

# The Extent of Surgical Patients' Understanding

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**Abstract** The notion that *consent* to surgery must be *informed* implies not only that information should be provided by the surgeon but also that the information should be understood by the patient in order to give a foundation to his or her decision to accept or refuse treatment and thus, achieve autonomy for the patient. Nonetheless, this seems to be an idyllic situation, since most patients do not fully understand the facts offered and thus the process of surgical informed consent, as well as the patient's autonomy, may be jeopardized. Informed consent does not always mean rational consent.

## Introduction

“If all decisions by the patient could be made on an intelligent basis; if all patients had sufficient scientific background and sufficient knowledge of the human body; if the decisions of all patients could be sufficiently free of the fear of the unknown, of superstition and other extraneous influences upon the decision-making processes; if all patients were able to understand the physician and communicate with him; if the physician were not faced with these and various other impediments, doctor–patient accord would be a problem of manageable proportions.”

“LaCaze v Collier”, 434 So 2d 1049 (La. 1983)

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Surgery has five unique characteristics that set it apart from other medical specialties:[1]

- Surgery harms before it heals.
- It is invasive, since surgery penetrates the patient body.
- It is fallible, which means surgery is predisposed to human error.
- Surgical decision making is carried out, most of the time, under conditions of uncertainty.
- It is prone to risks, complications, and sequelae.

Because of these reasons, surgical informed consent (SIC) should be considered the highest point of a patient–surgeon relationship, grounded on trust and fiduciarism. John Gregory introduced the concept of fiduciarism and was responsible for the change of medicine from a trade into a profession [2]. He considered a physician must be in a position to know reliably the patient's best interests, should be concerned primarily with protecting and promoting the interests of the patient, and should be concerned only secondarily with protecting and promoting his own interests.

The first seed of informed consent can be found in Plato, who distinguished free and slave physicians, who took care of free and slave citizens, respectively, “... the other doctor, who is a free man, attends and practices upon free men; and he carries his enquiries far back and goes into the nature of the disorder, he enters into discourse with the patient and with his friends, and is at once getting information from the sick man, and also instructing him as far as he is able, and he will not prescribe for him until he has first convinced him ...”

The process of SIC includes providing the patient with the required information in three steps:

- Disclosure of information pertaining to the surgical condition and treatment options.

- The course of action recommended by the intervening surgeon.
- Understanding of the information provided by the patient and/or his or her family group and/or surrogates.

Therefore, the process is not completed simply with the release of information but, for a SIC to be really valid and ethical, surgeons should try to ensure the patient has understood the information. This represents a very difficult aspect of the SIC process [3].

Ideally the patient should be able to [4]:

- understand the medical problem
- understand the proposed treatment
- understand alternatives (if any)
- understand the option of refusing treatment
- appreciate reasonable and foreseeable consequences of accepting the proposed treatment
- appreciate reasonable and foreseeable consequences of refusing the proposed treatment
- make decisions not substantially based on delusions or depression.

But is ‘informed consent’ to surgical treatment an oxymoron? While the concept of consent is old, the notion that such a consent must be informed is relatively recent. Informed consent may be described as “when information is disclosed by a physician to a competent person, that person will understand the information and voluntarily make a decision to accept or refused the recommended medical therapy or procedure.” [5]

The need for patient understanding is self-evident: providing surgical patients with the necessary information facilitates decision making and enhances autonomy only if patients are able to understand that information. Confusion remains about the boundaries of the duty of surgeons to ensure that patients understand the information provided, and this gap is seen everywhere and at all times. Honesty and integrity of the surgeon and a trusting patient–surgeon relationship based on fiduciarism, with strict adherence to ethical principles and behaviors, can solve most problems arising from the understanding of surgical therapeutic options. Often, legal documents and forms interposing between patients and surgeons only serve to harm their relationship.

Yet, the ability of individuals to understand the information provided and make decisions in their own best interests may be questioned based on knowledge gained in the last 35 years regarding health literacy and the cognitive and intellectual limits to decision-making skills [6, 7]. People receive little training in health decision making and as a result rely upon very simplified arguments. These heuristics may serve them reasonably well in many situations, but can lead to serious mistakes and especially to manipulation, according to how options are introduced. If

the purpose of information is to make patients informed, knowledgeable, and able to take rational decisions in their own best interests, the notion of consent as informed may be considered a legal fiction [5]. This is why it is so important to address these issues from an ethical point of view.

The process of SIC should ideally be long enough that the surgeon and patient can build a space of mutual understanding about the illness and the treatment. However, this situation often cannot be achieved due to time constraints, number of patients, lack of resources, hospital processes, and other factors. Therefore, the patient enters the process of surgical healthcare losing his or her individuality.

The SIC process is the best and sometimes the only means to modify the usual vertical and paternalistic relationship between the surgeon and the patient and/or the relatives into a horizontal perspective, where *one* shares with the *other* the risks and contingencies that shall intervene while trying to solve the disease in the most beneficial and least invasive way. This important action enables the patient to take part in the decisions that he or she will live with during the therapeutic process and is a key aspect of the patient–surgeon relationship.

From this point of view, the acting surgeon should consider three important elements:

- The awareness that *one* is relating to the *other*, a person who wants and demands the acceptance of his or her autonomy.
- The understanding that this connection takes place in a field of communication that has precise foundations in the employment of language.
- The acknowledgement that the surgeon is dealing with an individual who suffers not only from a disease but also from the burden of suffering, in a subjective condition of fear and uncertainty, knowing that besides his/her rights, he/she has no other means to control his/her illness and that the therapeutic process of healing is in the hands of a third person.

Humans are beings that speak; then language is only a tool for mutual understanding with the desire to know and reach the other. The understanding between human individuals is based in two fundamental pillars: culture and language, which are the founding framework of SIC.

The word should be the tool that doctors and surgeons must thoroughly understand, depurate, and enhance, because physicians are those with the knowledge of the history, origin, and evolution of disease, and therefore are able to provide the ethical contents to such an important process: the SIC. This is the process where the art of language shows up in all its greatness, art that can connect minds, retaining each other’s cultural and social

background, and convey with simple expressions the information required to understand all aspects of the illness, including different therapeutic alternatives so the patient can achieve a free and autonomous decision.

The patient has no other option. When confronted with decision making, even if well informed, he or she will decide in a field of uncertainty, and there is even the possibility that the patient will choose to ignore the condition and refuse to make a decision, or decides to face the situation and keep a dialogue in which the surgeon must follow a strict ethical conduct whose only bounds are the legal frame and the *lex artis*. When the patient–surgeon encounter takes place, the surgeon must be aware that the *other* is in need and thus in a weak position.

The surgeon must ask his or her conscience what attributes he or she must display to make sure this asymmetrical situation does not harm the patient, and this answer encompasses an ethical dimension. Besides, when someone, voluntarily or not, is exiled from his or her own culture, it is very important to allow that individual to keep his or her own identity, because the firm belief that his or her identity has a strength, a value, and a nurture will allow him or her to face and interact with another culture.

Gaps between the theoretical and legal doctrine of SIC and daily surgical practice are a concern for the worldwide surgical community. [3]

In light of cognitive limitations, the legal rhetoric of informed consent appears unreasonably optimistic about the ability of information alone to guarantee that patients will make decisions in their own best interests. Many courts have recognized that the informed consent laws place surgeons at the mercy of unhappy patients who, enlightened by perfect hindsight, assert that their decision to accept treatment was in error.

One area in which patients and human beings exhibit difficulty is in the intuitive assessment of uncertain events, often resorting to heuristics (simplified decision rules), which can be useful but tend to lead to suboptimal decisions. In that sense, people may estimate the frequency of an event by the ease with which they can remember instances of it happening. Therefore, the risks may be exaggerated when individuals have prominent, available experiences with them. On the other hand, risks with which a patient has no familiarity may be subjectively underestimated, leaving the patient unhappily surprised when the risk happens. Many times they firmly believe ‘it can’t happen to me’. Even when probabilities are perceived accurately, the way in which potential outcomes are presented or framed to a patient may still affect the final decision to accept or refuse surgical treatment.

Every single surgeon worldwide is confronted with the dilemma of what to inform the patient regarding his or her condition and the proposed treatment in order to be

faithful, truthful, and ethical. Many will consider that explaining common risks (even if they are not serious) and very serious risks, such as death or severe injuries (even if they are not common), is enough. But the spectrum is so broad that, many times, more precise guidelines are needed. Besides, the real dilemma is whether the surgeon should comply with the law or with the real needs of his or her patient. By asking the patient about specific concerns, the surgeon can invite the patient to let him or her know of any ‘special’ informational needs they may have that are not obvious to the surgical team. Many standards have been developed to answer the question of how much information is considered adequate, the most useful being the so-called ‘balanced model’, based on the most important and relevant interests, values, and goals of the patient, as identified by the patient and his or her surgeon.

However, the issue of understanding remains. We must distinguish the capacity and the competence of a patient when confronted with providing consent. Capacity is a legal concept and is presumed to one who is an elder, while competence is the ability to understand the information relevant to a treatment decision and to appreciate the reasonably foreseeable consequences of a decision or lack of a decision and has to do with the sphere of cognition. To make things worse, a patient may have the capacity to provide SIC but is not fully competent to do so, since his or her cognitive competencies are impaired and not due to any mental disease but simply to limited health literacy.

Cognitive competency includes all the mental and superior processes that develop and participate between the reception of information and the reply to that information. They include all complex mental functions that operate upon the perceptive representations or those recovered by memory in different intervals and include perception, reference, appraisal of similarities, classification, storage, information recovery, logic deduction, schemata, language manipulation, thinking, and memory [5].

All these characteristics and properties are included in the concept of health literacy and comprehension, which are defined as the ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions and follow instructions for treatment and postoperative recovery [8]. Different instruments measure cognitive capacity and health literacy, and practicing surgeons should be aware of them (Mini Mental State, Realm, etc.).

Some predictors have been defined regarding the rate of comprehension during the SIC process, the total consent time being the strongest [9]. Others are race, ethnicity, age, and type of operation.

It is also worthwhile to know the opinions of the surgeons and anesthesiologists regarding the disclosure of risks and complications, in order to comply with the legal

requirements of the SIC process. In their research, Osuna et al. [10] found that 22 % of the surveyed surgeons consider disclosing information about potentially harmful risks may be worrying and disadvantageous, 38 % consider informing patients about details of alternative treatment modalities confusing, and 20 % think that discussion of risks may dissuade the patient from undergoing a beneficial procedure.

Nonetheless, there is agreement about the poor retention and/or comprehension of the information provided during the SIC process. All researchers have reported similar results regarding the retention of topics after preoperative consultation [6], the limited understanding of the risks of the procedure, [11] or admissions of not reading the consent form. [12]

The minimum and desirable standard should at least include the following:

- overall understanding of the provided information
- evaluation of the amount of given information
- comprehension of the risks
- comprehension and understanding of the benefits related to the surgical procedure.

However, a recent meta-analysis of 23 studies [7] concluded that an adequate overall understanding by the patients of the various aspects of the SIC was reported in less than one-third of the studies, and the degree of that understanding was in fact not satisfactory; an appreciable proportion of patients did not comprehend the risks of the planned surgical interventions. Similar results have been reported by Mulsow et al. [13]

A critical requirement to a surgeon–patient relationship built upon trust and respect of patient autonomy is that patient autonomy should be respected and enhanced. Following these principles, surgical patients consenting to an operation being performed upon their body should have a reasonable – if not perfect – understanding of the nature and characteristics of the procedure, along with the options, potential risks, and outcomes of the proposed action, so as to follow the guidelines of Judge Benjamin Cardozo who stated in 1914, “every human being of adult years and sound mind has a right to determine what shall be done with his body.”

The SIC process concludes with a legal document requiring signature by the patient, thus indicating, a priori, that agreement was reached regarding the therapeutic options, discussions were maintained, and clear options were dismissed. But signing the document (‘the paper’) is considered a legal burden. Moreover, most of the time, this form is signed without any additional reading and thus loses the essence of its real utility.

So, while SIC is the cornerstone of the ethical conduct of a surgeon, as crystallization of the principle of respect

for patient autonomy, there is a contrast between its theoretical considerations and the real world.

In conclusion,

- The understanding of the information provided raises the neglected problem of whether surgical patients have the cognitive abilities to employ that information to make well grounded choices regarding their treatment.
- More detailed knowledge is required about how patients and their surgeons interact, leading to an understanding of how communication can be developed and improved.
- It must be understood that the SIC – though a legal instance – is an ethical encounter between two individuals, one with a need to heal his or her disease and another who has the expertise, wisdom, and knowledge to provide surgical healthcare. Hospital processes involving information disclosure, communication, and understanding of each side should be improved.
- Health literacy and its impairment is a very sensitive issue, and ethical principles should be taken into account for the resolution of conflicts.
- It is wise to remember Justice Bray’s decision in *Salgo versus Leland Stanford, Board of Trustees* (1957), which was the first where the term *informed consent* was used. The verdict stated: “... at the same time the physician must place the welfare of his patient above else and this very fact places him in a position in which he sometimes must choose between two alternative courses of action. One is to explain to the patient every risk attendant upon any surgical procedure or operation no matter how remote; this may well result in alarming a patient who is unduly apprehensive and who may as a result refuse to undertake surgery in which there is in fact a minimal risk; it may also result in actually increasing the risks by reason of the physiological results of the apprehension itself ... The other is to recognize that each patient represents a separate problem, that the patient’s mental and emotional condition is important and in certain cases may be crucial, and that in discussing the element of risk a certain amount of discretion must be employed consistent with the full disclosure of facts necessary to an informed consent ...”
- “Your patient has no more right to all the truth you know than he has to all the medicine in your saddlebag ... he should only get just so much as is good for him ... Don’t be consistent, simply be true” [14]

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