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Roles of Customs, Cultures, and Languages in Informed Consent*

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The work in this paper is based on primary research on how to obtain informed consent to medical treatment and or procedure among patients; this study was carried out in Papua New Guinea in both urban and rural health settings across customs, cultures, and languages in two provinces, on the basis of qualitative interviews with healthcare professionals including doctors, nurses, other healthcare workers, patients, and traditional healers. We emphasize the views of consent with participants of customs, cultural, and languages regarding informed consent. There are factors between peoples of differing circumstances which can greatly alter how they view consent. Some groups would involve people in the decision-making process that may not traditionally be involved in the decision making of a medical decision. Other groups may dislike certain medical procedures as in Papua New Guinea (PNG). And certain people have different views on what should be disclosed of the patient's condition. Customs, cultures, and languages are common phenomena which continue to affect the daily lives of many thousands of people. It is unclear in PNG about the characteristics of customs, culture, and language on health care because there is no published information on informed consent and issues that affect the making of informed consent.

Keywords: customs, culture, language, informed consent

Introduction

A patient should be informed of anything which would affect his or her personal decisions, such as anything which would upset any belief the patient has, particularly among female patients where rules of custom are adhered to in the community (Culver & Gert, 1982). Where customs, beliefs, and opinions of individuals are taken into account in informed consent, patients make better considered decisions which affect their health care (Saldov, Kakai, McLaughlin, & Thomas, 1998).

Beliefs associated with illness experiences are embedded in customs and cultural values that may have implications for the implementation of informed consent processes (Marshall et al., 2006). The differences in these values could influence judgements about the amount and kind of information that should be disclosed by healthcare professionals to the patients. The health care professionals may know ways of treating the patient-doctor relationship. In situations such as dealing with women patients, usually the physician and patient

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participate in the process of deciding what the best mode of treatment is for the patient. Unless the patient willingly forgoes her decision-making power and leaves her fate in another's hands, then the doctor must work at creating an atmosphere conducive to the patient's understanding and response to the various treatment options. This paper examines the issues of customs, culture, and language on informed consent and studies how informed consent is obtained by health care providers and how they handle the situation.

Nature of Healthcare

There are also inequities within the population groups because of high unemployment and low literacy in the community. The basic health care is unaffordable or out of reach for most of the local population; therefore, the majority still patronizes traditional healers for their health care needs. Under these circumstances any offer of medical assistance is often seen as better than nothing, thus encouraging undue influence, coercion, and medical paternalism. Perhaps there is a further dichotomy in the organization of the healthcare services in Papua New Guinea (PNG), which is dual in nature, consisting of public health care and private medical service. The private service is patronized by a small portion of the population who can afford private health care insurance or possess the financial means to pay for the private care.

Within certain social and economic positions in a society, the issues of patients being misinformed can be more or far less prevalent. Some ideas may not translate well across language barriers or other ideas may seem more offensive within certain cultural boundaries. In other traditional settings where inhibiting customs are widespread, patients may refuse to make a medical decision for their health care needs. A patient may have cultural beliefs or opinions which would affect his or her own personal decisions, and though they may not be supported by scientific evidence, they are still completely relevant to the patient's final decision, and so the information given should be relevant to that.

Medical Understanding Within Informed Consent

The goal of informed consent prior to treatment has always been the same, to focus on the health of the individual patient (Parmar, Gunvanti, Sangita, & Ashish, 2016). 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 (Minei, Arafia, Kaipu, & Minei, 2020). 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 (Minei, Rachelyn, Ronald, & Kaipu, 2019).

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 (Minei et al., 2020). 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 (Marshall, 2007).

The doctor has a duty to explain the patient's medical condition, the recommended treatment (including the other treatment options available), and the benefits, risks, and possible complications of the recommended treatment.

How Important Is Getting Informed Consent from the Patients?

Doctors' Side

In this study, in terms of information usually given by doctor-respondents to patients, majority of the doctors give the diagnosis (94.74%) and procedure (94.74%) for treating illness of the patients. The doctors also inform of the likely complications (89.47%) and possible treatment options (84.21%) to the patients. Some of the doctors (5.26%) even inform the patients on changes in the treatment if ever the first procedure did not work out. In PNG, the patients feel uncomfortable to meet or even speak about their medical conditions to the healthcare professional and for a female patient she refuses to be examined by a male professional (Minei et al., 2020). This is one difficult issue that affects the formalities where the professional would wish s/he could perform prior to giving medical treatment.

A study involved 800 physicians and 1,252 adults (US Government Printing Office, 1982). They were examined how much information patients want, and examined the behavior in terms of the patients' attitudes and experiences regarding disclosure of information. Most of the participants wanted their doctor to tell them almost everything about their medical conditions, even ones which are unfavorable. In that study, physicians recognized that patients are desirous of information. Physicians were asked "How many patients who come for treatment want the doctors to give them a candid assessment of their diagnosis and prognosis, even if it is unfavorable?" Physicians said over 86% of the patients in the study want to know the truth. This finding implies a need for caution since the survey had shorter duration and many participants in the survey, the less chance that the participants' attitude and behavior could change in a one-time survey. It would indeed be remarkable if a follow up study would be conducted. The study also showed that certain participating groups showed interests in the study. The old age participants and those who have long stay at the hospital have lessened interest in the study than those who have their family physician for less than a year scored high above average in patient involvement in decision making (Meisal & Roth, 1983). If it follows logically then, the long duration may be over-represented in a cross sectional study. Despite the findings, other studies conducted elsewhere confirmed that the study subjects want full disclosure of information (US Government Printing Office, 1982). The conclusion of the study reviewed that it is evident that the patients would like to be informed of various aspects of their treatment and prognosis. Physicians believed that most patients would understand the information which is provided.

In the President's Commission survey (US Government Printing Office, 1982) physicians were asked "What percentage of their patients would say they understand most aspects of their treatment and condition if reasonable time and effort are devoted to explanation?" In terms of understanding about 40% of physicians answered that 90-100% of their patients could understand and an additional 34% said that 70-80% could understand. However, this does not mean that physicians spent more time to ensure their patients understood the information given. Nonetheless the finding shows that patients have their own beliefs or opinions, which prevents them from actively seeking information or from retaining information provided. Findings from other studies suggest that a critical factor which determines patient understanding is the manner in which doctors present diagnostic information

(Victoria Law Reform Commission (LRCV), 1987). In general patients' responses to physicians' verbal conversation (or vocalization) is important in communicating to the patients in a clinical setting. Based on this, Harrigan and co-worker (Harrigan, Gramata, Lucic, & Margolis, 1989) sought to evaluate physicians' vocal behavior. Respectively, 30 doctor-patient interactions were analyzed. The workers found that greater weight was given to vocal cues when interpreting contradictory messages. Interestingly, the study showed that females are more accurate in decoding and transmitting nonverbal and vocal cues. The speech rate was associated with dominance; the faster the rate of speech the more dominant the physician was perceived. Such verbal cues possibly have a greater impact in situations such as continuing treatment for a severely handicapped child. Harrigan et al. (1989) repeatedly demonstrated that the powerful impact of such cues on an individual's evaluation of another's intent came from attitude, competence, empathy, and interest.

Generally, patients do not usually like to talk to the healthcare professionals about their illness or vice versa. They would choose to speak with a nurse or their guardian to communicate with the healthcare professional. In an informed consent case, a young man was advised by his physician to undergo a laminectomy in an effort to alleviate back pain.[1] The physician, aware that one percent of laminectomies resulted in paralysis, did not advise the patient of the risk because he believed this might cause the patient to reject the useful treatment. After the procedure, the patient fell from his hospital bed and was paralyzed. It remained uncertain whether the laminectomy procedure or the patient's fall caused the paralysis.

To avoid the situation as in the example above, it is essential so that the patient can make a decision. However once the information is given, the doctor may ask the patient to sign a consent form. When signed by the patient, this form gives the doctor legal permission to perform the procedure (Minei & Kaipu, 2020; Chima, 2018).

The patient expects the care worker to be truthful in doing his or her job. Generally, women care more about their personal details and personal things. They would speak about their personal health and give personal details and things that they would not routinely disclose or see.

Patients' Side

In this study, in terms of the knowledge of patients about informed consent to medical procedures, 13.79% of patients said that they do not know what is informed consent; 6.9% of patients do not think informed consent is important before doing a medical procedure; patients (58.62%) said family can hinder patients prevent them from signing consent form.

Especially women care about their person and abide by their customs (Minei & Kaipu, 2020). It is only when that personal information potentially becomes available to a wider audience that she worries of losing her control over her information and how it is used. The health care provider is in that privileged position so that s/he can help. Some health information is private, but that does not mean that patients need to tell everybody everything, or that healthcare workers should expect to know everything about the patient (Minei & Kaipu, 2020). The care worker needs to know as much as is necessary to provide proper care, and no more. However, for female patients, their mothers or guardians ensure respect for the patient's integrity is demonstrated by allowing the patient to make a decision about what is too private (or unnecessary or unacceptable) to disclose.

[1] Canterbury v Spence, 464 F.2d 772 (D.C. Cir 1972) at 790-791 (subjective standard "places the physician in jeopardy of the patient's hindsight and bitterness").

The healthcare professional plays also the role in delivering those benefits to others. To be successful s/he will need to communicate clearly to the patients what is reasonable for them to expect, and what responsibility can be shouldered by the care professional. The patient makes his or her decision regarding care following consultation with the family members or a representative.

Patients and healthcare professionals should work together so that the expectations of patients and cares are similar and they can understand each other's responsibilities. There are factors that may impede the effective operation of informed consent, thus considerations such as customs, costs of treatment, and poor understandings of the medical condition of the patient are issues that affect both the patient and healthcare worker. Majority of patients do not feel comfortable to speak to healthcare professionals and the communication between the parties often fails.

Communication hindrance is attributed mainly to differences in education, status, culture, and other features which distinguish healthcare workers from their patients; these findings are similar in other studies on informed consent (Chima, 2018). In PNG, women often stick to their traditional customs, beliefs, and practice more than men … young girls or single women allow their parents to make their decisions. Married women on the other hand allow their husbands to make their medical decisions. There is strong desire to protect women and their roles they play in the community (Gel Del & Joffe, 2005).[2] There requires more educational awareness to empower the women (Chima, 2018) though it is not the focus in this study.

Does It Really Matter to Patients?

For many years, common medical practice meant that medical care professionals make decisions for their patients. This paternalistic view has gradually been supplanted by promoting patient autonomy, whereby patients and physicians share the decision-making responsibility. Consequently, doctor-patient relationships are quite different nowadays than they were two decades ago. Does it really matter to the patients? Yes, absolutely this issue matters to the patient. Conflicts still abound as the medical community and those it serves struggle to define their respective roles in informed consent. The informed consent process as it currently exists often fails to accomplish its purposes (Hallinan et al., 2016).

Hallinan and co-workers (Hallinan et al., 2016) state that long and complex informed consent documents and processes may obscure the information most relevant to the potential patient and appear to be designed primarily to serve the role of protecting institutions and meeting regulatory needs rather than to inform the potential participant. The law and ethics of informed consent both reflect and enforce the move from doctor-centered to patient-centered decision-making (Allmark, 2010).

Attention is given to the status of customs, its role in the processing of health care decisions in informed consent. This study looked at aspects of custom, one that affects women patients and studied the perspectives of the respondents regarding inform consent. It strove to determine what medical community is described as an effective explanation of informed consent for a standard patient and how this explanation changes towards people who belief in their ways of live and promote their local customs. This issue is common among the peoples in resource poor settings especially in developing countries.

[2] Women, mothers, wives, and daughters work to feed the family, manage the household, look after the sick, and operate the day to day activity of the family. There is increasing emphasis on the active obligation of females to be part of the management plan, take responsibility for their sick and treatment, and take responsibility for their recovery and future health.

How the Care Providers Handle the Situation with Patients?

The people still hang onto their traditional customs, beliefs, and opinions that affect their health care decisions; they often look to their village elders, family, and parents for advice in times of sickness or death in the family but where the law implies consent it is not often obtained. Whether a patient is attended at the modern healthcare facility, special requirements must be prescribed when patients are subjected to medical treatment or undergo a procedure. Documentation of a well-defined process, not only on paper, may not only protect the healthcare professional from exposure to liability but increases the patient's autonomy in decisions concerning health and encourages compliance with treatment; and advances the interests of both patient and doctor. Lack of informed consent can reinforce a claim of medical malpractice, and could well undermine relevant health care policy to protect patient autonomy.

Majority of the patients in PNG use modern healthcare facilities have some notion of informed consent; however, not many people understand what it is. Many patients learn about the term when they are being attended to by healthcare workers. And for many of them the term means, "anything given is good to get well soon". There are not much changes in terms of patient's attitude towards entering a healthcare facility and seeing a healthcare professional. To many patients, a doctor or nurse, they are magicians. They make them get well soon.

Compare Again to Other Studies

In the larger literature many research workers including academics, researches, and medical and legal professionals have expressed their viewpoints on informed consent. Writings are mainly based on experiences of workers and court decisions in the US, Australia, UK, and Canada. For the reports and publications, they are based on information collected through qualitative research means and majority are descriptive. The findings concluded that informed consent is important and that it requires special attention in terms of legal protection for the rights of patients (Chima, 2018). The large majority of workers in informed consent were conducted at the hospital settings; most workers employed cross section surveys (Parmar et al., 2016).

The workers generally described the prevailing situation based on the local medical settings and the reports cited gave unvarying results or in other words findings show the necessity of informed consent in clinical care. Resources including funding to collect data and the time availability of research workers, many involved doctors at the hospital; there were serious shortcomings encountered by researchers in the implementation of the studies. There were flaws encountered in the studies mainly relating to sampling of the participants, appraising of the data, the ways in which data were collected, and data were collected by multiple observers (Parmar et al., 2016). Other notable observations were due to the understanding of the local settings and its people who were subjects in the studies. It is imperative to understand the circumstances in which the patients live, the socio-economic standing of the community, and how people live in their local settings. Those were issues in the conduct of research where many workers fail to consider prior to rendering their official duties.

Despite the poor collection of the research data, many workers showed consistency in their findings and some trends emerged from the prior knowledge about consent.

Studies in Africa populations (Chima, 2018) and Asia populations (Saldov et al., 1998) relating to informed consent revealed findings agreeing with my study. For example, doctors have knowledge of informed consent and majority of doctors said that informed consent should only apply to critical cases. In another example, patients considered that language, religious views and beliefs and opinions could hinder the signing of the consent form. However, in many situations the studies on informed consent were largely constraint by poor methods to collect

data and how was the target population or group studied? If only part was studied, how was it selected? Was the sample a representative one, chosen by acceptable methods? If not, the sampling could bias. I observed in many of the previous research studies have many inaccuracies in their findings. What might be deemed appropriate is to use more rigorous study methods such as prospective study design and employ huge sample size.

As for the court decisions, majority of the decisions for informed consent cases have been based on the disclosure of information, that is, medical professionals have failed to obtain informed consent. In one consent case, a doctor told a woman he would only be repairing some cervical and rectal tears; instead he performed a hysterectomy (Berg, Applebaum, Lidz, & Parker, 2001). If the patient was advised by her physician, the process nevertheless appeared so alien to the way the patient would normally make healthcare decisions. She did her best to understand the procedure she would undergo to the point where her comprehension failed and so her physician just had to decide for her. Acquisition of information relevant to decision-making is the first important step. The patient should be provided with all the information required, or additionally requested, to make a decision about undergoing the procedure. Information should be provided both verbally, visually, or textually. In this case there were not many opportunities provided to the patient to consider and use them in the decision whether to consent or refuse the procedure. The patient did not understand the procedure and this in itself made her consent uninformed and thus she lacked any sense of autonomy. Alternative grounds for legal proceedings do exist. Actions may be brought in contract and in negligence. In many instances, patients may be taken to have consented to certain disclosure of information, especially disclosure for purposes related to their own treatment, such as to other health service providers who assist their doctor to facilitate diagnosis but treatment of family members can not ordinarily be implied and will be likely to breach the duty of confidentiality, unless the disclosure is covered by some exception recognized by law.[3]

Still, law on medical decision-making holds that "simple" decision-making is insufficient; the choice must also be informed.[4] Though people may not understand everything about a procedure, and they do have the right to make foolish choices, they still need to know what they are being foolish about, but they do not need to know and understand everything about all the possible impacts participation might have on their lives. From the legal perspective the emphasis is on what is disclosed to someone giving consent, not what the person understood, given that it is hard to "get a handle" on what was actually understood. There have been interesting cases in which the focus is on understanding because the subjects involved have questionable capacity to decide. There have also been cases in which it is important to show that a person actually understood something critical, such as the fact that if s/he does not have a limb amputated, the result is death. If the person did not understand this, their consent was not valid. Understanding the circumstance of health care services and familiarity of the nature of informed consent is important; however, without the benefit of published reports

[3] In other jurisdictions, the courts have extended this protection to other health care relationships for example, nurse-patient. Negligence was held in a New Zealand case to be the basis on which an obligation of confidentiality arose. There is no clear authority on this point in England and Wales in the medical context, although the potential for such an action can be seen by analogy to an action for negligent breach of disclosure of a police informer's identity. In that case the principle of such an action was recognized although on its facts the case failed. An examination of the laws in PNG, especially laws relating to health care, reveals that there are only a few laws which may be relevant to informed consent. It is unclear how much information each of the laws, rules, or regulations offers on informed consent to medical treatment in PNG.

[4] Immunization policies are public health and may be not based on individual choice or informed consent. Research thinks it a public health matters. In many developed countries parents have refused their children vaccinated without medical reasons. Some have done so at little or no cost or risk to their children by sheltering behind protection provided by other vaccinated children.

on informed consent and lack of judicial precedents, it is difficult to characterize the interplay with informed consent, ethics, and law.

Understanding the Community and Obstacles to Informed Consent

Informed consent process is an ongoing exchange of information between the medical care professional and the subject and could include, for example, use of question-and-answer sessions, community meetings, and videotaped presentations. The caregiver professional ought to understand the local setting where the healthcare facility is situated, the population it serves, common health problems, and the impact of these and other factors would have on the lives of people on their basic values, priorities, norms and beliefs, opinions, and behaviors. There are interrelated problems with informed consent. I mention some examples of the obstacles to informed consent.

Comprehension and Capacity

Language is an issue in securing informed consent; obstacles to comprehension go beyond the obvious linguistic barriers. The intervention of a healthcare worker (or interpreter) may help but different concepts of illness and issues of translation and cultural bias on the interpreter's part would compromise the extent to which information is understood. PNG is one of the most heterogeneous countries in the world, having over 800 indigenous tribes and languages where recognition of individual rights is poor and the divide in language, customs, and traditions has led to many different groupings in the community. Among the cultural groups there may be little or no understanding of biomedicine and healthcare workers, lacking knowledge of traditional belief systems, and may wrongly conclude that the individual lacks capacity.

Literacy

Many people live in different parts of the country. Majority of the patients are unable to read and write in their own languages. The communication amongst the population is largely verbal and is heavily relied upon. To ask for a signature may thus cause disorientation of the patient. Illiteracy does not mean the information is misunderstood but it does mean the information must be presented in another or a special way. Obtaining patient's informed consent in this case must be seen to be a continuing process of negotiation between the healthcare professional and the patient. This implies a long-term relationship of trust.

Autonomy

The notion of autonomy varies considerably between cultural groups. In contrast to the emphasis on personal choices in western countries including USA and Europe, communal and hierarchical concepts of decision-making take precedence amongst the indigenous populations mostly in developing countries. The family members, even clan elders, will frequently participate in making decisions on many issues including medical for and on behalf of a relative. The sense of wellbeing depends on a feeling of personal control (Saxena, 1994). Dein and Kamaldeep (2005) expressed that the western idea of respect for the individual may conflict with traditions that define persons by their relations to others. In the doctor-patient relationship elements such as loyalty, integrity, solidarity and compassion may be more important in situations such as this among the indigenous populations and minority groups, than autonomy.

Disclosure of Information

The patients must have adequate information if they are to play an important role in making decisions that reflect their own values and preferences, and the physicians play a key role as educators in this process. Treatment

with no consent at all, actual or implied or inferred based on the patient's conduct, or treatment is substantially different from that to which the patient consented, or unauthorized substitution of one treatment for another, the situation could fall within the definition of battery, especially when involving invasive procedures. The extent of information is disclosed to individuals at the clinical settings varies due to circumstances in which the individuals operate and live that influence their health care outcome needs. For example, when a life-threatening condition such as cancer is diagnosed, the custom in many parts of the world is to tell the family relatives rather than the patient. This is generally true in PNG. Among such groups the disclosure of negative information is considered potentially harmful (Dein & Kamaldeep, 2005), and health personnel will sometimes collude with the family relatives to prevent the patient discovering the diagnosis (Chaturverdi, 1994). Diversity in the practice of disclosing information would alter the requirements for informed consent in the medical context (Marshall et al., 2006).

Familiarity with Conduct of Research

Patients and groups living in rural areas and isolated from the mainstream society have little grasp of scientific method, and without such understanding a consent form will make little sense. This may be partly a cultural issue, though low literacy amongst the people in the communities is also an important determinant. Work in countries in South Asia, including India, Pakistani, and Bangladesh, showed no difference from the general population in their attitudes toward participating in clinical trials (Husain-Gambles et al., 2004). There is no difficulty with informed consent in any context, especially when the researcher is an outsider and the potential subjects are patients and healthcare workers. It was an unequal power relationship and yet there was general feeling of obligation and support for this study. Where an asymmetry in knowledge and authority occurs and we have not confronted such a case, this must raise doubts about the validity of consent (Murray, 1994).

Misconceptions

There is a great deal of misconception towards legal status of informed consent. In PNG majority of the people live in their indigenous settings, trust their doctors to do the right thing and do not mind after saying "yes" to a medical procedure, and they are made better. Patients believe that they have no right to change their mind after saying "yes" to undergo a medical procedure. The level of understanding of health care seems low among indigenous populations and issues of custom and culture have bearing on the patients' decisions for health care (Joseph et al., 2008).

A small group of Christians believe in faith healing and use prayer and other religious activity rather than medicine to take care of complicated medical difficulties (Guzder, 2009). Some of those patients may have died of treatable diseases like childhood diabetes, measles, and diarrhea after medical care was not taken. Cases such as this should have resulted in criminal charges or convictions for those responsible (Guzder, 2009). Religious needs, regardless of whether or not an institution accommodates for those needs, can often come into conflict with the western ideals for medicine.

Any attempt by healthcare workers to explain the issues would cover scientific research and how it works but there would be difficulty in addressing a tradition of healthcare in which spiritual and religious values and a host of different healing methods are deployed alongside conventional medicine. For instance, in an informed consent study in settings of African descent, researchers compared voluntary participation and understanding of informed consent among the individuals with hypertension living in United States and Nigeria (Marshall et al.,

2006). Survey questionnaires were used to evaluate factors associated with voluntariness and understanding of the study's purpose. It found that there was a need for more effective approaches and interventions to improve comprehension of consent in genetic research among ethically and linguistically diverse populations.

The process of receiving healthcare, however, involves the sharing of information and thus potentially threatens individual control over privacy. When patients seek treatment, they give health professionals (e.g., doctors, nurses, and others) access to their bodies, provide information about their habits and personal relationships, and provide access to their otherwise private world. It is through the intrusion of medical tests results, records of which and other known information about the patient are kept before they do. This implies a duty of confidentiality. Thus the professional duty of confidentiality arises because of the loss of privacy in that it refers to the duty of doctors not to disclose to others the information that a patient divulges and the corresponding right of patients not to have the information they divulge made available to anyone else (Richards & Louise, 2014).

Challenges Within Informed Consent

In general, the challenge with the idea of informed consent among the patients 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 (Douglas, 2007). 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) (Saldov et al., 1998; Marshall et al., 2006); 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 (Chaturverdi, 1994; Hiroyuki et al., 1991). The customary rules in many countries deprive non-western cultures of their proper positions of power and actually devalue their notion of autonomy (Husain-Gambles et al., 2004). The idea of informed consent has 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

patients' 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 is aimed to observe that the participants understood their participation. There were no risks involved in the study and a significant proportion of participants recognized that they were participating in a research as opposed to seeking medical care.

Conclusion

In this study I only discussed the informed consent tendencies of PNG such as those in the National Capital District and Central Province. If one is to study PNG wide on the idea of informed consent, the results obtained could be beneficial for developing the idea of informed consent further. The medical community can adopt ideas from other 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 situations they come from.

In the forthcoming section, finally, we present our views regarding the work on the investigation on how providers grant informed consent and handle the situation with patients of customs, culture, language differences. Several findings came to light after the interview of patients and the analysis of their interview responded.

Customs and Cultures Within Informed Consent

In PNG indigenous local customs could influence judgements about the amount and type of information that should be disclosed to the patients by healthcare professionals for informed consent. The need for an important doctor-patient relationship and discussion is clear; as without an understanding of the patient's beliefs, a doctor may completely overlook relevant information and fail to achieve valid informed consent (Allmark et al., 2010). 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. From what we gathered in our interviews, people who were attending the clinic said spouses who are less educated do not understand the family planning procedures or what it entails. Other healthcare workers present that time described a common situation between the patients, spouses, and nurses. 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 fact, many patients are surprised that the doctors go to so much trouble to inform them in the first place. 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.

There are many people of different cultural groups, most of whom would require medical advice at some point in their lives. I studied how healthcare professionals obtain informed consent and handle the situation of patients with widespread customary and cultural differences. This study is conducted amongst the healthcare professionals, traditional healers, and patients 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. The idea behind this study 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. I noted as well that if the doctor felt that the patient is responding to the treatment well, then what would she/he do to the patient?

I 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. Patients 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 (Dein & Kamaldeep, 2005). Others may argue that there are certain situations in which someone must be making decisions for the patient. In Manus Province of PNG young adult male 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 (Dein & Kamaldeep, 2005). 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. A physician's responsibilities are clearly informed in the practice code of conduct. Patients may accept or refuse treatment based on their customs, beliefs, or opinions.

The perception in PNG is that the indigenous customary procedures have a big impact on the decision making for medical treatment. The degree to which we should respect, or challenge such behaviors, customary rules, and practices, is a recurring tension in the multicultural and contemporary health care context. And further, I say that the peculiarities of customs of indigenous people may explain some of the actions relevant to informed consent. One aspect important in influencing the provision of clinical care is to value or appreciate the work of doctor-patient relationship in the context of informed consent. The current practice within PNG is that all medical professionals are held to a specific standard of informed consent when treating their patients. It is improper and even illegal for a doctor in the modern medical environment to perform a treatment on a patient who did not agree to a treatment with full knowledge of what the treatment is, how the treatment is performed, and the major complications that this treatment could potentially cause.

I look at the issue of informed consent with such cultural differences in mind. My goal is to identify and consolidate the process of granting informed consent within the doctor-patient relationship. There are many patients from different parts of PNG and all of which have been receiving medical treatment. There are different hospitals and healthcare facilities in the study areas. The traditional healers who attend to patients most in the rural areas have been considered in this study. To examine the situation, I discuss the situation regarding how informed consent is obtained from patients within the medical settings.

On Religious, Cultural, and Economic Considerations

One's religion also can affect the medical practice in much the same way as cultural considerations. There are times where certain religious practices are in opposition with western ideals as informed consent. In some cases, religious belief complicates the medical situation. A male doctor said female patients who come from Islamic cultures tend to dislike being examined by members of the opposite sex. In fact, doctors have argued that they are the only doctors in the institution or in the local area. In another situation, parents of young patient who needed blood transfusion were refused by his parents not to receive it because their religion would not allow them and so the son did not receive it or go through the procedure; they were from the Jehovah witnesses. There are many of times that the ideals of a certain faith contradict the ideals of the medical community. In similar setting family members and community elders have stood in defended the medical team and demanded that patients' life is too important to be safe than the religious faith. Actually this situation worked out for the medical team and patient received blood transfusion.

The ideas of the elderly represent a perspective of the past where the idea of informed consent is different compared to the current idea. For example, the elderly patient would just agree with the doctor without saying anything. The doctor says no need to inform their patients and the patient would go along with the doctor so the treatment is given to the patient. In another case, doctors would deal with the close family relative about the patient's health condition then with the patient. Doctor should identify the patient's family members to explain about the patient's health conditions to them. The use of family members as ad-hoc interpreters is avoided when possible in the medical community. In larger institution, this is largely avoided and forbidden, for a simple reason that they are not trained to interpret. While most medical care professionals interviewed agree on the importance of family members to interpret, there are others who do not agree when it comes to signing consent forms.

Patients and 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 barriers 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 patients from the rural areas could pay immediately pay because they cannot afford the costs for both the treatment or procedure. Doctors believed that any concerns whether religious, cultural, or economic should be addressed in order to obtain a proper informed consent. Patients with different cultural or linguistic backgrounds make medical considerations based on their socio-economic background, and this is seen through the existence of rural health centers and most patients turn to traditional healers. Patients who choose to be seen by traditional healers for treatment see this as a low cost opportunity as something convenient. A nurse practitioner said that the decision to see traditional healers is made hastily because of the convenience and affordability of the low cost rural care service. Many medical care professionals feel that treating a patient comes first in priority, and that any sort of monetary considerations comes after.

On Trust and the Role, It Plays

Trust is a basis of any relationship[5], but may be more salient in relationships characterized by vulnerability or by imbalance in power or capacity[6] such as in the case between the patient and the physician, where the patient

[5] The NZ Times, May 25, 1999.
[6] 1905. Mohr v William. Minn. 261, 104 N.W. 12.

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 (Sugarman, 2015).

Many patients demonstrated understanding to attending health services. 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, many patients visit both modern care facilities and traditional healer practice. Consent undoubtedly has a discursive basis; it is always associated with a choice; patients have signed consent forms thus agreeing to the procedures or treatment. Not many patients know what consent form is and its purpose. Patients have the right to withdraw from the treatment at any time.

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 (Chaturverdi, 1994). In many situations 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.

There is not much a provider of healthcare can do without violating certain patients' rights. The sensitivity of the topic however requires that the issue should be addressed with great care. The relevant stakeholder groups in law and medical practice, academics, industry, government, associations, community leaders, patients and consumer interest groups should work together to deal with the circumstances where the issue lies especially with the patient's custom taking a more determinant role in their healthcare than the patient would otherwise like. I say now that there exists a vast discrepancy between what informed consent ought to be and what patients perceive it to be.

Preserving Community Norms and Family Relationships

The most important goal of informed consent is that the patient should have an opportunity to be an informed participant in his or her healthcare decisions to safeguard and ensure the preservation of individual rights. The pragmatic suggestions aim to facilitate and document a good-faith effort to involve patients in medical decisions to whatever degree they are interested and able. Such practice complies with the ethical spirit of informed consent and should minimize legal conflict by fostering a deep and nuanced respect for patients.

I 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. This practice complies with the ethical spirit of informed consent and should minimize legal conflict by fostering a deep and nuanced respect for patients.

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