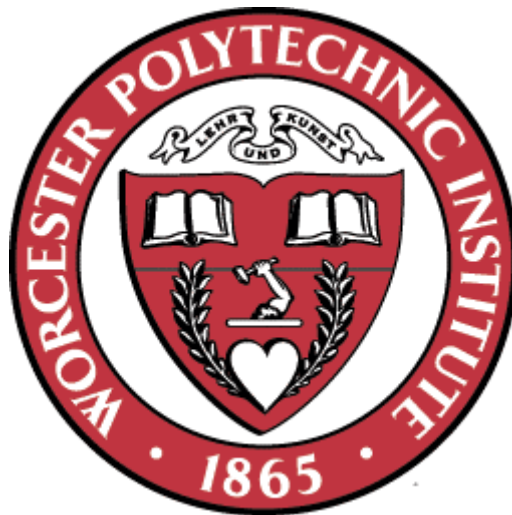


Cultural Differences and the Understanding of Informed Consent



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Abstract

This project examines the delivery of informed consent in the medical field across cultures, with specific attention to potential barriers from linguistic differences in Worcester, Massachusetts. On the basis of qualitative interviews with medical professionals such as interpreters, doctors, and others, we investigated the accommodations and approaches to addressing such differences using interpretative analysis approaches. Our results emphasize distinctions in views of consent with patients of cultural difference, the significance of interpreters within the consent process, and the importance of trust within doctor-patient relationships.

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Authorship

Nathan Ferron was involved in the acquisition of interview opportunities with several key interviewees, secretarial duties and note-taking during meetings and interviews, and much of the later-stage editing process.

Mario Alvarado was involved in the finding of interview opportunities via phone call with several interviewees, coordination of the trips to introduce ourselves in person to interviewees and institutions, acted as interview facilitator, and edited the report throughout.

Nour Krayem was involved in reaching out to people to interview through phone calls and live visits, supporting the interviews with follow-up questions, and edited the report.

All report sections were discussed and written as a collaboration and edited as a group. Each section had one or two primary authors, and the non-primary authors focused on editing. Primary authors are listed below in Table 1.

Table 1: Report Authorship by Section

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1. Introduction	Nathan Ferron
2.1.1. The Belmont Report	Nour Krayem

2.1.2. Nuremberg Doctor Trials and Nuremberg Code	Mario Alvarado
2.1.3. Tuskegee Syphilis Experiments	Nour Krayem
2.1.4. Human Cell Lines	Nathan Ferron
2.2.1. Legislation	Nathan Ferron
2.2.2. Court Precedence	Mario Alvarado
2.3.1. Medical Culture Regarding Informed Consent	Mario Alvarado and Nathan Ferron
2.3.2. Criticisms of Informed Consent	Mario Alvarado and Nathan Ferron
2.3.3. The Role of Culture in Informed Consent	Nathan Ferron
2.4. Worcester Community	Nathan Ferron

3.1. Interviewing Medical Professionals	Mario Alvarado
3.2. Mapping the Delivery of Informed Consent	Mario Alvarado
3.3. Analysis of the Situation of Patients of Cultural and Linguistic Difference	Mario Alvarado
3.4. Determination of Effectiveness of Current Informed Consent Delivery	Mario Alvarado
3.5. Rationale for Methods	Mario Alvarado
3.6. Challenges With the Methodology	Mario Alvarado
4.1 On Society and the Role it Plays	Nathan Ferron
4.2 On the Role of Interpreters	Nathan Ferron
4.3 On Religious and Cultural Considerations	Nour Krayem
4.4 On Economic Considerations	Mario Alvarado
4.5 On Trust and the Role it Plays	Nour Krayem and Mario Alvarado

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Executive Summary

In current practice within the United States, 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. While giving such explanations may seem to some as a very obvious step in the doctor's routine, these explanations have only been an official practice since about 1979, when the Belmont Report was created. Before that, the medical world had no such official guidelines. These guidelines themselves were created to prevent such medical atrocities such as the Nazis' use of prisoners as medical test subjects, the intentional prolonging of suffering for African American syphilis sufferers in the Tuskegee experiment, and the use of several people's cells in research without those people's knowledge. People have even questioned whether the modern model of informed consent is functional, proposing changes to it and even alternative methods of consent.

One area where questions still arise with regards to informed consent is in regards to people of differing cultures. A large number of factors between people of differing cultures can greatly alter how they view consent. Some groups have strong dislikes for certain medical procedures that may be commonplace in emergency situations. Other cultural groups involve people in the decision making process that may not traditionally be involved in the making of a medical decision, such as is the case in more traditional Japanese culture. Still others have different views on who it is that should be informed of the patient's condition.

Our project aimed to examine these cultural issues and see how they have been dealt with in modern medical situations. We interviewed professionals from several local institutions and practices to learn about their perspectives regarding informing patients of cultural difference, such as those who do not speak English. We wished to identify and map how different medical practices in the local area go about informing patients of linguistic or cultural difference in order to obtain their consent. We worked to analyze how such patients experience the process of informed consent in the medical setting through the dialogue with clerical workers and medical translators. We strove to determine what the medical community described as an effective explanation of informed consent for a standard patient and how this explanation changes towards people of cultural or religious difference. We examined the methods of delivering informed consent in the medical field when accommodating for patients of cultural and linguistic differences.

To these ends, after gaining the approval of Worcester Polytechnic Institute's IRB, we started out by seeking interviews with several medical professionals such as doctors, nurse practitioners, translators, and others. During these semi-structured qualitative interviews, we asked them several questions based on the perceived role of the interviewee within the informed consent

process. We asked questions pertaining to how informed consent unravels itself across cultural barriers. Other question topics included how the issue of language is addressed, how the medical professional deals with people of alternative cultures, and the interviewee's understanding of informed consent itself. Interviews with different types of providers were conducted with different sets of questions, and each of these interviews were open enough to allow for probing questions in order to gain additional information when the opportunity presented itself. We analyzed the data using interpretative approaches and qualitatively counted the various themes and concepts from each question and response, and uncovered patterns in the various provider perspectives. We examined the provider perspectives and opinions using a visual table for comparing themes and concepts.

When examining these accounts for the role of culture and society within the medical community, we found that in general, people who have recently arrived in the United States tend to ask fewer questions. From what has been taught and instilled into these from their culture of origin, doctors and other healthcare providers were to be respected due to their high levels of education, and as such questions were rarely asked. A similar account could be found from elderly natives of the United States. As the idea of informed consent is only a very recent one in the medical field even in our own society, those who grew up several generations back lived in a culture much similar to that of modern immigrants with regards to how doctors are viewed.

We found the role of interpreters to be significant to the functioning of hospitals and even smaller practices. Specifically, there is a great need for qualified interpreters in the medical setting to properly deliver informed consent. As such interpreters are trained to know many of the more technical medical terms and are also trained to assume several different roles depending on what the current need is, such highly trained interpreters are indispensable. The same could not be said of phone interpreters, on the other hand. Most of the medical professionals interviewed felt that although phone interpreters were useful when there was no other option, they were far less useful than having an interpreter there in the room. This was due to the idea that a significant portion of communication is body language. In regards to the idea of ad-hoc interpreters, professional interpreters who were interviewed felt that using family, friends, or others as interpreters was not the proper thing to do. These interpreters felt that using such unqualified interpreters resulted in important information being lost in translation. Other medical professionals, on the other hand, felt that there was some value in using ad-hoc interpreters. These professionals argued that while professional interpreters were necessary for surgical environments, allowing family or friends to interpret for other purposes helped to put the patient at comfort and at ease. In regards to translating consent forms, there was some pushback from doctors who argued that signing consent forms in another language would require them to have all proceedings with a patient in that language, which for many doctors is hard to accommodate for.

Religious needs, regardless of whether an institution accommodates for these needs, can often come into conflict with the Western ideals for medicine. In cases where the conflict is minor, different doctors go about the situation in different ways. Some healthcare providers, when they cannot accommodate for the patient, will refer them to a provider who can. Others will insist that the patient seek out another doctor when they cannot accommodate. Still other providers will attempt to convince the patient to allow the procedure or action. This variation of treatment is still true in major cases. In some cases, the institution may fight to be allowed to perform a procedure when they think that it is for the patient's best interest, especially when children are concerned. In circumstances where the issue lies with the religious community taking a more active role in a patient's health care than the medical community may like, there is often not much a provider can do without violating certain patients' rights.

For some patients, their views on the informed consent process change when economics are brought into consideration. Some patients will be skeptical or outright refuse a treatment which they feel will be too expensive. Some patients from other cultures will even fear expensive treatments, thinking that their inability to pay will result in punitive action against them. In other cases where the patient is in an institution made specifically for lower-cost treatments, the patient may be more permissive or even more dismissive of the informed consent process. Some providers have explained this as a patient being more grateful for a lower-cost treatment.

Trust and honesty are of paramount importance to the patient-provider relationship. Providers of health care hold a lot of power in the relationship, and patients have to trust that the providers are not going to abuse this power in order for the relationship to work. Providers should work towards making the situation for a patient as comfortable as possible in order to help build the trust needed for the relationship to work. Honesty is a key tool in making sure this is accomplished. Providers must also be honest and open about what is going to be done in a procedure in order to gain any sort of proper consent.

1. Introduction

In the United States, an average group of 100 citizens will visit hospitals 381.9 times per year, or about 4 times a year per person (Schappert et al. 2008). With people visiting these institutions with such frequency, the issue of informed consent will come up quite often as patients have to consent to any number of procedures. The term “informed consent,” originally coined by lawyer Paul G. Gebhard in a 1957 medical malpractice suit wherein the Stanford University hospital was sued for failing to fully disclose the inherent risks in a medical procedure, developed during a time of increased concern in regards to the way people were being treated within the medical community (Pace 1997). Hospitals, clinics, and other medical institutions have come up with many different ways to approach the issue of informed consent. While many healthcare providers sit down with patients and discuss the potential results of medical procedures, others may suggest that a patient sign consent forms without a proper explanation of the procedure or treatment. A detached, impersonal situation between provider and patient could potentially push away patients and open the door for a patient to be misinformed going into a medical procedure.

Within certain social and economic positions in a society, the issue of patients being misinformed can be far more or far less prevalent. Some ideas may not translate well across language barriers, or perhaps other ideas simply seem more offensive within certain cultural boundaries. In some studies concerning African Americans, as an example, the participants felt as though by signing consent forms, the physician was gaining some form of legal protection while they themselves were signing away their autonomy (McCabe et al. 2005).

In this project, we attempted to look at this issue with such cultural differences in mind. Our goal was to identify and map the process of granting informed consent within the doctor-patient relationship and to analyze the effectiveness of models of delivery for at-risk communities of cultural difference. In the local Worcester area, there are many different cultural groups, all of which require medical advice at a point in their lives. There are also many different hospitals and clinics in the area which assist the people in the area, allowing this study to draw information from as many of these sources as time allowed for. We met our project goal by utilizing qualitative research approaches such as interviews directed at professionals in the medical field in order to understand the situations people of cultural difference experience when seeking medical advice, and to understand the information presented to such in order to obtain their sufficiently informed consent.

2. Literature Review

In this chapter, we discuss some of the literature that will help to introduce those who are not well-informed of the issue of informed consent to see just how the complexity of the issue unfolds. We first discuss some of the historical background regarding the creation and development of informed consent as an idea. We then present the current legal backing and enforcement of informed consent. We continue this description into the areas of informed consent that may be of philosophical concern in the local area, as well as cultural considerations that may or may not currently be addressed by the current informed consent model. Finally, we conclude with a description of the Worcester community regarding various cultures in the area and local institutions that handle their medical situation.

2.1. The History of Informed Consent

In this section, we discuss several of the historical events that played a significant role in the creation of informed consent as an idea. First, we discuss the Belmont Report, a document that formed the legal and philosophical basis for much of how informed consent is today. Following that, we discuss the 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's period of control, and how these trials developed the Nuremberg Code and idea of voluntary consent. We then move on to discuss the Tuskegee syphilis experiments, in which many poor African American men were being studied in the United States in regards to the clinical effects of syphilis without proper consent from the individuals. Finally, we discuss the creation of a few human cell lines for research, most notably including the creation of HeLa cells.

2.1.1. The Belmont Report

In 1979, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research drafted a guideline for research, the Belmont Report, which identifies three principles essential to the ethical conduct of research with humans: the ideas of respect for persons, beneficence, and justice. Upon these principles the current regulations and guidelines for human subject research adopted by the Department of Health & Human Services, or HHS, were founded. The first of these principles, respect for persons, is central to the Belmont Report. This concept describes how to best protect a subject or patient's autonomy. The Belmont Report argues that in order to respect the autonomy of a patient, one must ensure that the views of the subject are properly weighted. Unless a patient's actions will harm others, their choices must be respected. Denying individuals their ability to make their own decisions, or keeping information from them that would allow them to reach a decision, impede upon this idea (Belmont Report, 1979).

The second of the principles in the report, that of beneficence, refers to a researcher or doctor's responsibility to do minimal harm to a patient or subject while creating maximal benefit to the community at large or to the individual themselves. As is stated in the report itself, "[p]ersons are treated in an ethical manner not only by respecting their decisions and protecting them from harm, but also by making efforts to secure their well-being. Such treatment falls under the principle of beneficence. The term 'beneficence' is often understood to cover acts of kindness or charity that go beyond strict obligation. In this document, beneficence is understood in a stronger sense, as an obligation" (Belmont Report, 1979). The report argues that this responsibility of doctors and researchers in this regard is non-negotiable. One cannot claim to be performing a study for the right reasons if in the process their subjects are put under extreme pain or other such trauma (Belmont Report, 1979).

The final principle of the Belmont Report, that of justice, refers to the idea that one must treat all like cases equally. As the report itself puts it, "[j]ust as the principle of respect for persons finds expression in the requirements for consent, and the principle of beneficence in risk/benefit assessment, the principle of justice gives rise to moral requirements that there be fair procedures and outcomes in the selection of research subjects" (Belmont Report, 1979). The authors argue that in the recent past, research has selected for the poorer or otherwise socially vulnerable populations, namely due to the ease of recruiting them. The Belmont Report mentions the cases of the Nazis performing experiments on prisoners in their concentration camps as well as experiments such as the Tuskegee experiments which targeted at-risk populations for their research. The Belmont Report asks that experiments cease to target at-risk populations for the research in the development of treatments and other advancements that would help only those who can monetarily afford the help (Belmont Report, 1979).

The Belmont Report helped to address many of the societal issues around medicine that had yet to be acknowledged. It helped to provide a solid basis for the rights of patients across many different clinical organizations, improving the plight of patients and granting them far more control over the matters of their health. As Cassell said in his examination of the effects of the Belmont Report, "[i]n the early 1950s, medicine was about making the patient better and keeping optimism when the patient could not get better. By the 1990s, medicine was about the treatment of specific physiological systems, as directed by the patient, but as limited by the society's concern for justice" (Cassell, 2000).

2.1.2. Nuremberg Doctor Trials and Nuremberg Code

The Nuremberg Doctor Trials were an important step in the history of informed consent and respect for patients, and led to the drafting of the Nuremberg Code in 1947. The doctor trials were not just murder trials; they were trials against the cruel and unjust treatment of patients, as well as trials against the violent and unnecessary research topics, such as discovering new methods of killing (Weindling, 2001). Nazi doctors during World War II conducted such

research experiments through the forced participation of their patients, mainly including their prisoners in the concentration camps. These issues were addressed with a new level of scrutiny and importance during this time period, and resulted in the development of more serious rules of medical ethics (Swain, 2011). The beginnings of informed consent and other medical ethics issues were outlined by U.S. physiologist Andrew Conway Ivy, where he noted the idea of “voluntary consent” and that it is “absolutely essential” (Swain, 2011). Ivy declared that it is required to inform the volunteers of medical trials of the hazards before they could give their consent. Ivy then recommended that an “international, legalized Code of ethics” needed to be drafted and published with the purpose of protecting human beings being used as experimental subjects. Dr. Leo Alexander developed a Code with six points, each a crucial part in the protection of human subjects. Through collaboration with Ivy, Alexander fully defined Ivy’s idea of “voluntary consent” by stating that consent “required the absence of duress, ‘sufficient disclosure on the part of the experimenter, and sufficient understanding on the part of the experimental subject of the exact nature and consequences of the experiment for which he volunteers to permit an enlightened consent’” (Weindling, 2001). The Code also contains five other points, but the most important and the one which inspired a new understanding of informed consent within the evolving field of medical ethics is the first. The medical field, as well as the medical research field, were further developed and ethically reinforced after the Nuremberg doctor trials. Now with more structure and integrity, the idea of informed consent could develop and grow stronger as new issues arose. (Weindling, 2001)

Atrocities such as these caused nations around the world to begin forming organizations to prevent such things from happening again. Following the public outrage over the Syphilis Study at Tuskegee in the United States, Congress established the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in 1974. Now clarified by the National Commission and its guidelines, all research was now mandated to be guided by ethical principles in regards to human subjects. This allowed human subject research and medical care to become more ethical. (Weindling, 2001).

2.1.3. Tuskegee Syphilis Experiments

A more local historical event that necessitated the creation of the idea of informed consent was the syphilis experiment at Tuskegee, Alabama. Beginning in 1932 and ending in 1972, this study was performed on 399 poor African American sharecroppers suffering from latent syphilis, as well as 201 other men who were not infected in Macon County, Alabama. The researchers involved informed the patients that they were to be treated for “bad blood” (Adams et al, 1996). The participants were given several benefits for their participation in the study, including free medical examinations, meals, and burial insurance. The one thing that they were not provided with was treatment for the fatal syphilis infections that nearly two thirds of the participants had. The researchers purposefully prevented these men from getting any medical help from any other sources while steadfastly refusing to treat the issue (Adams et al, 1996).

By this time, treatment had already become available for syphilis in the form of penicillin. Despite the fact that this cure existed and that there was the possibility that these men were spreading the infection to others, the only things that the doctors did for the patients involved invasive medical examination techniques that did not help to treat the disease. In spite of this, the doctors continued to tell the patients that these procedures were treatments and not merely examinatory. In one example, when the researchers desired to perform spinal taps on the subjects of the study, the letter that was sent to them concerning this matter made mention that “[t]his examination is a very special one and after it is finished you will be given a special treatment if it is believed you are in a condition to stand it” (Brandt, 1978). There were claims that actually treating this disease was a prohibitive cost for the doctors, but there was little to no sign that the option of treatment was even considered by the research staff. One researcher involved in the study went as far as to say that “we have no further interest in these patients until they die” (Brandt, 1978). In their first published paper, it was revealed that only about 16 percent of all members of the experimental group failed to show signs of morbidity. In contrast, this number was about 61 percent in the control group (Brandt, 1978).

This study has led to damage to the trust relationship between the African American and medical communities. Adams et al. conclude that for some, examples such as this and others implied just how little society valued their lives at the time. The authors also conclude that for many others, it still shows just how exploited the African American community is. (Adams et al, 1996).

2.1.4. Human Cell Lines

When consent from a patient is not gained, it does not necessarily mean that a patient is directly harmed. On the other hand, this lack of harm does not excuse the lack of consent. One of the most infamous examples of a patient not being harmed directly but failing to be informed is the case of an African-American woman named Henrietta Lacks. In 1951, she went to Johns Hopkins Hospital for bleeding that did not coincide with her cycle. Upon inspection, a mass was found in her cervix. After testing negative infections, primarily syphilis, a biopsy of the tissue was obtained, and it was decided that Lacks had cancer. She left after a radium capsule treatment and told no one of her illness, hiding her return trips. Eventually, on October 4, 1951, Lacks died after the cancer had spread throughout her body. After a while, as is mentioned by Watson through her research, the incident was mostly forgotten by her family, and she was rarely spoken of among them. This quiet was to end in the early 1970s, when researchers wanted several members of her family to give blood samples to learn more of Mrs. Lacks genetic makeup. Upon further inquiry, her family discovered that a part of her was still alive and growing strong (Watson 2010).

For years, researchers had been trying to plate human cells so that they could use them to perform noninvasive research. For years, all cell lines that the researchers tried either lived for a mere few days or did not live at all. One of these researchers, Dr. George Gey, was working on

this unsuccessfully for years at Johns Hopkins. When he got his hands on Henrietta's biopsy, he plated these as well, only to find that they would just keep growing in the plate. The cancer cells of Henrietta Lacks had become the first human cell line ever grown (Watson 2010). Over the years, these cells, now referred to as HeLa cells, would become the gold standard for human cancer cell lines, being referred to in more than 74,000 scientific publications (Wagner 2013).

After several events leading to outrage among the Lacks family, notably including one case where the genomic sequence of HeLa cells was published leading to the family feeling as though their privacy had been compromised (Collins 2013), special rules became established for the HeLa cell lines by mutual agreement between the National Institutes of Health and the Lacks family. Specifically, this agreement called for all publication of the HeLa cell line's genomic sequence to be put into a special database, the creation of a HeLa Genome Data Access Working Group in order to process data access applications, and acknowledgements for Henrietta Lacks and her family in any research using the cells. While the family themselves do not earn any monetary compensation, they do in fact have representation on the Working Group (Wagner 2013).

Of course, even in contemporary times not all cases like Henrietta Lacks's work out so smoothly to address a wrong. In 1991, a case called *Moore v. Regents of the University of California* made it all the way up to the California Supreme Court. Moore went to a UCLA Medical Center in order to be treated for hairy cell leukemia. After being tested, his doctor by the name of Golde discovered that Moore's tissue samples would be perfect for research. Without informing Moore, Golde removed several tissue samples, blood samples, and even Moore's spleen from his body and used them for research. From this, Golde patented a cell line, earning him significant royalties. Moore sued, claiming that the cells taken from his body were his personal property. Ultimately, while the court ruled that although Golde was in the wrong for failing to inform the patient, Moore's suit failed due to the patient not expecting to retain possession of his cells (*Moore v. Regents of the University of California – Case Brief Summary*).

2.2. Laws and Legality Regarding Informed Consent

In this section, we discuss the laws and rulings regarding informed consent that affect our area of study. First, we discuss the laws that govern the process of informed consent within Massachusetts. We then go on to discuss a few of the court cases that establish precedence for the national idea of informed consent.

2.2.1. Legislation

While the law seems to acknowledge the existence of informed consent, it does not often seem to clearly define it. In the Massachusetts general laws, Chapter 111, Section 70E, the rights of patients and residents of medical facilities are outlined. In a list of various rights, the right "to

informed consent to the extent provided by the law” (Mass. Gen. Laws ch. 111, § 70E.) is noted. However, within the law the concept of informed consent is not mentioned or even defined. On the other hand, this same section seems to define various different parts of informed consent without outright naming it. Some examples of various other rights provided by the Massachusetts law for patients include the right “to refuse to serve as a research subject and to refuse any care or examination where the primary purpose is educational or informational rather than therapeutic” (Mass. Gen. Laws ch. 111, § 70E.), the right “to refuse to be examined, observed, or treated by students or any other facility staff without jeopardizing access to psychiatric, psychological or other medical care and attention” (Mass. Gen. Laws ch. 111, § 70E.), and in the case of rape victims, the right “to receive medically and factually accurate written information prepared by the commissioner of public health about emergency contraception” (Mass. Gen. Laws ch. 111, § 70E.).

Of great note, Massachusetts law also requires that interpreter services be provided to patients, as is outlined in the Massachusetts general laws, Chapter 111, Section 25J. As is required by this law, “[e]very acute-care hospital...shall provide competent interpreter services in connection with all emergency room services provided to every non-English speaker who is a patient or who seeks appropriate emergency care or treatment” (Mass. Gen. Laws ch. 111, § 25J.). Each hospital has the responsibility to hire translators according to their best judgement and “[b]ased on the volume and diversity of the non-English speaking patients or persons seeking appropriate medical care or treatment” (Mass. Gen. Laws ch. 111, § 25J.). Institutions must comply with this law in order to be licensed or relicensed. If a patient cannot get proper treatment due to the hospital having inadequately staffed themselves with the appropriate translators, said patient has the right to bring the matter into court, being entitled to at least \$250 in damages as well as payment for legal fees (Mass. Gen. Laws ch. 111, § 70E.).

2.2.2. Court Precedence

Much of what governs informed consent is not explicitly written into law; rather, much of it comes from previous court trials and other such precedence. Justice Cardozo, jurist who served on the New York Court of Appeals, stated that “[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body” in context to the case of *Schloendorff v. Society of New York Hospitals* (*Salgo v. Leland*, 1957). In 1957, before the Belmont Report and the Nuremberg Code, several societies decided that people had the right to decide what happened to them. The modern trend of discussion in informed consent is that the “value of patient autonomy is greater than the value of physician beneficence” (Culver and Gert, 1982). This trend can be seen in the ideas of “valid consent” discussed by Culver and Gert, and is questioned and reconsidered by the ideas of “shared decision-making” declared by Cathy Charles (Charles et al, 1997).

2.3. Philosophical Discussions and Cultural Understanding within Informed Consent

In this section, we discuss current ideas regarding the modern idea of informed consent. We start this discussion by mentioning several different views within the medical community regarding informed consent. We then discuss several criticisms of the idea of informed consent, as well as several suggested improvements to the process. We continue on to discuss how cultural differences can complicate the informed consent process. We then wrap up this section with a discussion on the role of interpreters within the idea of informed consent.

2.3.1. Medical Generalizations Regarding Informed Consent

Within the medical community, there is a prevalent concept known as paternalism or paternalistic care. This concept refers to a sort of behavior wherein “the paternalist is aware that his or her actions would be opposed by the patient if the patient knew about it, and that the paternalist must have some expectation that in the long run the patient will agree that the action taken was correct” (McKinstry, 1992). The idea behind this sort of action is that the doctor thinks that he or she knows best. The writers believe that it is not necessarily a bad thing if they assume that a patient will consent to a certain treatment or even that it is acceptable to ignore a patient’s requests if it is for the good of the patient. Many would argue that a patient has ultimate knowledge of what would bring them the most happiness, and as such this sort of behavior is inexcusable. Some others would argue that there are certain situations in which someone must be making decisions for the patient. A child who does not want the pain of a shot, for example, would likely have his or her desires be 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 (McKinstry, 1992).

While a patient is usually capable of granting or denying consent to a physician, there come times when the patient is not capable of giving this consent. In such cases, the medical community has taken to the ideas of presumed consent and implied consent. The concept of presumed consent covers the idea that there is a sort of standard for what an average patient will consent to in a medical setting. Most patients who are in severe pain likely do not wish to continue to be in pain, so one may assume that most patients will consent to pain medication in such an event, even if they themselves are not currently capable of giving this consent. The concept of implied consent refers to the idea that one can assume a patient’s state of consent from how he or she usually behaves. If an individual is known to be of a certain faith that does not accept a certain medical procedure, it can be assumed that this patient will likely not consent to this procedure. In such an emergency, these ideas allow doctors the ability to treat a patient rapidly in a case where they must act rapidly (Posts et al, 1996).

2.3.2. Criticisms of Informed Consent

As the idea of informed consent has developed and been criticized, no clear answer has come to fruition in regards to how it can best be implemented. Culver and Gert discuss the nomenclature of informed consent and the implications between the words. The name these authors give throughout their book for their ideal for the informed consent process is “valid consent”. To them, this term is seen to be a more symbiotic nomenclature to “informed consent”, as the phrase “informed consent” suggests that the only necessary criterion for consent to be acquired is the administering of relevant information to the patient. “Valid consent” further suggests a need for validity regarding the patients’ decisions, and ultimately their consent (Culver and Gert, 1982).

Valid consent is not the only alternative proposed for informed consent. Some believe in an idea called shared decision making. This idea refers to a specific way of treating the patient-doctor relationship. It describes a mode of conduct in which at least two involved parties, usually the patient and the physician, both participate in the process of deciding what the best mode of treatment is for a patient. Unless the patient willingly forgoes his or her decision making power and leaves their fate in another’s hands, then the doctor must work at creating an atmosphere conducive to the patient understanding and responding to the various treatment options out there. The two parties must share their information in order to make a proper decision. The doctor needs to at least describe the various treatments in reasonable detail, and the patient must give any information they’ve gathered about the situation. Most importantly, both parties must agree to a single decision. Though both parties do not necessarily need to think that this is the best treatment, both must agree that the treatment is viable. In this facet, shared decision making differs from others. Most other models grant the patient the full right to choose their treatment. In this regard, the patient must be satisfied that the treatment works the best for them, and the physician must be satisfied that this treatment is both safe and valid (Charles et al, 1997).

Ideally, according to Culver and Gert, a patient should be informed of all the various alternatives to their treatment, including the severity and probability of any complications which could arise. A patient should also be informed of anything which would affect their personal decision, such as anything which would upset any particular beliefs the patient has (Culver and Gert, 1982). A patient may have religious or cultural beliefs which would affect the patient’s own personal decisions, 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. 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 administer valid informed consent (Culver and Gert, 1982).

While most would agree that informed consent is important to patients, there may be times where denying a patient information may lead to their benefit. W. J. Coggins and Peter Graham offer a noteworthy example in which a patient benefitted from not being told all of the details. In this

case, an eccentric fisherman referred to by the locals as Uncle Charlie came to a doctor believing that he had fish scales coming out of his eyes. The doctor could see that this was not the case, but upon further testing, noticed that Uncle Charlie had the beginning stages of congestive heart failure. He prescribed the man placebo eye drops and medicine for his heart. When Uncle Charlie came back for his second visit, he had stopped taking both the pills and the eye drops, as his eyes were no better. The doctor, in order to get the fisherman to take the medicine, told him that the medicine would assist with a sluggish circulation issue. Through this, he convinced the patient that the fish scales would not be able to settle in his eyes (Coggins et al, p 139-141).

This case brings up the question of whether or not the patient's right to be healthy supercedes their right to be informed. Coggins and Graham argue that the above case is justified. Uncle Charlie was a known eccentric in his community and yet was an isolated man. They argue that were the doctor to try and take his time to explain to the fisherman exactly what cardiac arrest meant, not only might Uncle Charlie not understand the explanation leading to time lost for both men, but also that the doctor could lose credibility with the patient and lose his chance to treat him. The writers also argue that it was likely impossible to treat Uncle Charlie while divorcing the diagnosis from the man's delusions. They make the case that as the easiest way to treat the man was to use a shared frame of reference in order to convince him to be treated, doing so was in the man's best interest (Coggins et al, p 139-141).

2.3.3. The Role of Culture in Informed Consent

Cultural traditions are a driving force in the lives of many people, and the issue of informed consent is no exception. One such example can be shown in the elderly Japanese population in Hawaii. Within their culture, there is a strong belief that the needs of the family unit are more important than the needs of the individual. In the nation of Japan, this belief is often shown in cancer cases, where doctors will withhold the diagnosis from the patient and instead inform their family. This cultivates an idea that the patient take a passive role in their health care, which is in great contrast to the more Western ideas of informed consent (Saldov et al. 1998). Of course, Japanese Americans are far from the only cultural group for whom the current ideas of informed consent may not be perfectly suited. Another study examined the issues of this topic for those of Navajo culture. One of the key issues when attempting to follow the ideal of informed consent with these people is the fact that Navajo, as a language, was not a written language originally. In order to create the typical legal documents needed to obtain consent in Navajo, significant linguistic expertise is necessary, and even then, in order to properly convey the ideas of informed consent one needs to resort to awkward translations and phrasings. In this study, the translation of experimental diabetes consent forms into Navajo resulted in very few places in the resulting document where native speakers did not feel confused or worried. The section on procedures and benefits ended up implying that patients had to consent before doctors could look at their medical charts. The concept of placebo groups, while translated fine, held unfortunate cultural

implications regarding patient autonomy. Overall, as is the case with many linguistic barriers, ideas may be lost or drastically different from one language to another (McCabe et al. 2005).

The aspect of religion in regards to cultural differences also cannot be ignored. Many religions take issue with several procedures that hospitals typically perform when quick action is needed and consent may not be able to be obtained within the timeframe needed to save the patient. Most notably is the case of the Jehovah's Witnesses. This sect of Christianity believes quite strongly that a person's blood is heavily tied to who and what said person is. They believe that any morally questionable behaviors could potentially be transmitted from one individual to the next through a blood transfusion. As blood transfusions are often used in emergency situations when doctors do not truly have time to ask the patient whether it is acceptable if they do this, or when the patient may not even be conscious to give consent, this issue can be easily disregarded when it can be a vital part of the consent process (Escobedo et al. 2007).

Further complicating this issue is the idea that different cultures express pain differently. In Western culture, pain is generally seen in medicine as a thing to be reduced in all reasonable circumstances. Throughout the philosophical and bioethics communities, "[t]he lay, medical, and bioethics literatures tend to equate pain and suffering, and most people assume that the greater the pain, the greater the suffering" (Posts et al, 1996). However, it can be argued that this is not an adequate viewpoint for all circumstances. There are situations both culturally and personally where pain can be viewed as a good thing. In two extreme examples, the Yanomamo tribe of South America and the Dugum Dani of New Guinea engage in daily battles with axes, clubs, and spears as a form of entertainment. Pain is viewed more as a point of pride among them or simply a part of the natural order rather than a point of suffering (Free, 2002). As pain is a key concept in the issue of healthcare, having these differing values on whether or not pain is acceptable can lead to issues with the consent process (Posts et al, 1996).

When a patient is not capable of giving consent to a procedure, someone must assume whether the patient would consent or not. 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 (Posts et al, 1996).

In general, the challenge with the idea of informed consent in American medicine comes with the fact that the Western ideal of medicine comes, unsurprisingly, from Western ideologies. The idea of autonomy itself, the idea that one must be able to freely choose what they do, has been the central concept of informed consent even when it was first brought up as an idea in court cases and in its key founding documents such as the Belmont report. However, the idea personal

freedom as a major concern is a very Western idea. In many other cultures, autonomy does not raise as high of a concern, instead being replaced by other concerns. The Japanese valuing the family unit over the individual or the Jehovah's Witnesses refusing life-saving treatment because their spiritual needs overcame their personal ones act as excellent examples of how the American and Western ideas of informed consent do not translate perfectly across cultural boundaries. As is put by Posts et al, “[b]y mechanically applying narrow Western-defined doctrines of autonomy and informed consent, American law deprives non-Western cultures of their proper positions of power and actually devalues their notion of autonomy” (Posts et al 1996).

2.3.4. The Role of Medical Interpreters in Informed Consent

In any community with a sufficient population which has a limited English proficiency there are concerns with society’s ability to be able to accommodate for these people. As stated in the section above regarding legislation, Massachusetts law requires health care facilities have appropriate interpreter services, or the ability to facilitate a patient with these service. Professional interpretation helps improve the trust and understanding between doctors and patients with a language barrier.

There is a significant distinction between interpretation and translation. Interpreters are individuals who bridge the language gap orally, whereas translators deal with writing. An interpreter is far more important for a discussion with a doctor than a translator, because much of the communication between patients and doctors is personal. For this reason, having the role of an interpreter is separate from that of a translator. Professional interpreters are preferred in encounters with patients and doctors, rather than ad hoc interpreters which is anyone not financially compensated and employed by interpreter services. It is the belief of authors such as Flores et al. that using professionally trained interpreters lessens the risk of misinterpretation that can come with those who are far less trained. (Flores et al., 2003)

2.4. Medical and Cultural Situation within the Worcester Community

Perhaps one of the most vital things to examine in informed consent is those who are responsible for the upholding of informed consent itself, the medical institutions. As one local example, Saint Vincent Hospital comments on the issue of informing the patient on their website. While listing many of the rights that patients have while under their care, they state that patients “have the right to be make (sic) informed decisions regarding your medical care” (Saint Vincent Hospital). The hospital specifies these rights even further, noting that one should be informed of one’s health, involved in the care and treatment decisions, able to deny themselves treatment, and allowed to help develop their discharge plan. Other related rights they specify include the right to ethics consultation service and the right to complete information on all alternative treatments that are medically viable, though strangely they specify this only for breast cancer.

Several times they mention in differing ways that the patient has the right to informed consent (Saint Vincent Hospital).

UMass Memorial Hospital writes its list of patient rights in much the same vein. They grant the patient the right “[t]o refuse to be examined, observed or treated by students or any other staff member without jeopardizing access to psychiatric, psychological, or other medical care and attention” (UMass Memorial Health Care). The hospital list many of the same rights as Saint Vincent Hospital and there are few differences in their descriptions of the rights. Much of what is written by both institutions is a restatement of the Massachusetts laws (Mass. Gen. Laws ch. 111, § 70E.).

Within Worcester itself, there is a wide variety of different groups of people, especially in regards to racial diversity. According to the 2010 census, of the 798,552 people living in Worcester at the time, about 86 percent of the population identified as white. Of other races, about 0.25 percent identify as Native American or Native Alaskan, 4.0 percent identify as Asian, 4.1 percent identify as African American, 0.03 percent identify as a Pacific Island native, 2.4 percent identify as of mixed race, and 3.6 identify as a race not listed in the census. In addition, 9.4 percent of the Worcester population identify as being of Hispanic or Latino origin (Census Viewer, 2011). There is an interesting trend that appears when examining the difference between the 2010 and the 2000 censuses. Despite the 5 percent growth in population overall, those identifying as white in Worcester have decreased in number by 5 percent. In contrast the African American population grew by 77 percent, the Asian population by 31 percent, and the Latino population by 45 percent. While the white population may have the majority, the minorities are growing quite rapidly (Drici, 2013).

Ethnically, Worcester is even more varied. There is a wide variety of people from different parts of the world. In terms of immigrants living in Worcester, there are several groups whose total population makes up more than 5 percent of Worcester’s total population. Brazilians make up 9.63 percent of Worcester’s population, Vietnamese constitute 9.51 percent of the population, Ghanaians 8.64 percent. Dominicans 7.15 percent, and Albanians 5.28 percent (The Research Bureau, 2013).

Religious affiliations in Worcester county, while largely Christian, do include many different faith groups. 71.7 percent of all people living in Worcester county claim to be Catholics. Concerning other Christian denominations, 13.5% of the county consider themselves of a mainline Protestant denomination, 5.7 percent consider themselves of an Evangelical denomination, and 2.1 percent consider themselves Orthodox Christians. Despite the large percentage of the Worcester county population that consider themselves Christian, 7 percent of the population consider themselves of a faith not given above. Within that group, 4.5 percent of the population consider themselves Jewish, 1.3 percent consider themselves Muslim, and 0.6

percent consider themselves Unitarian Universalists. There are also several Buddhist, Sikh, and Bahá'í congregations in the area, though the survey shows that a very small number of individuals consider themselves of these faith (City-data.com).

As a community as diverse as the Worcester one would result in cultural disagreements within several different areas, we decided that we as researchers would delve further into the issues of informed consent within this community. To address these issues within a community would be of benefit to all in it. The sensitivity of the topic, however, required that we address the issue with great care. After having considered these factors and others, we developed a method for moving forward with our research.

3. Methodology

This project is designed to study the relationship between patients and the medical community in regards to informed consent through the examination of the accommodations medical officials make when interacting with groups of differing cultures and languages. More specifically, we examined the considerations that doctors, interpreters, and other medical professionals take into account when dealing with patients with such cultural or linguistic differences. Our objectives to complete this project are as follows:

1. Interview professionals from several institutions and practices to learn about their perspectives regarding informing patients, namely those of cultural and linguistic difference.
2. Identify and map how different medical practices go about informing patients of cultural or linguistic difference in order to obtain their consent.
3. Analyze how patients of cultural or linguistic difference experience the process of informed consent in the medical setting through the dialogue with medical professionals.
4. Determine what the medical community describes as an effective explanation of informed consent for a standard patient and how this explanation changes towards people of cultural or linguistic difference.
5. Determine the extent and effectiveness of communicating information that the medical community uses prior to consent when accommodating for patients of cultural or linguistic difference.

3.1. Interviewing Medical Professionals

We began with the task of identifying institutions where patients of cultural difference would seek medical attention. The identification of the departments within these institutions which deal with patients of at-risk communities was the first step to seeking relevant interview contacts. Our first objective drove us to find and interview professionals regarding their perspectives in the medical field. In order to frame our first objective we used research questions that we want to answer:

- How does a patient, especially one with some form of cultural or linguistic difference, look for an institution that could grant his or her medical needs, and how are these institutions made accessible to the public?
- Which institutions are most likely to facilitate patients of cultural or linguistic difference?
- How sensitive is the topic of interviewing patients about the issues of informed consent?
- How do medical professionals help in providing a patient perspective of the informed consent process?

We first established contact with various medical practices across Worcester by emailing, calling, and visiting several of these institutions and their workers. Our sample phone call transcript can be found in Appendix A, and our sample Email transcript can be found in Appendix B. Through these methods, we contacted interpreters at UMass Memorial Hospital, as well as doctors and surgeons who practice in the Worcester area. We also connected with medical assistants, nurse practitioners, clerical workers, and medical technicians in the Worcester and Boston area. We contacted these people in the medical community for their permission for us to begin with interviews. These familiarization interviews were designed to take no longer than 20-30 minutes of their time. However, many of the participants were willing to speak with us for an hour or more. Because of the sensitivity of the subject matter, we promised the interviewees confidentiality of the information they share through the informed consent form we give them. This was done in order to consider the privacy of the patients they associate with, and to assure that anything said will not affect interviewees' job situations. The interviews were performed using responsive interviewing, to be explained later in Section 3.5. The information gathered from the interviews with doctors, translators, medical technicians, and other clerical workers allowed us to better identify and map the process of the delivery of informed consent to patients of cultural or linguistic difference. These meetings gave us the opportunity to familiarize ourselves with the medical institutions within our study.

Throughout the course of the study, acquiring interview opportunities was a challenge. Medical professionals are busy people, as there are always new patients coming into their office. Finding a time where both our research team and a potential interviewee were available was difficult, and the issue of the topic's sensitivity made it even more difficult to find willing potential interviewees without undergoing a process of explanation.

3.2. Mapping the Delivery of Informed Consent

In order to analyze the effectiveness of the current processes of delivering informed consent information, we aimed to uncover what sorts of methods or models of communication were used for the purpose of conveying information to patients by the medical institutions in the Worcester area. Once we had both succeeded in familiarizing ourselves with local medical institutions and in gaining IRB approval from Worcester Polytechnic Institute, we uncovered this information through examination of the interviews performed in the previous section. To make sure our interviews and meetings were effective and time-efficient, we made sure to clarify our project structure and goal. We had also clarified what we seek to learn and discover from the interviewee. In order to frame our second objective, we used research questions which we want to answer:

- What models of communication are used to convey information to patients, and do these differ between different procedures?

- When translators are involved, how does the process of delivering informed consent change?
- How does the process of delivering informed consent change across cultural barriers?

Doctors are typically the main means through which a patient will interact with the medical setting, and addressing their relationship with patients was thought to be key to understanding how informed consent unfolds in practice, and thus interviews with doctors focused on how patients and doctors treat each other, as well as how doctors interact with patients of cultural difference. We also looked into 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. A full set of our standard interview questions for doctors can be found in Appendix C.

While there is a great deal of overlap, doctors, nurse practitioners, and interpreters all deal with different nuances of the informed consent process. As such we asked any potential interviewee a set of questions depending on his or her job, and 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 doctors and other medical officials, we uncovered other potential interviewees who also play an important part in the process of delivering informed consent information to the patient. Medical interpreters offered a window into the social situation the patients experience during the informed consent process. These various people in the medical community all offer different and beneficial perspectives into the informed consent process, and how patients handle the situation.

Originally, we hoped to interview patients of various practices and institutions in the Worcester area in addition to their workers. However, due to the sensitivity of the subject, it did not seem feasible to interview patients directly. Interviewing patients who were undergoing treatments ran the risk of uncovering unwanted personal information, and interviewing patients who could be defined as being a part of an at-risk community such as those of a linguistic or cultural minority ran the risk of putting them more at-risk. Instead, through interviews with medical officials, translators especially, we uncovered as much as we could in lieu of speaking to a patient directly.

3.3. Analysis of the Situation of Patients of Cultural and Linguistic Difference

We sought to analyze the interview responses from the groups of medical professionals such as doctors, interpreters, and nurse practitioners in order to understand and discover social perspectives that developed within the medical community around its treatment of patients. In particular, we interviewed medical interpreters due to the fact that they directly interact with the patients and doctors, and voice the struggles or concerns of the patients of cultural or linguistic difference. Interviews with interpreters aimed to answer how groups that are less accessible to the medical community are communicated with in a medical setting. Interview questions with

interpreters focused on how other medical officials react towards patients who cannot easily communicate, as well as any challenges they have encountered in conveying concepts to the patients. A set of research questions were used when constructing the interview questions for interpreters:

- How often are medical translators/interpreters involved in the informed consent process?
- Do patients who need a translator or interpreter often struggle with the process of informed consent?
- When clerical workers are involved in the process, how comforting and informative are they to patients of cultural or linguistic difference?

A full set of our standard interview questions for translators can be found in Appendix D.

Clerical workers in the medical community often handle much of the paperwork in a hospital setting and therefore are heavily involved in the consent process due to having to interact with the patients in relation to these forms. Questions that we asked these professionals involved how patients treat these forms as well as the relationship between these professionals and the patients during this process. A full set of standard interview questions for clerical workers can be found in Appendix E.

Since we did not have access to patients, we once again had to closely examine the interviews of the medical professionals themselves to glean the ideas of those patients with cultural or linguistic difference. By taking a look at how these professionals view these patients, we attempted to obtain an idea of how these patients consider these topics. It is not as good as getting the information directly from the patients themselves, but this information from medical professionals grants us valuable perspectives of the informed consent process between patients and professionals.

3.4. Determination of Effectiveness of Current Informed Consent Delivery

Ultimately, we worked to analyze the perspectives of different medical officials involved in the process of information delivery as well as the perspectives of patients of differing cultures and linguistic backgrounds, all in regards to the informed consent process. Through analysis of the interview material, research on the history of the different perspectives of informed consent, and further study of the policies of local institutions on informed consent, a framework of effective explanation was to be developed. The following research questions framed our developing analysis of the informed consent process in the Worcester area:

- How do providers who deliver informed consent handle patients of cultural or linguistic difference?
- What are a provider's understanding and expectations of the informed consent process?

- What are a patient's observed understanding and expectations of the informed consent process?
- Are the current methods for granting informed consent sufficient?
- Are there still serious concerns or internal debates between providers on the issue of informed consent?

Once we completed interviews, we examined the responses to our interview questions using what Berg described as “interpretative approaches” for analysis (Berg, 2007). Through a general interpretative orientation, we analyzed all the interview responses in order to “uncover patterns of human activity, action, and meaning” (Berg, 2007). We used content analysis and counted qualitatively the various themes and concepts from the responses to questions in our interviews. We examined the responses from same occupation providers of different institutions, as well as the responses to the identical, essential questions we asked to medical professionals of different occupations and counted perspectives which complemented, as well as perspectives which conflicted. Where questions and responses would lead to similar themes and concepts through probing questions, we also included these in the analysis.

In Appendix J, a table is presented as a tool for counting and analyzing the themes and concepts which are the perspectives of the various providers interviewed. By taking the resulting data from the interviews and examining it against our research questions for this section, we developed a list of key findings from each of our interviewees. These key findings were then examined against each other in each category, and from this various consensuses and disagreements were obtained with regard to each question.

3.5. Rationale for Methods

Many different authors and researchers have put much thought into how to best perform a study, and several of these researchers' suggestions have been taken into account. Rubin, for example, describes two essential research theories, critical theory and interpretive constructionist theory. Rubin explains that with critical theory, “researchers emphasize action research, arguing that research should redress past oppression,.. help minorities,.. and as such is a means of empowering the oppressed” (Rubin 2005). The circumstance of a patient with a significant cultural difference receiving informed consent information in an inadequate way is oppressive, and so the observation of how this scenario is avoided is crucial to our research. Also, interpretive constructionist theory allows researchers to interpret different points of views people have as meaningful. “Constructionists expect people to see somewhat different things”, and through the understanding of these different “cultural lenses” researchers are able to study the ways people share meaning, and so the decisions of how to facilitate these people with different cultural backgrounds can be made conscientiously (Rubin 2005). Through a “mixing” of critical theory and interpretive constructionist theory, a model of approaching interviewing research was developed. Rubin describes this as “responsive interviewing”, and this is the approach our

research is going to take. We will establish “a relationship during the interviews, and generate ethical obligations for the interviewer” (Rubin 2005). Through this sort of open-ended, discussion-based interviewing, we have formed a relationship with our interviewee in a similar way as to how an informed consent discussion arguably should be held among doctor and patient. In order to successfully meet our research goals by having successful interviews, strong practice on the discussion-based semi-structured interviewing, as well as well-developed, open-ended questions were both necessary.

Open-ended questions provide a platform for qualitative interviewing and analysis. Open-ended questions, as described by Foddy, are a proper set of questions for qualitative interviews which ignore the quantitative aspects of other question sets such closed-ended questions. (Foddy, 1993). Foddy goes further to describe claims supporting the use of open-ended questions. Open-ended questions do not suggest answers to the respondents. The answers to these questions indicate a respondent’s level of knowledge about the topic, and they allow for identification of complex influences and frames of reference among respondents. Thus, we formed a set of questions which could help indicate a level of knowledge patients had about the topic of informed consent, as well as granting us the ability to identify where these answers are coming from in terms of the cultural influences each patient has. The questions, as well as research on the policies of patient care at hospitals and clinics were beneficial to the project, as it created a backbone from which all the interviews can rest upon.

3.6. Challenges with the Methodology

One of the largest challenges with the methods used here involved the fact that there was not much of an opportunity to get the perspective of the patients. Due to the issue of confidentiality with patients, it was unreasonable to ask any current patients to be interviewed for such a project. Doing so would not only be intrusive towards the patients, but also potentially harm the credibility of the institution associated. In order to compensate for this, several of the questions asked to the medical professionals have attempted to glean how patients feel in the medical setting from their own experiences.

Another challenge came with privacy and confidentiality. If handled improperly, interview questions could have resulted in social or occupational harm to those interviewed. We avoided this by assuring confidentiality to all interviewees in our informed consent forms. When we referred to these interviews in our notes and writing, we used little identifying information. If interviewees thought that these interviews put them at risk, they may not have answered honestly in order to protect their position. As such, the assurance that they would not be identified in the paper or any other writings respected their rights. If an interviewee absolutely needed to be identified for any reason, all information put into the paper that related to them was disclosed to the interviewee for their approval.

As the project progressed, we became aware of the issue of conducting many interviews. Because doctors and other medical professionals have busy schedules with many different appointments scheduled in a single day, arranging a time when a potential interviewee was both able and willing to be interviewed was difficult. We broached subjects of a sensitive nature in these interviews and as such, many institutions were unable or unwilling to allow their employees to be interviewed, or at the very least were skeptical of the prospect of being interviewed. The hardest part of the process was gaining the interviews needed to properly approach the subject.

4. Findings

In this chapter, we present our discoveries regarding the investigation of informed consent and how providers grant it and handle the situation with patients of cultural difference. Several findings came into light after the semi-structured interviewing of patients and the analysis of their interview responses. We interviewed three medical doctors, two from private practices and one a UMass trauma surgeon. We also interviewed six medical interpreters from UMass, one being the coordinator of education for medical interpreters. We interviewed two nurse practitioners from Worcester low-cost walk-in clinics and one nurse from a private practice. Finally, we gained anecdotal interviews from a few clerical workers and medical technicians who could not fill out our informed consent forms. The responses from these interviews indicate different perspectives of the patients' and providers' situations in different locations of the medical community in central Massachusetts. These findings show the perspectives on the medical situation of our society through providers at private practices, hospitals, and walk-in clinics.

4.1. On Culture and the Role it Plays

Our interviews suggest that people who grow up in societies where the idea of informed consent is underdeveloped tend to be more passive in their roles in the informed consent process. From what we gathered in our interviews, people who have recently come to the United States tend to ask fewer questions than people who grew up in the United States, in regards to what their procedures or treatments entail. One interpreter who interprets Portuguese whom we interviewed (henceforth referred to as Interpreter A) described a common situation between Brazilian patients and their doctors. Interpreter A said that when doctors in Brazil present informed consent forms to a patient, the patients often simply sign the paperwork without question. Interpreter A said the Brazilian 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, many patients are surprised that the doctors go to so much trouble to inform them in the first place. Interpreter A told us that, while in Brazil the informed consent laws are similar to those in the United States, rarely do medical professionals actually respect these laws. According to Interpreter A, these medical providers in Brazil often do not often require that their patients sign any sort of informed consent paperwork. While this may be illegal, it is still the practice. Another interpreter who we interviewed (henceforth referred to as Interpreter B) works to translate Nepali. Interpreter B said in Bhutan and Nepal there are not even laws concerning informed consent and so in these countries informed consent is even less of a concept (Interpreter A, Interpreter B, Interpreter C, Administrator A, personal communication, February 19, 2015). In some cases, the fact that a patient from a foreign country is having things explained to them is enough to make them concerned about a procedure. As was said by one Portuguese interpreter (henceforth referred to as Interpreter F), the idea that the doctor comes in with a serious face explaining all of the risks that the procedure can cause is enough to make a patient say that they do not want to follow

through with the procedure. In cases such as this, as an Albanian interpreter said (henceforth referred to as Interpreter D), the provider must explain that it is the policy of the institution to tell the patients the potential risks of a procedure before they go through with the procedure. Interpreter D also brought up another related issue in that according to them, many times, a patient not used to the process will often ask the interpreter for an opinion. For interpreters, this is a huge ethical issue, as the interpreter cannot make any decisions for the patient. (Interpreter C, Interpreter D, Interpreter E, Interpreter F personal communication, April 16, 2015).

The ideas of the elderly represents a perspective of the past where the idea of informed consent is different compared to the current idea. While not a different culture in the traditional sense, it is hard to doubt that the way today's society views the idea of informed consent is very different when compared to how it used to view the process. When interviewing one doctor (henceforth referred to as Doctor A), Doctor A said that elderly patients oftentimes would try to simply agree with whatever it was that Doctor A would recommend. Doctor A said this is likely due to the fact that they grew up in an age which Doctor A referred ironically to as "the Golden Age of Medicine". In this time, according to Doctor A, doctors had no need to inform their patients. Doctors in the past could suggest any sort of treatment for the patient, and the patients would often simply go along with it in order to be treated (Doctor A, personal communication, February 26, 2015). In an anecdotal perspective from Doctor A's office specialist, the specialist said that older patients almost never read any of the consent forms and merely trusted that the employees of the office were being honest with them. A nurse working both at a hospital and a private practice (henceforth referred to as Nurse A) said that these individuals are also in general harder of hearing and less in tune with the technology of today, making explanations more complicated in general and bringing up the point that there are also more mechanical than social concerns at play when it comes to the elderly as well (Nurse A, personal communication, April 3, 2015). An interpreter for Spanish and head of the training program for new interpreters (hereafter referred to as Interpreter C) said that in the old days in the United States, the medical community did not want to deal with the paperwork associated with the consent process and that this did not change until litigations in the 60's over doctors operating on the wrong side of patients changed this (Interpreter C, Interpreter D, Interpreter E, Interpreter F personal communication, April 16, 2015).

In some cultures, there is also an issue over who exactly it is that the doctor deals with. While in the United States the patient is the one who the doctor deals with primarily, there are other cultures in which the doctor deals primarily with the patient's family. As Interpreter C said, this is the case in most other cultures. Another Spanish interpreter (hereafter referred to as Interpreter E) described a story where one of a Dominican patient's family members pulled Interpreter E aside and say not to tell the patient anything about the treatment. Interpreter E and the other medical staff there had to explain that the patient had the right to know about his or her treatment. Interpreter C also described having seen medical videos from Japan before in which

the doctor would never communicate with the patient, instead dealing directly with the patient's family. According to Interpreter C, absolutely everything was concealed from the patient in these videos (Interpreter C, Interpreter D, Interpreter E, Interpreter F, personal communication, April 16, 2015).

4.2. On the Role of Interpreters and Translations

In the medical community there is the concern of individuals with a language barrier, resulting in a need for skilled interpreters among various medical professionals. Medical professionals find interpreters vital to obtaining proper informed consent among those they do not share a language with. In larger institutions where there is a dedicated budget for hiring various interpreters, the role of interpreters is described as essential to the functioning of the hospital. As an Interpreter C said, in such institutions the interpreters are highly skilled and trained (Interpreter A, Interpreter B, Interpreter C, Administrator A, personal communication, February 19, 2015).

There are different roles an interpreter can play, depending on what a patient or situation needs at the time. The methods of interpretation interpreters use, and the levels of intervention they can take form a complex system, and it entails more than the simple act of oral communication between individuals. This method was described to us by Interpreter C. First and foremost, interpreters are trained to act as a conduit between the doctor and the patient. They are familiarized with medical terminology in order to better understand and interpret anything that a doctor or patient might say, and are instructed to translate everything that is said during an appointment so that nothing is hidden. If the patient the interpreter is interpreting for is asked for medical information, such as for the name of a prescribed medication and the patient does not remember, interpreters are also trained to take an intervention role if they know the answer to this and can facilitate the meeting. Interpreters are also asked to take a role of a cultural broker, as there will be times where the patients do not understand a situation due to cultural differences. Interpreter C noted a case where a Spanish-speaking patient was asked to "say a sentence", and due to the fact that the word for "sentence" in Spanish is the same as that for "prayer", the patient began to recite a prayer. Interpreter C believes using professional interpreter services is beneficial to the patients and doctors, and it is essential not only because the understanding of informed consent is important for patients before accepting a procedure or treatment, but also because the current informed consent forms are not translated into other languages besides English and Spanish at their institution. From our findings in other interviews, we have also determined that informed consent forms are not translated into other languages at private practices and walk-in clinics. When the forms are not translated in writing to a certain language, an interpretation of what the forms entail is essential (Interpreter A, Interpreter B, Interpreter C, Administrator A, personal communication, February 19, 2015).

An administrator of interpreter services at this institution (henceforth referred to as Administrator A) described the process of selecting which interpreters to hire for full or part time work is

carried out. Specifically, the administrators and supervisors hire and manage the interpreters based on how many requests for certain language interpretations they receive. In the event of them not having an appropriate interpreter on staff, they will use a phone service to interpret for them (Interpreter A, Interpreter B, Interpreter C, Administrator A, personal communication, February 19, 2015). In smaller institutions, doctors do not have the budget to handle a dedicated interpretation staff. In these cases, such as is the case of Doctor A, their offices are set up with phone interpreter services or video call services on iPads for use if need be. In the case of some more complex languages, they may have to obtain a plug-in translator to help their communication. Doctors at private practice find any interpreter services, whether phone, video, or live of key importance, because they facilitate their patients' understanding of the medical procedures, and understanding of informed consent before a procedure. If patients do not understand that which is being explained to them, Doctor A said they will not even consider continuing onwards with the procedure (Doctor A, personal communication, February 26, 2015). In these cases, the need for quality translations is not something to be taken lightly.

There was a consensus among several of the medical professionals interviewed on the limitation of phone-based interpreters. Many of these professionals, while seeing the use and importance of phone interpretations, do not feel that they are as effective as face-to-face interpreters. One doctor who practices at a private gastroenterology practice (henceforth to be referred to as Doctor B) described phone interpretation services and the experience with them as shakier and more cumbersome in general to use. Doctor B spoke of how in conversation, one can judge what someone is saying by reading his or her body language (Doctor B, personal communication, April 6, 2015). Interpreters we interviewed all agreed with this in their interview. As Interpreter C described, approximately sixty percent of communication is through body language (Interpreter C, Administrator A, personal communication, February 19, 2015). One trauma surgeon who works in a larger institution (henceforth to be referred to as Doctor C) had a regular staff of interpreters available and felt more comfortable using those interpreters to communicate than phone interpreters Doctor C did not know. Doctor C also said that during the course of a phone interpretation, comments would have to be repeated several times, making the conversation more difficult (Doctor C, personal communication, April 13, 2015).

Qualified interpreters are necessary for the informed consent process, and cannot be replaced by informal interpreters. The use of family members as ad-hoc interpreters is avoided when possible in the medical community. In larger institutions, this is largely forbidden. Interpreter C said family members are never used for interpretation especially regarding informed consent unless doing so is quite literally their only option. Doctors are required to identify the interpreter used for any sort of informed consent paperwork. They must either retrieve the interpreter's signature or, in the case of using phone services, an identification number to prove that the meeting was interpreted. The entire process is streamlined to remove the rogue element that such ad-hoc interpreters can add. Interpreter C added insight as to why these family interpretations are so

distrusted. These cases are to be avoided for the simple reason that ad-hoc interpreters are not trained to interpret. Even when considering the institution's own doctors, the hospital prefers the use of medical interpreters over multilingual doctors. While doctors who are multilingual are allowed to speak to their own patients in any tongue they are fluent in without an interpreter, the hospital prefers that an interpreter be present. Multilingual doctors cannot act as an interpreter on the behalf of another doctor (Interpreter A, Interpreter B, Interpreter C, Administrator A, personal communication, February 19, 2015). However, this is not a unanimous rule for all medical institutions. One nurse practitioner who works in a low-cost walk-in clinic (hereafter to be referred to as Nurse Practitioner B) said that if they have a patient who does not speak English well, and they have a member of their staff who can speak the language, they will use their bilingual staff (Nurse Practitioner B, personal communication, April 16, 2015).

In smaller institutions such as private practices and walk-in clinics, ad-hoc interpreters are used when professional medical interpreters are not available. Doctor A said that bringing family or friends to interpret for a patient was allowed for their first few visits. This is done to help bring a sense of comfort and trust to the patient (Doctor A, personal communication, February 26, 2015). Nurse A corroborates this sentiment, saying that providers at walk-in clinics will accommodate patients in much the same way during in-office visits (Nurse A, personal communication, April 3, 2015). Despite this, ad-hoc interpreters are not allowed to interpret for patients during informed consent meetings in regards to actual procedures. It is only allowable for in-office visits. According to Doctor A, one of the main issues with these types of interpretations is that they may fail to translate exactly what the doctor is saying due to the interpreters themselves not understanding certain terminology and will insert their own words into the interpretation in order to try to explain it (Doctor A, personal communication, February 26, 2015).

While most medical professionals interviewed agreed on the importance of skilled interpreters, there are some who do not agree when it comes to consent forms. Among some doctors, there is a negative view of creating informed consent forms in alternative languages. Nurse A said several doctors in the local area were against the idea of translating all consent forms into Spanish. While Nurse A was still in favor and understanding of the need for skilled interpreters when they are needed, Nurse A said that when an individual signs an informed consent form in a certain language, the expectation is that all following communications with the patient must be in the language of the consent form. According to Nurse A, a majority of healthcare providers do not speak Spanish. For smaller private practices as the one Nurse A works in, this creates complications for the doctor (Nurse A, personal communication, April 3, 2015).

4.3. On Religious and Cultural Considerations

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. There are times where certain religious practices are in opposition with Western

ideals such as informed consent. In many cases, religious belief complicates the medical situation. As Doctor A has experienced, those who come from Islamic cultures tend to dislike being examined by members of the opposite sex. While Doctor A said that some doctors will insist that they are the only doctor in their institution or local area that can perform a certain task or procedure, the Doctor A argued that the proper course of action was to refer them to a different doctor that would meet their needs (Doctor A, personal communication, February 26, 2015). Doctor B on the other hand, had a different perspective. In Doctor B's practice, if a patient had some issue concerning the doctor, Doctor B would say he was the only doctor in the practice, and if the patient did not want Doctor B to treat them, the patient had to go elsewhere. Somewhat similarly, in the small-town hospital that Doctor B was associated with, such a request would be rather hard to accommodate due to the much smaller pool of doctors the hospital has available to them when compared to much larger institutions (Doctor B, personal communication, April 6, 2015). In the interview with a nurse practitioner from a local walk-in clinic (henceforth referred to as Nurse Practitioner A), Nurse Practitioner A told of a patient that initially refused to get treated due to the nurse needing to touch the patient's feet. Nurse Practitioner A explained to the patient that it was necessary to touch the patient's feet to complete the procedure as well as the fact that it would be a very brief procedure before the patient acquiesced. While it was unclear from the interview the exact reason for the patient's initial rejection of the treatment, this response was in regards to a question on whether a patient had ever rejected treatment for religious or cultural reasons. In some cultures and religions (Islam, for example), it is forbidden for unrelated and unmarried people of different genders to touch each other. It is quite possible that this patient had a religious concern such as this in regards to his or her initial rejection. (Nurse Practitioner A, personal communication, April 2, 2015) According to Doctor C, there are also times where there is no conflict, but a situation where people of religious difference ask for more to be done due to some form of religious difference. Doctor C also mentions that in many cases where religious concerns are a factor, the patient has often had the conversation many times before and knows to volunteer the information themselves. (Doctor C, personal communication, April 13, 2015)

There are plenty of times that the ideals of a certain faith contradict the ideals of the medical community. One of the most common cases is that of the Jehovah's Witnesses. As was explained in Chapter 2, transfusing blood is against the belief of Jehovah's Witness, and therefore most will speak up against blood transfusions. In one case that was brought up by Interpreter C, there was a child patient who had a chest tumor and needed to undergo surgery. Doctors anticipated that they may need to perform a blood transfusion on the patient. The child's parents were Jehovah's Witnesses and refused to allow the procedure. Due to the child being a minor, the institution decided to bring the matter to court. The issue was settled between the two legal teams when it was agreed that the transfusion could occur if the blood was covered in such a way that no one could see it. The parents were involved as little as possible, with the issue mostly being

settled between the church and the hospital (Interpreter A, Interpreter B, Interpreter C, Administrator A, personal communication, February 19, 2015).

For patients who are members of faiths with elders or an equivalent spiritual leader of their community, a patient may make their decisions based on the decision of this elder. Doctor A said that in the Amish community, many patients are required by their community to gain the consent of their elders for any procedure they may get. In the case of Doctor A, who is a urologist, this often came about in relation to women who were incontinent and were given free prescriptions to help them. Doctor A would later find out that these women had not taken this medicine due to their community elders refusing to allow them to take it due to incontinence being viewed as normal by these elders. In the views of Doctor A, these elders have no right to deny a procedure on behalf of someone else. However, Doctor A also could not go to the elders and try to convince them otherwise, as this would constitute a HIPPA violation due to these patients not giving Doctor A explicit permission to speak about their medical issues to these elders (Doctor A, personal communication, February 26, 2015).

4.4. On Economic Considerations

Patients and the 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. Differences in economic understanding and considerations can be found between patients who were raised in different parts of the world. According to interview responses, non-native patients (those not born and raised in the United States) are sometimes concerned with the economic difficulties presented by the medical field because of a lack of understanding of the process in the United States. These concerns overshadow and obstruct the necessary information they are receiving during the informed consent process. During Interpreter B's interview they said that patients who come from different countries without knowledge of the medical situation in the United States would not think to get treated because of the thought of not affording the payment. Clarification of this sort of situation and the informed consent situation is facilitated by interpreters when they act as cultural brokers. (Interpreter A, Interpreter B, Interpreter C, Administrator A, personal communication, February 19, 2015) An example of a patient whose concerns overshadowed his need of care was brought up by Doctor A regarding a patient from Guatemala. This patient was concerned about his procedure with Doctor A because he could not immediately afford that which was presented to him. He thought that if he could not immediately pay he was running the risk of being sent to debtor's prison. It was then clarified to him that in the United States there is no debtor's prison, and there were alternative methods for payment regarding his procedure, which eased the concerns of the patient. Doctor A believed that any concerns whether religious, cultural, or economic must be addressed in order to obtain a proper informed consent. Patients with different

cultural or linguistic backgrounds make medical considerations based on their socioeconomic background, and this is seen through the existence of various low-cost or free medical options directed towards these individuals (Doctor A, personal communication, February 26, 2015). Providers treat patients who, when presented with a low-cost or free option for medical care, often dismiss a thorough or proper informed consent process. These patients, according to our findings, see a low-cost medical opportunity as something convenient. When the patients are satisfied with this convenience they will overlook their part in the decision-making process of informed consent. The responses from different interviewees demonstrate that how a patient's decision is made varies in reason. Doctor A described a hypothetical situation where a patient dismisses their autonomy and decides to go along with a procedure without truly addressing their opportunity to make a decision. In such a situation, Doctor A would then decide during a non-emergency appointment to give the patient more time to think about their decision, and possibly seek a second opinion. (Doctor A, personal communication, February 26, 2015) Nurse Practitioner A, on the other hand, described different situations at a low-cost walk-in clinic. Nurse Practitioner A mentioned that in these clinics patients tend to quickly make informed consent decisions without concern. Nurse Practitioner A believes the decisions are made hastily because of the convenience and affordability of the low-cost walk-in clinics. (Nurse Practitioner A, personal communication, April 2, 2015) There is some corroboration for Nurse Practitioner A's point, as Nurse Practitioner B also said that convenience could be a factor. Nurse Practitioner B said that the point of such walk-in clinics was convenience, as for some patients even talking with their primary care doctors might be more difficult than going to the clinic. (Nurse Practitioner B, personal communication, April 16, 2015) During an interview with an emergency medical technician (henceforth referred to as EMT A), EMT A said that the fact that patients at free clinics needed to sign the consent forms in order to be treated almost seemed as though it was equivalent to payment. EMT A saw this as an issue, as it establishes what is almost like an economy for their health service in what is supposed to be a free clinic. (EMT A, personal communication, February 10, 2015)

Many providers feel that treating a patient comes first in priority, and that any sort of monetary considerations come after. Doctor C said as much, saying that doing what is best for the patient medically comes first, and that you usually figure out the economic concerns after the fact. (Doctor C, personal communication, April 13, 2015) Doctor A felt in much the same way. Doctor A said that in most cases, the provider can get what they need for the patient, as well as that there are places to help the patients with economic concerns. In fact, Doctor A said that for about thirty percent of what he or she did as a doctor was never paid for. Doctor A never used a collection agency, instead allowing the patients to pay on good faith or stretch out payments. However, if a patient failed to pay, Doctor A could not allow them to be treated again (Doctor A, personal communication, February 26, 2015).

4.5. On Trust and the Role it Plays

Medical professionals were concerned with trust and honesty in regard to the informed consent of patients. Doctor A said that most doctors hope to go over the procedure or treatment step by step with the patient and make sure that the patient fully understands prior to consenting. Doctor A in the interview said that he “must explain what is done, why is it being done, and what the risks are.” (Doctor A, personal communication, February 26, 2015) Through this perspective we can see that doctors believe that the delivery of informed consent is essential and therefore they want to go over the consent forms carefully with patients. The process of respectfully seeking informed consent is one way that a doctor can gain trust from his patients and build a confident relationship. This respect for the patient’s decision through discussing informed consent and procedures is not only to build trust, but it is also a doctor’s way of reflecting important aspects of the Belmont Report. The Belmont Report, as discussed in the Section 2.1.1., states that there must be a “respect for the autonomy of the patient”, and that “one must ensure that the views of the subject are properly weighted.” Doctor A said that they would allow a patient with a language barrier to bring a family member or close friend of theirs as an ad-hoc interpreter during a first encounter because using a professional interpreter, or phone interpreter at first visit alienates the patient. This shows that doctors are willing to forgo a proper interpretation in order to facilitate the patient’s comfort. If the patient preferred to have their family member to translate the doctor would not refuse because he wants his patients to feel comfortable and to trust that the doctor cares about the patient’s autonomy (Doctor A, personal communication, February 26, 2015).

Furthermore, the findings show that honesty plays a major role between doctor and patient relationships. Doctor A said “doctors can get a patient to sign whatever they want, if they present it the right way. They can make it look like what they want, but there is an honesty issue in doing so” (Doctor A, personal communication, February 26, 2015). Doctor A said if they notice that the patient is just accepting a procedure or diagnosis without thinking about it, Doctor A will recommend the patient get a second opinion on the matter, or give the situation some time to develop before they come to a conclusion (usually referring to non-emergency or urgent decisions).

Interpreter C described a behavior which came up in various other interviews, as well as in the literature, the issue of paternalistic care. Paternalistic care, as described in Section 2.3.1., is a sort of behavior in which the doctor thinks they know what is best for a patient because of the medical knowledge and experience they have developed in their careers. Interpreter C described this sort of doctor behavior as something which happens in other countries as a result of the culture surrounding doctors and other intellectual officials in non-native patients’ communities. Patients in other countries trust the decisions their doctors make and do not question them, because “the doctor knows best” (Interpreter A, Interpreter B, Interpreter C, Administrator A, personal communication, February 19, 2015). Interpreter E said non-native Spanish patients will

sometimes say to their doctors “after God, you doctor,” clarifying the amount of trust patients can have in their providers. (Interpreter D, Interpreter E, Interpreter F, Interpreter C, personal communication, April 16, 2015). With this amount of trust and respect patients feel for their providers, it is imperative that doctors do not take advantage of it, and make sure they return this respect by offering a fully informed consent process.

Doctor C describes situations as a trauma surgeon, and the decisions which sometimes are not easy to make. Sometimes there is no clear answer for surgery, and a couple options present themselves as equally complicated with no better outcomes, so Doctor C describes these paths and allows the patient to make the decision based on the possible results. Patients often look for Doctor C’s decision on the matter, but Doctor C says that there is no clear answer (Doctor C, personal communication, April 13, 2015). Doctor C does not make the decision in these cases, because they are obligated to present the options to the patient, even if the decision to make is difficult. This shows that the doctors want the patient to fully understand the risks and benefits of various procedures or treatments, because if the patient just accepts a procedure which will seriously alter or affect their daily life, this would be harmful to both patients and providers.

5. Conclusions and Recommendations

Our interviews suggest that many of the cultures which have different views than the modern American society on how the medical community should work seem to have a similar idea of a doctor-driven process where the doctor is considered the knowledgeable party and has the greater idea of what the best situation or treatment for the patient is. In Western medicine, this sort of paternalistic relationship has largely fallen out of favor in the medical community. We consider this an improvement, as it means that more people will ask more questions of doctors and nurses. It also means that the former atrocities such as the Tuskegee syphilis experiments, in which the patients were not truly aware of what was being done to them, are far less likely to occur when a patient must explicitly be told what is being done to them. In addition to this old paternalistic view on medicine, other cultures believe in a family-centric idea of consent where the patient himself or herself is involved little in the actual consent process, and family is informed of the patient's medical situation and expected to make medical decisions. In this study we only discussed the informed consent tendencies of a select few cultures, such as those of the United States, Brazil, Nepal, Japan, several Latin American countries, and others, and even those were only touched upon. There may be a multitude of practices in countries not represented here that this study has missed. If one were to perform an international study to examine the idea of informed consent within the bounds of the societies being studied, 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.

Another question that arises from the idea of skilled interpreters versus untrained interpreters is the question of just how much more effective the skilled interpreters are when compared to a more casual interpretation. If there was one thing that most (if not all) medical professionals in this study agreed upon it was that quality interpreters were essential when it came to obtaining consent for complex procedures and treatments. What is not agreed upon is how pressing a procedure needs to be before these skilled interpreters need to be called in. Many doctors feel that an ad-hoc interpreter is adequate for a standard office check-up, and many of these doctors feel that doing so can even help bolster trust in their relationship with the doctor. The interpreters themselves argue that their use is vital for all procedures which require a patient to understand the discussion with their provider. One possible study that others could conduct would observe patients who require interpreters as willing test subjects during a standard meeting with a provider where a procedure is explained to them. In this proposed study some of the subjects would have skilled interpreters and others have unskilled interpreters, and one could analyze the subjects' understandings of what is explained to them afterwards, analyze errors of interpretation within the discussion, and then compare the two groups of subjects. A similar study to perform would be to examine the efficacy of using bilingual doctors versus skilled interpreters. Whether

or not the use of bilingual doctors is a viable option could help hospitals and other institutions save on their already restrictive budget for interpretation staff.

It would be helpful if patients would always inform healthcare providers of any religious or cultural considerations that the provider should be aware of, but this may not always occur. When patients inform a doctor of their religious or cultural concerns in regards to a treatment, their wishes should be met if the doctor is able to meet them. That being said, there is the implication that a patient must be open with their provider in order for their situation to be considered. If a doctor or other provider has any reason to believe that there may be some sort of religious or cultural concern to be had with a patient, the provider should ask for the sake of clarity. If doctors are not already required to perform some sort of cultural sensitivity training, it may be wise to enact this practice in order to be better informed of possible concerns that a patient may have in regards to their treatment on cultural or religious grounds, but this solution may either be time or cost efficient. That said, requiring new or prospective doctors to attend such a class would be beneficial to the situation of those of cultural or religious difference.

In order to address the economic issue of how cost affects informed consent, we recommend that low-cost/free clinics and health care facilities clarify and reinforce a patient's ability to discuss their medical situation with a provider. As our results show, if a patient is not accustomed to the medical process of insurance paying, especially with the case of non-native patients, there can be misunderstandings regarding their medical situation which will inhibit a patient's ability to receive care. However, patients who are satisfied with receiving low-cost or free care may dismiss their ability to make an informed decision because they are satisfied enough with the convenience. There is a belief in various societies that the doctor's knowledge puts the doctor in the lead position of making a decision and asking too many questions inconveniences the doctor. This belief coupled with the convenience of low-cost care puts patients in a situation where they may build a habit of avoiding the informed consent discussion. The medical community should make patients aware of their ability to make an autonomous and informed decision and encourage it. With these considerations made, patients will leave their medical situations satisfied and without concerns about procedures and treatments performed on them, and providers will avoid upset patients and the conflicts which may arise.

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Appendix A

Phone-call Transcript:

Hello, my name is _____. I am a student at WPI (Worcester Polytechnic Institute) conducting a research project with a team of 2 other students.

If you could spare a minute of your time, I'd like to give you a quick explanation of our project. Our research project encompasses the social concerns of informed consent in the medical field, and we are researching how the delivery of informed consent functions across cultural barriers in the Worcester community. (such as language, ethnic, and economic differences)

We called you because we believe you can provide us with insightful information regarding our project, and you can...

TO SECRETARY: ... direct us to opportunities to meet and interview people who can help.

TO DOCTOR: ... assist us by meeting and interviewing with us regarding our project.

(Also SAY something about why you specifically contact who you call)

If you would like to contact us further, our group email is informed-consent-igp@WPI.edu

If you would like more information, such as our methods, plans, and sample questions, or our consent forms for review, we are more than willing to send those to you.

We are available (Time Availability). We are also free to meet during non-work hours; our schedules are flexible. Our interviews and meetings should not take up more than 20-30 minutes of time.

Appendix B

E-mail Transcript:

SUBJECT: WPI Research Group Seeking an Interview Opportunity

Dear Mr./Mrs./Ms./Dr./Prof. _____

We are team of students at Worcester Polytechnic Institute who are conducting a research project encompassing the social concerns of informed consent in the medical field as a part of our Interactive Qualifying Project, a project which analyzes an issue in the community through applied research. More specifically, we are researching how the delivery of informed consent functions and changes across cultural barriers in the Worcester community.

We have contacted you because we believe you can provide us with insightful information in regards to how cultural, ethnic, and religious differences can have an effect on the delivery of informed consent. As part of this project, we would like to interview medical professionals who can provide us with valuable information relating to the topic so that we may learn more about how it unfolds in practice.

If possible, we would like to meet with you within the next few weeks. We are available from (Time Availability), all at your convenience. Our schedule is flexible, and we may be able to meet at other times if this is more optimal for your schedule. We should not take up more than 20 to 30 minutes of your time.

We thank you for any help you can provide us in our pursuit. You may send any replies to our email alias, informed-consent-iqp@WPI.EDU.

Sincerely,

Mario Alvarado, Nathan Ferron, and Nour Krayem

Appendix C

Questions for Interviews with Doctors

Background Questions:

1. Were you raised in the United States?
 - a. If not, what country were you raised in?
2. What is your job title and what do you do?
 - a. How long have you worked in the medical field?
3. Do you have any other relevant experience?

Main Questions:

1. How often do you work with patients who do not speak English?
 - a. (If the doctor is multilingual) Does your place of work put any specific emphasis on giving you patients that can speak (language)?
2. How does informed consent apply to your professional duties?
3. To what extent do you feel is necessary to inform a patient about a procedure?
4. Are certain types of patients more or less agreeable than others?
5. Could you explain a situation where a patient ever backed out of a procedure because he didn't understand?
6. Could you explain a situation where a patient ever rejected a procedure you had to perform on them due to some sort of cultural, religious, or other relevant concern?
7. How do you deal with a patient who refuses a certain treatment for cultural or religious reasons?
8. Have you ever had a patient attempt to waive their rights to choose their care?
9. Suppose a patient cannot afford the treatment you recommend, but the alternatives are nowhere near as effective. What do you do?
10. Describe if possible the culture around informed consent in the medical community. Is there a culture around how patients of at-risk communities are treated?
11. How do you go about explaining a diagnosis or procedure to a patient of cultural difference?
 - a. What sort of resources do you use or share in order to inform them?
12. Do you find that you need to explain things more to certain types of people rather than others?

Appendix D

Questions for Interviews with Interpreters

Background Questions:

1. Were you raised in the United States?
 - a. If not, what country were you raised in, and does that country speak the language you interpret?
2. How long have you worked in the field?
3. Do you have any other relevant experience?
4. What languages are you fluent in?

Main Questions:

1. How do doctors tend to act around patients who do not speak their language?
 - a. Did the doctor give the simplest explanation to a complex situation?
2. How often do you come across medical terms that are difficult to interpret or translate from English?
 - a. What do you do in these circumstances?
3. Are there any concepts that do not interpret easily or well during the process of delivering informed consent?
 - a. Do you think an incorrect translation ever hurts a patient's trust or willingness to consent?
4. How much do you know about the culture of the places that speak the languages you interpret?
5. Are there any cultural or religious traditions in the areas where this language is prevalent that prevent them from going through with certain medical procedures?

Appendix E

Questions for Interview with the Supervisor of Interpreter Services

Background Questions:

1. Were you raised in the United States? If not, what country were you raised in?
2. How long have you worked in the field?
 - a. How did you come into the field, and how would you describe it?
3. Do you have any experience as an interpreter?
4. What languages are you fluent in (to be skipped if not an interpreter)?

Main Questions:

1. Across all of the interpreters and translators in the hospital, about how many languages are represented?
 - a. How do you decide which languages you need regular interpreters for?
 - i. On what basis are these decisions to represent a language made?
 - b. How is this information advertised to patients? (The information about Interpreter Services)
 - c. Does the hospital employ many bilingual doctors?
 - d. What is done when you come across a patient who does not speak a language hospital staff speaks?
2. In your experience, how do doctors tend to act around patients who do not speak their language, and how is this dealt with during the informed consent process?
3. Do interpreters ever experience situations where some medical concepts do not easily translate?
 - a. If these situations come up... Do you think this affects a patient's willingness to consent during the informed consent process?
4. Are the interpreters that are hired often natives of a country that speaks the language? (Relevant because of interpreters' understanding of the cultures they are interpreting for)
 - a. If they are not native speakers, how long have these interpreters typically studied the language and culture of the people who speak it?
 - b. How does informed consent indicate other areas of interpretation difficulty?

Appendix F

Questions for Interviews with Clerical Workers

Background Questions:

1. Were you raised in the United States?
 - a. If not, where were you raised?
2. What is your job title?
 - a. How long have you worked in the field?
3. Do you have any other relevant experience regarding human resources or the medical field?
4. Do you speak any other languages besides English?

Main Questions:

1. How often do you work with patients who do not speak English?
 - a. How do you deal with people who do not speak English?
2. Are you familiar with the phrase “informed consent”, and can you explain to us your understanding of it?
3. What is your role in the informed consent process?
 - a. How important do you feel the consent forms are, and why?
 - b. Do you feel that you and your co-workers understood what the consent forms were saying and describing?
4. How often did patients read through the consent forms or involve themselves in the process?
 - a. Are there certain types of patients who tend to ask less questions?
 - b. Do patients take the informed consent process seriously?
 - c. How often do patients ask you questions, and do certain kinds of patients tend to more?

Appendix G

Questions for Interviews with Doctor's Assistants / Provider's Technician

Background Questions:

1. Were you raised in the United States?
 - a. If not, what country were you raised in?
2. What is your job title and what do you do?
3. How long have you worked in the field?
 - a. Do you have any other relevant experience?

Main Questions:

1. How often do you work with patients who do not speak English?
2. Are you familiar with the phrase "informed consent", and can you explain to us your understanding of it?
3. How does informed consent apply to your professional duties?
 - a. To what extent are you required to inform a patient about a procedure?
 - b. What demographics of patients are more or less agreeable than others?
4. Could you explain a situation where a patient ever backed out of a procedure because he didn't understand?
 - a. Could you explain a situation where a patient ever rejected a procedure you had to perform on them due to some sort of cultural, religious, or other relevant concern?
5. If you can tell what is wrong with a patient based on what you have seen from test results, are you allowed to tell them if there is something seriously wrong?

Appendix H

Notes of Interview with UMass Interpreter Services

Subjects: Interpreter A, Interpreter B, Interpreter C, Administrator A

Interviewers: Mario Alvarado, Nathan Ferron, Nour Krayem

Date: February 19, 2015

Location: UMass Memorial Medical Center

Time in: 3:30 PM

Time out: 4:40 PM

After introductions were exchanged between the interviewers and interpreters, the informed consent forms and interview protocol were explained by Mario Alvarado, and followed with the asking of interview questions in Appendices B and C:

1. Side Note:
 - Interpreter vs. Translator: Translator works with written word, Interpreter works with oral word.
2. Background Info
 - Interpreter MG raised in Bhutan, left when 18 years old, spent childhood there, went to Nepal, came to US in 2010, interprets for Nepali. Can speak Hindi, not as fluent. 4 years of work in field. Madhu also worked as teacher before coming to the US.
 - Interpreter JC began interpreting at age of 30, from Brazil. He interprets Portuguese. 10 years of work at UMass.
 - Interpreter EM worked as interpreter full time, now does not work full time instead coordinates the education and training of interpreters. She now translates Spanish, and occasionally interprets Spanish. Comes from Argentina, raised there, went to college there, arrived in US 27 years ago.
3. How do doctors tend to act around patients who do not speak their language?
 - “Patient comes to hospital”, The system is completely organized. All the booking is done in the system, they know ahead of time, and have requests as soon as possible from the clinics. Can book the interpreters for tomorrow. When the patient books an appointment, the clinic books an interpreter for the same time. The system collects a patient's race, ethnicity, and preferred language. They are well-prepared.
4. How often do you come across medical terms that are difficult to translate from English?
 - Not anymore, if the interpreter is not clear on the translation, they can ask the doctor to explain further in simple terms. Their interpreters need to complete a medical translation course. Uses advanced terminology and such, the interpreters know highly technical terms and are reviewed yearly. (At UMass Hospital Centers... this may not be the case for other interpreter services) (at umass they use very hard words because they trained to do so but other hospitals they use simple words; this might be one of the reasons patients didn't understand informed consent . show they always use simple words

so the patients don't get hard time understanding the procedure because they might be shy to ask for clarification could that be a case ?) The vocabulary of translators is technical, and they have the skill to ask for explanations if needed.

5. What do you do in these circumstances?(**words different meanings**)

- When there is a translation that does not quite work in a language, ex: allergy in Ghanan, you first have to understand what the word is, how it works, etc. From there, when you understand the term, you are able to go around the word. Some asian or african languages / dialects may not have the words to translate, such as bacterium and virus.

- There is a special term in Nepali, for operation, they can understand the exact word. Bhutan and Nepal, for example, have a difference in history where Bhutan was under great British influence and can understand a few English words, but the Nepali people were not and do not have this same influence.

6. Are there any concepts that do not translate easily or well during the process of delivering informed consent? **because of patient coming from different country , experience something new**

- Health care proxy does not translate well.

- Interpreters have to be careful with the provider explaining things, they cannot leave them out, as the provider has to explain. The provider has to explain through them clearly. (doctor job to explain things , so the interpreter have to be one to one translating everything the doctors says)

7. Are they more often directly interpreting what a provider has to say?

- Yes, They have to get rid of as much of their own influence as possible.

- The structure of how much the interpreter intervenes is like a pyramid. They are first just the conduits. They have intervention roles, as a clarifier, which they have to request from the provider or patient.

- With cultural misunderstandings, They sometimes have to intervene as a cultural broker. They also may need to be a patient advocate. If, for example, they are allergic to a dye, and they do not remember its name, they have to speak up for the patient.

- A patient had a miscarriage. Went to see the doctor, and during a discussion with the doctor, the patient finally said that she just wanted to 'get out of there'. The interpreter translated literally, but was aware of the tone of voice even though the statement literally meant what it said. The patient was suicidal and wanted to just get out. The doctor said that they would 'get them out of the clinic as soon as possible', not having yet been explained the context of this statement. The interpreter asked to take the doctor out of the room, and it was realized that the patient was depressed.(**Story :the interpreter make a further explanation than what the doctor say to clarify the words had different meaning in their country)**

- Years ago in psychiatry, the psychiatrist was assessing an Alzheimer's patient. Asking the patient to perform tasks, doctor asked patient to say a sentence, asked to translate literally. Patient started to pray the lord's prayer, the old woman with little

education only took in her mind the word sentence, which also means prayer in Spanish.

(Story)

- Translations need to be literal and transparent, but may need to change in cultural context.
 - The translators need to interpret body language as well. “60% of language or so is body language.”
8. Does this happen fluidly?
- They always talk to the provider about it.
 - Personality of interpreter plays into this greatly. Some are more advocates. They must verify that the patient understands.
9. Do you think an incorrect translation ever hurts a patient’s trust or willingness to consent?
- If an interpreter is catching himself or herself committing an error, the interpreter immediately has to rephrase. It’s about honesty, it’s reiterated during training. If they do not understand, they have to ask in order to understand.
 - Due to mispronunciation, a misinterpretation can occur
 - A Vietnamese interpreter (English is often second language) was working with a person diagnosed as autistic, but the interpreter understood as artistic. First experience with autism. Came to understand what it actually meant and re-translated. Learned from the experience.
 - Once confused sick and six. So many words that are similar that any interpreter may confuse terms that are pronounced similar. Context should soon make them realize their error.
 - They need to be very careful about the patient’s clarity.
 - They tried to ask the provider if they don’t understand.
 - In the Russian and some Latino culture, patients talk about the hand and point to the arm, or say the foot and touch the thigh/leg. They say foot for leg, and hand for arm. A phone interpreter may be able to confuse this.
 - Spanish patient was saying they have a broken camillia (shin) and was pointing to wrist. Small area did this, but everywhere else that is incorrect.
 - Translators need to have an open mind with regionality.
 - There are many different interpretations based on regions, even for the same country. A Vietnamese interpreter is able to tell the difference between North/South Vietnam based on accent (perhaps)
10. How much do you know about the culture of the places that speak the languages you translate?
- Jose’s father never consented to a colonoscopy (in Brazil) due to medical error/malpractice. After doing a lot of work in Brazil, the law is the same in Brazil, but does not apply. In Brazil, medical providers are not required to sign. Technically this is illegal in Brazil, but it is done anyways.
 - In Bhutan / Nepal there are no laws regarding the informed consent of a patient.

- Patients do not ask questions. It is cultural. They figure the doctor knows, you are not supposed to question doctors.
 - Doctor and teacher are highly respected people, people try to not ask questions, great respect is placed on highly educated words.
 - Brazilian patients just sign. They are informed, but they just sign. They are very surprised that doctors tell them so much. Some do not want to know. They are surprised that they need to sign.
 - They ask about risks. This starts when they are more familiar about the system.
 - They ask this in most appointments. Namely about side effects.
 - Most doctors don't read the informed consents line-by-line going through with all of the minor points, they hit generalizations and major points. They do not go too deep into it. Some go through literally.
 - Informed consent is translated only in Spanish, not in every language. Even in Spanish, they often give the patient consent, but the doctor has to explain
11. Are there any cultural or religious traditions in the areas where this language is prevalent that prevent them from going through with certain medical procedures?
- A few patients who speak Spanish / Portuguese are Jehovah's
 - In the 90's, there was a child going into surgery for chest tumor. Needed consent for transfusion, family said no. As child was a minor, they had to go to court. The court came to hospital, appointed lawyers, UMass legal team. The parents were outside reaching an agreement with the legal team, the parents were crying, the Church eventually allowed it, but the blood if necessary would have to be covered so that no one could see it. Everything went well, and the transfusion was unnecessary, but the plan of action if a transfusion was necessary was set.
 - Many Jehovah's witnesses will come with the elder of the Church. He is the person who knows / advisor.
 - In Bhutan, white clothes are only used for the dead bodies at funerals. But the doctors use them to identify dirt.
12. If family comes with, how open are doctors usually to allowing this?
- Family is encouraged.
13. Has a parent ever had significant influence during an appointment?
- They can discuss between patient and family.
 - Interpreters are required to translate this conversation, even if it is requested that the interpreters do not. Even if they say that they dislike the doctor. Everything said by both parties, must be translated. This rule is explained
 - Interpreters translate in the first person. This allows them to convey emotions better
14. How many languages are represented in the UMass staff?
- By last fiscal year's stats, 130-something languages. System catches all languages requested, even with those dialects spoken by few people.

- If they do not have a translator, they contract phone interpreters, and sometimes interpret through web conference.
- In the event that there are no available translators at all, they resort to family
 - This is not ideal, as they are not trained to interpret
 - Family members cannot do informed consent, unless there is a rare, rare case where there is no qualified interpreter at all. They will resort to telephone or video chat if necessary. The doctor needs to document who interpreted, numbers in the event of a not-in-person translation. If a provider forgets to log the number or get a signature from the interpreter, this is a legal issue

15. How many regular interpreters on staff?

- Have a pool of around 35-40 regular staff interpreters between part / full time.
 - A pool of around 70 including contracted.
 - Divided among 3 campuses.
 - Certain that are always here. Madhu has to travel between all campuses.
 - Main languages represented – 5. Spanish, Portuguese, Vietnamese, Arabic, and Albanian.
- Decided by statistical volume of patients in UMass Memorial.
 - Worcester is the second-largest city in Mass for relocation of refugees.
 - Years ago, less than 100 interpretations in one year. Nowadays, over 135,000. Reflects how the Worcester community has grown with influx of refugees from Arabic lands, etc.
 - Director of interpreter services knows the statistics and when it is the moment to ask Admin for positions.
 - Language needs fluctuate on a day-to-day basis. Cannot give interpreters their schedules until 3 the day before. Emergency room and in-patients come in and they need to call in asap requests.
- When are new interpreters hired?
 - The service is free by fed. regulations. They have to provide the best possible service and need to stay cost-effective. It is a financial decision based on demand.
 - Madhu used to be a contracted interpreter for Nepali, however as the amount of patients who required a Nepali interpreter increased and was consistently an amount, the interpreter services hired Madhu more full-time.
 - Bilingual doctors must be trained to interpret. It is a no-no for them to do otherwise.
 - Through the years, there has been a discussion about bilingual staff being interpreters. Wrong translations can often be posted due to bilingual

staff. The interpreters need to catch these. Physicians often call in order to be qualified as interpreters.

- A policy exists that allows the doctor to treat their patients in a language, but they may not act as an interpreter for another doctor
- They may add stuff in conversations when doing so.
- This is mostly done with anesthesiologists.
- Unfortunately, this does happen with informed consent at times that they do not know about.
- It is acceptable for doctors who are fluent in a language to speak to a patient in said language, but it is usually recommended that they have an interpreter present

16. Side Note:

- There is an article that they can photocopy for us where a mother from Columbia in her 20's with her child with a birth defect of transposition of the great arteries. Child was admitted, physician requests interpreter to ask for a research opportunity, not the treatment. Mother was overwhelmed, just came to the states, the baby was hooked to all sorts of things. The interpreter detected that the mother was lost (as in, no longer listening). The interpreter had to act as a cultural broker. Finally, there was no consent due to the mother being overwhelmed. Her husband was still in Columbia. Many cultures do not like the mother making the decision.

Appendix I

Notes of Interview with Doctor/Surgeon

Subject: Doctor A

Interviewers: Mario Alvarado, Nathan Ferron, Nour Krayem

Date: February 26, 2015

Location: WPI Library

Most Recent Relevant Place of Work: A Private Urology Practice in Worcester

Time in: 3:10 pm

Time out: 4:30 pm

1. After Explaining what the project was about, this conversation was prompted:
 - Particularly with Religious preferences, you come across many legal grey areas. In his practice, the main issue is that of circumcision (he is a urologist).
 - You cannot force any issue. You may only say, “here’s the risk, here’s the benefit”.
 - By law all the provider really needs is one consenting parent to conduct a procedure, however a provider will not even consider it without both parents consenting. This is because family-changing issues could arise if there is a conflict of interest.
2. What do you understand about informed consent?
 - For a physician, providing a patient with enough information to make a decision, an informed decision. Not just what a physician thinks is best.
 - Has to be in their language. Do not use families, this has caused a lot of problems.
 - Use video call translators on Ipads
 - Major languages: Portuguese, Spanish, Asian languages, Arabic
 - More complex: Albanian, etc. For these, they usually get a plug-in translator
 - Must provide the significant risks that a patient has in a procedure. Do not even consider a procedure that they do not understand.
 - When it can truly be life-or-death, they need to understand. When they get in there, the doctors may need to perform things on the fly. Explain the possibilities.
 - Resident at Tulane. Performing a circumcision on a neonate. Usually done with clamps, cut around it, some small bleeding after. The resident decided to try to cauterize it, because of metal clamp, ended up burning off the entire penis. Had to explain to the parents that he made a mistake, that he needed to fix it now, and that there was no time to explain. Correction method is to convert to female. Resident backtracked, said it was common, this was wrong. Must move forward.
 - Must explain what is done, why is it being done, and what the risks are.
 - Residents used to explain the consent, and the doctor would do the surgery. This resulted in wrong limbs being cut off.
 - It is a huge issue, mistakes happen, they try to reverse them.

- When the surgeon tries to perform, they will often make sure that the correct side is being done by confirming vocally and physically. They then mark the body on the right side.
 - There is a time-out period. They explain the procedure with the surgeons.
 - When he started with medicine, the informed consent was very simple, just telling them the very basic gist of what is going on and then assuring that it would be fine. The people who explained it were not the same as the people who performed the procedure.
 - “I agree to let you do what you just said, and I trust your judgement”
 - Any physician who does not understand this is not adequate.
 - Physicians often lose sleep when procedures do not go as planned.
 - Sometimes they have to explain that a procedure may not work or even cure the issue (often with cancer). Any side effect that could happen must be explained.
 - Don’t list everything, anything that can happen in 5-10% of patients or more must be told.
 - “When you’re done, you don’t shove the paper under them and say ‘sign it’”
 - Ask the patient what they want, what do they expect.
 - He has cancelled surgeries before, as the patient did not understand what the surgery was. He recommended that they get a second opinion as he felt that he might not have been explaining it to them in a way that they understood.
 - Has a friend that he has worked with. Had a patient that did not want surgery on her bladder. Thought that she would die of heart concerns and figured that she would die of it. Explained that she may bleed due to the cancer, and the only solution would be to put tubes in later. She still declined. The doctor explained it wrong.
 - Can get a patient to sign whatever they want, if they present it the right way. They can make it look like what they want, but there is an honesty issue in doing so.
3. Were you raised in the United States?
 - Raised in US.
 4. How long have you worked in the medical field?
 - Worked in urology for 20 years. Has been in the field for 30.
 5. Do you have any other relevant experience?
 - Used to work in a Pharmacology lab where they drew blood from people in accidents for drug testing.
 6. How often do you work with patients who do not speak English?
 - Every single day.
 - Office set-up is with phone translation devices.
 - Over 50 languages regularly. Most common are Spanish and Portuguese, French towards his area.
 - Does not lend well to office visits to bring in a translator.

- During the first visits, they ask if they speak English, and if not, they ask to bring in someone they know to translate to build trust.
 - Down the road, they need a formal translator and they cannot risk a mistake.
 - Problem with family members is that you may be saying one thing and they may be saying another because they do not understand the medicalese.
 - Must speak without slang, clearly and in plain English.
 - Trust is not always there. When it is not, they must ask if there is anything they can do to make it better. If not, they recommend a second opinion.
 - Females who do not want a male doctor and vice-versa. In his field, males do not want to go to a female urologist.
 - Racial issues still exist. Don't want you if you're white, don't want you if you're black. If that's they're feeling, that's they're feeling. They have to stay polite and just give them a list of new doctors.
 - "I don't want a doctor like you." "I like a different kind of doctor."
 - Distance is a factor. Some may not want to drive out to Worcester. This is why satellite offices exist.
 - Office set-up can make them uncomfortable.
 - You have to make them comfortable. "Empowered is the most important word"
 - Have to make them feel empowered to make the decision.
 - Patient has to understand how, why, etc.
7. Did you ever receive patients from a local hospital? Which hospitals?
- UMass Mem. UMass U., St. Vincents, Marlborough UMass, etc.
8. How does informed consent apply to your professional duties?
- Surgeon. It's mandatory for ANY procedure, even minimal ones.
 - Even a catheter, a minimal 30 sec procedure, they have to inform them.
 - Anything that involves an invasive act (putting something in the human body, except maybe drawing blood) needs consent.
 - If you're a good doctor, you do it because it's the right thing.
 - When he is a patient, he is a patient, not a doctor. Still wants it explained.
 - If you don't inform, you're going to get sued. It's not just monetary issues anymore, you can get your license revoked.
 - If you think you informed the patient properly, if something comes up that you think you explained, the patient thinking that you did not can screw you.
 - People who are doing higher-risk surgery (sex change and such), they are making you give consent on digital recording.

- With sex change, $\frac{1}{3}$ commit suicide, $\frac{1}{3}$ are unhappy, $\frac{1}{3}$ are satisfied.
 - Thinks that informed consent is the right thing to do.
 - It is mandatory hospital law in addition to that.
 - If somebody claims that you did not do a sufficient job for consent, the patient does not go to the operating room.
 - There is always a nurse present. They can tell you that they do not think the patient is well-informed.
9. Are certain types of patients more or less agreeable than others?
- Prisoners are very difficult patients to consent with.
 - Most did something to get out of the prison. Self-inflicted.
 - Goal is to stay in the hospital as long as possible. Even if they're chained up.
 - Because of this, they will fight you tooth-and-nail on any consent form.
 - Old days, they are forced. Can still do this, but you better have a damn good reason for it.
 - Nowadays, they simply say that if you don't want the procedure, you go back to prison.
 - Previous practice, the Amish.
 - Certain code, have to gain consent of the Elders in the community
 - Often issues with the women, especially incontinence. Give them medical samples, but later find that they would not take it because the elders would say that they are fine and that this is normal.
 - Elders do not have the right to consent.
 - Cannot go to the Elders and attempt to convince them, as this is a HIPPA violation. Cannot speak to anyone other than the patient and anyone they allow the doctor to speak to explicitly about the procedure.
 - Had a young man rapidly losing weight, never seen a doctor for it. Had prostate cancer, no questions asked. Not much to do at that point, could possibly buy 2-3 years. Wanted to talk to wife, as had kids. Patient denied him to tell the wife under any circumstances.
10. Could you explain a situation where a patient ever backed out of a procedure because he didn't understand?
- Patient had trouble urinating since 22, now 43. Barely comes out. Past history was significant only because of UTIs. Scoped in, found a scar that blocked the urinary channel. Not sure how deep, but it is definitely there. Needed to go into the scope with a laser, carve the scope, put in a tube, take it out later, control is retained. Patient consented, was Spanish. Day of, asked to be shown the instruments of the operation. Refused after seeing the tools. He misunderstood because 1) did not want to go to sleep,

2) did not want anything of that magnitude to be used. Thought they were going to use the scope again.

- Thinks the patient was scared, that's okay, people get scared. If it was life-or-death, you get a little more forceful. But in this situation, patient had it for 20 years, go home and think about it.

- 54 year old man born with 1 kidney. (1 in 10 people have this) comes into ER, horribly inflamed left side, high fever, extremely close to dialysis. Single kidney was infected with a huge kidney stone. No way to cure non-surgically. Patient was adamant that religion (not sure what religion) would not allow it. Would only agree to antibiotics. Would not go away until surgery. They talked about what they could do differently. Could possibly stick a needle into the patient with a CT scan, usually use heavy anesthesia. Patient refused anesthesia, went through with it finely. Same with the ultrasound used to break up the kidney stone.

- Jehovah's witnesses come from a quote in the bible that says "Thou shalt not drink the blood of animals"

- If he is bleeding to death, but he did not give consent for the transfusion, what should he do?

- Older doctors say that you give it, easier to defend a live patient than a dead one.

- No longer acceptable, try to use fluids, convince the family to allow it.

- May be alive, but would be shunned.

- Don't deny treatment, refer them elsewhere.

11. Have you ever had a patient waive their rights to choose their care?

- Can't do that.

- Patient may say that they do that, but it still must be informed consent.

- Difficult to do with them. Must explain really slowly.

- When they request pain pills, cannot give until consent is given, as narcotics prevent consent.

- 17 year old, was gonna take a bladder stone out. Would have been quick, but the patient had a reaction to the Anesthesia. Had a whole load of complications, patient never consented, but the anesthesia doctor allowed it.

- You have to know what you're doing.

12. Suppose a patient cannot afford the treatment you recommend, but the alternatives are nowhere near as effective. What do you do?

- Try to work with the patient. There are places that can help them.

- In this state, there is no excuse not to have insurance, if you do not have this,

- This occurs largely with illegal aliens. This is when you get in social workers.

- In an emergency, they just go through with it and figure out cost later.

- Young guy from Honduras. Horrible abscess in kidney. They went through with the surgery, got the social worker involved after.

- In most cases, you can get whatever you need for the patient.
- UMass has Free Care.
- In his independent group, the insurance may not pay, they can stretch out payments.
 - 30% of what they did they did not get paid for. Never used a collection agency, does not believe in them.
 - Would try to let them pay on good faith, calling them up. Cannot accept a patient again who does not pay.
 - Fabulous Mass health care, but the issue is that it does not pay for elective treatments (comfort things). Nor should they, it is taxpayer money. Patients will get angry with you for this. “You owe me this”. You can live without it, it is not a necessity.
 - Issue with informed consent. People confuse elective care with necessary care.

13. Describe if possible the culture around informed consent in the medical community. Is there a culture around how patients of at-risk communities are treated?

- Grew up with doctors before true consent. If the doctor said that you have something to be done, you did it.
 - Had tonsillitis, doc came to the house, said to take out the tonsils of all four kids.
 - Used to be called the Golden Age of Medicine.
 - Doctors compensated well, paid well, truly were gods.
 - Now doctors should treat the patients with respect.
 - Patients may have too much freedom now.
 - “Doctor shopping”. Getting a lot of second, third, etc. opinions. Disease may progress out too far after a while.
 - Need to weigh how hard to push with how hard to hold hands
 - Also teaches young doctors, they have lost the ability to talk to people.
 - Old doctors had the ability to talk to people, now they don't even look at the patient when they take the patients' history.
 - Many young doctors do not even know the patients' names. Or what he looks like. Or if he has family. Etc.
 - Everything available with a fingertip. Everything can all be done medically before the patient even gets on the examining table.
 - It's changed, mostly for the better.
 - The issue is that many doctors now “fly scared”.
 - Explain everything that could possibly go wrong instead of what could reasonably be expected to go wrong.
 - If the doctor does not want you as a patient, they will attempt to purposely try to scare you off. They'll tell you that they think you should get a second opinion and that they cannot help you.

- Hard to ignore appearance / hygiene, but must try to help a patient with that little problem. Maybe enough to change the patient's life for the better.
 - If there is a high chance of death, they will also tell them
14. Are there any issues in the medical community regarding people of different cultures?
- Personal issue. Every doctor sees stereotypes, try not to let it affect you.
 - He will walk to any bedside with an open mind, until you do something to make them do otherwise.
 - They'll talk about the patient afterwards, but you do not let it affect you in the procedure.
 - Patient came in to his office who was overweight, had to refuse the patient due to the table's weight limit, patient thought he just hated fat people.
 - Be careful to explain why you are refusing service.
15. When explaining a procedure with patients who do not speak the same language, what resources are used to help the understanding?
- You draw pictures. Use graphs, keep it simple.
 - Go from point A to point B, simple shapes for organs and issues.
 - When you're dealing with different cultures, you've gotta be so very careful.
 - In Islamic cultures, women do not want to be examined by a man.
 - Some doctors will push ahead, saying they're the only ones in this hospital who can do this. This is wrong. Refer them to a doctor elsewhere who can do it.
 - This is a melting pot, we've all got different cultures.
 - It's all about comfort.
 - Some doctors take it personally. Do not do this.
 - Doctors can be made uncomfortable.
 - Went to Catholic grade school. Now has a horrible fear of nuns, they were allowed to hit you with a ruler, lock you in closets, etc.
 - In comes a nun to his office, gives him her history, he starts sweating. Nun notices, immediately assumes he went to Catholic school, assured that she would not hit him. Ended up operating on her, never got more nervous in his life. Paced outside, rocked when operating.
16. Have you ever refused a patient because you were uncomfortable?
- Woman brought old father for kidney issues. In great shape, incidentally found this kidney issue. Found what they thought was a tumor on the kidney. He was 91, would watch him, but would not act until it grew rapidly. Patients were insistent, but he refused.
 - "You're entitled to my knowledge, you're not entitled to my surgery"
 - Turned people away because they were misinformed, or wanted the thrill of surgery.

- Man came into office saying that testicles hurt. All tests show up normal. Story started to change, eventually figured out that he wanted a sex change but was using this as an excuse.

- Cannot warn other doctors, but can ask for records of previous doctor visits. Can refuse treatment if they refuse, however.

- If you tell me I cannot have access to your information, but you find out anyways, you just committed a HIPPA violation and can lose your license.

- With prisoners, you can immediately lose your license.

17. Do you find that you need to explain things more to certain types of people rather than others?

- Don't think it's a cultural thing, but there are people who can be obsessive-compulsive.

- Categorize: Engineers. They keep records, charts, minutia. They come in with graphs, charts.

- Gentleman who was 84, get up late at night to pee. Part of the aging process. Came in with a journal of when he peed, measured the volume of the pee, color, made charts, documented when he ate, documented the size of his prostate when he got it examined, cross-checked with journals from other countries, asked him if he read these journals.

- Certain occupations this happens with.

- Lawyers. Maybe not on them, but the physician may just take more care with them as defense

- OB GYN gets sued more than others

- OB/GYN patient sues her three times as an attorney. Came in as a patient. Lawyer assured her that it was not personal, but the doctor could not bring him/herself to do it. Ended up suing, but had no leg to stand on.

- Who will just nod their head?

- No real trend, if there is, it would have to be the elderly. Those who grew up in the "Golden Age of Medicine". Different generation. Grew up with a doctor who just held their hand and said that they would take care of everything

- The patients will sometimes expect that he can treat any issue, not just what they specialize.

- The elderly are the most trusting, but they are also the first to come out against you when you violate their trust. They talk about you.

- When he was first married, he would go to the mall to get ice cream. Very isolated town. Patient approaches, he was going to say hi, patient ducks away from him. Comes back the other way, patient sees him again, ducks

away again. Approached him about it, the patient was concerned about the fact that he had seen him naked. Doctor assured him that this was not the case.

- You may have one concept of medicine, the patient may have another.

18. Any patients from out of the country, are they alarmed at the process?

- Understand the process, more terrified of the procedure.
- Very uncomfortable setting, strange men speaking in terms you do not understand. You have to calm them down, do anything that you can in order to make them calm. It's not the consent process, it's the fear of being in a foreign country and needing treatment.
- Guy in Guatemala came in needed a kidney stone removed, had no money to pay, feared going to debtor's prison. Had to explain that this was not a thing in America.

Appendix J

Table 2A: Analysis of Interview Responses, Part A

Provider	List of Providers	How do providers who deliver informed consent handle patients of cultural or linguistic difference?	What are a provider's understanding and expectations of the informed consent process?
Doctors and Surgeons	Doctor A:	<p>In first time visits, Doctor A asks the patient how well they know English and if not too well they are allowed to have a family or friend interpreter for introductions and background.</p> <p>-Doctor A will not use family interpreters for informed consent, as problems with interpretation and misunderstanding commonly occur.</p>	<p>-For a physician, they must provide the patient with enough information to make an informed decision. Not just the information which the physician thinks is necessary. Often more information is needed for clarification for the patient.</p> <p>-Must provide the significant risks which will occur in a procedure or treatment.</p>

	<p>Doctor B:</p>	<p>Most of what Doctor B does is not so highly technical that he does not need someone who understands the technical language as interpreter, but if it happened and the doctor needed an interpret doctor B gives the patient a choice, some would prefer to use hospital interpreter services (which are available), some actually prefer to have a family member interpreter.</p>	<ul style="list-style-type: none"> -Inform consent only been giving when dealing with highly technical things, not for a simple procedures. -Doctor B use various sources to explain diagnosis to patients who do not speak English well in a very simple way. He use videos, models, charts, of relevant organs, and teaching sheet that been used to fifth grades.
	<p>Doctor C:</p>	<p>Interpreter over the phone or in person depending on availability.</p>	<ul style="list-style-type: none"> -Always try to explain things to the person, if they're consentible. In emergency situations, they have tried to consent people if they have the time to do it .If it will not delay and the patient will not die. -Never had to take a patient to the operating room without their or their family's consent. -Patient health is primary. In the emergency situation were doctor C works, they always use assumed consent. -Whether or not English speaking, do what needs to be done when getting consent. - Cannot always tell if they are a native speaker, sometimes they are just so

			sick that they are just not going to comprehend regardless.
Nurses and Nurse Practitioners	Nurse Practitioner A:	Use an interpreter if they don't speak English well. if they speak a little they can use their family members or phone interpreters , on-call.	-Inform consent is getting a patient's consent for certain procedure. They consent the patient for whatever procedure they should make. By sinning in kiosk patient is consenting to speak with the nurse.
	Nurse A:	- Can use family or friends as interpreters. If none are available, need to use a phone interpreter.	- Must have informed consent for any procedure - It is of the utmost concern for any medical care provider.
	Nurse Practitioner B:	For patient who don't speak English they use phone call translation service. Just the Nurse, the speaker phone interpreter, and the patient will be there.	Use informed consent for a lot of things They sign, they understand, they give us permission to treat them Use it prior to any procedure that they would do, namely with almost-surgical procedures Use for a lot of more procedural and general treatments. It's part of the registration process.
Medical Interpreters	Interpreter A:	When the patient books an appointment, the clinic books an interpreter for the	N/A

		same time. The system collects a patient's race, ethnicity, and preferred language. They are well-prepared.	
	Interpreter B:	If they do not have a translator, they contract phone interpreters, and sometimes interpret through web conference.	N/A
	Interpreter C:	N/A	<ul style="list-style-type: none"> - Most doctors don't read through informed consent papers line-by-line, just hitting general points. - Some do go through literally on all points
Clerical Workers and Medical Assistants	Technician A:	In regards to translators First: if they bring someone with them, certified or not, they first ask if they are a legal guardian or health proxy, if no to both, ask the patient if they give permission to let them speak through them. If no one is brought, they connect with a translation line who then provides a translation service.	They tried to make use simplistic term, to inform the patients who have a lack of understanding English, so they get well informed and they easy understand the procedure they going to do. They make it brief and concise.

Table 2B: Analysis of Interview Responses, Part B

Provider	List of Providers	What are a patient's observed understanding and expectations of the informed consent process?	Are the current methods for granting informed consent sufficient?	Are there still serious concerns or internal debates between providers on the issue of informed consent?
Doctors and Surgeons	Doctor A:	N/A	The interpreter Must speak without slang, clearly and in plain English. If the doctor felt that the patients still not well informed on the procedure, he don't do the procedure and he give the patient second opinion?	Problem with family members is that you may be saying one thing and they may be saying another because they do not understand the medicals.
	Doctor B:	Patients who have cultural or religious concerns that would stop them from consent will bring up their issue to their providers so the providers take it in a considerations.	Doctor B utilizes phone interpreters if the patient requests, and an interpreter cannot readily be supplied. Doctor B, doesn't like phone interpreters due to the fact that they miss the body language.	Doctor B doesn't need a professional interpreter when explain inform consent because Doctor B usually use simple word to explain it.

	Doctor C:	Some patients who are coming from other countries male in the family can sometimes be the one who makes most of the decisions even if female is patient.	-Little more variability with phone interpreters -Less comfort -Have to sometimes repeat multiple times.	Language with an interpreter usually isn't an issue. Things get lost in translation, and there are varying levels of skill in interpreters
Nurses and Nurse Practitioners	Nurse Practitioner A:	-Patient's usually on minute clinics didn't ask a lot of question regarding their treatment assuming their questioned been answered by filling in the kiosk before getting talking to the nurse. -Patients are thankful for the convenience they have at free clinics.	They have limited service to the patients what every practice that does not' fit to their scope they refer them to the primary care and they will take a vital sign.	N/A
	Nurse A:	People don't read the forms, even when the procedure is in big block letters at the top.	- At the Hospital were Nurse B works now offers classes where they can get information for elective surgery. - If someone signs an informed consent	- There is a debate on the topic of having consent forms in Spanish

			<p>in Spanish, Spanish is assumed to be their primary language. Any type of contact/procedure with the patient must then be in Spanish. Doctors who don't speak Spanish will have a really hard time to work with this</p> <p>-A majority of the health care providers do not speak Spanish</p>	<p>- If a patient signs a consent form in Spanish, all further meetings are expected to be in Spanish, and not all doctors can readily accommodate this.</p>
	<p>Nurse Practitioner B:</p>	<p>Patient who don't speak English comes with a family member to translate for them.</p>	<p>Phone interpreter are Clearly a little bit difficult when they can't understand you or you can't understand them.</p>	<p>Phone interpreters are A lot of repetition and time-consuming Interpreters themselves are very helpful, never a situation when they were not helpful.</p>
<p>Medical Interpreters</p>	<p>Interpreter A:</p>	<p>- Patients from other cultures do not tend to ask questions. It is a cultural thing.</p>	<p>-Interpreter uses advanced terminology and such, the interpreters know</p>	<p>Health care proxy does not translate well for patient</p>

		<ul style="list-style-type: none"> - They feel that you are not supposed to ask questions - Some foreign patients will just sign the form regardless of the extent of information, and will even be surprised at how much is being told to them 	<p>highly technical terms which might make the patient have hard time to understand the inform consent</p> <ul style="list-style-type: none"> -interpreters have to get rid of as much of their own influence as possible when they interpret to the patient it's a rule they have to follow. - With cultural misunderstandings, They sometimes have to intervene as a cultural broker. They also may need to be a patient advocate - A phone interpreter may be able to confuse about the patient clarity. -Translators need to have an open mind with regionality. 	<p>coming from different countries</p> <ul style="list-style-type: none"> -Translations need to be literal and transparent, but may need to change in cultural context. -The translators need to interpret body language as well. "60% of language or so is body language." - Personality of interpreter plays into this greatly. Some are more advocates. They must verify that the patient understands.
	<p>Interpreter B:</p>	<ul style="list-style-type: none"> - Doctors are highly respected people, and people therefore don't tend to ask questions. 	<ul style="list-style-type: none"> - Family members cannot do informed consent, unless there is a rare, rare case where there is no qualified 	<p>N/A</p>

		<ul style="list-style-type: none"> - Great respect is placed on highly educated words. -some patient coming from different countries they think they can't take any design without the husband consenting. 	<p>interpreter at all.</p> <p>They will resort to telephone or video chat if necessary.</p> <p>-It is acceptable for doctors who are fluent in a language to speak to a patient in said language, but it is usually recommended that they have an interpreter present</p>	
	<p>Interpreter C:</p>	N/A	<ul style="list-style-type: none"> - Informed consent is only translated into Spanish, not every language. - Even in Spanish, the doctor still is required to explain beyond the form. -Bilingual doctors must be trained to interpret. 	<ul style="list-style-type: none"> - There is a discussion on whether or not bilingual staff (not already interpreters) could act as interpreters - Currently, a doctor can treat a patient in any language they are fluent in, but they may not act as an interpreter for another doctor - Even if a doctor can speak the language, a qualified

				interpreter is still recommended
Clerical Workers and Medical Assistants	Technician A:	Patients who don't speak English bring someone with them certified or not, they first ask if they are a legal guardian or health proxy, if no to both, ask the patient if they give permission to let them speak through them.	They make the explanations of the procedure very brief so they save time.	Patients who are not from here are actually easier than those who are. Those who are from here tend to ask a lot more questions. Foreigners ask very few questions.

Appendix K

Subject: Doctor C

Interviewers: Mario Alvarado, Nathan Ferron, Nour Krayem

Date: April 13, 2015

Location: Doctor's Office

Time in: 1:35 pm

Time out: 2:30 pm

- Background
 - Raised in the US, as was family
 - Trauma Surgeon
 - Emergency surgeon, operate on people with a life-threatening problem
 - Tenent for almost 3 years
 - Including Med School, Training, 12 years
- How often do you work with non-English speakers?
 - Infrequent, but 1/3 of patients were non-primary English speakers.
 - What measures does your institution take?
 - Interpreter over the phone or in person depending on availability
 - About 1/2 of time it is a phone interpreter
- Is there often enough time to explain the procedures to patients?
 - Whether or not English speaking, do what needs to be done when getting consent.
 - It's assumed consent
 - Cannot always tell if they are a native speaker, sometimes they are just so sick that they are just not going to comprehend regardless
 - How do you go about getting assumed consent?
 - Whether they think they are going to die in a very short amount of time, whether they can find someone to communicate or not, whether they find family
- What do you usually do in regards to the post-consent process?
 - Don't usually talk about the OK part
 - They will try to find family and talk to them before they go to the operating room, time permitting, always try to find afterwards.
 - Cannot understand what happened immediately after a procedure due to anesthesia.
- How often do patients disagree with what was done to them?
 - People can be unsatisfied, never had someone say that they were unhappy that their life was saved
 - Never had someone say "you shouldn't have done that"

- How does informed consent apply to your job?
 - Always try to explain things to the person, if they're consentible.
 - In emergency situations, they have tried to consent people if they have the time to do it
 - If it will not delay and the patient will not die.
 - Never had to take a patient to the operating room without their or their family's consent.
 - Patient health is primary.
- How far do you feel you need to go for consent?
 - Explain things very clearly and as simply as possible
 - Explain the things that might affect them afterwards.
 - Go through the risks
 - Go through the biggest risks first, no matter how infrequent.
- Any patients that are less understanding than others?
 - Education level factors in, can usually tell who has what education level
 - Language with an interpreter usually isn't an issue.
 - Generally an education issue
 - Is there a difference between those born in the US and those who are not?
 - There can be
 - Consent usually doesn't change that much
 - How you approach people and cultural issues can change
 - Who is head of household can be different
 - Male in the family can sometimes be the one who makes most of the decisions even if female is patient (described as an issue)
- What is usually the level of interpreter skill?
 - Hard to know
 - Gets worried when asking yes or no questions and there is a lot of discussion between interpreter and interpretee
 - Things get lost in translation, and there are varying levels of skill in interpreters
- Is there a difference between phone and in-person interpretations?
 - Little more variability with phone interpreters
 - Less comfort
 - Have to sometimes repeat multiple times
 - Know the interpreters here, random people from the company.

- What do you understand of the interpreter process?
 - Have to have some medical knowledge / training
 - Introduce themselves, confirm the language that they are speaking, confirm the dialect
 - Had an issue in residency when the language was correct, but the dialect was not.
 - Introduce medical team and patient, then look to guidance from them as to what to do next
- Have you ever had a patient backed out of a procedure because of not understanding?
 - Hasn't happened. Tell people that things are optional and that the options aren't very good. Had a potential life-threatening decision, wasn't immediate but within the next few days. Opted for the operation.
 - Left the room for the patient to make the decision.
 - If people are not on board with the treatment, presents them with the options and lets them decide.
 - In trauma, there is a lot of socioeconomic difference.
 - People are allowed to make bad choices.
 - Will tell them that a procedure is in their best interest.
 - Elderly, the outcome may unfortunately be a foregone conclusion. Give them the option of not operating, but explain the case of quality of life.
 - Had to explain to a couple in their 90s that an operation probably was not a good idea. Couple never really discussed this. Given her age, it would have been multiple operations. Feeding tube / tracheotomy. Got them done, never really got home, lasted a few weeks. Over a couple of hours, had several conversations with the husband and wife, as well as with son.
- How often do patients come in with full understanding?
 - Often it is other medical problems that complicate things.
 - Elderly, cancer.
 - Have to ask them if it is really the right thing for them.
 - In one case, there was a discussion of hospice that was an entirely brand-new topic for them.
 - Want everything done regardless of previous medical problem.
- Have you experienced any situation where the patient backed out for cultural/religious reasons?
 - Remembers the opposite. Patients who want more done because of religion/culture

- Patients have usually had these conversations in these cases and know the risks and what they want.
 - Are surgeons more willing to accommodate?
 - It's their decision.
 - Sometimes don't offer patients procedures if it's not going to help them.
 - Can defer treatment if they think it is futile.
 - Didn't think it was entirely futile with the elderly couple, but did not think it was good either way.
 - If you don't think it's possible to do a procedure with these accommodations, then you don't do it.
- Any other situations where you deny surgery for any other reason?
 - Another elderly person in multi-organ failure already. People can be too sick for an operation. Some people don't understand. In communicating with the family, they said that they could get her better and then get her into surgery, but she would have never gone home again. Their goals were not in line with this. They prioritized comfort, comfort measures were established only. Patient liked to dance, dancing was most important thing, was never going to again if that happened.
- Ever had a patient waive rights to choose to care?
 - People say that all the time, “do what you need to do”
 - Goal is to get them better
 - Still have the conversation with them anyways, still try to get consent.
 - If they can't make a decision, they still try to talk to family/friends
 - Try to find out what their priorities are
 - Time to have all of these discussions is when they are still capable of it.
 - Need to know what they would want and what they are willing to go through afterwards.
- Any sort of demographic where they are more often to tell them to do what is best?
 - Young people are less like that.
- When you go to inform the patient, and patient says to do whatever, is it required?
 - It's both. Trying to build that relationship, make sure that they know what is going to happen.
- How long are relationships with patients?
 - Varies.
 - Chronic patients who have had for 6+ months

- Most are on 2-month scale.
 - Longest running one is over 2 years, will never be fixed, just mitigating issues.
- How much time is spent getting to know what the patient wants and what the options are?
 - Both are important.
 - They occur together, figure out what they want and value from this.
 - Not entirely sure what they might find when they operate, run through the gambit.
- Any sort of economic issue with procedures?
 - Depends.
 - You want to have the best outcome possible.
 - Medically speaking, try to do the medically most important part and worry about the economics afterwards and figure out how to deal with it.
 - Usually you figure something out.
- After giving patient the feel of what's gonna happen, is there ever anything that commonly goes unaddressed? What are patients' other concerns?
 - There really haven't been too many
 - The most common thing is pain meds / pain.
 - No major complications come up afterwards.
- Describe culture around medical consent in the community
 - Often have issue with palative care in ICU
 - Surgeons tend to do a pretty good job of explaining unless patient is dying in front of them
 - It's what he's been told from an unbiased source.
 - Have had medical patients where their overriding issues are their other medical problems.
 - Is usually a big shock that their current surgical issue is not the biggest problem.
 - Can't fix that, can make it worse.
- What's the relationship between surgeons / doctors / etc.?
 - If it's a medical patient, they will often consult them on the floor
 - Often consult the medical team.
 - It's pretty good, no major issues.
- How do you go about explaining procedures to patients of cultural difference?
 - Pull up a picture on the web
 - Visual cues
 - Simplify the language as much as possible.

- If patient is a little unsure about the procedure and it is not immediate concern, what do you tell them to think about?
 - Offer to talk to their family.
 - Offer literature / information.
 - Offer second opinion.
 - Would not do anything that's not beneficial to somebody.
 - Gradiations of good / bad
 - Will do things that help but may not be the best option.
 - In the end, it's their decision.
 - Often there's no right answer.
 - There's good answers and better answers, also wrong answers.
 - Will never offer a wrong answer.
 - When time is given, is it usually because they have not come to a decision?
 - Sometimes there is no clear right answer
 - Sometimes the problem isn't in the textbook, there's a lot of other problems at the same time.
 - How can I help you to decide?

Appendix L

Subject: Nurse Practitioner B

Interviewers: Mario Alvarado, Nathan Ferron, Nour Krayem

Date: April 16, 2015

Location: Phone Interview

Time in: 1:10 pm

Time out: 1:50 pm

- Background
 - Raised in US, as were parents
 - Family Nurse Practitioner (Chief Nurse Practitioner)
 - Oversees the staff at Auburn
 - Also treats patients
 - Started with ReadyMed last October
 - Nurse Practitioner for 10 years, Nurse 5 years before that
 - Was an EMT in late teens
 - Was a member of the Fire Dept. as an EMT from 16-18
- Patients who don't speak English?
 - Once every 2 weeks
 - What do with these patients?
 - Some times, they come in with a family member to translate for them
 - If they don't, they have a language vine, which is not in the company but is a phone call translation service
 - Just the Nurse, the speaker phone interpreter, and the patient
 - Interpreter introduces self
 - How feel about phone interpreters?
 - Clearly a little bit difficult when they can't understand you or you can't understand them
 - A lot of repetition and time-consuming
 - Interpreters themselves are very helpful, never a situation when they were not helpful
 - No regular interpretation staff, some staff may be bilingual
- Informed consent application
 - Use informed consent for a lot of things
 - They sign, they understand, they give us permission to treat them

- Use it prior to any procedure that they would do, namely with almost-surgical procedures
 - Use for a lot of more procedural and general treatments
 - Is part of the registration process
- Any complications with the process with cultural/linguistics?
 - Make sure with an interpreter that they understand
- To what extent is it necessary to inform a patient?
 - In the case of a wound needing stitches, explain, go into detail, make sure that they know what can happen if they choose to do it as well as if they choose not to do it
 - The form that they sign lists exactly what we are doing for that
 - It has to be specific and nothing beyond that
- Certain demographics agreeability?
 - If someone is coming and they need something done
 - Haven't really come into any difficulties
 - Convenience a factor?
 - Purpose of the institution is convenience.
 - Might be more difficulty if they want to see their primary care doctor
 - It's not anything that they have to do on their end
- Patient backed out because misunderstanding?
 - Yeah, sure
 - Patient came in with an abscess, had it done to other areas in the past, super anxious about the entire process. It is a painful procedure. Patient said that she would scream and say that she would tell them to stop, but told the Nurse not to stop
 - Had she not warned the nurse, the nurse would have had to stop
- Patient rejected for culture/religion?
 - Have had situations where cultures don't believe in certain treatments
 - Blood transfusions can be an issue
 - The patient, during discussion, mentioned that the patient could have been anemic, could result in a blood transfusion, patient said that the doctors could do just about anything but could not do a blood transfusion
 - You could do something to help someone, but they don't consent to it
- Economic concerns?

- A very common situation that they deal with
- Have to really take the cost of anything you're going to do into consideration
- If they don't consent to it then they're not going to do it.
- Have to find the cheapest medication that you can get
- If you have a particular antibiotic in mind, then you call up a few places and see who has the cheapest one
- Describe culture around consent in medical community?
 - It's an important tool for patients
 - No negative reactions to it from patients
- Explaining to patient of cultural difference?
 - They have educational handouts that they can provide at the end of procedures
 - Can print out in Spanish
 - Can pull up pictures for the patient
 - Use interpreters

Appendix M

Subject: Interpreters D, E, F, and C

- Interpreter F had to leave part way through the interview due to being needed for an appointment, and Interpreter C came in later into the conversation

Interviewers: Mario Alvarado, Nathan Ferron

Date: April 16, 2015

Location: Phone Interview

Time in: 2:09 pm

Time out: 3:00 pm

- Background
 - D: Albania, moved here 17 years ago, major in French language in home country, changed to psychology when moved here
 - Moved Here 1998
 - Started working as soon as arrived, English was 1st foreign language started in 2nd grade, knew there was a large Albanian population, worked at family health center as an interpreter there for a while, worked as an independent contractor for a while, now is staff
 - E: From El Salvador, came here 32 years ago, was 14 and did not speak English, went to High School in Boston, went to Northeastern University, background as EMT, came to Worcester, learned about this because the coordinator of Education was putting together a group of bilingual Spanish/English speakers to play the role of a patient, found it fascinating that E could do this and get paid, been here about 20 years, is a realtor in spare time
 - F: Been here for 21 years, came from Brazil, got a scholarship to study music at Berkeley, graduated in 1999, tried to survive as a pianist for a while, still does a lot of music, brought people to the hospital to help sometimes, applied for a job, did the training course and has worked here since 2004, started as an independent contractor and became regular staff
 - E: Being an interpreter itself, you become a lot of everything, you are a social worker at times, many different things, whatever you need for the job
- How long for training?
 - F: We were tested to see our level of efficiency, the course is about 6 Months
 - D: Working as an interpreter means that you have to have continuing education credits, is provided every month, lectures on different topics, there is testing on an annual basis now.
- Are you fluent in any other languages?
 - F: No, can get by in Spanish
 - E: Same with Portuguese
 - D: French, Italian, Studied Turkish for 1 year

- E: If you do get to learn, it's your responsibility to keep up with it.
- F: Learning a language is a matter of time, effort, and need
- When I want to learn something, you learn something
- Any other relevant experience?
 - D: Licensed in mental health
 - Very frequently discuss among us the way we experience emotions, especially when we hear bad news. Move from one experience to another
- How do doctors tend to act around patients of other language?
 - F: Each doctor is a world, is different
 - D: The way that I see it, Doctors are human beings, they have their own skills of communication
 - When they have a part of communication skill, they can do it through the interpreter as well
 - It is a teaching hospital, we see that they are trained very well to work
 - Keep eye contact with a patient, know the interpreter is the third party
 - Some that say tell the patient, tell the patient
 - Look at the patient
 - Try to direct conversation between the doctor and the patient
- Are you obligated to help these doctors?
 - F: We try to bridge the gaps
 - D: We do speak in the first person, so they kind of get that they have to shift the eye contact and attention to the doctor
 - E: Look down or look at the patient to direct conversation
 - You dictate what can happen in that interview
 - We're not there but we're really running the show to make the communication as transparent as possible
- Any concepts that don't translate easily or well?
 - D: Question is two parts, one is linguistic and the other is their level of understanding
 - Linguistic: You try to follow the standard of your profession, try to convey the word
 - Understanding: You know their level of education and their understanding, try to make sure that they understand the concept and/or risk factors; try to convey as clear as possible
 - Is different with different levels of education
 - I do struggle; when there is a patient who really does not seem to understand, you have to tell the doctor that they really don't understand
 - E: If there are high level terms and the patient don't understand, you have to tell the doctor
- Ever had a patient who had been introduced to informed consent for the first time?

- F: The idea that the doctor comes with a very serious face and explains the list of risks, have had many times the patient says the list of risks, the patient has said “I don't want to do this”
 - All depends on the doctor's explanation, some explain that it is very rare, others are more pragmatic
 - There are patients who have seen the informed consent process, but it may not have been as open in Brazil
- D: Some will give the most pertinent risks or only focus on the benefits, the patients panic
- C: In many countries, health care is much more paternalistic
- D: The patients will ask why they are doing this, you have to explain that it is the policy of the hospital that you sign that you are informed and you go into it knowing what it is happening
 - The patients will refuse saying that they are only trying to cover themselves
- C: The patient was having a serious infection after an amputation, the patient was in another world
- What happens when a patient is clearly just signing?
 - F: When the patient says that they understand, you have to believe them. If it is very clear, there is not much else to do.
 - D: There are providers on the other hand, who will ask the patient to explain back to them what they said to make sure that they understand
 - F: It's coming from them though, not from us
 - D: When they feel more comfortable, they will ask more questions
 - F: Techniques that they use, something very subtle, but not controlling
 - D: They don't feel embarrassed when they don't understand (is the goal)
- How often come across medical terms where there is not a good translation for?
 - E: If I come across a term, ask the doctor to clarify in a better way, write it down, and do my own research.
 - Doesn't happen often, but it does come up
 - D: It is a big part of our training, when we come across something that is not there
 - What I call rare is genetic disorders, it is not a big part of D's population
 - Appreciate it when another interpreter comes across another term and lets them all know
 - When there is something rare, the doctors stop and fill them in so they know when they go in
- Is there much of a prep time?
 - D: If there is a genetic disorder, they get told ahead of time and they know a day ahead
 - E: In a perfect world, they do this. But sometimes, you are just taken to the room

- C: With modern technology, they have a dictionary in their hands and can just research it in front of the doctor
- D: Is very important to for me to understand what it is said
- E: The meat and potatoes of it is the meaning, you need to understand what is being said
- How is informed consent in home country?
 - D: Still have ties and strong connections with home country, have a good understanding, if there is something that I don't understand from newcomers.
 - Less explanatory, but from all I know (has 2 people in family who are surgeons) they explain with pictures all the risks involved
 - E: Before came over, the norm was if you're seriously ill, they talk to the family and there is a taboo on telling the patient his/herself, the family makes the decisions for them
 - C: I think that in most cultures, it is a family decision. Over here, it is very focused on autonomy.
 - In Spanish ICU, you might find many patients, more than a nuclear family
 - E: Patient from Dominican had a serious condition, had a family member pull E aside and tell them not to tell the patient anything, had to regroup and explain that the patient had the right to know
 - D: Patient who had really bad news, explained to the patient, next time you saw, came straight to D, blamed D for the news, almost thought that it was a safety issue because she was that upset, had to explain the role of the interpreter to her
 - There are providers that are more open, but there are others that want to go by the book
 - Some are very culturally sensitive, family doctors will ask the patient if they would prefer to discuss with the patient or the family members
 - For end-of-life decisions, it is very sensitive, they don't want to go there, don't have the concept of thinking what they want for their own end of life
 - There are some that understand, others that don't want to go
- Any sort of cultural or religious traditions that prevent certain procedures?
 - D: Not in Albania
 - Is protocol that they ask a series of questions to every patient, safety questions, never had a cultural or religious belief interfere
 - E: If a patient comes from my country, mostly humble background, more interested in knowing what is happening to them, the informed consent process is foreign to them. It's more of a learning experience than anything, because they are so humble they are more willing to allow it
 - Whatever you say, doctor
 - I'm in your hands

- C: After God, you
 - D: In regards to alternative treatments, you have to tell the patient that they have to choose the treatment, have to explain to them that they have to choose, they ask the interpreter all the time
 - C: Is a big ethical no-no, they cannot decide for them
 - D: Even when they understand everything, they still want the opinion
 - E: Has not had the same experience of patients asking for advice
 - E: Years ago, patient from very remote area of Guatemala, explained all the consent forms to the patients, the patient was frustrated because in Guatemala they would have just put the organ in.
 - C: Many years ago, saw a video from Japan, they would never tell the patient what they were doing with the patient, everything was through the family, they would even show the organ to the family afterwards
 - They conceal absolutely everything from the patient
 - It's culturally. In the old days, medicine was like that even here. If you need a surgery, they would go ahead and proceed with whatever.
 - Medicine in the old way did not want to deal with the paperwork.
 - Changed due to litigations around the 60's, there were issues of operating on the wrong side
 - D: Not only the legal part of it, in the last few years it has evolved
 - In end-of life, they have put more importance on respect
 - C: Used to not be any education for it
- How do you feel about withholding information from the patient at the patient's request?
 - D: Oftentimes, the patient will ask to have the family informed, not the patient. Is a bit of a shock.
 - When the patient does consent in this way, they might just use vague terms, such as “your disease”
 - E: Has not really dealt with this before
 - When it comes up, it is usually the family requesting this, not the patient.