.
REFERENCES


Appendix A

INSTITUTIONAL REVIEW BOARD APPROVAL

Approval Notice
Initial Review (Response To Modifications)

August 29, 2011

Mohamed Hindy
Oral Medicine and Diagnostic Sciences
Oral Medicine and Diagnostic Sciences
Dentistry, M/C 838
Chicago, IL
Phone:

RE: Protocol # 2011-0589
“Analyzing the Effects of Treatment Perception, Attitude and Motivation Towards Dental Treatment on Dental Patients’ Decision Making”

Dear Dr. Hindy:

Your Initial Review application (Response To Modifications) was reviewed and approved by the Expedited review process on August 18, 2011. You may now begin your research.

Please note the following information about your approved research protocol:

Protocol Approval Period: August 18, 2011 - August 16, 2012

Approved Subject Enrollment #: 40

Additional Determinations for Research Involving Minors: These determinations have not been made for this study since it has not been approved for enrollment of minors.

Performance Site: UIC
Sponsor: None

Research Protocol:

a) Analyzing the Effects of Treatment Perception, Attitude and Motivation towards Dental Treatment on Dental Patients’ Decision Making; Version 2; 07/28/2011

Recruitment Material:

a) List of Talking Points; Version 2; 08/12/2011

Informed Consent:

a) Decision Analysis; Version 2; 07/28/2011

b) A waiver of informed consent has been granted under 45 CFR 46.116(d) for recruitment purposes only (minimal risk; preliminary identification of potential subjects from records; subjects will sign a consent document containing all elements of consent at enrollment)
INSTITUTIONAL REVIEW BOARD APPROVAL (continued)

HIPAA Authorization:

- A waiver of HIPAA Authorization has been granted preliminary to research for identification of potential subjects from records

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

- (5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for non-research purposes (such as medical treatment or diagnosis).
- (6) Collection of data from voice, video, digital, or image recordings made for research purposes.
- (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

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<td>08/16/2011</td>
<td>Response To Modifications</td>
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<td>08/18/2011</td>
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Please remember to:

- Use your research protocol number (2011-0589) on any documents or correspondence with the IRB concerning your research protocol.

- Review and comply with all requirements on the enclosure, "UIC Investigator Responsibilities, Protection of Human Research Subjects"

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-2014. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Sandra Costello
Assistant Director, IRB #2
Office for the Protection of Research Subjects
Appendix A (continued)

INSTITUTIONAL REVIEW BOARD APPROVAL (continued)

Enclosures:

1. UIC Investigator Responsibilities, Protection of Human Research Subjects
2. Informed Consent Document:
   a) Decision Analysis; Version 2; 07/28/2011
3. Recruiting Material:
   a) List of Talking Points; Version 2; 08/12/2011
4. Data Security Enclosure

cc: Richard Monahan, Oral Medicine and Diagnostic Sciences, M/C 838
    Alan Schwartz (faculty advisor), Medical Education, M/C 591
    Privacy Office, Health Information Management Department, M/C 772
Appendix A (continued)

INSTITUTIONAL REVIEW BOARD APPROVAL (continued)

August 13, 2012

Mohamed Hindy
Oral Medicine and Diagnostic Sciences
Oral Medicine and Diagnostic Sciences
Dentistry, M/C 838
Chicago, IL
Phone

RE: Protocol # 2011-0589
“Analyzing the Effects of Treatment Perception, Attitude and Motivation Towards Dental Treatment on Dental Patients’ Decision Making”

Dear Dr. Hindy:

Your Continuing Review was reviewed and approved by the Expedited review process on August 9, 2012. You may now continue your research.

Please note the following information about your approved research protocol:

**Protocol Approval Period:** August 17, 2012 - August 16, 2013

**Approved Subject Enrollment #:** 40 (Limited to analysis of data from 16 subjects)

**Additional Determinations for Research Involving Minors:** These determinations have not been made for this study since it has not been approved for enrollment of minors.

**Performance Sites:** UIC

**Sponsor:** None

**PAF #:** Not Applicable

**Research Protocol(s):**

b) Analyzing the Effects of Treatment Perception, Attitude and Motivation towards Dental Treatment on Dental Patients’ Decision Making; Version 2; 07/28/2011

**Recruitment Material(s):**

b) Not Applicable – Data Analysis Only

**Informed Consent(s):**

c) Not Applicable – Data Analysis Only

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

(5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or
Appendix A (continued)

INSTITUTIONAL REVIEW BOARD APPROVAL (continued)

diagnosis).
(6) Collection of data from voice, video, digital, or image recordings made for research purposes. (7)
Research on individual or group characteristics or behavior (including but not limited to research on
perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social
behavior) or research employing survey, interview, oral history, focus group, program evaluation, human
factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

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<td>08/09/2012</td>
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Please remember to:

➔ Use your research protocol number (2011-0589) on any documents or correspondence with the IRB
concerning your research protocol.

➔ Review and comply with all requirements on the enclosure,
"UIC Investigator Responsibilities, Protection of Human Research Subjects"

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek
additional information, require further modifications, or monitor the conduct of your research and
the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended
and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please
contact OPRS at (312) 996-1711 or me at (312) 996-9299. Please send any correspondence about this
protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Marissa Benni, M.S.
IRB Coordinator, IRB # 2
Office for the Protection of Research Subjects

Enclosure(s):
1. UIC Investigator Responsibilities, Protection of Human Research Subjects

cc: Richard Monahan, Oral Medicine and Diagnostic Sciences, M/C 838
    Alan Schwartz, Medical Education, M/C 591
    Privacy Office, Health Information Management Department, M/C 772
Appendix B

RECRUITING MATERIAL APPROVED BY INSTITUTIONAL REVIEW BOARD

1. You are being asked to be a subject in a research study about “Dental Patient Decision Making.”

2. Talk about the purpose of the research.

3. Talk about procedures involved. Type (interview questionnaire, written questionnaire) and duration of participation.

4. Benefits of the study. (Benefits for improving dental care for the society, and there will be no direct benefits to the subjects for participating in the research).

5. Research study risks, privacy, and confidentiality issues.

6. Mention to the patient that you are not involved in clinical student supervision or clinical work for the further treatment needed starting from this point of time.

7. Mentioning that there is no compensation for participating in the study.

8. Mentioning that subject can withdraw at any point without affecting relationship with [study site].
Appendix C

INFORMED CONSENT

[Name of Study Site]
Research Information and Consent for Participation in Social Behavioral Research

Analyzing the effects of treatment perception, attitude and motivation towards dental treatment on dental patients’ decision making

You are being asked to participate in a research study. Researchers are required to provide a consent form such as this one to tell you about the research, to explain that taking part is voluntary, to describe the risks and benefits of participation, and to help you to make an informed decision. You should feel free to ask the researchers any questions you may have.

Principal Investigator Name and Title: Mohamed Hindy, DDS, Clinical Instructor
Department and Institution: Oral Medicine and Diagnostic Sciences, UIC College of Dentistry
Address and Contact Information: 9242 Waverly Ct, Darien IL 60561. Day phone #: 3475894870
Sponsor: N/A

Why am I being asked?

You are being asked to be a subject in a research study about “Dental Patient Decision Making”. This research study will include an interview and questionnaire to determine factors influencing patient decision making and measure the level of their participation in the decision making process. You have been asked to participate in this research because you are over 18 and presented today to the urgent care clinic in [study site] with a problem related to a “restorable tooth” and opted for tooth “saving” or “extraction” or “no treatment”. Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future dealings with the [study site]. If you decide to participate, you are free to withdraw at any time without affecting that relationship. Approximately 40 subjects may be involved in this research at [study site].

What is the purpose of this research?

To determine factors that potentially influence dental patients’ decision at the point of choosing between saving and extraction of restorable teeth by exploring motivations,
Appendix C (continued)

INFORMED CONSENT (continued)

beliefs, attitudes and emotional feelings and to measure the level of patients involvement in the
decision making process.

What procedures are involved?

- This research will be performed at the [study site] in the dental clinic.
- Your participation in the study will be today only following reading and signing this consent
  form by participating in an interview and answering a questionnaire.
- The participation will last for about 15-20 minutes
- The study will start with an interactive interview questionnaire between the investigator and
  the patient that should take about 10-15 minutes. The patient will then be handed a
  questionnaire consisting of 12 items in which the patient will be responding to each item on a
  scale ranging from strongly agree to strongly disagree and should take about 5 minutes to be
  completed.
- The interview will be audio-taped.
- The study participant will be assigned to a study group based on the patient’s treatment choice
decision which is “saving” or “extraction” of the tooth or “no treatment selected”.

What are the potential risks and discomforts?

- To the best of our knowledge, the things you will be doing have no more risk of harm
  than you would experience in everyday life.
- Research data collected from the participant will not include any personal identifiers
  that can risk confidentiality. Protected health information collected for research subjects
  recruitment purposes will be destroyed immediately after enrollment.

Are there benefits to taking part in the research?

This study is not designed to benefit you directly. This study is designed to learn more about factors
influencing dental patient’s decision making and the level of dental patient involvement in the decision
making. The study results may be used to help dental patients in the future.

What other options are there?
You have the option to not participate in this study.

What about privacy and confidentiality?

- The people who will know that you are a research subject are members of the research team.
  Others in the clinic may know that you are participating in the research study. Otherwise
  information about you will only be disclosed to others with your written permission, or if
  necessary to protect your rights or welfare or if required by law.
- Research data collected for each individual will be coded by a case number (1, 2, 3…) in the
  order of enrollment and participation in the study without any personal identifiers included.
Appendix C (continued)

INFORMED CONSENT (continued)

• When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity.

• The de-identified data collected in the research study will be maintained indefinitely under the supervision of the research principal investigator for reference in future studies.

• The audio-tapes recording the interviews will be destroyed following the research data analysis.
• The UIC IRB and State of Illinois auditors may review research information in order to monitor the conduct of the research.

Will I be reimbursed for any of my expenses or paid for my participation in this research?

You will not be offered payment for being in this study.

Can I withdraw or be removed from the study?

If you decide to participate, you are free to withdraw your consent and discontinue participation at any time.

The Researchers also have the right to stop your participation in this study without your consent if: They believe it’s in your best interest.

Who should I contact if I have questions?

Contact the researcher “Mohamed Hindy, Clinical instructor and Master student at phone # or email address: Or contact faculty sponsor “Alan Schwartz, Associate Professor at phone or email address:
• if you have any questions about this study or your part in it,
• if you have questions, concerns or complaints about the research.

What are my rights as a research subject?

If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at uicirb@uic.edu.

Decision analysis, version#2 (07/28/11), Page#3of 4
Appendix C (continued)

INFORMED CONSENT (continued)

Remember:
• Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University. If you decide to participate, you are free to withdraw at any time without affecting that relationship.
• The investigator will not be further involved in the clinical service provided to the patient starting from the point of introducing the patient to the research.

Signature of Subject or Legally Authorized Representative

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I will be given a copy of this signed and dated form.

_________________________________________  __________________________
Signature                                                                 Date

_________________________________________
Printed Name

_________________________________________  __________________________
Signature of Person Obtaining Consent        Date (must be same as subject’s)

_________________________________________
Printed Name of Person Obtaining Consent
Appendix D

SEMI-STRUCTURED INTERVIEW QUESTIONNAIRE

Patient age: Level of pain (on a scale from 1 to 10):

1. If you had dental restorations placed on your teeth,
   a. Can you tell me about your past experience with dental fillings? (Listen to and record answer, and if they didn’t specify item, ask “Did the fillings last as long as you expected?”
   b. Did this influence your decision today regarding the selected treatment? And how did you think about it?
   c. When you were considering getting dental treatment, tell me about how you found the information you needed to decide on what treatment. (Listen to and record answer, and if they didn’t specify item, ask “Did you find helpful information about dental treatment or dental restorations longevity?”)

2. How do you feel about getting dental treatment that takes several appointments (multiple visits)? Does this affect your final decision?

3. Do you fear from going to the dentist? If yes, how do you think this can impact you regarding treatment decision making? (For example, avoidance of treatment or avoiding multiple visits, etc.)

4. Root canal treatment
   a. Have you ever had a root canal treatment? Tell me about it.
      Explore: How did it come out in the end? Did things happen the way you expected?”
   b. What do you know about root canal treatments?
   c. What do your family and friends say about them?
   d. How do you think what you’ve heard affects your decisions about root canals?

5. Did your treatment options include any surgical procedures (for example, crown lengthening)? If yes, how do you feel about that?

6. How did the dental provider approach your pain relief? Were you offered a same day treatment procedure to relieve your pain?
**Appendix E**

**LIKERT SCALE QUESTIONNAIRE (OPTION SCALE)**

Please respond to each question by shading the circle corresponding to Strongly agree or Agree or Neutral or Disagree or Strongly Disagree, reflecting your experience from today’s dental visit.

<table>
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<th>The dental provider identifies a problem(s) needing a decision making process</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>o Strongly agree o Agree o Neutral o Disagree o Strongly Disagree</td>
</tr>
<tr>
<td></td>
<td>o Strongly agree o Agree o Neutral o Disagree o Strongly Disagree</td>
</tr>
<tr>
<td>2</td>
<td>The dental provider states that there is more than one way to deal with an identified problem</td>
</tr>
<tr>
<td></td>
<td>o Strongly agree o Agree o Neutral o Disagree o Strongly Disagree</td>
</tr>
<tr>
<td>3</td>
<td>The dental provider lists “options” about how to deal with the problem, including the choice of “no action,” if feasible</td>
</tr>
<tr>
<td></td>
<td>o Strongly agree o Agree o Neutral o Disagree o Strongly Disagree</td>
</tr>
<tr>
<td>4</td>
<td>The dental provider explains the pros and cons of options to the patient (taking “no action” is an option)</td>
</tr>
<tr>
<td></td>
<td>o Strongly agree o Agree o Neutral o Disagree o Strongly Disagree</td>
</tr>
<tr>
<td>5</td>
<td>The dental provider checks the patient’s preferred information format (words/numbers/visual display)</td>
</tr>
<tr>
<td></td>
<td>o Strongly agree o Agree o Neutral o Disagree o Strongly Disagree</td>
</tr>
<tr>
<td>6</td>
<td>The dental provider explores the patient’s expectations (or ideas) about how the problem(s) are to be managed</td>
</tr>
<tr>
<td></td>
<td>o Strongly agree o Agree o Neutral o Disagree o Strongly Disagree</td>
</tr>
<tr>
<td>7</td>
<td>The dental provider explores the patient’s concerns (fears) about how problem(s) are to be managed</td>
</tr>
<tr>
<td></td>
<td>o Strongly agree o Agree o Neutral o Disagree o Strongly Disagree</td>
</tr>
<tr>
<td>8</td>
<td>The dental provider checks that the patient has understood the information</td>
</tr>
<tr>
<td></td>
<td>o Strongly agree o Agree o Neutral o Disagree o Strongly Disagree</td>
</tr>
<tr>
<td>9</td>
<td>The dental provider provides opportunities for the patient to ask questions</td>
</tr>
<tr>
<td></td>
<td>o Strongly agree o Agree o Neutral o Disagree o Strongly Disagree</td>
</tr>
<tr>
<td>10</td>
<td>The dental provider asks for the patient’s preferred level of involvement in decision making</td>
</tr>
<tr>
<td></td>
<td>o Strongly agree o Agree o Neutral o Disagree o Strongly Disagree</td>
</tr>
<tr>
<td>11</td>
<td>An opportunity for deferring a decision is provided</td>
</tr>
<tr>
<td></td>
<td>o Strongly agree o Agree o Neutral o Disagree o Strongly Disagree</td>
</tr>
<tr>
<td>12</td>
<td>Arrangements are made to review the decision (or the deferment)</td>
</tr>
<tr>
<td></td>
<td>o Strongly agree o Agree o Neutral o Disagree o Strongly Disagree</td>
</tr>
</tbody>
</table>
VITA

NAME: Mohamed Hindy

EDUCATION: B.D.S. (with honors), College of Dentistry, Alexandria University, Alexandria, Egypt, 2004

D.D.S., College of Dentistry, University of Illinois at Chicago, Chicago, 2008

M.S., Clinical and Translational Science, University of Illinois at Chicago, Chicago, 2012

PROFESSIONAL EXPERIENCE:

General Dentistry (Private Practice), Oak Lawn Dental and Implant Center, Oak Lawn, Illinois, September 2009 to present (part-time)

Clinical Instructor, Oral Medicine, College of Dentistry, University of Illinois at Chicago, Chicago, Illinois, 2008 to present (part-time)

General Dentistry (Private Practice), Burbank Dental Associates, Burbank, Illinois, 2008 to present (part-time)

General Dental Practitioner, Sharq el Madina Hospital, Alexandria, Egypt, 2005 (3-month rotation)

General Dental Practitioner, Smoha Hospital, Alexandria, Egypt, 2005 (3-month rotation)

General Dental Practitioner, Italian Military Hospital, Alexandria, Egypt, 2004 (3-month rotation)

PROFESSIONAL MEMBERSHIP: American Academy of Implant Dentistry