

# Informed consent and expectation management: A case study

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### ABSTRACT

**Purpose:** To explore patient responsiveness when exposed to an online educational tool and to determine level of engagement in their medical care/treatment as a consequence of this exposure.

**Method:** More than 2,400 patients were exposed to the Emmi Solutions online, interactive and illustrated education tool for the procedures of gastric bypass, total hip replacement and colonoscopy. These procedures were chosen to reflect an elective surgery, a significant surgery (non-elective) and an elective diagnostic procedure. Patient responses were then analyzed to determine the level of engagement through feedback questions and comments, as well as determination of the value of the experience as rated by the patient.

**Results:** More than 80 percent of patients felt that the online educational tool enhanced their understanding of the procedure/treatment. Specific comments and ratings reflect that the patients were more informed after the experience, and more than 90 percent felt sufficiently impressed with the tool to share it with their friends/family.

**Conclusions:** Utilizing an interactive educational tool enhances the patient's appreciation for the specifics of the treatment/procedure, increases their awareness of risks, provides information and comfort in knowledge and increases their confidence in the provider of the treatment/procedure. A significant percentage of the patients even engaged their family and friends in reviewing the tool, illustrating significant engagement in their pre-treatment/procedure experience.

*By David Sobel, MD, and Pamela L. Popp, Esq.*

### INTRODUCTION

The doctrine of obtaining a patient's informed consent prior to performing a medical or surgical procedure remains a cornerstone in supporting patient autonomy, advocacy and care. As Justice Cardoza wrote in 1914, as the modern view of informed consent was taking shape, "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body." The belief that the "doctor knows best" is not only dated but discounted by current patients.(1)

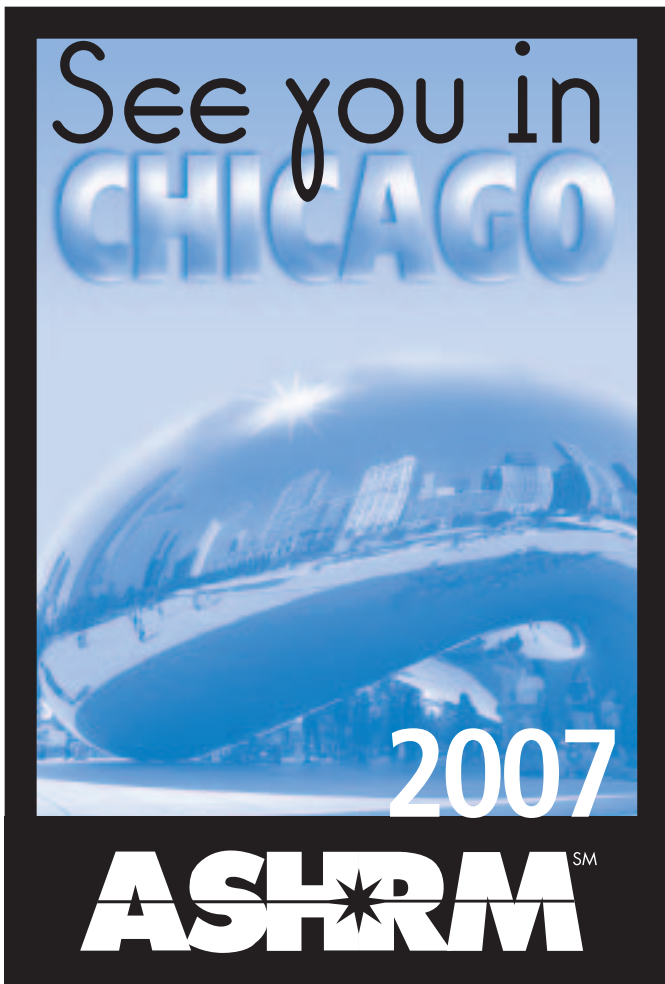
Today, it is accepted that the patient is best suited to make decisions regarding his or her medical care. Mock juror research supports the belief that patients desire significant autonomy in their healthcare decision making.(2) To do so, the patient must be armed with complete and accurate information. Doctors and patients are clearly aligned regarding this sentiment, as physicians agree that the more informed and engaged the patient, the better the patient's expectations in regards to their healthcare outcomes and responsibility.

However, significant challenges still exist in the informed consent process for both the provider and the patient. Physicians are burdened with ever-increasing patient volumes and the need to educate these patients regarding the complex and, at times, unpredictable behavior of disease. Patients can be challenged by: a) their inability to remember all that they are told in the physician's office; b) their bias to focus on future gains rather than potential risks and c) the impact of social beliefs on their receptivity to treatment.(3)

In addition, it is now well understood that the risk of malpractice litigation is closely tied to the physician's ability to communicate with the patient and to set reasonable expectations regarding the potential outcomes from the medical or surgical therapy.(4, 5)

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*Traditional informed consent, where the physician relays the risks and benefits of the procedure or treatment to the patient, often leaves the patient feeling overwhelmed and confused.*

While much has been written encouraging providers to find ways to engage their patients in treatment and procedure plans, little has been suggested as a way for this engagement to be effected. Traditional informed consent, where the physician relays the risks and benefits of the procedure or treatment to the patient, often leaves the patient feeling overwhelmed and confused by the quantity of information provided. In fact, on average, approximately 80 percent of the information conveyed to a patient in a clinic setting is summarily forgotten. It is, therefore, not surprising that 70 percent of all medical malpractice cases brought by patients assert a claim for lack of proper informed consent. In fact, between the years 1997 and 2003, the average award in a medical malpractice lawsuit for lack of informed consent was \$1,152,426 (median, \$410,000) (6)

It may be easy to suggest that providers simply spend more time with their patients. (7) However, in today's hectic and volume-driven healthcare environment, elongated conversations are hardly a realistic alternative. Instead, providers are searching for ways to provide the information to the patient while still sustaining the proper provider/patient relationship through the process. (8)

The evolution of technology has allowed for the development of interactive educational tools that can benefit both the patient and provider in this fashion. Emmi Solutions, one such tool provider (and an ASHRM partner; see note on Page 24), has been gathering patient feedback data from the 200,000-plus patients who have now had the chance to review the EMMIPrep tool over the past two years. Currently, greater than 25,000 patient surveys regarding various aspects of the patient education experience have been returned.

#### **METHODOLOGY**

In order to look at a varied sample of data, the decision was made to select patient feedback on the procedures/treatment of three specific areas: total hip replacement, gastric bypass surgery and colonoscopy.

Gastric bypass was chosen because it is typically an elective procedure that requires significant pre-operative patient education and is associated with significant morbidity and mortality. Total hip replacement was chosen because it is generally performed on an elderly population who may be additionally challenged with respect to memory, knowledge retention online computer use. Finally, colonoscopy was chosen because of its importance as a cancer screening diagnostic and the patient's concomitant aversion to undergoing the procedure. (9)

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## *The tool is intended to help prepare patients and their families for an upcoming medical or diagnostic procedure.*

At their pre-operative appointment, the patients received the Web site address and a unique password to allow access to the EmmiPrep tool. The tool is intended to help prepare patients and their families for an upcoming medical or diagnostic procedure. Using multiple learning modalities and medical animations, the tool guides patients through the experience from pre-op to post-op, including risks, benefits and alternatives. The patients then reviewed the online education tools at their leisure, at home, prior to the surgical date. Each review of the tool took the patient approximately 20 minutes.

During the review by the patient, opportunities are given to type in questions and/or to review a specific section before proceeding to the end of the tool. At the conclusion of the patient's review, survey feedback questions query on the topics of enhanced/verified knowledge of the procedure, how the tool reflected on the provider who provided the tool, and gauged whether the patient shared the tool with one or more family members.

### **PATIENT FEEDBACK**

The patient feedback was grouped into the following areas for analysis: 1) whether the tool enhanced the patient's understanding of the procedure/treatment, 2) whether the tool provided information that the patient did not receive from their provider, 3) whether the tool provided comfort to the patient in knowing the steps for pre- and post-treatment requirements, 4) whether providing the tool to the patient enhanced their confidence in the provider, 5) if the tool answered specific questions that the patient had on the procedure and finally, 6) whether the patient then shared the tool with either family or friends for their review.

The clear message in this feedback data is that patients, once engaged, become much more involved in their care, to the point of even engaging friends and family in the information exchange. Specifically, the patients supplied feedback data that showed opportunities for prevention of adverse events, examples of increased patient satisfaction/expectation management and an increased comprehension of applicable risks.

### **Increased the patient's understanding of the procedure**

Patients indicated that their knowledge of the actual steps of the procedure was significantly enhanced after reviewing the online tool. Greater than 86 percent of patients reported a better understanding of the colonoscopy procedure; 85 percent had a better understanding of the total hip replacement surgery and 80 percent had a better understanding of the gastric bypass surgery. In fact, as one gastric bypass patient noted, "It was incredibly thorough yet I didn't feel I was being overburdened with information."

### **Provided information that the patient did not receive from their provider**

While indicating that the patients did have a strong appreciation for the information provided by their physician, nearly 70 percent of patients indicated that they did receive additional information from the online program that they did not receive from their physician. The key is not whether, in fact, the amount of information was actually increased, but instead the level of the patient's recollection and understanding of what information was provided by their physician. Therefore, it is possible that the patients truly did not learn new information after viewing the program, but instead better appreciated the information that they did have.

In specific comments, many patients indicated that the information validated their own online research. While not specifically addressed, it is a logical assumption then that this tool may also allow for the correction of wrong or incomplete information that may have been obtained by the patient through other means, including other research, discussions with family and friends or through publications such as marketing materials for specific treatments or programs.

### **Provided a level of comfort in knowing more about what to expect from the procedure**

Between 56-68 percent of patients felt increased comfort by going through the online tool, both increasing their familiarity with the procedure and reviewing the information provided. Specific comments indicated that being more aware of the pre- and post-procedure requirements allowed the patient to better prepare for the procedure, sometimes by eliciting the help of friends and family to assist in care needs.

One specific comment by a patient outlined her concerns that she was previously unaware of – that she might need some personal assistance after her discharge from the hospital. By learning of this need before she went in for the procedure, she was able to make arrangements for family to be available for her care post-op.

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### **Enhanced the patient's confidence in their provider**

Particularly in hip replacement surgery, it was surprising that 62-75 percent of patients indicated that they had more confidence in their provider in light of the availability of the Emmi tool. Several specific comments indicated that the patients felt more trust of their surgeon knowing that the surgeon wanted them to have complete information before they underwent the procedure.

### **Answered questions that the patient had about the procedure**

More than 50 percent of patients indicated that they had questions that were answered by the Emmi tool that were not answered by their physician. It's possible that these patients may not have even had the opportunity to ask all of their questions of the physician, or even have had the chance to formulate questions while in the physician's office.

The use of the tool allowed the patients to think about healthcare needs in the privacy of their own home, at their chosen pace, and to digest the implications of those care needs. In some instances, patients may be too embarrassed to ask their doctor a specific question. As one patient undergoing a colonoscopy explained, "I would probably not discuss the questions that Emmi answered with my doctor. That is just how I am. So it was a great help in that respect."

### **Provided information on risks not covered by the provider**

Over 60 percent of the patients indicated that they learned risks from the tool that were not covered by their physician. While it is impossible to measure specifically which physicians covered each of the risk areas, the more important finding is that patients felt that they better understood the risks of the procedure after reviewing the tool.

A better-informed patient can then set more realistic expectations for their treatment and outcome. As one healthcare provider undergoing a hip replacement explained, "even though I am an RN and knew a lot of what was presented, it was very helpful to have it presented simply and concisely. When something is happening to you personally, a lot of your expertise deserts you!"

A few specific comments highlighted the importance of the patient's appreciation of risks: One patient indicated that she was allergic to antibiotics (noted to be customarily used for post-op care) and another indicated that she had a specific metal allergy. The increased awareness of the risks allows the patients to think about their specific history, situation or peculiarities that might come into play during, or after, the procedure. One patient indicated "it gave me a good understanding of what to expect before and after surgery. I didn't know there were so many risks at hand."

### **Shared with family or friends**

Most significant was the finding that more than 92 percent of the patients who were given access to the tool shared it with family and friends after reviewing it themselves. This is significant not only in the actual sharing of the healthcare information itself, but also in the finding that the patients are willing to engage their family and friends in their own healthcare choices and decisions. One patient commented, "I like the fact that my family and friends that will be helping me can see this and get a good understanding of what I will need for a speedy recovery." Having active family involvement can empower the patient to anticipate and put into place a support group for post op support or care.

### **Narrative comments**

Of interest, 972 patients across all three procedures chose to write specific narrative comments in their survey questionnaire. These comments were all individually reviewed and stratified into three categories: 1) positive comment, 2) negative comment or 3) neutral comment. Neutral comments were those instances where the patient provided additional information without opining as to the effectiveness or quality of the interactive modules.

In total, 738 gastric bypass patients provided comment, 629 (85.2 percent) of which were positive, 13 (1.8 percent) were negative and 96 (13.0 percent) were neutral. Additionally, 112 of the total hip replacement patients provided comment, 78 (69.6 percent) of which were positive, 6 (5.4 percent) were negative and 28 (25.0 percent) were neutral. Finally, 122 colonoscopy patients provided comments, 96 (78.7 percent) of which were positive, 11 (9.0 percent) were negative and 15 (12.3 percent) were neutral.

The positive comments praised the ease of use and the quality of the educational program. The neutral comments often focused on the patient's personal health and emotional state. For instance, one patient indicated an allergy to antibiotics, where another questioned whether she wanted to proceed with the procedure. Finally, the negative comments primarily involved difficulty with viewing the module on their computer and the redundancy of the content as compared to their communication to their physician.

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## CONCLUSION

Technology innovations present opportunities to engage patients in their care even before the treatment is performed. By allowing patients the opportunity to learn about the procedure at their own pace, the technology provides them the time to consider their own medical history and needs, and to reflect on these in regards to the schedule procedure or care.

The ultimate patient engagement is the acceptance of a realistic outcome based on their own medical conditions and the expectation management that occurs with this acceptance.

By utilizing this technology as part of the patient and physician relationship, providers increase the patient's knowledge about the procedure and encourage full participation in the making of health-care decisions.

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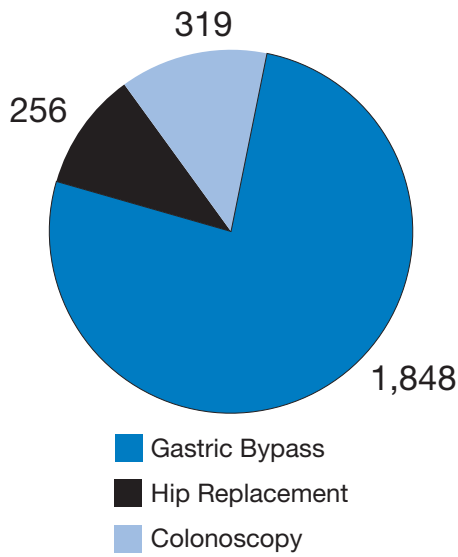
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### Chart 1: Informed Consent Issues

1. Inability to remember all that is told in the physician's office
2. Bias to focus on future gains rather than potential risks
3. Impact of social beliefs on receptivity to treatment

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**Chart 2:**  
**Volume of Feedback Responses**



**Chart 3:**  
**Patient Feedback Results**

