

### **Informed consent for surgical care in East Africa**

#### **ABSTRACT**

In the developed world one of the pillars of ethical conduct in surgical practise is informed surgical consent. In low income developing countries only a few researchers have explored the practise of surgical consent pre-operatively. During the informed consent process, independent decision-making and autonomy are recommended by the World Medical Association (WMA) Declaration of Lisbon. Family and cultural background, education, religion and socioeconomic status may all influence informed consent in surgical practise. This review reports the author's personal experience of the practise of surgical consent among surgeons in Uganda and reviews the specific challenges faced in East Africa. In Uganda, administration and documentation of informed consent is still inadequate. Better medical ethics education and proper communication skills in medical schools needs to be addressed. Refresher courses on medical ethics and communication skills may also be necessary for fully trained surgeons.

*Keywords: informed consent; Uganda, East Africa; medical ethics; communication*

#### **Introduction**

Globally accepted guidelines on informed consent were only produced in the 20<sup>th</sup> century although surgical practise has been guided by ethical principles for centuries. Documents from the ancient Egyptian, Greek and Roman civilisations have shown how patients had to agree to doctors' interventions (1-3). In Europe, Christian physicians carried out much of the medical care and also became renowned for the care they gave to their patients. However they adopted an authoritative attitude towards their patients. They had the financial advantage, influence and had the tools to cure which gave them the power. For centuries, Christian physicians were a powerful figure in society resulting in poorly educated patients rarely having the confidence or knowledge to disagree with them (1).

In the 1950s, the term 'informed consent' appeared after discovering that during World War II, Nazi party doctors had been performing experiments on unsuspecting prisoners. This resulted in a growing recognition in the medical community that medical or surgical intervention should require the patients' agreement and also be legal (1). In 1981, the World Medical Association Declaration of Lisbon published the first draft in the World Medical Association (WMA) as a declaration) (3).

In 2015 this declaration was updated and highlights the duty of surgeons and physicians to ensure autonomy and justice of patients. The patient has the right to the information which is necessary to make his/her decisions and the right to give or withhold consent to any diagnostic procedure or therapy (4). Patients' autonomy should always be respected in order to respect the patients' rights as an individual but also to make decisions that may affect their lives (5-9). It should be noted that one way to ground respect for autonomy is respecting individuals' rights.

Surgery is an invasive practise with a higher intensity and frequency of association risks compared to general medical care. Therefore a more rigorous consent process for improved shared decision making is necessary. In order to role model for their students, surgeons should be well grounded in professional and ethical practise in University teaching hospitals (10). Nowadays surgeons are expected to ensure that their patients understand the clinical information given to them to the best of their capacity and then voluntarily authorize the procedure (4). This legal ethical framework has gained universal acceptance in East Africa and globally and should be applied in surgeons' everyday practise.

### **A personal experience working in the first two weeks in General Surgery in Northern Uganda**

Whilst practising emergency surgery in the rural part of Northern Uganda apart from lack of resources, diverse challenges were encountered in obtaining informed consent from patients. There was hardly any room for independent decision making among the female patients irrespective of age (10). Out of fifty (50) adult patients operated on by one foreign surgeon, twenty five (25) verbally consented with the help of a Ugandan doctor as a translator. Whilst the other twenty five (25) were fluent in English and did not require a translator. The consent process involved explaining the procedure, reasons why the surgeon thought they needed the operation, consequences of not having the surgery and complications that can occur post-operatively. Time was also given for the patients to answer any further related questions. Out of these fifty (50) patients in this group, forty (40; 80%) requested for the agreement to treatment by another family member which was either the wife or husband in thirty (30; 75%), mother-in-law in (9; 22.5%). Only one (1; 2.5%) patient requested for another family member in particular his brother in the decision-making.

When treating minors a further challenge was encountered in the application of informed consent. Out of a total of twenty (20) patients there were five (5; 25%) patients under the age of 18 years requiring an emergency laparotomy. They came to hospital on their own and were only accompanied by another minor. The surgeons' acted in what was deemed in their best interests to have the operation even though no clear legislation was in place for unaccompanied minors. For a trained surgeon it may appear obvious to make a decision based on the patients' best interest. This diminishes the need for informed surgical consent. However reality is more complicated and patients hold their own perspectives on surgery performed on them. The risks perceived vary upon their beliefs and personal values (11).

In many parts of rural East Africa, colostomy management is a problem because of unacceptability, unavailability and unaffordability of colostomy bags (12). A limb amputation may also drastically affect the quality of life of the patient. A challenge with performing these surgical procedures in rural parts of East Africa is education in stoma care and postoperative physiotherapy. There is also a social stigma associated with mutilated patients returning to rural societies.

Surgeons' tend to face a dilemma when performing a fifth or sixth caesarean section on a woman living several miles from hospital in rural Africa. Birth control is still difficult in many situations and having another pregnancy may result in a ruptured uterus which may prove to be fatal. Surgical options are limited whilst these situations are not uncommon and some surgical colleagues of the author have performed tubal ligation without informed consent from the patient.

## **Discussion**

This review focuses on the challenges faced and the practise of surgical consent in low income developing countries in East Africa. Studies conducted in Sub-Saharan Africa have looked at the effect education has on consent discussions. The knowledge of practise in informed consent showed an increase with the level of education. The reasons for leaving all decisions to surgeons included trust (faith in the surgeon's knowledge), beliefs (leaving their health in the hands of God) and an inability to understand the information provided by the surgeon (13).

It is the surgeon's attitude and knowledge towards informed consent which determines its effectiveness although the patients' education plays a vital role (14). In some parts of Sub-Saharan Africa the demand for medical students is growing however clinical ethics teaching is still limited (15). A study conducted in Nigeria in 2015 showed that poor communication between doctors and patients is often reported and that only 37.5% of final year medical students were satisfied with their knowledge in medical ethics (15). The practise of informed consent in surgical practise should involve a sufficiently details conversation between the surgeon and the patient. An improvement in surgeon-patient discussions is needed in Sub-Saharan Africa.

In a study conducted in Uganda, consent was found to be obtained from nurses that may have little knowledge of the procedure and before each surgical procedure only half of the surgeons reported obtaining informed consent (16). In this study the respondents stated that very often patients are so many that surgeons did the operating whilst nurses would help in consenting which is a form of task shifting. Other respondents indicated that informed consent was obtained by the anaesthetic clinical officers or the anaesthesiologists. These findings highlight the fact that the practise and knowledge of an adequate informed consent process are not well appreciated by many surgeons (16). The same study which was conducted in a University teaching hospital showed that only 24% could identify the surgeon performing the operation and 17% of patients did not know which type of surgical procedure was performed on them (16).

It should be stressed that the surgeon who is going to operate should obtain informed consent which is a continuous process which commences as soon as the patient meets the surgeon and should continue post-operatively to facilitate the patients' understanding of the operation, anticipated risks of the operation, benefits and the postoperative follow up period. Good communication skills, ability to listen to patients' wishes and concerns, knowledge about the surgical procedure and providing adequate information is required to provide an adequate informed consent to patients by the surgeon. Busy surgical departments in hospitals in East Africa which have a lack of regulations regarding consent and are high volume patient centres may fall below the standards required for the patient to make an informed decision.

At the core of many Sub-Saharan African cultures is a strong family. In African culture, younger members of the family and children are the responsibility of the head of the family for taking decisions regarding their care and consent (17). A study in Nigeria showed that the majority of decisions (61%) were made by their husband and only 6% of women were able to make an independent choice regarding their own health. Education and wealth, religion and region of residence were amongst the factors responsible with women's independent decision-making (18).

The practise of informed consent is unavoidably influenced by financial resources. A recent study in West Africa found that relatives who contribute financially to their family member's care tend to receive more information than the patient sometimes without the consent of the patient (19).

In African communities relying on the rumours of traditional healers due to poor education may be the only source of information regarding health. In Sub-Saharan Africa traditional healers using

non-evidence based treatments are popular and 60-80% of people tends to rely on this more accessible and cheaper alternative treatment (20). These traditional healers have the acceptance, respect and credibility in rural African communities (10). Many of these communities trust shamans who possess a knowledge of healing and a special power. Patients do not participate in any decision-making process. If they are involved in the decision-making process it is interpreted as a lack of trust. This paternalistic approach may result in the surgeon being requested to make decisions on surgical care in the hospital setting. These beliefs coupled with a poor communication among hospital staff makes effective transmission of information for the patient to take informed consent difficult (19).

The practise of consent may also be influenced by the attitudes and beliefs towards health. Therefore illness is framed to be unexplainable or unjust with such beliefs and surgeons play no role in treating them however their treatment may only be accomplished through the will of God. Therefore patients tend to have no interest in consenting for a surgical procedure and have little ownership of their health and well-being.

A comprehensive approach to obtaining informed consent by developing a consent template that has an adequate amount of information to facilitate the informed consent process may be necessary given the challenges faced in our setting (11). Continuing medical education with a focus on medical ethics should be mandatory in the surgical curriculum of all trainees in General Surgery with refresher continuing medical education courses for fully qualified surgeons. Challenges associated with obtaining informed consent during surgical care are not limited to East Africa but also to other parts of the world due to different reasons (21).

## **Conclusions**

Within resource-limited settings special emphasis should be placed on surgical consent where there is a higher amount of surgery-related risk. In Uganda as in many parts of East Africa the administration and documentation of informed consent for surgical care is still inadequate in hospitals. In these professionally challenging environments better medical ethics education and proper communication skills in medical schools needs to be addressed. This will improve surgeon-patient discussions and provide an interactive environment for sufficient detail to be explained to the patient. Resources should be in place to provide comprehensible information to patients depending on their level of education. Refresher courses on medical ethics and communication skills may also be required for fully trained surgeons.

## **CONSENT**

Not applicable

## **ETHICAL APPROVAL**

As per international standard and University standard ethical approval has been collected and preserved by the author.

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