Back to 2.1

Cases for Discussion

- **Case 1**

An adult woman with symptomatic gallstones is brought to the surgeon by her husband. After examination and going over the investigations, the doctor recommends laparoscopic cholecystectomy. Communication is primarily between the husband and the surgeon since he is the only one asking questions. The RMO brings out the consent form and the husband signs it.

What are the ethical and legal issues in this situation?

- **Case 2**

A 15 year old girl is brought to the ER with abdominal pain and is diagnosed with acute appendicitis needing appendectomy. She is accompanied by her parents.

What is the role of the patient in the informed consent process?

What is the role of her parents?

- **Case 3**

An unconscious male is brought to the ER by his wife and his brother after a road traffic accident. He is assessed by the neurosurgery team who decide on an emergency craniotomy to evacuate an expanding extradural hematoma.

Who gives consent: his brother, the patient’s wife, the physician, or is no consent required in this situation?

What if the patient was brought in by a taxi driver and has no accompanying family/friend?

How does the process of informed consent take place?

- **Case 4**

A 75 year old mentally competent man is suffering from a rectal cancer that requires surgery. His sons and brothers bring the reports to a surgeon to confirm diagnosis and discuss the treatment plan. They plead with the surgeon not to tell the patient about the diagnosis of cancer and to proceed with surgery which involves colon resection and temporary colostomy, followed by reversal. They are willing to sign all consent documents.

How should the surgeon proceed?

Who should sign the informed consent?

What is the requirement in Pakistan law?

Back to 2.1

Teaching Video

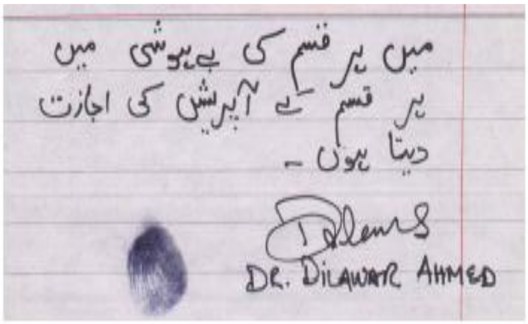
The Sound of Silence: https://vimeo.com/51587494

This movie explores cultural questions of informed consent from women in a hierarchical, male centred society. It raises issues of respecting and exploring the patient's wishes even when the individual appears disinterested. It also explores the issues of privacy, empathy and caring in the interactions between physicians and patients.

Back to 2.1

Examples of Inappropriate and Appropriate Informed Consent Forms

Inappropriate Informed Consent

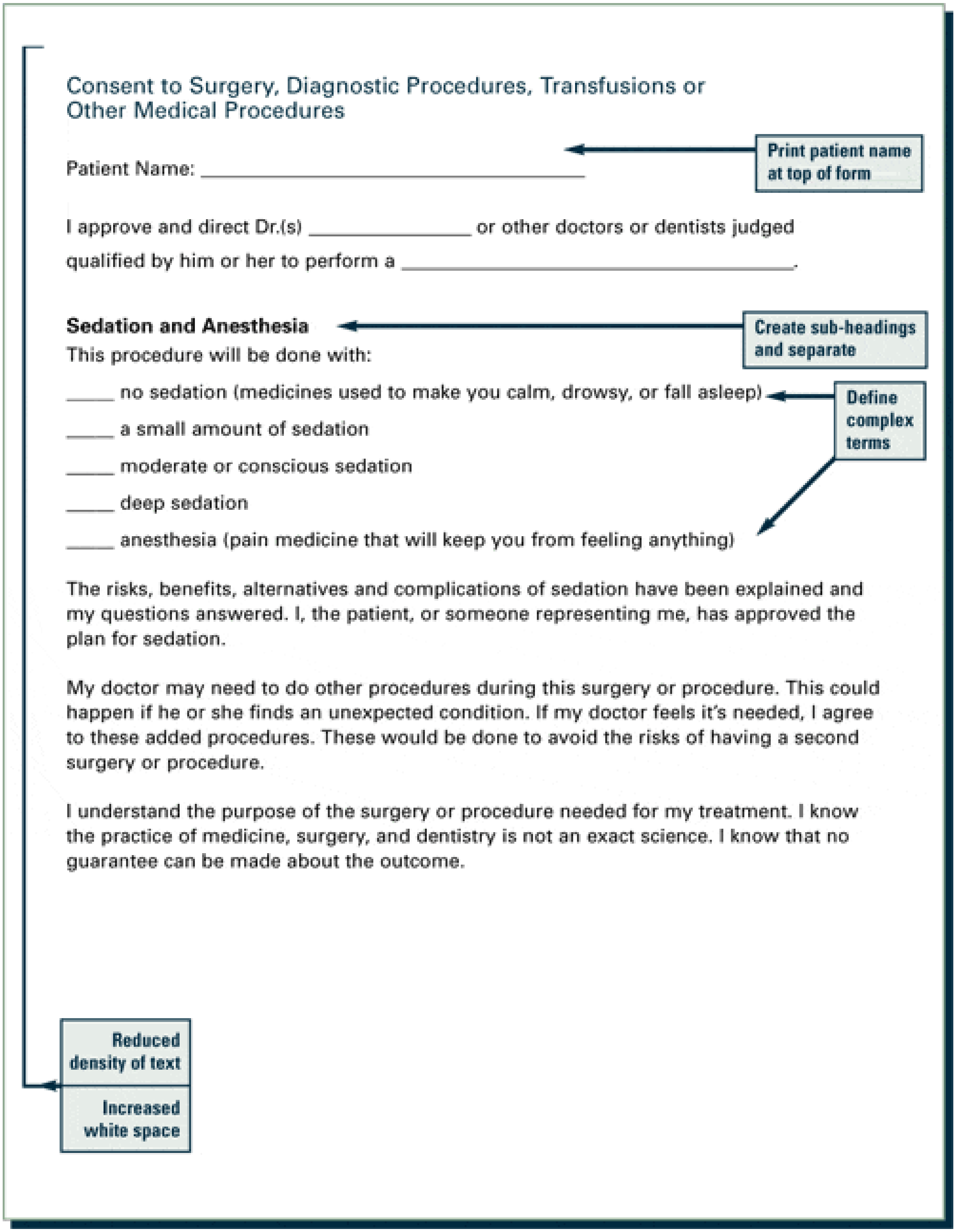


میں ہر قسم کی بےہوشی میں
ہر قسم کے آپریشن کی اجازت
دیتا ہوں ۔

DR. DILAWAR AHMED

“I hereby give my permission for any type of operation to be performed on me under any type of anesthesia,” with a thumbprint and a doctor’s signature.

Appropriate Informed Consent



Consent to Surgery, Diagnostic Procedures, Transfusions or Other Medical Procedures

Patient Name: ______________________________

Print patient name at top of form

I approve and direct Dr.(s) ____________ or other doctors or dentists judged qualified by him or her to perform a ______________________________.

Sedation and Anesthesia

Create sub-headings and separate

This procedure will be done with:

_____ no sedation (medicines used to make you calm, drowsy, or fall asleep)

_____ a small amount of sedation

_____ moderate or conscious sedation

_____ deep sedation

_____ anesthesia (pain medicine that will keep you from feeling anything)

Define complex terms

The risks, benefits, alternatives and complications of sedation have been explained and my questions answered. I, the patient, or someone representing me, has approved the plan for sedation.

My doctor may need to do other procedures during this surgery or procedure. This could happen if he or she finds an unexpected condition. If my doctor feels it's needed, I agree to these added procedures. These would be done to avoid the risks of having a second surgery or procedure.

I understand the purpose of the surgery or procedure needed for my treatment. I know the practice of medicine, surgery, and dentistry is not an exact science. I know that no guarantee can be made about the outcome.

Reduced density of text

Increased white space

Back to 2.1

Farhat Moazam, “Families, patients and physicians in medical decision making: A Pakistani perspective,”
The Hastings Center Report, vol. 30, no. 6 (2000): 28–37.
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Families, Patients, and Physicians in Medical Decisionmaking: A Pakistani Perspective

Farhat Moazam

In Pakistan, as in many non-Western cultures, decisions about a patient’s health care are often made by the family or the doctor. For doctors educated in the West, the Pakistani approach requires striking a balance between preserving indigenous values and carving out room for patients to participate in their medical decisions.

After training and practicing as a physician in the United States for many years, I accepted an academic position at a medical university in Pakistan. One of my first experiences there was to tell two brothers sitting across the desk from me that all investigations indicated their elderly father had widespread metastatic cancer, and therefore not long to live. The patient, who lived with the oldest son and his family, was not present during this conversation, although an unmarried daughter, a daughter-in-law, and an adult grandson were. After listening attentively to what I had to say, and obviously upset at this news, one of the sons said, “We do not want him to know that he has cancer. How long he lives is in the hands of God in any case, and it is not right to make my father lose hope while he is so ill.” He then added, “Doctor Sahib, tell us what we should do next. You know best. You are not just our doctor, you are like our mother.”

In these words lies the essence of decisionmaking when illness strikes a member of the family in Pakistan. It is the family rather than the patient who takes center stage in this process. In the case of a conscious patient, the family and physician will generally protect the patient from the anxiety and distress associated with the knowledge of impending death. This is done by not disclosing the diagnosis or disclosing it in ambiguous terms. The “doctor sahib,” (sahib has an Arabic root meaning “lord”) remains the authority in matters relating to disease and medical interventions. She or he is often symbolically inducted into the family and is expected to direct rather than just facilitate medical management. In the final analysis, however, God, not man, controls life and death.

This model, in which religion and the extended family play a primary role in matters dealing with illnesses, particularly terminal illnesses, is shared by many Eastern cultures, but contrasts significantly with the situation prevalent in many western countries. In secular Western societies, patient autonomy is generally accepted as the cornerstone of medical ethics when it comes to choices involving medical care and end of life decisions. The competent patient is considered an autonomous and rational agent who is sovereign over her fate and the locus for all choices regarding therapeutic interventions[1]—witness the fact that by 1991 more than forty states in the U.S. had enacted “living will” statutes that allow competent people to refuse therapeutic measures in the event of terminal illness even if they are no longer competent, and that trump opinions of family members and physicians. In that year also the federal Patient Self-determination Act went into effect, requiring that all adult patients admitted to a hospital be told of their right to formulate an advance directive.[2]

The principle of autonomy has also been extended to incompetent patients who do not have advance directives through court rulings and the legislature.[3] The substituted judgment standard works on the premise that the personal autonomy of the once competent patient must be extended to her current state of incompetency, with the surrogate functioning as an instrument to determine what the patient would have wished done under the circumstances, if he or she were still competent.

The autonomy model is not without critics, however, especially in a pluralistic society. Joseph Carrese and Lorna Rhodes, for example, have noted that many Navajo consider advance care planning to violate their traditional values.[4] Nor is the exclusion of families from decisionmaking universally valued. Empirical research by Leslie Blackhall and colleagues has shown that Korean and Mexican Americans, among others in the United States, feel that families not patients should hear a terminal diagnosis and be the primary decisionmakers.[5]

Undoubtedly the realities of American society, an amalgam of people from many different ethnic groups, have helped bring such issues to the forefront. In recent years, medical, bioethical, and legal literature has begun to address the need for families to have a greater role in medical decisionmaking.[6] A number of court decisions and legislative actions in the last decade have moved toward giving families greater decisional authority in the area of disputes about terminal care as well.[7] More importantly, almost 80 percent of the world's population resides outside North America and Western Europe. For many, families play a major if not primary role in therapeutic decisions, including end of life situations.

Medical decisionmaking in Pakistan offers interesting contrasts to secular societies. Although the country came into being as an independent nation in 1947, its people have longstanding cultural traditions and religious beliefs that place the family at the center of one's existence. Lives are spent within extended families in which power structures are clearly defined. Familial relationships are not merely horizontal but also vertical across three or more generations. In such societies, Arthur Kleinman notes, the individual is viewed as "sociocentrically enmeshed in inextricable social bonds, ties that make interpersonal processes the source of vital decisions."[8] In Pakistan, family-centered decisionmaking works in tandem with an active, directive role assumed by the physician that stresses the principles of beneficence and non-maleficence rather than patient autonomy. In this deeply religious society, morality is rooted primarily in what is perceived as the religious obligations of the family and the physician toward the patient rather than stemming from a secular, reason-based philosophy that emphasizes the legal rights of individuals.

The following reflections on the interconnectedness of the patient and the family, the dominant role of the physician, and the impact of religious beliefs and socioeconomic realities on medical decisionmaking flow from my experience of having practiced both in the United States and, for more than a decade, in Pakistan.

Families: Ties that Bind

The family is the fundamental unit of society in Pakistan, a country with over 130 million people. Almost 65 percent of the population is rural, and 95 percent of the citizens are Muslims. In contrast to the pluralistic society of the United States, Pakistan offers a fairly homogenous milieu insofar as values and sociocultural norms are concerned. Religious belief plays a central role in the life of men and women from all social strata and is a major influence on all public and private activities. Historically, Islamic teachings have regarded all fields of human activity as coming under the umbrella of religion. There is no separation of state and religion, and no activity is considered purely secular in the life of a Muslim.[9] Moral authority and a sense of right and wrong are derived from religious tenets.

Although the functioning of the judiciary is based on the British legal system, Article 198 of the Constitution of the Islamic Republic of Pakistan states that no law shall be enacted that is considered "repugnant" to the injunctions of Islam.10 Islam does not recognize a central church or religious priesthood and ministries. Direction is sought through the Quran, the Muslim holy book considered to be the Word of God, and the Traditions, Sunna, of the Prophet Muhammad. These sources form the basis of Islamic law, the Shari'a that guides all private and public conduct, and is similar in many ways to the Jewish Halakhah. If no direct answer to a moral or ethical dilemma in personal life can be gleaned through the Shari'a, "subordinate sources," in the form of opinions from Muslim scholars or jurists, are sought.

For Muslims, religion defines the role of the individual, the family, and the physician in life passages including birth, illness, and death. It frames familial and filial responsibilities, obligations of physicians, decisions that involve end of life situations, and how death itself is to be viewed. This remains a seminal difference from many Western societies, in which moral direction for these events is usually sought through human reason, a concept rooted in the secular philosophy of Kant and Mill. Whereas rationalism fuels the ethical and legal discourse of human relationships in secular societies, in Pakistan religion and an interpretation of divine injunctions are the driving forces.

People generally live together in extended families, and it is not uncommon to have three generations living under one roof or in close proximity to each other. It is not unusual for children, particularly sons, to continue to live with their parents following marriage, leading to strong vertical, intergenerational relationships. Personal identity takes second place to the collective family identity and consciousness. Family obligations and harmonious living are considered moral imperatives, second in importance only to submission to the will of God. Discourses that revolve around the rights of individual members in a family, including what one "owes" to another or the issue of "rights" between parents and their children, are alien.[11] Mark Kuczewski's observation, while discussing the family's role in decisionmaking in the United States, that "medical ethics has rediscovered the family," would be incomprehensible to most Pakistanis.[12] In Pakistan, for the vast majority of the population, you are your family, and your family is you.

Family obligations are considered a moral injunction from God. Aging parents in particular are to be treated with patience and humility.[13] The Prophet said, "the best beloved of God is one who loves his family the most."[14] Increasing wisdom is attributed to advancement in years and the gray-haired "elders" of a family are to be respected and obeyed. Relationships and connectedness are defined through mutual trust, care, and obligations rather than competing rights of individual members. This forms the paradigm for the way humans must relate to one another within a family, not only in life but also when death is at hand. Concerns regarding "erosion of the patient's autonomy and subordination of the patient's interest to competing interests" of other members in the family would not resonate well in the social context of Pakistan.[15] A legal concept of advance directives and living wills by an individual regarding her end of life care is alien to Pakistani cultural norms.

Family members generally avoid disclosure of terminal diseases like cancer to patients to avoid "burdening" them further and to allow "dying in peace." This is perceived as a form of caring, particularly toward elderly family members. "Death with dignity," oft repeated in English literature, is seldom raised as an issue in Pakistan. Members of the extended family with whom the patient resides generally undertake decisions regarding terminal care for both competent and incompetent patients. Nursing homes for those who are aged, terminally ill, or incompetent are unknown in Pakistan; such individuals are cared for at home by the family. Although affluent families may hire nurses for home care of a family member who is ill, care giving in most cases is a shared responsibility of the female members of the extended family. These may include a wife, unmarried daughters, or daughters-in-law. As families are both hierarchical and patrilineal, the oldest male member plays a pivotal role in major decisions, with a varying degree of input from the patient and other family members.

The physician is often "adopted" into the family unit by being referred to as mother, father, or older sibling. After being addressed by pediatric patients in the United States as "Doctor" for many years, it was a novel experience for me when children in my clinic in Pakistan were instructed to call me "Aunty" or "Doctor Aunty." Male physicians are referred to as "uncles." Parents and even grandparents accompanying the child, while conversing with me, often expressed their respect by referring to me as being "like a mother" or an "older" sister to them. It is interesting that in this strongly patriarchal society, the mother is awarded a position of respect that is superior to all other relationships. This is based on the Prophet having said that janat (paradise) lies under the feet of a mother. Therefore, equating a female physician with a mother is indicative of reverence and can confer an incredible degree of authority.

The phenomenon of placing a health care professional in the role of a family member has received some attention in psychosocial literature emanating from Pakistan. Riffat Zaman, an American-trained psychologist, notes that the "cultural pattern" is generally one in which "one confides in and trusts family members rather than strangers."[16] Thus "even when the therapist is a stranger to begin with," the patient eventually begins to see the therapist in "the role of a family member." In her opinion, Pakistani patients will often feel more comfortable seeking therapy from someone known to them or their family rather than a stranger. Similarly, I believe that awarding physicians an adoptive kinship reflects a collectivistic culture (as opposed to one that is individualistic) that experiences life primarily as a mosaic of interdependent family relationships that extend from the cradle to the grave.

Within the extended family, relationships are generally well defined based on gender and age. From childhood, members are taught to respect authority, a characteristic that has also been observed in other non-Western cultures.[17] In Pakistan, according to Zaman, help is usually sought from an authority figure within the family, usually a parent or older sibling, who is expected to be not only supportive and facilitative, but also directive in the advice given.[18] This is construed as a sign of caring rather than as an intrusive act. Zaman, when comparing her experience as a psychotherapist in the United States to that in Pakistan, states that the "idealized neutrality" of the therapist in the West does not hold up well in such a culture. According to her, in Pakistan, at the end of a session patients wait expectantly for the therapist to provide a "solution on which they should or would act."

In my own practice I often sensed a prototype of a parent-child interaction, with many families expecting me to play the role of an "elder." In the United States I was sometimes asked by a patient, "What would you do if you were in my place?" In Pakistan this is more likely to be phrased "What do you think I should do?" Interaction with a physician thus takes the form of recourse to an authority figure and not merely a consultation with a medical expert.

The Physician: An Instrument of God

In Pakistan, the physician is held in high esteem by a society that respects authority and condones hierarchical systems. This is also true of other oriental societies, such as Japan.[19] In Pakistan, however, reverence and respect toward physicians is due not only to their knowledge and scientific expertise but also to the historical position accorded the art and science of medicine in Islam. The privileged position of physicians is derived through a historical understanding of the healer as an instrument of divine mercy. This became clear to me through several personal experiences caring for patients in Pakistan.

One was a conversation I had with the father of a frail newborn in the neonatal intensive care unit. The baby was critically ill and close to death. He had a perforated intestine, but there was a small chance that surgical intervention might save his life. The father interrupted my explanation—a product of my own "Western" education in the necessity for seeking the decision maker's informed consent—of the patient's disease and the nature and risks of the surgery we were contemplating. He told me that I did not need his permission because while he believed in God up there (he pointed to the sky), here on earth he held the same trust in me. In effect, he was signifying to me that just as he could not question God's wisdom and

His divine plans, when it came to decisions regarding corporal matters of his ill child he put the same faith in me, the physician. Another instance was my conversation with a grateful mother taking her child home after a long hospitalization and several surgical procedures. After thanking me for my surgical, scientific expertise, she added a caveat. It was clear, she said, that I was a good doctor because God had put shifa (the power of healing) in my hands. Again, I was perceived as having a kind of connection with God in my role as a physician.

According to al-Ruhavi, a famous Muslim physician of the ninth century, a physician “imitates the acts of God as much as he can.” One of the Arabic words for a physician is Hakim. It means one who has knowledge and wisdom and is also a name for God.[20] According to a Muslim scholar of the fourteenth century, “after performing God’s worship and the basic duties of Islam, there is no greater service to God than to treat patients.”[21] In Islam, many scholars have historically assigned a high religious priority to medicine, second only to ritual worship. Al-Ghazali, an eleventh century Muslim theologian and philosopher, considered the profession of medicine to be a fard-kifaya, collective duty, of Muslims, in which some members must assume this religious responsibility for the good of the community.[22]

Under the auspices of the Islamic Organization of Medical Sciences, a conference on Islamic medicine was held in Kuwait in 1981 to mark the beginning of the fifteenth Islamic century.[23] Participants, consisting of physicians and theologians of Muslim countries, met with a view that there was a need to integrate Islamic medical ethics with modern medicine. The Quran and Sunna were used as the basis for arriving at a consensus. The conference ended with the formulation of a detailed Islamic Code of Medical Ethics that described the practice of medicine as “an act of worship” and the physician as an “instrument of God.”[24] This reinforces the belief that respect and reverence for the physician are due not only for her scientific knowledge and expertise but also for her religious responsibility, a striking contrast to a secular understanding of the physician as a well-trained expert who provides a service to consumers and clients in a contractual relationship.

There are strong religious prohibitions in Islam against physician-assisted suicide or direct actions that hasten death. This is related to a Quranic verse that for one who takes a life it is “as if he killed all humankind.”[25] The language of the Islamic Code of Medical Ethics is one of obligations and duties of the physician with a lesser focus on the rights of the patient. The code states that “it is the process of life that the doctor aims to maintain and not the process of dying,” and prohibits the physician from taking any “positive measure to terminate the patient’s life.” It forbids ending the life of a patient “even when motivated by mercy.” The issue of a patient’s right to request assistance or take steps to end his or her life is therefore not an option in Islam.

The code mentions that physicians must obtain consent from patients. However, when urgent intervention is required “to save life” the physician is stated to be morally obligated to proceed with what he or she believes is essential. This is based on a rule by Muslim jurists that “necessities override prohibitions.”[26] Among many Muslim physicians this is applied in instances when saving a life may require medical intervention without consent from the patient. Pakistani physicians will also usually turn to family members for consent when a patient is reluctant to accept an intervention that is considered essential to save his or her life. For example, an anxious, elderly woman with congestive heart failure needed an urgent coronary bypass, but developed dangerous arrhythmias each time the issue of this major surgery was broached with her. Following a discussion with her son, with whom she lived, the consent for the surgery was obtained from him. The patient was merely informed that the surgeon needed to do “a test,” and the surgery was undertaken uneventfully. Such collusion between the family and the physician would have been ethically and legally problematic in many Western societies. In this case, at the time of discharge, the patient, having been informed of the subterfuge following her recovery from surgery, warmly thanked the surgeon for proceeding with the necessary intervention and saw her son’s decision to assume responsibility for consenting on her behalf as an act of filial love.

Although family members are taken into confidence, physicians in Pakistan generally use substantial discretion when it comes to disclosing a grave prognosis or terminal illness to the patient. In the absence of a legal requirement or a tradition of living wills, physicians rarely disclose terminal disease to the patient or often do so in ambiguous terms. Portions of the Islamic Code of Medical Ethics dealing with the issue of disclosure state that the patient has "a right" to know about his illness, but that the physician's "way of answering should be tailored to the particular patient in question." The physician is advised to find "suitable vocabulary" depending on the situation and delete "frightening nomenclature." If necessary, "coinage of new names, expressions or descriptions" is suggested. This is very much the case in Pakistan, where physicians tend to interpret informed consent contextually, tailoring the extent, time, and nature of disclosure based on their and the family's belief as to what and how much the patient should be told.

Avoiding full disclosure of terminal disease and using ambiguous terminology has also been reported from other societies, particularly in regard to cancer. In an international survey of the attitude of physicians in revealing the diagnosis of cancer to patients, fewer than 40 percent of oncologists from Africa, Hungary, Japan, Portugal, Italy, and Spain were reported as using the word cancer when talking to patients.[27] Commonly substituted words included "growth," "tumor," "mass," etc. Although recent studies, particularly in Japan, indicate a trend toward greater acceptance of revealing the true diagnosis to the patient, a reluctance for full disclosure is still not uncommon in many cultures. The 1995 survey by Carrese and Rhodes reported a strong Navajo cultural belief that presenting such information to patients is detrimental to their health and welfare "negative words" could hurt the patient.[28]

In Pakistan, reluctance to reveal the diagnosis of terminal disease appears to be largely based on the family's concern to protect the patient from additional distress. In my experience, at times this mirrored a cultural reluctance on the part of some patients to learn all the facts even when they suspected a grim prognosis. Since Muslims believe in a divinely predestined time of death, which no human has the power to alter, discussions regarding the duration of remaining life are seen as meaningless.

Religious Beliefs and Concepts of Death

A few governmental and many private health care institutions in the country now offer tertiary level medical and surgical interventions, including open-heart surgery, major joint replacements, in vitro fertilization, and neonatal surgical interventions. Although poverty and lack of third-party payers limit access to private institutions, government-run health services are heavily subsidized and available to the general population. Life-prolonging measures in the event of terminal illnesses are beginning to gain ground, particularly in urbanized parts of the country, through progressive importation of scientific technology and increasing numbers of Western-trained physicians. Despite the secular and scientific nature of medical science, religious beliefs continue to shape how patients and educated families perceive terminal disease and impending death. Death, when it occurs, is generally considered to be through divine ordinance and not necessarily a failure of science. Malpractice suits against physicians and hospitals do occur, but the cases are few and far between due to a legal system that is not conducive to this form of litigation.

There is a strong belief that life is merely one stage of human existence and that death can occur only at a divinely appointed hour. Following physical death, humans are believed to return to God and a spiritual life.[29] The focus for a patient and her family when critical illness strikes is often not so much on a fear of death but rather on preparation for the "next" life through worship and prayer. A conversation with the grieving father of a dying five-year-old boy demonstrated to me the role of religious faith in making sense of even the tragic deaths of children. Despite radical surgery and chemotherapy for a renal tumor, the child's cancer had spread rapidly. The parents had maintained a vigil at their son's bedside for days as the battle to save his life was slowly lost. With tears in his eyes, the father (a lawyer) told me it seemed that God had ordained just so many days on earth for his son, and expressed his belief that medical science could never defeat death. Human intellect could not comprehend God's plans or question His will. Thus medical science and technology are accepted as having limits, and death is seen as the will of God.

The conversation among patients, families, and often the most "scientifically" trained physicians is usually peppered with references to the will of Allah and His control of events on earth. While transmitting news of a successfully performed surgical procedure that is expected to have a good outcome, a surgeon will invariably add *inshallah*, "if God wills." A family reporting that the patient is recovering well from an extensive medical intervention will always remember to end this news with *mashallah*, "with the grace of God" or *subhanallah*, "praise be to God."

Hospitals with technology that can extend the life of those who are terminally ill are not yet as widely available in Pakistan as in the industrialized world, and most patients die at home amidst their families. The final hours are spent in prayers and recitation of the Quran, activities in which all members of the extended family and close friends participate. Whether the relentless march of science in prolonging life and postponing death in intensive care units and a greater accessibility of this technology in Pakistan over time will change the prevalent attitude toward life and death remains to be seen.

Economics and Family Decisionmaking

Despite a small affluent sector, in Pakistan the average per capita income is approximately $430. (The 1997 Encarta lists this figure as $19,000 for the United States). Health care often not the best is provided free in overcrowded government-run clinics and hospitals, but patients usually pay cash for medications as well as a fee for specialized investigations. There are no third-party payers and few health insurance schemes in the private and public sectors. Private hospitals, with a better standard of care, sometimes maintain a budget for the treatment of the indigent, but primarily run on a system of fee for service.

Poor and middle class family units often consist of three-generation households with one or more breadwinners who pool their resources for the extended family. Familial obligations, particularly to aging parents and the care of several children in the household can have serious financial implications for the family in case of protracted illness of any one member. In his analysis of the decisionmaking process in Japan, Michael Fetters uses the term "family autonomy" to refer to the societal norm for dealing with medical issues.[30] In his opinion, although physician paternalism characterizes patient-physician relationships in Japan, the family, particularly the male head of the household, forms the locus for decisionmaking. By necessity, decisions must take into consideration the financial survival of the family rather than preferentially emphasize any one member's rights in isolation. The same is often painfully evident in Pakistan, a much less affluent society than Japan, where there are no public financial aid programs to cover health costs in the case of protracted or life-threatening illnesses. Such situations can be morally troubling and a source of considerable anguish for physicians, who believe that professional and moral obligations to provide medical care should be based on need rather than an ability to pay.

I was faced with such a situation when a three-year-old girl was brought to the emergency room severely dehydrated from prolonged diarrhea that had been refractory to treatment by a general practitioner. Her only chance for survival, I believed, was through admission and parenteral hydration. The grandmother and father accompanying her refused admission, requesting instead a prescription for medications that could be given to her at home. The father was a tailor, the sole breadwinner in a family with six children and two elderly grandparents. Due to a festival later that week he had a large number of requests to stitch clothes and thus an opportunity to earn much needed money. The entire family, including the children, were needed at home to cope with the additional work. Admitting the child to the hospital at this point would not only be an added expense, but would also reduce the manpower for work as one family member would have to stay with the child in the hospital. When I insisted on the admission, the grandmother pointed out to me that while my concern as a physician was for this one child, the family had another five at home who needed food and clothing.

This case presents a stark example of the socioeconomic realities in Pakistan that force families with limited resources to make distressing choices and leave physicians in a moral quandary. The survival of the entire family unit superceding the interest of an individual member is an extreme example of family autonomy and a form of distributive justice at the micro level. In countries with effective social services and government financial aid programs this degree of family autonomy would perhaps not arise. In Pakistan, it remains a daily reality for families and health care professionals.

On another occasion I was asked to consult on a sixteen-year-old boy with Down syndrome who was left a quadriplegic due to cervical spine subluxation. All surgical attempts to stabilize his spine had failed and the progressive and complete paralysis of his respiratory muscles now made him ventilator dependent. He was unable to breathe without mechanical support, but remained awake and fully conscious. Prior to this event he had lived in a remote village with his extended, middle class family composed of twelve people. The family, very fond of their youngest member, had pooled resources to bring the patient to the private, tertiary care, university hospital in the city hoping for a cure. During the subsequent two months of hospitalization, the family sold their only car and part of their land to help defray the cost. They were now not in a position to pay any more. A brother, one of the family breadwinners, had lost his job because he would not leave the patient alone in the unfamiliar surroundings of the hospital. After two months in the hospital, the life of the patient was evidently pitted against the survival of his entire family. Distressed at what he saw as prolonged suffering on the part of the patient, the brother told me that if they had known of this outcome, they would never have brought him to this hospital with its “machines and specialists” and his brother “would have died at home in peace.”

In Pakistan and other developing countries, skilled physicians and surgeons are no longer difficult to find. State of the art technology is beginning to take root in the public and private sectors. The opportunities for prolonging life are on the rise, but there are few support services outside hospitals and the associated increase in health care costs can bring with it devastating financial and emotional burdens for many families. The issue of arriving at a fair distribution of health care services in the face of limited resources is becoming a vexing one for even affluent countries. Recently, it has been suggested by some that in “futile” cases at least (with the admitted difficulty in agreeing on the definition of futility), it may be morally justifiable to give family interests and the issue of distributive justice decisive weight over the interests of the individual.[31] But the circumstances in impoverished countries like Pakistan can lead to even more intensely troubling dilemmas for physicians. Patients like the two I have described, who do not fit even the broadest definition of “medical” futility, can raise wrenching issues about which is the morally correct choice or indeed, whether a morally correct choice exists at all.

Finding a Middle Ground

In recent years, a narrow focus on patient autonomy has been criticized as being non-contextual and based on an abstract concept that the individual is isolated and disconnected from the many relationships within which he or she actually exists. The Pakistani family-centered model of decisionmaking, in contrast, works on the premise that the family exists in mutually trusting and interdependent relationships that stress caring and love rather than individual rights. When illness strikes, the physician is expected to act as an authority figure who is seldom questioned in the therapeutic arena.

Decisionmaking by the family, if strictly authoritarian, may hold inherent risks for some members of the family unit. In patrilineal families, the norm in many Eastern societies, there can be inadequate representation of the interests and wishes of certain family members, often women, who are economically dependent on the male head of the family or are powerless for other reasons. An unquestioned acceptance by the physician of implicit agreement on the part of such members to every decision that is made on their behalf can carry risks for the most vulnerable family members. This was illustrated in a case that was brought to my attention by a Pakistani surgeon. An elderly woman came with her son, with whom she had lived for many years, to be scheduled for an elective biopsy of a breast mass. During the meeting with the surgeon, the son mentioned that his mother also had gallstones and requested that a cholecystectomy be done along with the breast biopsy. The patient, who was present during this exchange with the surgeon, did not disagree and accepted without questioning the son's signature for both procedures on her behalf. As a son consenting for the mother is not an unusual occurrence in Pakistan, the surgeon interestingly, also a woman made no attempt to question the patient directly regarding her wish.

Just prior to being administered general anesthesia in the operating room, the patient told the surgeon that she did not wish the cholecystectomy to be done, something she had not verbalized in the presence of her son. Much to the anger of the son when he was informed later, the surgeon complied with the woman's request. The son expressed his concern that it was in the best interest of his mother to have had her gallbladder removed to avoid another anesthetic and surgical procedure in the future. When she shared this episode with me, the surgeon confessed that instead of accepting the common tradition of a male in a family signing the informed consent for female members, she should have probed the patient's own wishes and been sensitive to what might have been fear and anxiety on the patient's part regarding the cholecystectomy.

Although in this case the patient did eventually voice her preference in the absence of her son (perhaps due to the gender of the surgeon), undoubtedly many cases occur in which the concerns and wishes of a competent patient are ignored or overridden in a nonparticipatory process of decisionmaking. An unquestioned, face value acceptance by the physician of cultural norms can jeopardize respect for the individual as a person, a prerequisite for the covenant between a physician and her patient. It is often easier and certainly less time-consuming to take refuge behind a veil of uncritical respect for cultural norms. In societies like Pakistan, physicians can utilize the tremendous respect they command to assess each encounter with a patient and family carefully to strive for a participatory process of decisionmaking, particularly when some members of the unit have been dealt a stronger hand culturally.

With rising literacy rates (albeit slower in women) and greater awareness, in time Pakistani physicians may well face an increase in the number of patients who wish to know more about their illness and prognosis. An automatic assumption that family members must be given the details of the disease while this information is withheld from the patient may become difficult to defend. However, my own experience suggests that in the social context of Pakistan there can be considerable variation in patients' responses to offers of full disclosure of illness. A measure of sensitivity and discrimination is needed in the context of the prevalent, widely accepted societal belief that caring involves shielding one's family members from distressing news.

This was illustrated for me by the case of an intelligent, educated, sixty year-old woman hospitalized with abdominal pain and diagnosed to have a large, unrespectable malignant liver tumor. As is accepted, I gave this news first to her only son, with whom she had lived since the death of her husband a few years previously. He felt strongly that telling his mother she had cancer would depress her and make her "lose hope." He felt she should be told that she had a liver "infection." He added that since her husband's death, she had always relied on him for all major decisions. Conceding that he knew his mother better than I did, I told him that as his older sister a kinship he had bestowed on me I felt it was important to judge first whether his mother would indeed not wish to know a diagnosis that carried major implications for her. After a while we reached a compromise: I would not use the word cancer but would tell her she had a large "tumor," but I would not lie to her if she asked me a direct question regarding the nature of the tumor, including whether it was malignant. The son assured me that she would not and he was right. During several conversations with the patient in which we talked about her "tumor," despite several openings I offered her, she never once questioned me about what kind of tumor it was or whether this would affect the duration of time she had left to live information I had been certain she would wish to obtain. On the other hand, I have come across other patients over the years who have not only asked questions of varying depth, but have also indicated their preferences in decisions regarding their medical care.

A shift away from an authoritarian family decisionmaking process is possible, but the physician must use discrimination, judging encounters with each patient and family on their own merit. With appropriate rapport with the family and sensitivity to the wishes of a particular patient, cultural norms can be challenged. In Pakistan, the physician as a matriarch can also work toward neutralizing some of the unfair leverage that one family member may have over another in the decisionmaking process. A young couple brought their infant to me with a nonfunctioning kidney that needed to be excised. When the time came to discuss the surgery, the husband asked the wife to take the child out to another room to feed her. He then requested that I give him the details of the nephrectomy but tell his wife only that a "biopsy" was needed. He was concerned that she was too tender hearted to stand the shock of being told that the kidney would have to be removed and he did not wish to upset her. As I had already been inducted into the position of mother by the young man, I informed him that mothers had the right to decide themselves how much they wished to know about the medical plans for their children. The anxious woman was called back into the room and, on my questioning, expressed a wish to be told exactly what surgery was needed for the child. As I proceeded to do so in my role as the "wise" matriarch, the husband's apprehension gradually subsided.

Deeply entrenched religious beliefs and cultural norms that emphasize the primacy of the family and well defined roles within it are realities in Pakistan. I believe that replacing a system of supportive interdependent relationships within families with another that focuses on disconnected individual rights exclusive of family interests is neither feasible nor desirable. However, a shift to some kind of middle ground is necessary. This can be facilitated if physicians play a role befitting a Hakim, bestowed on them through long-held cultural and religious traditions. As my own experience illustrates, there is room for flexibility between a rights-based, patient-centered model of decisionmaking and another in which the identity of the patient and individual members may be lost in the collective consciousness of the family unit. A dynamic balance can be found that preserves important cultural values of duty and caring within families and introduces a possibility for individual members to participate in their own medical decisions. In Pakistan the physician, with her unique standing in society, is ideally suited to serve as the catalyst to begin a move toward such a middle ground.

This being said, the other risk to patients in Pakistan ironically comes from the physician herself. It lies in the potential for abuse of this unchallenged power that physicians command in a country where the population is largely illiterate and economically disadvantaged. Unquestioned authority of the medical profession and a fatalistic belief among the population regarding illness and death can leave patients open to exploitation by unscrupulous physicians. I am aware of instances in which improper care or medical negligence was camouflaged by references to divine predestination leading to the death of a patient. Institutional and organizational checks and balances of physicians and the medical profession as a whole are variable in effectiveness even in many institutions where they exist. Furthermore, there is a general lack of awareness of individual rights and redress through the judicial system, which is not accessible to most. All these factors combine to leave patients and their families exposed to exploitation by health care professionals.

In religious societies like Pakistan, physicians have been expected traditionally to draw their professional morality from duties and obligations. But times are changing. The medical education of physicians for some years now has been occurring in a secular, scientific milieu, and Pakistani physicians are no exception. According to Fazlur Rahman, a professor of Islamic thought at the University of Chicago, the medical tradition in Muslim societies is losing "the warmth of the cultural home in spiritual terms."[14] With the progressive shift to medical specialization and increased use of impersonal technology, all with undoubted benefits, physicians in Pakistan are moving away from close relationships with patients and their families to an approach that is distant and akin to the contractual model prevalent in the West. Such relationships require an informed, literate population and a society with well-established, effective checks and balances through institutional, professional, and governmental bodies. If these are absent or do not function well, patients and their families have little recourse against exploitation. In the Pakistani context at least, within the family-physician-patient triad it is the physician who can be the most influential in working toward a model that respects a cultural tradition of family caring yet draws the patient into the decisionmaking process.

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Back to 2.1

Aamir M. Jafarey, Arshi Farooqui, "Informed consent in the Pakistani milieu: the physician's perspective," *Journal of Medical Ethics*, vol. 31, no. 2 (2005): 93-6.
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Informed Consent in the Pakistani Milieu: The Physician's Perspective

A. M. Jafarey, A. Farooqui

Abstract

Informed consent enjoys an unassailable position in both clinical and research situations as a safeguard of patients' rights. Keeping the patient involved in the decision making process is easier when there is direct communication with the individual. The Pakistani milieu offers challenges to this process because crucial decision making is often done by family members or is left entirely up to the attending physician. There seems to be a general acceptance of this shifting of focus from the individual to other players. This also raises certain ethical dilemmas for physicians who may feel uncomfortable with communication which excludes the patient or in accepting a paternalistic primary decision making role. The objective of this informal qualitative study was to ascertain physicians' perceptions regarding the process of information delivery to the patient in the Pakistani context and the various influences acting upon it.

Introduction

The stipulation that an individual be fully conversant with all the relevant facts is central to the concept of informed voluntary consent both in research and clinical situations.[1] Only then can the process of informed consent play the role of a safeguard that upholds autonomy and acknowledges the fundamental position of the individual's choice.[2] Centrality of the individual in the medical decision making process is sacrosanct in the West with the patient actively involved in all discussions with the physicians.[3] The importance of individual autonomy however is challenged in many Eastern cultures.[4] In the Pakistani context, there are several other factors to consider in crucial decision making situations. In some cases, the patient opts to exclude himself from receiving information and participating in discussions regarding his management, delegating family members to make the decisions. Alternatively he may invite his physician to use his best judgment and choose the best option for him. In other situations, the family members may insist on excluding the patient from the decision making loop. This family, physician, and patient triad in Pakistani society in medical decision making has been comprehensively documented by Moazam.[5] A tradition of living in extended families, often with shared incomes, strengthens the role of the family in major decision making situations like selection of marriage partners, financial transactions, and in making decisions about medical treatment.

Requests from patients like ''Doctor Sahib, you are like my elder sibling or parent. You know what is best you decide for me'' are not uncommon in this part of the world. How should the physician proceed when the onus of decision making is thrust upon his shoulders? Should he accept the imposed paternalistic role and proceed according to his own best judgment, respecting the patient's right to exercise autonomy and decision not to know? Or should he still insist on involving the patient? Is the physician, in performing his ''duty'' to convey information to the patient irrespective of the patient's desire actually respecting the patient's autonomy?[6]

In another common scenario, a family member may take the physician aside and ask him to carry on with his management but not to tell the patient that she has a life threatening disease as she is ‘‘faint of heart’’ or would not be able to ‘‘sustain the shock’’. Here again the physician faces the conflict between upholding the patient’s right to know and respecting the desire of the family to shield the patient from bad news.

This change of focus from the individual to the family or the physician raises the question of the role of individual autonomy in this culture and the whole concept of informed consent. Who needs to be informed and who will participate in making the decisions? The apparently different set of ground rules gives rise to numerous ethically challenging situations in clinical practice in Pakistan.

There is paucity of information regarding the various factors affecting the process of information delivery and medical decision making in Pakistan and the importance of the different key players influencing the process. This informal qualitative study was designed to gain deeper insight into physicians’ perspectives regarding this process. The objective was to evaluate how physicians at this institution approach such situations in their clinical practice. What are their guiding principles in the process of informing the patient about his disease, its prognosis, and treatment? We also explored the impediments they face in the process and ascertained the level of satisfaction with their practice in this regard.

Methods

This informal qualitative study was conducted at Aga Khan University Hospital, Karachi, Pakistan, and a private sector tertiary care hospital. Three approaches were used which included focus group discussions, individual in-depth interviews, and informal discussions to gather data. The perceptions about informed consent from various levels of physicians including professors, associate professors, assistant professors, senior instructors, fellows, and chief residents were obtained. These physicians were from specialties including surgery and allied fields, gastroenterology, oncology, rheumatology, family medicine, cardiology, neurology, and invasive radiology.

The commonality among the various specialties listed above was based on their interaction with patients and frequent need for passage of information from them to the patients. Their diversity lies in the different kinds of diseases they deal and the various modes of interventional and non-interventional treatments they apply in the dispensation of healthcare.

A facilitator introduced the topic to the participants of the focus group discussion and put forward non-leading questions to highlight the issue being discussed. In each focus group 10–12 physicians from various specialties participated in the discussion. In order not to influence the proceedings, the facilitator did not participate in the discussion. Comments were recorded and simultaneous notes were also taken. These were immediately transcribed and authenticated by both the authors. The transcribed material was then analyzed for identifying the various responses from each group and then grouped accordingly in the result. We stopped after the fifth focus group discussion because of overlapping information.

Seven key informants who had not participated in the focus group discussions or the informal discussions were identified from major specialties. Verbal consent was taken from each participant. The facilitator used the informal free conversational approach for the interviews, the main aim being to obtain personal experiences that would further expand on the perspective. These interviews were transcribed immediately after the meeting and the transcriptions individually analyzed for identification of the key points.

Five informal interviews were carried out on the basis of convenience sampling. Physicians who were available for the interview were requested to participate in the exercise in an informal manner. A verbal consent was also obtained from them before the interview. These interviews were also transcribed immediately after the meeting. Again the transcriptions from each individual were analyzed for key points.

Results

The discussions were focused in the area of information delivery in the process of informed consent and the roles played by the various key participants. Apprehensions regarding the various pitfalls inherent to this process in our society were also debated. The physicians also talked about the extent of their moral satisfaction with the process of information transfer as practiced at present and suggestions for improvement were put forward, keeping in mind cultural and social values.

Information

Most participants felt that it was the physician's duty to bring the patient into the decision making process. The prevailing opinion across the different focus groups was that regardless of the opinion of the patient or the family, the physician is obligated to deliver at least some basic information to the patient. It was a general opinion that information about the disease and the treatment ensures participation and helps the patient respond better to the management. The patient could therefore not absolve himself from his right to know what was happening to him and nor could the family take away this right from him.

There was wide divergence of view regarding the extent of information to be provided, from giving encyclopedic levels of information to outright deception. The majority felt that the process needs to be individualized, and a tiered approach was suggested, starting from the basic facts and going further based on the patient's demands. Some participants emphasized outlining the risks versus the benefits of a particular therapy to the patient. There was no consensus on how to identify essential information from the "details" that could be omitted.

The issue of voluntarily withholding information came up repeatedly in the discussions. Most participants agreed that it was perfectly acceptable to use alternative words like 'growth'' or ''mass'' rather than use the term ''cancer'' and this did not amount to deception. The general view was that the patients usually already knew or suspected strongly what was wrong with them, especially patients with malignancies.

Some of the physicians were comfortable with entirely excluding the ''more distressing'' facts about their disease or giving a more ''optimistic'' picture to the patient. Physicians as opposed to surgeons were more comfortable in withholding the exact diagnosis if they felt that revealing all the facts could enhance the distress of the patient and not contribute meaningfully towards the management. ''You can be evasive regarding the diagnosis if the patient does not ask you directly'' said one physician. This group however was of the firm opinion that if a procedure has to be undertaken, it has to be explained to the patient even if the family says otherwise. This was necessary to ensure the patients cooperation for the procedure.

Role of the Family

When a family member is taken ill, it is common to see several family members accompanying the patient to the doctors' office and if a patient is admitted for treatment, one can often see several family members camping outside in the open for days. ''Not only does the patient bring his family along when he comes to visit the doctor, at times it seems he has brought along the entire family tree!'' remarked one participant.

''There is no difference between the patient as an individual and his family. Both are one and the same.''

All participants accepted the key position enjoyed by the family in decision making processes in Pakistan. Many of the participants refused to draw a distinction between the patient and the family in this culture, claiming that they are inseparable and should be addressed as a one unit. ‘‘There is no difference between the patient as an individual and his family. Both are one and the same’’ said one physician. Several participants pointed out that the doctor first confronts the family members with the diagnosis, especially when suspecting cancer, before approaching the patient. Often a joint strategy is hurriedly arrived at between the physician and the family before approaching the patient. The question asked by many was “how then can the role of the family be relegated to anywhere below that of the patient himself?”

Apprehensions

Several participants voiced their apprehensions in following a Western oriented blind information delivery policy without considering the wishes of the patient and the family. One fear of spelling out details of the diagnosis, the prognosis, and possible complications of procedures was of scaring the patients away to other practitioners with a more reassuring ‘‘trust me, you will be fine’’ approach. Losing patients translates into losing valuable experience and revenue and is a tightrope that needs to be walked at times. As one relatively junior surgeon said, ‘‘I try and tell the patient all possible complications of a procedure so that if something does go wrong, at least he was forewarned. I however, tend to lose patients also by this approach as they sometimes choose to go to a surgeon who does not alarm them with all the possibilities’’. This candidly expressed fear of losing patients by providing too honest an informed consent may tempt physicians to ‘‘recruit’’ patients by giving a rosy ‘‘nothing will go wrong’’ picture. This appeared to be more of an issue for the relatively junior staff still in the formative stages of their practices and it came up several times in the discussions.

A concern that was voiced repeatedly was whether we as physicians were imposing ‘foreign’ values on the patients by thrusting upon them unwanted and unsolicited autonomy. Participants felt that they were unclear about the importance and the relevance of autonomy for the end user the patient and in dragging them into the decision making process we may actually be harming them in an unintended way. “The job of a doctor is to reassure and comfort the sick, not to frighten them” said one surgeon, quoting a patient.

Although physicians were generally willing to let the physician-patient-family balance remain undisturbed, a concern was voiced regarding the legality of making decisions in consultation with the family even if it was done at the insistence of the patient himself. It was pointed out that in the event of a complication there was nothing stopping the patient from turning around and saying that he was not made aware of the choices before the operation and then proceeding with litigation. Some participants felt that there was no mechanism in place to capture the dialogue between all concerned parties that went into the process of informing the patient, assessing his understanding, and getting his permission.

Factors Adversely Affecting the Process

Several factors came across as having an adverse effect on the process of informed consent. One such issue was time: process of obtaining a truly informed and understood consent requires time and patience, both deficient in busy clinical practices. A tiered process (as advocated above) requires that the understanding of the patient be gradually built up and comprehension verified to an extent that satisfies both parties. In busy practices this becomes more and more difficult. As one surgeon said, “I am quite satisfied with my interaction with the patient regarding the informed consent process right now but I am not sure if this would remain so as my practice gets busier.”

One fact that kept coming up was the influence of the level of intelligence of the patient on the quality of the interaction. There seemed to be an obvious hesitation on the part of the participants in equating the lack of intelligence with an inability to comprehend what was being told. Participants were however much more comfortable in saying that a higher level of intelligence did facilitate communication. It was emphatically added that a perceived lack of intelligence should not be a reason not to communicate. A common statement was “every effort should be made to come down to the level of the patient in order to explain the facts.”

Another area that raised forceful objections was in equating education with intelligence. Participants were generally of the view that both could not be equated and an uneducated person could be intelligent and vice versa. But a lack of education was also pointed out as a hindrance in satisfactory communication and again participants emphasized the need for more effort to get the message across to an uneducated patient.

A physician pointed out that the female sex carries with it its own issues in this society. In obstetrics practice for instance, women may be unwilling to acknowledge any information given to them or sign a consent document unless they have their husbands present. They may even be happier leaving the discussion entirely to their spouses, willingly assuming a back seat in the decision making process concerning their own health.

“I take ten minutes to tell the interpreter what is wrong with the patient and he takes inside of a minute to talk to the patient and obtain the thumb imprint.”

Another important factor for the hospital at which this study was conducted was that of consent through interpreters. Afghan refugees with no knowledge of the local languages or English constitute a significant proportion of patients in this hospital. Apart from one surgeon who had learnt enough Persian to get by, all other doctors used the volunteer interpreter service. None of the physicians were entirely satisfied with the use of the non-professional interpreters and, although they were fulfilling the legality by obtaining the signature or thumb imprint on the dotted line, they were dissatisfied by the quality of information delivered. “I take ten minutes to tell the interpreter what is wrong with the patient and he takes inside of a minute to talk to the patient and obtain the thumb imprint” said one doctor. Physicians had devised ways of getting around this problem like making the interpreter translate one sentence at a time to make sure all the facts were delivered. All voiced a desire to have a professional service of trained interpreters who know the importance of conveying the information correctly, checking comprehension and then carrying out the legal formalities.

Satisfaction with the Process

The level of satisfaction of the physicians with the information delivery process depended primarily upon the achievement of two criteria: delivering information to the patient and assessing comprehension. Those physicians whose practices allowed them to spend more time with the patients were more satisfied than those with busier practices. Experience in dealing with a variety of patients and families also made a difference.

One factor that helped physicians do the job better was interaction with a well-informed patient. Cardiac patients for instance, referred to a cardiologist for angiographies, were found to be generally well informed of their disease and the various options available. It was therefore easier to communicate with them and satisfactorily agree on a plan. It was stressed that publicity or educational material like brochures describing a procedure also appeared to facilitate the process for the physicians.

Physicians who do a specific variety of invasive procedures such as gastroenterologists and cardiologists, invasive radiologists, or physicians who see only a certain variety of patients, like oncology patients, were generally more satisfied by the process of informed consent. They had devised their own mental checklists of “must tell” points to the patients and as long as they used them, they were content. In fact, the only person “absolutely” satisfied by his practice of informing the patients of their disease, its prognosis, and the plan of therapy was an oncologist: “There are six things that a patient must know before commencing chemotherapy. I make sure they understand them and then I proceed.” Some physicians advocated the development of checklist type consent forms for major procedures in all fields. Even if it meant the form to be spread over several pages, all the important agreed upon points would be covered. The participants most unsatisfied with the process of information delivery were the surgeons.

Perhaps a wider variety of pathology that they see prevents them from devising these mental pathways for each patient.

Comments and Conclusions

The consent process has two distinct but not necessarily incompatible objectives. It acts as a tool to minimize chances of legal action resulting from a complication of therapy by providing prior information regarding the possible eventualities and getting the patient's agreement before proceeding further. It also emphasizes the moral responsibility of the physician in acknowledging the autonomy of the patient and ensuring his inclusion in the decision making process. Completing one component does not necessarily imply that the requirements for the other have also been fulfilled.[7] These sentiments were echoed by the participants in our study who felt that the consent form was a mere legality and its completion did not signify the conclusion of the moral responsibility of the physician in keeping the patient informed.

The recommended method for obtaining an informed consent in this hospital requires the consultant to have a detailed discussion regarding the various aspects of the recommended procedure with the patient at the time of booking for the procedure. The patient is asked to sign a printed consent form available in Urdu and English if he agrees with the plan. This exchange usually takes place in the out patients' clinic before admission for the procedure. Although the paperwork is taken care of, the patient obviously has the right to retract consent at any time. This delay from the time of signing the consent until the actual procedure enables the patient to have sufficient time to discuss and reflect on his decision, and he has the option of contacting the physician again for further clarification.

There was unanimity regarding the importance of delivering information to the patient regarding major aspects of the treatment and bringing him into the decision making loop. There has been an increasing trend over the past three or four decades towards more disclosure, even in cultures where physician paternalism is traditionally well accepted like Japan, and Eastern and Southern Europe.[8] Even in the US where personal autonomy has always been of overriding importance, physicians were much less likely to disclose the diagnosis of cancer to their patients in the early 1960s than they were by the end of the seventies.[9]

There was considerable lack of clarity regarding the extent of information considered adequate. Some physicians felt there was a place for evasiveness as far as disclosure of the diagnosis was concerned if it protected the patient from additional distress. The respect enjoyed by the physician in our society imposes certain moral responsibilities on them, one being the balanced presentation of facts which neither unduly alarm nor entice patients but facilitate decision making.

The quality of consent was clearly equated with the amount of time spent and the experience of the physician. Most physicians felt that lack of intelligence or illiteracy influenced comprehension negatively but could be overcome by spending more time in imparting information. Following checklists was found by some physicians to be an efficient way of delivering information, especially for routine procedures, and there were suggestions to consider devising checklist type of consent documents for all commonly performed procedures.

Most physicians also acknowledge the family and the patient as inseparable entities in this society and found it morally acceptable to include the family in the decision making process along with the patient. "In Pakistan, for the vast majority of the population, you are your family, and the family is you."[5] One way of officially endorsing the role of the family in the informed consent process is to identify a next of kin formally on the consent form as a legal representative of the patient. This could remove inhibitions that some physicians experienced in communicating "through" a family member rather than with the patient directly. With a legally identified and duly authorized next of kin the fear of litigation would also be eliminated.

An apprehension repeatedly surfacing was that physicians were basing practices on what they personally considered to be appropriate values. In the words of one surgeon, “The physician has the best interest of the patient in mind and it is in the best interest of the patient to know about the disease.” This paternalistic sentiment was echoed by others also. This viewpoint may not necessarily be shared by the patients. Are we attempting to respect the patient’s autonomy without actually knowing whether the patient understands the autonomy that we are insisting on upholding?

This study has brought out several areas of concern in the moral aspects of the existing informed consent process and a few practical suggestions have also emerged. A lacuna in our understanding that has been identified is in the area of patients’ values regarding autonomy and their opinion concerning the role of the various players in the process of informed consent. Another area that remained untouched in the discussions undertaken for this study is the teachings of Islam regarding individual rights and caregivers’ responsibilities.

Any attempt to gain a deeper insight into the role of the individual, family, and the physician in medical decision making in the Pakistani context will remain incomplete without going into the teachings of Islam in this respect. It is also imperative that the patient’s opinions regarding the role of the various influences acting upon the process are also taken into account so that policies and practices can be based on locally acceptable facts and not on imported ideals. These could be areas of further research in order to unravel the patient, family, and physician triad in the Pakistani society.

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