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Responding to Trust: Surgeons' Perspective on Informed Consent

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Abstract
Background Every day thousands of surgeons and patients negotiate their way through the complex process of decision-making about operative treatments. We conducted a series of qualitative studies, asking patients and surgeons to describe their experience and beliefs about informed decision-making and consent. This study focuses on surgeons' views.
Methods Open-ended interviews and focus group discussions were conducted with thoracic surgeons who treated esophageal cancer patients by esophagectomy, and general surgeons who routinely performed laparoscopic cholecystectomy. Their views were analyzed using a qualitative approach, grounded in the perspectives of the participants.
Results Five dominant themes emerged from the analysis: (1) making informed decisions; (2) communicating information and confidence; (3) managing expectations and fears; (4) consent as a decision to trust; (5) commitment inspired by trust. These themes are illustrated by verbatim quotes from the surgeon interviews.
Conclusions Surgeons carefully assess the risks and benefits of treatment before consenting to perform operative interventions. They are influenced by objective findings and by affective factors such as courage and the determination to survive expressed by their patients. They manage risks, doubts, and fears—both their patients' and their own—relying on trust and commitment on both sides to ensure the success of the surgical mission. The trust of their patients has a strong influence on the surgeons' decisions and actions.

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Introduction

> If I have a relationship with you as my patient, and we've gone through this together, it's harder to let go…if you get into trouble. I tend to push very hard to try to get them through.—Thoracic surgeon

Every day thousands of surgeons help patients with decisions about operative treatments. The literature prescribes a framework for thinking about this transaction that emphasizes autonomous decisions by patients and detailed disclosure by caregivers of risks, benefits, alternatives, and outcomes of treatments [1, 2]. Legal and institutional policy requirements underline disclosure of risk and prognosis; experts in ethics and law provide clear warnings against physician paternalism. Some scholars have questioned the doctrine of informed consent [3–5], recognizing problems with the complexity of medical information [6], the patient's confusion and vulnerability when ill [7, 8], and ambiguity or inconsistency among legal interpretations [9]. Some patients wish they could leave worrying about technical questions and hard choices to their surgeons; others avidly pursue detailed information about their treatment. Remarkably, surgeons and patients somehow negotiate their way through these complexities with reasonable success.

To understand this process better, we conducted a series of qualitative studies, asking patients and surgeons to describe their experience and beliefs about informed decision-making and consent. In our initial study, patients treated by esophagectomy for esophageal cancer told us that they preferred to delegate decision-making to their caregivers [10]. In a setting of vulnerability and fear, they turned over decision-making authority to an expert whose commitment and competence they trusted based on trusted recommendations from others rather than their own evaluation. Thoughtful reviewers and colleagues suggested we study the patients' perspective in a context of less frightening disease and treatment. In response, we studied patients who had recently undergone elective surgical removal of the gallbladder to treat chronic cholelithiasis [11]. These patients described a wider spectrum of initial attitudes toward surgical treatment, ranging from profound distrust to unquestioning faith. Regardless of their initial attitude and the pathway they followed through or around information about risks, benefits, and alternatives, all of the cholecystectomy patients ultimately managed their fear and doubt by making a "leap to trust" [12]. Trust in the competence and commitment of their caregivers and in the expertise they came to associate with the institution where they were treated carried them across the chasm of doubt that lies beyond rational analysis and decision-making.

In the current study, we focused on surgeons' views of informed decision-making and consent. We recorded and analyzed the experience described by thoracic surgeons who treated esophageal cancer patients by esophagectomy and general surgeons who routinely performed laparoscopic cholecystectomy. This is the surgeons' story, as told by them, interpreted by us, and taken back to surgeons for confirmation. We present it here to encourage further discussion within the profession.

Methods

Study design

We conducted qualitative open-ended interviews and focus group discussions with surgeons who treated patients suffering from the life-threatening illness of esophageal cancer, and surgeons who treated patients suffering from the less frightening condition of chronic cholelithiasis. The interviews were analyzed, and the predominant themes and concepts that emerged were presented to focus groups of surgeons for further discussion. This qualitative method of studying, grounded in the perspectives of the participants, is referred to by sociologists as a "grounded theory"; it is particularly useful for examining phenomena that involve social interactions [13, 14].

Participants

Potential interview participants were contacted personally and then sent an explanatory letter describing the study and inviting them to participate. The interview participants were nine thoracic surgeons and six general surgeons practicing in three major teaching hospitals in Toronto, ON, Canada. The interviewed participants included all of the surgeons who performed the esophagectomies and cholecystectomies on the patients interviewed in our two previous studies of patient perspectives [10, 11].

Three focus groups were then organized with convenience samples of general and thoracic surgeons who were attending Continuing Medical Education courses at the University of Toronto. Potential participants were contacted by the principal investigator, who described the study and invited the surgeons to participate in a 90-minute focus group discussion at a meeting that included lunch. The 19 thoracic surgeons and 12 general surgeons participating in the focus groups represented varied geographic settings in North and South America and diverse practice experience. In total, 28 thoracic surgeons and 18 general surgeons participated in our study.

Data collection

Fifteen face-to-face semistructured interviews were conducted using an interview guide developed for our previous studies of patient perspectives but refocused and refined through pilot testing to elicit the surgeon's perspective. The interviewers (D.M., E.I.), neither of whom are surgeons, asked open-ended questions, followed up participants' responses, pursued themes as they arose, and sought clarification or elaborations as required. Three focus groups led by the authors were both exploratory and confirmatory. They consisted of semistructured and free-flowing discussion of the participants' perspective on issues raised by the interview subjects and their critique of the investigators' findings.

Data analysis

The transcripts and investigator notes were analyzed using grounded theory analytic strategies designed to elicit themes from the data [13]. The "constant comparisons" analytic method used in this study consisted of three stages: open, axial, and selective coding [14]. During open coding, text segments that related to a theme or idea were identified and given a conceptual label. During axial coding, related concepts among transcripts were grouped into conceptual categories. During selective coding, core categories emerged as the central themes of the study. As is customary in qualitative research, data analysis began after the

first interview and continued after all the interviews were completed.

To verify our findings, we paraphrased and summarized the responses during each interview so the participants could confirm or refine our understanding. Presenting our emerging theory to focus groups that included participants from the population of interviewed surgeons provided a "member check" to strengthen the trustworthiness of our inferences. The additional members of the focus groups enriched the discussion of themes, providing a wider range of views. The lively interaction of a larger group of surgeons deepened the exploration of the issues and provided an opportunity to validate the conclusions in a larger context.

Research ethics

Written informed consent was obtained from participants. Interviews and focus group discussions were audiotaped, transcribed, rendered anonymous, and kept in secure storage to ensure confidentiality. The study was approved by the Committee on Use of Human Subjects of the University of Toronto.

Results

In all, 28 thoracic and 18 general surgical specialists reflected thoughtfully on their experience with informed decision-making and consent in rich and moving discussions of their responsibilities and concerns. Five dominant themes emerged from the analysis: (1) making informed decisions; (2) communicating information and confidence; (3) managing expectations and fears; (4) consent as a decision to trust; (5) commitment inspired by trust. These themes are illustrated by verbatim quotes from the surgeon interviews.

Making informed decisions

The surgeons reminded us that operations require both the patient and the surgeon to make an informed decision about undertaking the procedure. In discussions of the patients' decision-making process, the surgeons reported that they routinely disclosed to patients the diagnosis, prognosis, treatment alternatives, and inherent risks and benefits and were prepared to follow the patients' preferences for treatment. On the whole, they described compliance with the procedures and requirements of the ethical theory and legal doctrine of informed consent. Here is a typical description of this process.

> My job, at that point, is to outline the diagnosis, the extent of the disease, the treatment that is available, and the results of those treatments as they would apply to that particular patient. When the patient and the family have been given the data with which to make a decision, they should be making the decision, guided sometimes by me, but not told by me. And if they refuse my recommendations, that's fine.

Surgeons discussed the wide variation in their patients' level of background information and in the patients' mental and emotional capacity to make a decision regarding their care. They recognized that frightened patients with life-threatening illness seemed incapable of making an objective evaluation.

> What they want is confidence in the doctor treating them because they don't feel able to make that judgment. I would think that many patients don't even consider making that judgment. They want a good doctor, in their perception.

Important factors influencing the surgeon's decision to operate on an individual patient were described in terms of objective, "hard" findings (e.g., tumor stage, pulmonary and cardiac function) and affective, "soft" findings (e.g., courage and determination to survive—"I want to dance at my granddaughter's wedding"; a firm handshake). The surgeons explained that they might decide to operate on a patient whose estimated risk was high according to objective criteria if the patient demonstrated singular determination to recover from treatment or an intense will to live. This factor influenced the surgeons' assessment of a patient's candidacy for surgical treatment in general and for more aggressive procedures that might be required if more extensive disease were encountered intraoperatively.

> [In those circumstances] as long as the patient and the family understand the risks involved and are willing to take those risks, and you've explained clearly and documented that, then I would be prepared to proceed.

When the risk of death is unacceptably high, surgeons do not accede to the patient's desire for surgical treatment.

> Someone walks into your office today and has an esophageal cancer and you operate on him, and he dies of the operation the day after; he could have had 6 months or a year of life that you robbed him of.

They expressed intense awareness of their personal responsibility for the preoperative decision, as indelible as their linkage to the operative intervention.

Communicating information and confidence

Preoperative discussions helped prepare both the surgeon and the patient for difficult intraoperative and postoperative decisions and developments.

> [Esophageal cancer] is a disease process that requires a lot of communication between myself and the patient…and the family, and between the patient and the family. [It] is made somewhat less difficult by having discussed… preoperatively that a possible situation might arise where some tough decisions are going to have to be made. I think it helps, but it's nonetheless quite a difficult thing.

The descriptions of the surgeons' experience with communicating information about cholecystectomy were less charged emotionally and more fact-based, harmonizing with our gallbladder patients' descriptions: "The surgeon told me nothing new; I had heard it all before" [11]. Cholecystectomy surgeons expressed their concern that the patients be exposed to a fairly detailed account of what they should know about their disease and its surgical treatment, regardless of their prior level of knowledge.

> It's a teaching and learning process. You're teaching the patient about the disease, the recommended treatment, and other options…. The learning side is developing an understanding of who the patient is, where they live, and how what you do is going to influence them afterwards.

The comments and experience of general surgeons who perform liver transplants and complex hepatobiliary operations as well as cholecystectomies reinforced the sentiments of the thoracic surgeons, who emphasized the importance of instilling confidence and trust when discussing more frightening disease and treatment.

Managing expectations and fears

The surgeons' account of the expectations of patients referred for treatment of serious illness matched the views of patients in the esophagectomy study [10] who said, "It's cancer; it has to come out." Surgeons told us that:

> most patients today are quite informed by the time I see them. They want an operation…they come expecting that they've got a cancer, and I'm going to take it out…. They equate surgical excision with cure or potential for cure, and nonsurgical [treatment] with no cure and abandonment and death, and a lot of times that's true. So they want it badly.

The surgeons used information about outcomes and the experience of the team and the institution to reassure and encourage frightened patients with life-threatening illness.

The general surgeons emphasized the importance of ensuring that patients were sufficiently aware that laparoscopic cholecystectomy carries serious risks despite the apparent simplicity and safety suggested by minimal access incisions and a short hospitalization.

> The patient's perception…is like they're coming in and getting a haircut. They have no idea…. I tell every patient "don't forget this is major surgery inside; it's minor surgery outside." One general surgeon told us, "I usually tell them what the chances of dying in the operation are; it's the ultimate complication…. I tell them ahead of time that every operation, even the simple ones, are sometimes followed by some sort of complication…so they know in advance; and when a complication occurs, it's a big disappointment but not a big surprise.

A particularly troublesome issue was the management of the patient who is determined to be treated surgically despite prohibitive risk.

> One of the most difficult things to deal with is to convince them that they're better off without something…. They come to you thinking you have the magic answer, and they want you to say that. They don't like to hear the opposite.

This prejudice in favor of surgical treatment can become almost irrational when it is intensified by despairing fear of the progression of untreated cancer.

> I can't live with the thought of having cancer inside me. I want to take my chances and either die on the table, or, if I have a little chance of making it, I want to take that chance.—Esophagectomy study, unpublished data

For managing this problem, the surgeons distinguished with moral clarity between (1) their duty to operate to rescue victims of trauma (e.g., ruptured aorta or other injuries they themselves had not caused) despite a high risk of immediate death and (2) their justifiable refusal to perform elective operations that put a cancer patient at unacceptably high risk when there is no immediate prospect of death from disease but a poor longer-term prognosis.

The surgeons' comments reflected their awareness of the affective impact of their meeting with the patient, and how their manner, gestures, and tone could help patients manage fear and doubt. This psychological contract transcended the ritual of written consent.

> Informed consent starts when you shake hands with the patient because the value of information that goes from one individual to the other is based on the relationship formed in the short time that you have with the patient…the kind of eye contact, the dialogue, the body language and gestures that have a patient or a doctor say, "yes, I like this person, they

> seem to know what they're talking about, and I'm going to take their advice."

Consent as a decision to trust

The surgeons preferred to discuss the operation simply and directly with patients and families, attending to the signals of comprehension and concern.

> When I explain the nature of the operation, the risks and benefits, the options, what we do, and what they can expect to do when they get the operation, it's at that time that I try to assess how much they understand…what they want to know, what they don't want to know.

Surgeons disliked but accepted the bureaucratic, ritualistic aspects of discussing the planned treatment using the hospital consent form.

> I don't like it, but it's part of the thing you do, so you just do it…it's just part of the process…. It may be a necessary evil…but it changes from a discussion where you're on the same wavelength to a discussion where you suddenly become adversarial…now they have to commit themselves by signing their name.

Nevertheless, they accepted the necessity of reading and signing the form, indicating that it was good for both the surgeon and the patient because it required both parties to formally acknowledge and discuss some uncomfortable issues. The transaction provided an occasion to be sure the patient was told the things they needed to know.

> You have to tell the patients what they're in for…. I think the whole [consent] process is very important to the patient's healing,…for the patient to develop an understanding of what's going to happen during the operation, and what to expect afterwards…. In the course of talking to the patient about their outcome and family, I learn about them, how they might react, and I may be better prepared to deal with adverse outcomes.

This direct and usually decisive exchange forged the link that established trust and commitment on both sides.

> I think that's the time, when you're telling the patient the nitty gritty of the operation, the patient realizes that…by signing it they're entrusting their life to you.

Commitment inspired by trust

Surgeons described a progressive strengthening of their personal commitment to those patients they had decided were appropriate candidates for operative treatment.

> In the relationship between the doctor and the patient, that forms as soon as they meet, I think there's a foundation of empathy and respect and trust, without which nothing else happens… What we all try to do is have [that] foundation…and then you plug on top of that, "here's the problem…and here's what we can do to fix it."

Personal characteristics of the patients reinforced this bond, as did the intensity and challenges of the shared experience. The surgeons' commitment led them toward more aggressive intraoperative and postoperative management.

> [When] you're dealing with a situation that is more extensive than what you previously had thought… it's easier to approach the family and the patient postoperatively if you're more aggressive than if you're less aggressive… If I'm going to operate on those high risk patients, I'm committed to pulling them through that high risk [postoperative] period…I can't call it quits when someone gets into trouble.

Discussion of their commitment to get the patient through a difficult procedure and postoperative complications led to consideration of the cost of complex care. Surgeons told us that cost considerations should not and do not influence their decision about whether to operate. They passionately affirmed the view that the best interest of each individual patient comes first. Surgeons were adamant that the cost of a test or treatment must not bias a surgeon's judgment of its necessity, especially when the illness is life-threatening.

> I think we're in a little different situation…because esophageal cancer obstructs swallowing. You can't leave a patient like that. Cost has never been a factor in deciding the best way of treating patients… When it's obvious that a patient should be treated by this mode or that…and the hospital cost is going to be higher…that's tough, but that's the way life is… I'm not going to change my recommendation to the patient…based on the fact that my preferred management costs three times as much…or four times, or ten times.

Surgeons told us that cost considerations do start to play a role when repeated treatments appear not to be working.

> It might become a factor in my thinking down the road where things have gone bad and there are bad complications…one thing after the other, and the chances of survival are so little…you're losing the battle…the probability of succeeding is getting smaller and smaller, and the cost is getting higher and

higher. At that point it's part of our responsibility to think about those things—our social responsibility.

Discussion

Many accounts of informed decision-making and consent are framed in terms of the decisions made by patients; consent is "given" by the patient as if the surgeon were a vendor or petitioner. The surgeons in our study emphasized the other side of the transaction. They described a mutual decision about a mutual enterprise with benefits and risks to both parties. As part of this process, surgeons give their own implicit consent to accept the risks and responsibilities of performing the proposed operative treatment. The surgeons emphasized factors that influence their decision to offer the treatment to some but not all patients. The language of the surgical literature captures this concept in the term "patient selection," an important and required heading in reports of the outcome of surgical procedures.

A surgeon's decision to operate on a 92-year-old esophageal cancer patient who plans to dance at his granddaughter's wedding puts the surgeon as well as the patient at greater risk of complications; the surgeon risks criticism or rebuke by peers, even disciplinary restriction of the privilege to use hospital beds and operating rooms. Judgment in selection of such patients is a skill, and a surgeon's reputation is enhanced by good judgment about challenging cases.

The surgeons were empathetically aware of how difficult decision-making is for their patients and how incomplete their patients' understanding might be even after extensive and exhaustive disclosure [15, 16]. Their comments confirm bioethicist Onora O'Neill's [17, 18] clarifying formulation that "patient's choice" is a misnomer, generally limited to accepting or rejecting what is offered from a narrowly defined set of alternatives. O'Neill also reminds us that professional judgment is "not at the beck and call of patients." Despite the limits on patient choices in the unbalanced surgeon–patient relationship, there are significant options that can be offered to patients if we listen and customize our recommendations regarding their personal needs. Selecting a date or choosing the location of an incision or device such as a pacemaker pocket where it will not interfere with hunting or tennis, offers an enriching opportunity for surgeons to enter holistically into the world of the patient as person [19].

Communication between surgeon and patient about a proposed invasive procedure reflects the warrior culture of the specialty. Consultations and plans are direct and mission-oriented, not discursive. The conversation is like a surgical incision—penetrating, serious, only as long as necessary, and only a part of the overall operation. The time dimension is shortened and the depth is adequate and somewhat startling. Communication about the risk of death or serious complications is a visceral experience for both participants. Aware that one version of consent does not fit all candidates, surgeons titrate information to help manage fear in a dialectic exploration of how much detail to disclose. They are familiar with a variety of outcomes that could be discussed, perhaps to the patient's disadvantage and discomfort. The legal lens magnifies rare complications, leading lawyers and surgical colleagues, case-hardened by malpractice suits, to suggest that surgeons should inflict punitively complete and potentially terrifying disclosure of every imaginable problem. To manage this complex issue, most surgeons described simplifying and reducing these unfavorable outcomes into batches, such as failure of the mission of the operation, infection, and problems with healing, bleeding, or clotting. They offer the option to go into further detail about these potential problems. This usually elicits a response that the patient has heard more than enough. Foreshadowing the future without predicting it, surgeons hope they can provide some protection for the patient, the family, and themselves from the distrust that might develop if a complication ensues that was never mentioned.

Surgeons literally "en-courage" their patients, giving them courage to make the leap over the chasm of fear and doubt [11, 12]. One of the most powerful antidotes to fear is the courage and confidence of another person who fully understands the fearful prospect. Foreshadowing helps patients manage fear by familiarizing them with the hazards they may encounter on "the road ahead," a frequently recurring metaphor in our discussions of the experience of surgical treatment whose dangers are shared by surgeons with their patients. The surgeons gently foreshadowed potential problems by discussing the measures they would use to prevent or reduce the risks of bleeding, infection, and other complications. Gawande [20] and Mechanic and Meyer [21] described some of the remarkably simple and teachable behaviors and assurances that patients value during the process of developing a trusting relationship, such as eye and hand contact, sitting side by side rather than across a desk, listening, repeating the patient's statements of concern, and conveying understanding of the patient's fear and distress.

Surgeons have their own fears and doubts to manage. Ineradicably linked to the outcome of their decisions and interventions but vulnerable to unpredictable developments, they assign themselves unaccompanied responsibility for failure. Their statements "that's my death…my failure" have poetic intensity and personal meaning. Listening to their frank discussions of these feelings reminded us of the Confucian view that physicians are respected in society because they personally take on the suffering of the patient in addition to providing treatment.

The surgeons referred repeatedly to the effect of patient trust on their commitment. Karen Jones [22] described the feeling of obligation and commitment generated by trust; it bears a strong family resemblance to promise-keeping, though the promise is less explicit. The sense of obligation created by trust can become burdensome on the individual surgeon, on the institution, and on society when complications require prolonged and repeated use of expensive societal resources such as operating rooms, surgical teams, and postoperative intensive care units. Surgeons' fiduciary obligation to put patients' interest first [1], intensified by the level of commitment implicit in the ethic of surgery [23] and the powerful interpersonal bond forged by the patient's trust, makes it "harder to let go."

Limitations

Like all qualitative research, our findings are specific to the particular participants we have interviewed or met in focus groups. They are not generalizable to all surgeons or all surgical procedures. Nevertheless, they provide insight into the surgeons' experience and viewpoint, enriching our understanding of the process of informed decision-making and consent.

Conclusions

Surgeons carefully assess the risks and benefits of treatment before consenting to perform operative interventions. They are influenced by objective findings and by affective factors such as courage and the determination to survive expressed by their patients. They manage risks, doubts, and fears—both their patients' and their own—relying on trust and commitment on both sides to ensure the success of the surgical mission. The trust of their patients has a strong influence on the surgeons' determination and behavior. Trust creates a psychological contract, an implied promise to succeed, that binds surgeons to persist in their remarkably relentless pursuit of the best outcome for their patients.

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