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Culture within Informed Consent: Papua New Guinea Perspective

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Abstract: This paper examines informed consent in medical practice. We have explored the notion of consent and determined its underlying theory and important attributes. We argue that consent is a permissive state of mind that waives the right to bodily integrity. Once communicated to the actor the permission takes effect by justifying the intervention and legitimizing the virtuous exercise of the doctor's power. The process is usually formally documented by the reading and signing of a "consent form" by both the patient and the doctor who is proposing the treatment that takes place within a clinical setting. Many people grow up in the traditional communities where the idea of informed consent is undeveloped and tend to be passive in their roles in the informed consent process. We have gathered from this study that people tend to stick to their traditional customs and custom has become a source of their rules, brings people together, shares food, and uses for resolving issues in family, land, water rights, and compensation following disputes. In other words, peoples' ways of life revolve around their traditional customs. Family wellbeing decisions and especially health care are usually a family matter but not an individual. Going to receive health care services at the hospital or modern health care center for medical treatment is enough to make a patient say they do not want to follow through the clinical procedure including the process of informed consent. A medical consent form is a common form used in health care facilities to obtain medical consent for a certain treatment or medical procedure or dental. We found in the interview questionnaires that many patients do not understand the use of consent forms. We examined informed consent in the context of the people's culture and how the healthcare professionals handle the situation with patients that have widespread customs, beliefs and opinions which they strictly adhere to and practice.

Key words: Consent, consent form, medical procedure, culture, customs.

1. Introduction

It would be helpful if patients would always inform healthcare professionals of any cultural or religious considerations that the care provider should be aware of but this may always not occur. When patients inform a doctor about their cultural or religious concerns in regards to medical procedure or treatment, their wishes should be met if the doctor is able to assist them. That being said, then the patient must be open to the care provider in order for the situation to be considered and to get the doctor attending to such a group of patients to determine the situation for the benefit of those affected by the cultural or religious inhibitions.

We attempt to address the issue of culture in traditional custom in this presentation. We commence with providing a brief historical view of informed consent.

2. History of Informed Consent

We will briefly state some of the historical background regarding the creation and development of informed consent as an idea. There are several events that played a significant role in the creation of informed consent as an idea. We will only note them:

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(1) Belmont Report [1] which formed the legal and philosophical basis for much of informed consent today.

(2) Nuremberg Doctor Trials in which several high-ranking Nazi medical officials were tried after World War II in regards to the medical atrocities performed during the party' period of control, and how these trials shaped the Nuremberg Code and ideal of voluntary consent [2].

(3) Tuskegee Syphilis [3] experiments in which many poor Africa-American men were studied in the United States in regards to the clinical effects of syphilis without proper consent from the individuals.

(4) The creation of a few human cell lines for research, most notably the creation of HeLa cells [4].

Atrocities such as these and many others caused countries around the world to begin forming organizations to prevent such things from happening again. Many state governments established in-country laws for the protection of human subjects of biomedical and behavioral research.

In the next segment we will attempt to discuss the legality regarding informed consent. We discuss the laws relevant to informed consent within PNG. We say at the start that in PNG no informed consent case had passed through the PNG judiciary. We then go on to discuss the general situation in other countries and the perceptions of informed consent.

3. Legality regarding Informed Consent

We noted in PNG that a right to informed consent to medical procedures is not expressly declared in any health legislation. Nevertheless this right is certainly necessary since consent of any quality to medical, especially surgical, procedures incurs some risk of diminishing an individual's personal integrity. Such procedures further imply some level of invasion of a person's privacy at his or her most vulnerable time when a healthcare professional could relatively easily manipulate the decision-making process to achieve consent to the procedure. Section 49 ("Right to Privacy") of the *Constitution of PNG*, on a somewhat liberal interpretation, imposes some measure of control on the diminution of the person's integrity or invasion of his or her privacy. This provision declares that every person has the right to reasonable privacy in respect of his or her private or family life as well as his communication with other persons and his personal papers and effects, except to the extent that the exercise of that right is regulated or restricted by a law which complies with Section 38 "General Qualifications on Qualified Rights". The principal limitations of this right are:

(1) It is "reasonable", not absolute;

(2) Its scope of exercise can be regulated or restricted by a law, in which legislative restriction is characteristic of qualified rights and the right to privacy is a qualified right, not absolute;

(3) It covers a person's private or family life, his communications with other persons, and his personal papers and effects, the first and second of which are of immediate relevance here.

It is not unreasonable to consider that matters of private life include a person's emotions, state of health, financial status, ambitions and passions, and physical and spiritual well-being. These may affect the individual's private life as well as his family life because his personal microcosm revolves in consonance with the familial macrocosm. If he is married and has children, then of course they affect his wife and children besides his parents and siblings. Either way, his private life has impacts on his family life which in turn has impacts on his private life.

A person may disclose to the spouse or a parent or a sibling his state of emotion or health, medical procedure to be undergone and sense of fear and foreboding. The right to a further disclosure, unless unequivocally permitted, is not transferred to the spouse, parents or sibling but continues to remain with the person who continues to enjoy his or her right to privacy of communication. In this way he or she retains the right to autonomy of the person.

Where such communication is made to a healthcare professional in respect of a medical or surgical or dental procedure, it means opening up the inner person where a multiplicity of emotions are at play and permitting the healthcare professional a view into the person's inner emotions. The expected return is a full and candid disclosure of the nature of the medical condition and possibilities of the procedure. This reciprocity, that is, the healthcare seeker lifting the veil of his right to privacy and the healthcare professional fully and candidly disclosing the nature of the illness and the medical procedure in return places the outcome, namely, informed consent to medical procedure, within the ambit of the section 49 right to privacy.

We noted in many countries with regard to an individual's autonomy and bodily integrity that no right is held more sacred [5] or is more carefully guarded by the common law than the right of every individual to the possession and control of his own person [6], free from all restraint or interference of another [7]. Therefore, we say that it is an established ethical and legal principle that a medical doctor or other healthcare workers who provide medical treatment or perform a surgical or a dental procedure [8] on a patient without his or her consent is prima facie guilty of either a tort [9] (or a delict) or a crime [10]. The physicians need to understand informed medical consent from an ethical foundation, as codified by statutory law in many states, and from a generalized common law perspective requiring medical practice consistent with the standard of care [11]. Many research workers [11] place a significant interest on the concept of an autonomous individual who has the competence to act independently to take personal decision on varying options, based on past experiences, values and beliefs [12]. "Autonomous person" is described as having the capacity for, and often demonstrates, autonomous action which encompasses refusal to align with desirable social norms that operationalize compulsion, and downplay reflective thinking, comprehension and insight [13]. For example, a typical autonomous participant may endorse a consent form without reading the content in a relaxed atmosphere. The same participant may be psychologically disturbed after receiving life-threatening news. This same person has been told by the family and spouse-husband to refuse the medical procedure for a customary obligation that authorization needed to come from the family members including senior clan elders before taking the medical procedure. With any of these situations therefore the patient is not able to take an autonomous action. This implies that being able to take an autonomous action in different circumstances is more important than describing an individual as autonomous.

Traditionally consent legitimizes an otherwise forbidden act and or it creates new obligations [6]. To make new obligations is important to an agreement or contract. Consent's other role is to provide the rights-bearer with the control over that right. For example, it could change an illegitimate act into a permissible one. Alexander [14] said consent functions as a moral transformative by altering the obligations and permissions that determine the rights of others' actions. This claim while may be true for consent is over inclusive. For example, in a rape case, a male boss invites a female staff to hop in the official vehicle to leave her at her home. In the vehicle the boss then demands sex from the female staff and sexually penetrates her with his fingers. The female staff says "I took the invitation to accompany the boss to be dropped off at my home. Look, I do not particularly want to have sex with someone I do not desire; in fact I do not particularly want to be made to have sex. But I would certainly rather take an invitation to drive in the official vehicle than be made to give my private parts and body to him". That surely goes to show that she attached more value to her bodily integrity in general than to her sexual integrity in particular. Indeed it does. As we saw in the *PNG Constitution* Section 49 "Right to Privacy" and the *Criminal Code Act* Section 347 "Sexual Assault", though, she is not under a duty to

show her body parts and give her body to someone else, in so far as to lose her dignity. In this case, she would well prefer parting for good working relationship rather than going through a non-consensual sex. The notion of consent is primarily about a choice, an authorization that enables an action to be consistent with the legal doctrine of consent and is consonant with much of the philosophical literature on consent. O'Neill [15] describing what she calls "the ritual of consent", expresses the view that consent is nothing more than the patient choosing from amongst a small menu, "often a menu of only one item from which to choose that others have composed and described in simplified terms". Similarly another worker Caplan [16] notes that competent individuals or patients must be given the opportunity to control the provision of medical care even if death or disability may result. We say that much of what governs informed consent in many countries is not explicitly written into law; rather, much of it comes from previous court trials and other such precedents.

In the following segments we will discuss the ideas regarding informed consent. We begin the discussion by mentioning several different views within the medical community in the study areas. We discuss a few criticisms of the idea of informed consent, as well as several suggested improvements to the consent process. Then we continue on to discuss how cultural-customary differences can complicate the informed consent process.

4. Philosophical Discussions and Cultural Understanding within Informed Consent

We acknowledge that the goal of informed consent prior to treatment has always been the same, to focus on the health of the individual patient [7]. We say that with the increasing number of people visiting the healthcare institutions and with such frequency, the issue of informed consent will come up quite often as patients have to consent to any number of medical procedures. Hospitals, clinics and other medical institutions have come up with many different ways to approach the issue of informed consent. Many healthcare professionals would sit down with patients, listen and discuss the potential results of the medical procedures, and others may suggest that a patient sign consent forms without proper explanation of the medical procedure. We gathered from the questionnaires that the only time when a patient enters the care facility is when she/he is sick and the idea about informed consent is under-developed and the majority of the people do not understand the idea. With poor knowledge of information regarding the process leading to informed consent among the healthcare professionals, the issue of patients being misinformed can be far more prevalent. The situation could turn out badly between the care provider and the patient; it could potentially push away the patient, and open the door for the patient to be misinformed when going into a medical procedure. The term "informed consent", as the phrase suggests, requires consent to be acquired after the administering of relevant information to the patient. Valid consent further suggests a need for validity regarding the patients' decisions, and ultimately their consent [17].

Cultural traditions are a driving force in the lives of the majority of the people in the study areas and the issue of informed consent is no exception. One such example was a female patient attending a family planning clinic who was removed by her husband not to listen to family planning health education given by healthcare educators. Within the male spouse culture there is a strong desire to have a son in the family and this was a strong feeling expressed by the husband's parents and his family relatives. The wife did not like to have another child as she already had more children to look after and the children were still young for her to expect another child soon. In a similar situation a young male must seek authorization from his parents before receiving healthcare because his parents must know first his illness. Healthcare professionals would rather provide the individual's medical information to the patient's family than to the patient. In both cases,

the family needs are more important than the needs of the individual. This cultivates the idea that the patient takes a passive role in their health care which is in great contrast to western and developed countries. Given those situations, in order to properly convey the ideas to the patient, healthcare professionals need to resort to awkward translation and phrasings. For instance a healthcare professional needing to create a legal document to obtain consent has to resort to other means like speaking and understanding the local language, and should have significant understanding of the people's ways of life and their traditional customs within the local settings. This would result in less confusion among the patients and their families.

The impact of religion in addition to cultural differences also cannot be ignored. Many religions take issue with several medical procedures that hospitals typically perform, for example, when quick action is needed and consent may not be taken within the time-frame needed to save the patient, most notably in the case of Jehovah's witnesses. This study presents its findings regarding the study of informed consent and how doctors obtain it and handle the situation of patients with widespread customary and cultural differences.

4.1 Medical and Cultural Situation within the Study Areas

There are many people of different cultural groups, most of whom would require medical advice at some point in their lives. We used qualitative research approaches and interviewed the participants within the medical settings in order to understand the situations people with cultural difference experience when seeking medical advice, and to understand the information presented to such people in order to obtain their sufficiently informed consent.

Among the patients studied, based on their responses and narratives it became obvious that there is a prevalent concept of "paternalistic" care. This concept refers to a sort of behavior wherein "the paternalist" is aware that his or her actions may be opposed by the patient if she/he knew about it. The paternalist expects that in the long run the patient will agree that the action was correct [18]. The idea behind this action is that the doctor thinks she/he knows best. The patients said it is not necessarily a bad thing if they assume at some point that they will agree to consent to a certain treatment. We noted as well that if the doctor felt that the patient is responding to the treatment well, then she/he ignores the request if it is good for the patient. We argue that a patient has ultimate knowledge of what would bring them the most happiness and as such this sort of behavior of the doctor is inexcusable. Ideally a patient should be informed of all or any alternatives to their treatment including the severity and probability of any complications which would arise. We gathered through the patients' interview that they have customs, customary rules, cultural beliefs or religious beliefs which would affect the patient's own personal decision(s), and though they may not be backed by any scientific evidence, they are still completely relevant to the patient's final decision, and so the information given should be relevant to that [19]. Others may argue that there are certain situations in which someone must be making decisions for the patient. Young adults in the Manus Province of PNG depended on their parents to make important decisions including health. In a similar situation a child who does not want the pain of an injection, for example, would likely have his or her decision overruled by a parent or doctor. There may be cases where paternalistic behavior is necessary but it can easily be viewed as a denial of a patient's rights, even though it may be in the best interest of a patient's health [19]. It is known that when a patient is not capable of giving consent to a procedure, someone must assume whether the patient would consent or not. Trust is a basis of any relationship [15], but may be more salient in relationships characterized by vulnerability or by imbalance in power or capacity [20] such as in the case between the patient and the physician, where the patient is quite literally dependent

on the doctor for his treatment to give him happiness or endure the sickness. In the case of a patient with serious illness, such as cancer, it is therefore not surprising that few patients in this study described how they relied upon their physician to help them navigate their way through difficult decisions [21]. Many patient-participants demonstrated understanding about participating in this study. Inadequate access to health care and other poor socio-economic factors amongst the people could have affected many others who would have liked to participate. Perhaps there were patients who were so sick that would have contributed as well their sense of compulsion to participate. However no participants were turned away from participating in the study. Consent undoubtedly has a discursive basis; it is always associated with a choice. It is found in this study that only few patients have signed consent forms thus agreeing to the procedures or treatment. We found as well in this study that not many patients knew what consent form is and its purpose.

Patient-participants were told of their right to withdraw from the study at any time. This study noted that better understanding of the study and its conduct increased the interest of the patients to participate. A few patients were educated to the post graduate level and explained the research goals to other patient-respondents, encouraged them to enroll and participate in the study. It is a practice by patients that family members and spouses may give consent for and on behalf of the patient and this happened when few patients requested that they needed help to translate during the clinical meeting with the healthcare professional. The issue here is that such presumed consent assumes that the individual does not have any special cultural, religious, or other requirements that would make them go against the norm. Similarly implied consent only works if one knows the individual in question well enough to make that sort of judgement call. In emergencies where a patient may be unconscious or otherwise unable to give consent themselves, it can be quite easy for the medical community to accidentally assume consent that would not be given [22]. In the present study many patients have no issue with the doctors over this action if indeed to happen, and applaud the doctors prompt actions in times of emergency.

4.2 Criticisms of Informed Consent

In general the challenge with the idea of informed consent among the participants in the present study comes with the fact that the Western ideal of medicine comes from Western ideologies. The idea that one must freely choose what they do has been the concept of informed consent when it was first brought up as an idea in court cases and in its key founding documents such as the Belmont Report [1]. However the idea of personal freedom is brought in through Western ideas.

In many cultures autonomy does not rate as high of a concern, instead being replaced by other concerns of which there are many examples of which I name a few. Within culture, for example in PNG, valuing the family unit over the individual is normal (for example, family's authorization to receive or refuse treatment for the patient, family planning for the wife refused by the spouse); or the Japanese valuing the family unit as opposed to individual (for example right to know what goes on with the patient and receiving the test results of the patient) [23]; or the Jehovah's Witnesses refusing life-saving treatment because their spiritual needs overcome their personal ones. These beliefs are often shown in serious medical cases including cancer, where doctors will withhold the diagnosis from the patient and instead inform their family. This cultivates an idea that the patient takes a passive role in their health care, which is in great contrast to the more Western ideas of informed consent.

These examples illustrate just how the Western ideas of informed consent do not translate perfectly across cultural boundaries [22]. The customary rules in many countries deprive non-Western cultures of their proper positions of power and actually devalue their notion of autonomy [24]. The idea of informed consent had

developed and been criticized and no clear answer has come to fruition in regards to how it can best be implemented. One of the key issues when attempting to follow the ideal of informed consent with people in PNG is the fact that the indigenous people have traditional customs. Customs are unwritten rules and practices of the past which the people continue to use and embrace up to the present time. In rural areas custom is the rule and governs what goes on in the villages, amongst the people and their interaction with one another, and their attachments to their land, water, traditional sites and concerns over security and protection.

The medical care practice in the consent process, for diagnosis procedure, the explanation of risks and benefits, and all that goes on with the clinical procedure, demands significant time and linguistic expertise and even then, in order to convey the idea of informed consent one needs to resort to awkward explanations, translations and phrasings. On the medical charts and records, it states that the patient must consent first before undergoing the procedure or medical treatment that ends up implying that the patient had to consent before the doctor(s) can see them. In the present study, it was observed that the participants understood their participation, no confusion or a patient leaving the survey worried. There were no risks involved in the study and a significant proportion of participants recognized they were participating in a research as opposed to seeking medical care.

5. Methodology

We studied the participants' perspectives of gaining informed consent for routine medical procedures. We used qualitative methods by semi-structured interviews selected by purposive sampling. We examined informed consent of the doctors when interacting with patients of differing customs. We interviewed the healthcare professionals and traditional healers from several institutions in the study areas, and their practices to learn about their perspectives regarding informed patients, namely those with cultural difference; determined what the medical community describes as an effective explanation of informed consent for a standard patient and how this explanation changes with people with customary difference. Several findings came to light after the semi-structured interviewing of patients and the analysis of their interview responses. The findings show the perspectives on the medical situation through providers of patient care in private practices, hospitals, and walk-in healthcare clinics.

5.1 Interviewing the Participants

Minei et al. [7] in their study began the task of identifying the institutions where patients with cultural difference would seek medical attention. After checking the institutions he met with the healthcare authorities who deal with patient at-risk communities as the first step to seeking relevant interview contacts. His objectives were to find the relevant participants and interview them regarding their perspectives in the medical field. The research objectives were framed based on the question: how sensitive is the topic of interviewing patients about the issues of informed consent? He met with the medical services director and nursing director by meetings. Through these meetings he contacted the few doctors and nurses who assisted him to meet with the traditional healers within the medical settings. He also connected with other healthcare workers including pharmacists, dietician/nutritionists, physio-therapists, and met with the administrative staff of the healthcare facilities. Meeting dates were set and he spoke to doctors, nurses, other healthcare workers and the patients. He met with the traditional healers at separate meetings. Through this method, he was able to work out the participants of the study and the sample size (n) based on the information and observation he gathered during the meetings and some administrative information from the authorities. The participating groups were identified and he sought their permission for interviews

within the medical settings. This was a familiarization meeting with the potential participants who took about 60-90 min with each group. Because of the sensitivity of the topic studied he promised the interviewees confidentiality of the information they share through the informed consent form he gave them. He said the information gathered from the interviews with all the participants allowed him to better identify and map the process of the delivery of informed consent to patients with cultural difference.

The participant recruitment was planned for about 4-month period from January to April 2017. Multiple visits were made to the health care facilities and sites where traditional healers lived during this same period of time. The authority to conduct research came from the regulatory and gatekeepers who gave ethical and authorized approval to carry out the research. Following the authorization the principal investigator distributed the questionnaires to doctors, and nurses, healthcare workers and traditional healers. Questionnaires were distributed to the willing participants and the principal investigator made arrangements to collect them at the end of each day. Not surprisingly, none of the participants filled and or completed the questionnaires. Instead he was asked by the authorities to interview the participants during their tea or lunch breaks and meet with patients if they are interested to be spoken to. The task was a lot easier to deal with the traditional healers; they cooperated by gathering at a place of their usual meeting sites and he interviewed individuals who voluntarily came forward. The sample size dwindled to a level where the data are being used in this empirical study is based on 108 participants that were surveyed. Out of the total number the final sample size for each group is 19 doctors, 30 healthcare workers, 30 traditional healers and 29 patients.

5.2 Focus Group Discussion

Following the surveys, the focus group discussion team was set up for each domain. Participants composed small focus groups to allow for greater contribution of participants. All participants met the simple inclusion criteria, that is, any participant in the 4 groups can participate and a group can only take between 6-10 participants. Those who attended voluntarily selected themselves. There were not many differences in the participants in terms of language and culture and between the age groups. Because patients' level of participation is influenced by gender, age, and educational level, participants were matched as far as possible on these characteristics. Finally a total of 36 participants took part in the FGD meetings: 6 doctors, 10 nurses and other healthcare workers, 10 traditional healers, and 10 patients. He conducted a meeting each for the 4 groups. The meeting was held with the doctor-informants to understand how informed consent is being discussed by medical practitioners and their views on the practice of informed consent. On average most of the doctor participants are educated and there were more male than female doctor-respondents who participated in the FGD meeting and interviews. The FGD meetings for each cohort were held separately in the last week of March 2018 with one-hour duration, on average. FGD meetings were held at the School of Law conference room of the University of Papua New Guinea for patients living in NCD, while doctors' FGD was held at the Port Moresby Specialist Medical Center and the nurses and healthcare workers' FGDs were held at the healthcare facility sites, and patients from Central Province (CP) met at Kwikila District Hospital meeting room. The data collected were in the form of conversation, including tone of voice, silences (words and issues), and body language. Data collection was audio-taped or digitally recorded. Video camera was used and all materials from the meeting were transcribed by the principal author. All interviews were audio-recorded and transcribed verbatim. The memos supplemented interview data by documenting the date, time, and location, along with notes of the ideas and new insights related to the responses and interview procedure. Written consent was obtained by him before each meeting interview. At each meeting an individual

informant discussed his or her perception of informed consent, he reviewed this again with them, and asked if they had any questions or liked to say other things, however no participant said anything more.

The principal investigator gained anecdotal interview data from the healthcare facilities staff that did not fill out the consent forms. He also spoke with individual academic staff from the School of Medicine & Health Sciences and School of Law of the University. The responses from these interviews showed different perspectives of the patients' and the providers' situations in different locations of the medical community in the National Capital District and Kwikila District in the Central Province.

5.3 Mapping the Delivery of Informed Consent

In order to check the effectiveness of the current informed consent processes, we aimed to uncover what sorts of methods or models of consent were used for the purpose of obtaining and conveying information to patients by the physicians from the healthcare facilities they worked in. We uncovered these relevant findings through the surveys and the FGD meetings with the participants in this study. To ensure our findings were prudent we were effective and time-efficient, and the principal author explained the purpose of the research to the authorities and the participants—doctors, nurses/other healthcare workers, traditional healers, and the patients.

The doctors are the main means through which patients will interact in medical settings and so addressing their relationships with the patients was thought to be the key to understanding how informed consent unfolds in practice. Thus interviews with doctors focused on how patients and doctors treat each other, as well as how doctors interact with patients with cultural difference. We also looked at the medical culture that has formed around the idea of informed consent, in order to better understand the attitude medical officials possess towards the informed consent process [25].

All the other participants namely the nurses, other healthcare workers and traditional healers, all deal with the different nuances of the informed consent process and as such they too were interviewed. Each group was asked a set of questions depending on his or her type of work. Each semi-structured interview included identical background questions as well as questions attempting to target the same general concepts regarding informed consent and other such topics. Through familiarization with all the participants, this study also uncovered the other potential group who could participate as well; these were the translators who assisted those who were unable to speak well or not able to speak. They were not given consent to take part in the study.

5.4 Analysis of the Situation of Patients of Cultural-Custom Difference

The principal author interviewed the groups of healthcare professionals and the patients. He did this to understand and discover social perspectives that were developed within the medical community around its treatment of patients. He also interviewed the traditional healers who directly interact with the patients, particularly those who prefer to seek treatment outside of the modern healthcare facility or had withdrawn from treatment or refused treatment from a formally-recognized healthcare worker. There are others whose accessibility to the modern care facilities is difficult due to distance or invalidity to meet the medical expenses or concerns over the cultural, customs or linguistic differences. This group may be captured by the traditional healers. Interviews with the traditional healers aimed to answer how groups that are less accessible to the medical community are communicated with in their local traditional healing settings. Interview questions with traditional healers focused on how healthcare professionals react towards patients who cannot easily communicate, as well as any challenges that they have encountered in conveying concepts to the patients. In this study the healers do not

understand the concept of informed consent nor practice it. The healers are heavily involved in providing caring and for treatment they use mainly herbal leaves and juice to heal medical ailments, including sores, diarrheal diseases, respiratory illnesses (cough, flu), and they provide massage to the most serious sick patients.

The principal author spoke with other members of the traditional healers' families and persons in the local settings. He spoke with clerical and administrative staff at the healthcare facilities to glean the ideas of those patients with cultural differences. By taking a look at how these other people view the patient-participants he attempted to obtain an idea of how the patients consider these topics. It is not good to only get the information directly from the patients themselves but this information from healthcare professionals and the traditional healers grants us valuable perspectives of the informed consent process between patients and the medical professionals.

5.5 Rationale for Methods

There was no one particular method used to collect information. The circumstance of a patient-participant with a significant cultural difference receiving informed consent information seemed quite awkward and so the observation of how this was avoided is crucial to this research. To interpret different points of view of people as meaningful, this study facilitated the meeting allowing the participants to speak and construct the cultural meaning of sharing information conscientiously. Rubin and Rubin [26] describe this as responsive interviewing and the approach this research used. The principal author established a relationship during the interviews and generated ethical obligations to interview. It was sort of an open-ended, discussion-based interviewing. He had formed a relationship with the interviewees in a way similar to how an informed consent discussion arguably should be held among the doctor and patient. We say that the open-ended questions provided a platform for qualitative interviewing and analysis. Open-ended questions as described by another researcher [28] are a proper set of questions for qualitative interviews which ignore the quantitative aspect of other question sets such as closed-ended questions.

Thus the responses indicated the levels of knowledge patients have about the topic of informed consent as well as granting this study the ability to identify where these answers are coming from in terms of the cultural influences each patient is subject to.

5.6 Challenges with the Methodology

This study observed that generally patients would do anything to get well fast if their doctors require them to do so. Actually the patients must explain their decisions, listen to their doctors and be prepared to be persuaded. Similarly the healthcare professional must do the same so long as the patient's decision is appropriate. The parties must be open to listen to each other and thus the relationship should justify imposing positive obligations on them in a mutual dialogue where they are open to persuasion. Oftentimes patients would try to simply agree with whatever it was that the doctor would recommend and would often simply go along with it in order to be treated. Few patients grew up in an age referred to as "the golden age of medicine". In the present study, the customs, beliefs and opinions of the people are prevalent in the communities and practice of these traditional norms and how the people operate their lives is also crucial to a decision to consent. In some cultures, there is also an issue over who exactly it is that the doctor deals with. While it is not common nowadays there are certain cultures in which the doctor deals primarily with the family members. Traditions and practices of different cultural groups can involve more than just their cultural upbringing. One's religion also can affect the medical practice in much the same way as cultural considerations.

Patients and the healthcare providers treating them are often concerned not only with the various cultural or language barriers during the informed consent

process, but are also concerned with economic barriers and difficulties. Economic factors are present throughout different cultures. Because of this, patients of different cultures experience economic difficulties and barriers, and make medical considerations based on these barriers. Many care providers feel that treating a patient comes first in priority, and that any sort of monetary considerations come after. Doctors at the interview said as much that doing what is best for the patient medically comes first, and usually figure out the economic concerns after the fact. This study found too that medical professionals were concerned with trust and honesty in regard to the informed consent of patients. However, we say that the process of respectfully seeking informed consent is one way that a doctor can gain trust from his or her patients and build a confident relationship.

6. Findings

We present the results from the investigation of informed consent, how medical professionals facilitate it and handle the situation with patients of cultural customary differences. The findings came following the semi-structured interviews of the participant-respondents including doctors, nurses and other healthcare workers, traditional healers and the patients. The principal author spoke with other healthcare facility staff and other persons who were in the study areas but not gave the consent forms to fill out. The responses from these interviews gave different perspectives of the patients and healthcare providers situations in different locations of the medical community in the National Capital District and Central Province. These findings show perspectives on the medical situation of PNG through providers at the private medical practices, hospitals, healthcare centers and walk-in clinics.

6.1 On Culture and the Role It Plays

For consent, it is perhaps more accurate to view consent as generating permission rather than rights *per se* [28]. Although some of those permissions may also grant rights this will not be universally so. For example consider a consent given by a surgeon to perform an operation. However, this does not give the surgeon the right to operate since the patient still retains sufficient control of his or her right to bodily integrity to withdraw permission before the surgery. In PNG, many participants would leave the procedure just before commencing it for a variety of reasons, including traditional customs, religious beliefs and huge medical costs. Particularly customs and religious belief complicate the medical situation. For example, those patients who come from Islamic cultures tend to dislike being examined by members of the opposite sex. With this situation, a doctor will insist that she/he is the only doctor in the institution who can perform a certain task or procedure, or the doctor may refer the patient to a different doctor that would meet their religious inhibitions, or the doctor would ask them to go elsewhere. In this context consent operates as a form of waiver rather than as a transfer of a right [28]. It is apparent that consent acts to transform the status of an act between the actor and the consenter. It removes the consumer's right to complain about the act. For some acts consent provides the necessary justification and where those acts are beneficial in nature consent transforms the act into a morally good one (for example, a female patient refuses to be examined by a male healthcare professional). Consent, however, is neither necessary nor sufficient to make an act "good" [6]. Where a person is unable to consent the act is still justified if it is in the person's best interest (for example, emergency care situation). Where an act is wrong then consent is unable to make it right or even justify the act (for example, an under-aged girl is being raped by an over-aged adult male). Where the act is seen as a serious wrong, such as killing a person who wants to be killed then consent is wholly ineffective and both the act and the actor are condemned (for example an offence for murder, s. 300, PNG Criminal Code Act 1974). Where an act is seen as less seriously

harmful the act remains wrong but the person's consent may excuse the actor from moral blame (for example in a euthanasia case). Thus, while consent may be sufficient to alter the rights and obligations between the actor and the consenter, it is insufficient to make a wrong act right. Consent, if it is treated as a primary right, may be equivalent in nature to the right to life or the right to bodily integrity [6]. To discuss consent in this way is mistaken [29]. Consent is not a right in the same sense as these other rights. It is not something possessed equally by all persons within the rights-holding community. Persons who are incapable of giving or withholding consent still possess the right to bodily integrity but it is not necessary to gain their consent before, for example, subjecting them to an operation. Allowing others to provide proxy consent goes some way to creating the impression that the right may be more similar to the primary right than it actually is. Consent, however, is a derivative or secondary right. In the absence of a right to bodily integrity, consent would not be required to give someone the permission to interfere with our bodies.

We attempted to look at the issue with such cultural differences in mind. Our goal was to identify and map out the process of granting informed consent within the doctor-patient relationship and to suggest appropriate models of delivery for at-risk communities of cultural difference.

6.2 The Current Informed Consent Delivery

In this study a healthcare professional, Dr. A, a senior specialist physician, said he would allow a patient with a language barrier to bring a family member or spouse or close friend of theirs as an ad-hoc translator during the first visit in case he alienates the patient (Dr. A, personal communication, March 2018). This goes to mean that the doctors are willing to forgo a proper standard clinical rule to facilitate the patient's comfort. If the patient prefers to have his or her family member speak on their behalf the doctor would not refuse because he or she wants the patient to feel comfortable and to trust that the doctor cares about the patient's autonomy. Furthermore the findings show that honesty plays a role too between doctor and patient relationship. Dr. A said doctors can get a patient to sign whatever they want, if they present it the right way. Dr. A also said he had refused consent forms where a patient was just accepting a procedure or diagnosis without thinking about it. Dr. A said when that is noticed, he sends the patient to another doctor or he gives the situation sometimes to evolve before he sees the patient again and then he concludes. Dr. A said he has seen many patients who think the doctor knows it best for him or her. He said in this case he would talk to the patient and make him or her think about the importance of the medical conditions the patient has. Dr. C, a senior surgeon, said many patients in PNG behave in such a way as to show they think their doctor knows best for them (Dr. C, personal communication, March 2018). This shows that the doctors (Drs. A, B, C, D, E and F, personal communication, March 2018) want the patient to fully understand the risks and benefits of various procedures or treatments because if they do not and just accept a procedure or treatment which could seriously alter or affect their lives, this would be harmful to both patients and the care provider. We discuss the ideas regarding the modern informed consent where culture and traditional customs of the people are widespread and there is strong belief that the needs of the family unit are more important than the needs of the individual. This implies that the modern ideas of informed consent do not translate perfectly across cultural boundaries. By applying Western-defined doctrines of autonomy and informed consent, the Western law deprives the non-Western cultures of their proper positions of power and actually devalues their notion of autonomy [22]. There was no one particular method used to select and collect data from the participants in this study on understanding customs within informed consent. We contended that culture plays an important role between doctors and patients.

Given the existing situation amongst the participants

in the present study, these examples already demonstrate that current consent processes appear not ideal for PNG doctors. Meisel and Kuezewski [31] argue that rights-based approach to consent is too restrictive and often inapplicable to the clinical realities. For them, this was important because conceived as a process of shared decision making, informed consent can accommodate both patient autonomy and the physician's responsibility for the well-being of the patient. Instead of a model characterising doctors as technical experts advising their patients who then make decisions based on their own beliefs and values, they see consent as a shared process of decision-making. The problem with this is that it conflates consent with the process of enabling patients to give a valid consent to the intervention on offer [30].

6.3 Process Leading to Informed Consent

At this point it is worthwhile to state the definition of consent [6], "a state of mind of the patient with the intention of permitting an intervention formed as the result of a mutually arrived agreement." It describes how participants in this study made meaning of the aspects of consent in the context of their own practice and experience. In the current study consent involves more than just satisfying these elements; it also involves authorization whereby a person authorizes (or agrees to) a particular course of action. It implies that the individual or a patient agrees to undergo a medical procedure which comprises many other interventions which are all necessary steps in the medical treatment. Thus any discussion about consent requires not only the examination of its elements, but also consideration of its functions in the clinical context. Some commentators say consent should be seen as a process [31]. It should be preceded by a process of information disclosure, expert advice from the physician and negotiation [31]. Consent is a process not just a form. The process demands that information must be presented to enable individuals or patients to voluntarily decide whether or not to accept treatment [32]. The process ensures respect for people by providing the opportunity for thoughtful consent to ensure that participation is voluntary. This is modeled in Fig. 1 (adopted and amended) [6].

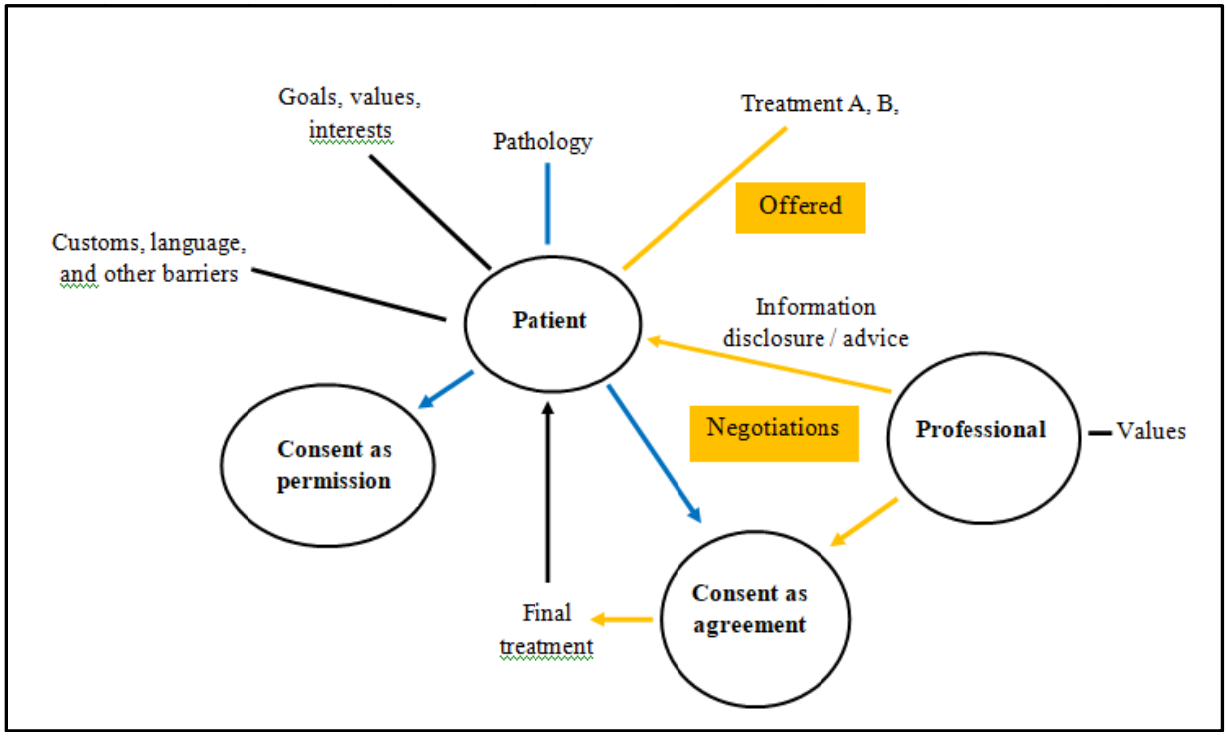

Fig. 1 Process leading to consent.

We explain the process; firstly, we say that the working definition of concept should be viewed by distinguishing it from the measurement of "subjective" and "objective" understanding. Secondly, based on the relevant literature as well as the principal investigator and author's own work experience in public health and epidemiological research on informed consent, we aim to systematize a set of methodological issues for understanding informed consent and the processes considered to obtain valid consent. In this model the medical care professional controls the treatments available. The medical care professional offers patients a choice of treatments, A and B in this case. In other situations, the healthcare professional may offer only one treatment to the patient or more than two, whether or not it is legitimate, which is independent of the patient's right to bodily integrity and is independent of consent as permission [33].

The parties (doctor and patient) are engaged in negotiations to determine the final management decision. The current study observed that the patients grew up in their local settings where the idea of informed consent is undeveloped and they tend to be more passive in their roles in the informed consent process. What was gathered in the interviews was that patients who were educated or completed college level education asked more questions in regards to what their procedures or treatment entail. This is where the process of patient autonomy meets with clinical autonomy. The patients may choose to waive their right to be involved in the decisional process, leaving the treatment choice to the doctor's discretion.

In the present study many patients leave the decision-making powers to their doctors, depending too heavily on the doctor's discretion. A male patient said the PNG doctors offer no thorough explanation of the informed consent process, and the patients do not consider the fact that they have a say in the decision. In fact, few patients told the investigator and principal author that although there is consent to take prior to the procedures or treatments, rarely do the medical professionals actually conduct this. Often they do not require their patients to sign any sort of informed consent paperwork. In fewer cases, the fact that the doctor comes in with a serious face explaining all the risks that the procedure could cause is enough to make a patient say that they do not want to follow through with the procedure. In this study he spoke to the patients during the survey field work and gave health education on informed consent. The patients were informed that before they go through with the procedure, the care provider must explain what it is as it is the policy of the institution. This model of consent is rights-based but it does not reduce the doctors' role to one of just a technician [6]. It recognizes that the doctors may not legitimately treat competent adult patients without their consent. Doctors are professional experts and the treatment options open to the patient remain under their control. In most informed consent processes, understandable written information is an important prerequisite for valid informed consent. To improve the quality of informed consent, a conceptual model for participatory procedure can be applied.

6.4 Model of Informed Consent

The framework presented needs further theoretical and empirical elaboration and clarification of several conceptual and practical challenges. It can be viewed from the above illustration that the principal investigator and author have put together the various strands of views [6] and findings in this study to create a model of the process leading to informed consent to medical treatment shown above thus as forming the basis for the Consent Model in PNG context. Finally it should be remembered that consent is a state of mind, which may change over time [6]. As such, even when patients have communicated their consent, doctors have a duty to ensure that their patient is still consenting at the time of the intervention. Generally respect for a person's autonomy is regarded as the basis for right to self-determination, independence, liberty and choice. The practical application of the principle is

informed consent. As highlighted above, various meanings have been given to the concept the most popular of which holds that right to privacy and principle of truthfulness are embedded within the concept of informed consent.

We propose an integrated conceptual model study into informed consent to medical treatment and plan an outline of the core issues for future research on informed consent in the latter. We will draw much of the discussion from the Models in Fig. 1 in the examination of informed consent in this study. In Fig. 2, we have argued that consent should be contextualized within the healthcare professional-patient relationship that grounds it. The context of the relationship actually establishes the mutual obligations that give practical substance to the theory and moral justifications underlying consent. Consent is the act of communicating the patient's mental attitude to the healthcare professional regarding what she/he proposes to be done to the patient. Consent is predicated on the patient's personal autonomy and his or her responsibilities and it must also account for the healthcare professional's autonomy and his or her responsibilities. The patient takes control over what happens to him or her just

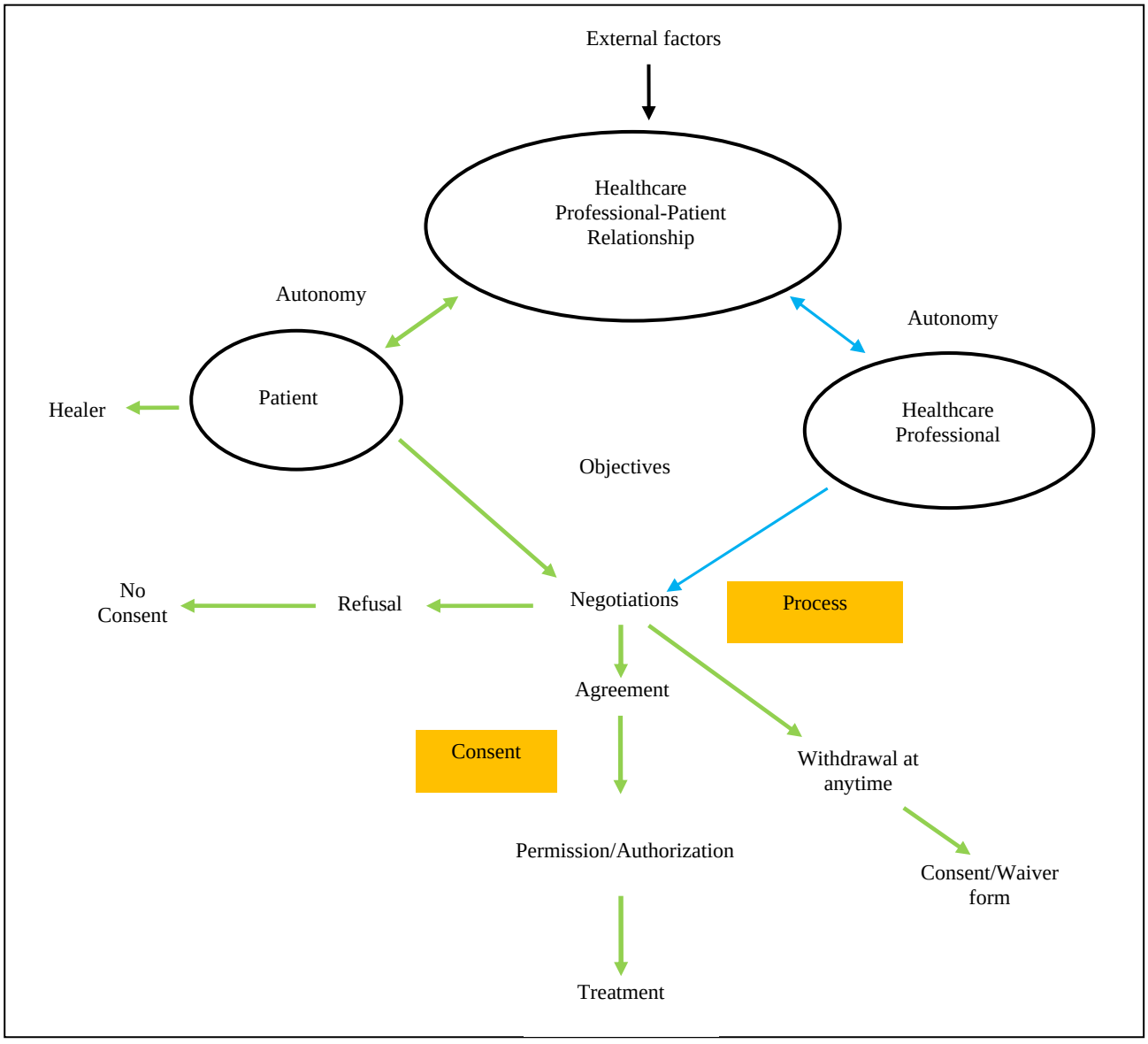

Fig. 2 Model of consent.

by consent which in turn allows the care professional the possibility to challenge the patient's decision(s) as irrational and to attempt to convince the patient to change his or her mind and accept the professional's advice. The healthcare worker's duties to the patient of beneficence and respect of autonomy meant that power to persuade becomes an obligation. The patient's obligation arises from the relationship and this is expressed through consent by which it requires the patient to respect the professional's role in the relationship.

6.5 Informed Consent Form

In PNG there is no one particular form made for informed consent as well as no legal requirement for consent to be in writing. From a legal standpoint, a patient's implied or explicit verbal or non-verbal consent is adequate to protect the healthcare professional against a claim in trespass. Nonetheless, to have a signed consent form does not necessarily mean the patient cannot later claim that she/he was not adequately informed for consent to be valid. In this study we note that those institutions including the hospitals, district hospital, private medical centers which require signing a consent form before the medical intervention are following internal clinical governance or professional guidelines rather than common law requirements. From where the patient-participants were recruited there was no specific consent form for medical treatment or procedure. The doctors in this study said that they do not have a specific consent form and many doctors said maybe it was not necessary for patients to sign a consent form for medical treatment. No wonder, many doctors have not been using consent forms at all. Indeed for Dr. C in this study consent was more than the signing of a form. For him, a patient's authorization to proceed with a surgical procedure was evidenced not by the signing of a form, but by their choices, actions and behavior. Many patients in this study said that by going to the healthcare facility means they have given their consent to be examined and receive medical treatment from the healthcare professional, which is what they have agreed to do. A nurse said that it would be unnecessary and excessive administratively to fill a consent form. Dr. A said that patients are not usually bothered with consent forms. However he said that consent is the agreement between the doctor and the patient to medical treatment or procedure that must be considered and the patient must be told about this. Further when asked about the purpose a consent form for medical treatment or procedure might serve, most patients commented not its terms of its moral significance (as a means of declaring their autonomy) but in terms of its potential use by the hospital and or its agents as protection against claims that could be brought by patients or their families for any adverse events resulting from the treatment or procedure.

7. Conclusion

Consent is justified by autonomy and is an expression of autonomy and so the patient must be competent to make his or her decision. The patient must be well informed which requires an understanding of the treatment chosen. The healthcare professional has a duty to facilitate the patient's autonomy by supporting them throughout the decision-making process. The extent of the disclosure depends on negotiation, with the patient having the right to waive information, or even to cede the treatment decision to the care professional. However where the patient waives his or her right to information, or cedes the treatment decision, the care professional should appreciate the implications of the patient's choice. The decision made by the patient should not be made in the absence of any influence from either the care professional or any family relatives of the patient who are allowed by custom or culture to influence the patient but in the absence of undue influence that attempts to control the patient's decision by unfairly exploiting the patient's weaknesses or vulnerability. In the present study, we gathered from the interview data

that respect for the elders including parents is an important duty among the young people obeys; generally patients allow their parents, spouse and family relatives to make their decision. This happens because the families live and eat together; and they share shelter. They trust each other and maintain any important information of private nature for family members alone (e.g., land issues, marriage, death, funerals, etc.) and family members adhere to it as it comprises many past experiences which taught them how to deal with such situations or related problems. Could this also amount to unfair exploitation of the patient's weaknesses or vulnerability? In this study it implies that the patient agrees to authorize his family to make his or her decision to undergo medical treatment or withdraw or refuse treatment and or remove the patient out of the hospital ward. This is a complex procedure which comprises many discussions and individual interventions from family members and healthcare professionals which are all necessary intrinsic steps in the comprehensive medical treatment for the patient. Nevertheless this would all go into nothing without the understanding of the parties in this situation. To an extent, any discussion about consent requires therefore, not only the examination of its elements, but also considerations of its functions in the clinical context, its institutional place, and the meaning of consent as spoken about by participants in this study.

There is a multitude of practices in many countries that this study did not consider. If a study was performed at an international scale to examine the idea of informed consent, within the bounds of the societies being studied, the results obtained could be beneficial for developing a global the idea of informed consent further. The medical community can adopt ideas from cultures by examining what these cultures do for the informed consent process, or at the very least can better take care of patients from other cultures by better understanding the situation they come from. Based on the above models, different forms of strategies could be designed and evaluated to aid understanding of informed consent. These interventions should be targeted at improving different aspects of the process leading to consent, with the main focus on the information giving process or on increasing the patients' understanding. The practical application of the consent model is that participant must receive appropriate information and that they can understand to enable them to make decisions about whether or not to take part in the process of informed consent should prevail.

Author's Contributions

AM: Conception and design, acquisition of data, analysis and interpretation of data, drafting of the manuscript, critical revision of the manuscript for important intellectual content, administrative, or material support, and supervision. SK: Critical revision of the manuscript for important intellectual content and drafting of the manuscript and technical support. JM: Critical revision of the manuscript for important intellectual content and technical support.

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Conflict of Interests

None.

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