Chapter 11
Who Decides? Informed Consent for Cancer Patients in Mexico

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11.1 Introduction

The Anglo-American model of applied ethics, notably as presented by L. Beauchamp and James F. Childress (2009), has dominated international bioethics. Many ethicists argue that there are fundamental ethical principles which should apply across all cultures and all nations, but the emphasis given to patient autonomy and informed consent (two fundamental ethical principles) can seem very peculiar for many other cultures.

According to the American Medical Association (2008), informed consent is:

> . . . a process of communication between a patient and physician that results in the patient's authorization or agreement to undergo a specific medical intervention

The College of Physicians and Surgeons of the Canadian province of Alberta (2002) considers that a patient competent to give consent (Grubb et al. 2003:89):

> . . . if [the patient] is capable of understanding what is involved in the medical treatment, including the procedure itself, its consequences and the consequences of non-treatment

Several studies have shown that the western values behind the principle of patient autonomy cannot necessarily be applied in a universal manner (Blackhall et al. 2002). Young (2001) describes the western principle of autonomy as demanding self-determination, assuming an individual subjective conception of the good,

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and promoting the value of individual independence, and Blackhall et al. (2001:59) makes the point that:

Ethnicity was the primary factor related to attitudes towards truth telling and patient decision making.

In many countries, the principal of autonomy is applied by involving the family in decision-making (Fan 1997). In this process of collective decision-making, families receive information about the patient's diagnosis and make the treatment decision, often without consultation with the patient who, for cultural reasons, has not been told the diagnosis.

In Mexico, the right to health was established in the Constitution, although, in the fragmented Mexican health system, half of the country's poorest people do not belong to the Social Security system. Many of them are instead affiliated with the Popular Insurance program (Seguro Popular), which leaves them with uncertain access to health services and some medications. Informed consent is an ethical obligation and a legal requirement specified in the Mexican Health Act (Secretaría de Salud 2007).

The National Cancer Institute (INCan) is an autonomous center of the Ministry of Health (SS). INCan is a high technology research center, providing specialized care to people with cancer. Most patients are low income, and not covered by social security. As an important cancer research center, INCan attracts a large number of clinical trials. In 2008, INCan evaluated approximately 40 clinical trial protocols sponsored by the pharmaceutical industry. Almost all patients with lung cancer were enrolled in clinical trials, followed by a large proportion of patients with breast cancer, ovarian cancer, kidney cancer, prostate cancer, leukemia and lymphoma. According to a member of the INCan ethics committee, approximately 40 % of INCan patients are participants in clinical trials sponsored by the pharmaceutical industry.

INCan receives public financing, and patients' fees vary depending on their socio-economic level. One percent of hospital patients receive free care due to their extreme poverty, while others pay on a sliding scale according to their family income. Medical care tends to be affordable but patients must also pay for other expenses which can be very costly, such as the price of medications (Secretaría de Salud 2001).

Given their economic worries, few patients ask about their illness and available treatment options. The wide social and educational gap – and frequently a cultural gap – between physicians and patients often results in poor communication, and patients tend to have difficulties understanding the information given by the physician (Kagawa-Singer 1996; Kleinman et al. 1978). For the same reasons, treatment recommendations are not communicated clearly between physician and patient.

Mexican law requires that the patient needs to be informed about his treatment options and needs to provide consent before participating in a clinical trial. The inherent characteristics of INCan patients (generally uninformed about health) and the communication problems between physicians and patients contribute to the lack of patients' understanding of the course and prognosis of their illness, their treatment options, and the risks and benefits related to each. Incomplete understanding has important ethical implications, and may have significant consequences in the acceptance and compliance with treatment, the economic impact, or the decision to participate in a clinical trial. Mexico has given little attention to these concerns and there is a risk that informed consent is neither free nor informed.

In clinical trials, communication problems may have other serious consequences. Informed consent is presented as a factor which guarantees participant protection during clinical trials, making the assumption that trial participants and/or their families understand the possible risks and benefits. If the participants and their families do not properly understand how to take the medication being tested, the results of the clinical trial will have little reliability.

This chapter describes patient perception of the information given to them by INCan physicians, together with the patient's ability to make conscious and informed decisions from the information received. The results of this study may be used to design a program to improve the relationship between physicians, patients and their families, and to increase patient/family understanding of the nature of the disease and its treatments. Study results could also be used to revise institutional policy for obtaining informed consent, to better protect the human rights of patients participating in clinical trials, and to improve the quality of data gathered.

11.2 Method

Initial interviews were conducted with hospital authorities, physicians, and social workers to document the medical and administrative requirements for admitting patients into the institution. From this information, a research instrument and an interview guide for focus groups were developed. The protocol was submitted for approval by the INCan Bioethics Committee.

To obtain epidemiologic and socio-economic data of INCan patients and to assure representative focus groups (Merton et al. 1956), a random sample was taken from the 3,735 patients who received treatment during 2007. Electronic hospital records were analyzed for 339 patients (95 % confidence interval, 5 % margin of error). Variables included in the study were diagnosis, age, gender, civil status (single, married, etc.), place of residence, years of education, occupation, monthly income, type of residence, and distribution of income (food, rent, services, etc.).

The socioeconomic information obtained from the patient records was reviewed by the INCan Department of Social Work to determine the socio-economic level of each patient and the corresponding treatment fees. There are seven levels based on the daily income. Level 1 is the equivalent of US$1.00 per day; Level 2 equals US $3.00 per day; Level 3 equals US$7.00 per day, and Level 7 equals a daily income of US$30.00 or more.

A semi-structured questionnaire was used to guide the focus group discussions around specific aspects of the medical and administrative information provided to patients. The questions were designed to explore the patients' perception and understanding of the information they received about their disease and their ability to use this information to make decisions about their treatment (see Table 11.3).

INCan social workers had previously drawn a random selection of patients for invitation to participate in focus groups. The focus groups were organized in a non-systematic manner. Each group was made up of eight patients who were either waiting for a consultation or who had received radiation treatment or chemotherapy on the day the group met. A social worker had previously explained the purpose of the group to each patient and had invited them to participate.

Patients who accepted the invitation to participate met in a small conference room. The sessions were informal, and began with a presentation by the coordinator explaining the purpose of the study. After assurances that the participation of each patient was voluntary, and guarantees of confidentiality and anonymity of information, verbal authorization to record the session was requested. The patients' verbal consent was recorded.

At the beginning, family (and/or household) members accompanying patients were allowed to be present at the back of the conference room. At the end of the first session, the patients interviewed were approached by their relatives, who also had comments relating to the questions discussed. For this reason, it was decided to form separate focus groups with patient's families. The invitation extended to participating families was also made in a non-systematic manner. Some family (and/or household) members were related to those participating in the patients' focus group, but the majority were not. A total of 32 patients (four groups of eight patients) and 16 family members (two groups of eight people) participated.

In each session the coordinator presented the topic of discussion to the participants and asked for age, place of residence, and diagnosis. Impartial questions were then asked to guide the group discussion. The comments were recorded, and notes were taken at the same time. Both the recordings and the notes were immediately transcribed and verified by the authors. The discussions focused on information about the process of obtaining informed consent and the roles of key personnel. Each session lasted for at least two and a half (2 and 1/2) hours. The transcribed material was analyzed using content analysis (Kipendorff 2004) to identify the different domain responses provided by each group, and the information was aggregated to obtain an overall picture.

Focus group participants did not receive any money for their participation, but were offered refreshments during the sessions as well as a small token (a pen, exercise book, and a plastic folder for their papers).

11.3 Results

11.3.1 Description of the Sample

Demography Electronic records of 339 patients who received care during 2007 were analyzed (9 % of all patients receiving treatment). INCan generally provides care for adults, and only 5 of the 339 patients analyzed were under the age of 18 years. The majority of patients (54 %) were between 40 and 70 years of age (Table 11.1).

Table 11.1 Demographic characteristics and diagnosis of the study sample

Number of patients		339
Age (years)	Median	48
	Range	17–91
Gender	Male	37.5 %
	Female	62.5 %
Place of residence	Mexico City and Mexico State	62 %
	Other areas in the country (Republic) of Mexico	38 %
Area of residence	Urban	47 %
	Semi-rural	34 %
	Rural	19 %
Tumor diagnosis	Cancers of the breast, cervix, and ovaries	36 %
	Gastro-intestinal cancers	17 %
	Skin (not melanoma)	9 %
	Prostate cancer	8 %
	Leukemia y lymphoma	7 %
	Cancers of the head and neck (throat and mouth)	7 %
	Other cancers	16 %

Female patients outnumbered male patients by a ratio of almost 2:1, which is probably explained by the high proportion of patients with cervical or breast cancers.

The INCan is located in Mexico City and most patients in the sample resided either in the Mexico City (also known as the Federal District with approximately 21 million people) or in the state of Mexico, which borders the city to the north and west. Although the country of Mexico has a network of cancer centers that provide treatment to uninsured patients in the 32 states of the Republic, 38 % of the patients in the sample resided in other states.

Approximately 47 % of the patients in the sample lived in urban areas, but urban housing in poorer neighborhoods in Mexican cities may lack basic services such as potable water. Patients living in rural and semi-rural areas represent 53 % of patients in this sample (Table 11.1).

Medical characteristics Data obtained from patient records revealed that the study included people with different types of tumors: breast and gynecological cancers (35 %); gastro-intestinal cancers (17 %); hematological cancers (17 %); prostate cancer (8 %), and skin cancers (7 %). Less frequent cancer types included cancers of the head and neck, lung, and testicles, etc. According to hospital authorities, the sample represented the incidence of cancers in patients receiving care at the institution (Table 11.1)

Education and occupation One fifth (20 %) of the patients in the sample had had no formal education. Of the remaining sample population, almost half (45 %) had 6 years or fewer in school, and only 6 % had completed high school or more.

INCan exists to provide care to the Mexican population not enrolled in the Social Security system. The sample reflects this population – 74 % of the sample were unemployed or had unpaid jobs. Only 3 % had work which required education or training.

Table 11.2 Socioeconomic characteristics of the study sample

		Percent
Years of education	No formal education	20
	1–6 years (primary)	45
	6–9 years	21
	9–12 years	8
	12 years or more	6
Occupation	Unemployed, or working without financial remuneration[a]	74
	Employment not requiring formal education	23
	Employment requiring education or training	3
Monthly family income	<$1,000 Mexican pesos[b]	7
	$1,000–3,000 Mexican pesos	55
	$3,000–6,000 Mexican pesos	28
	>$6,000 Mexican pesos	10
Proportion of income for food (monthly)	<$3,000 Mexican pesos	86
	$3,000–5,000 Mexican pesos	12
	>$5,000 Mexican pesos	2

[a] Including those employed in domestic service. Many women are forced to stop work due to cultural reasons

[b] The exchange rate varies between $10 and $12 Mexican pesos per US$1

Family monthly income Monthly income for the family as reported in the reviewed records is shown in Table 11.2. Almost two thirds (62 %) of the families of patients in the sample reported a monthly family income of less than US$300, with 7 % of families in this group receiving less than US$100 per month. According to our information, the income is distributed between food, rent, and other services, including transportation (Table 11.2). These expenses leave little or nothing for medical care or education.

11.3.2 Focus Group Interviews

Patients In the focus groups, patients responded to the questions (see Table 11.3) with a consistent interest in participating and a willingness to share their experiences. Answers to the first question showed two major areas of concern: (1) to have information about the stage of their illness and the possibilities for a cure, and (2) the possibility of being admitted into the hospital.

Responses to this question included:

> My major worry is to understand how advanced is my condition, because when you hear the word cancer your life stops... (Patient age 56, with breast cancer)
>
> I was very worried that they wouldn't admit me to the hospital; once I was admitted, I felt very calm and sure that I would be cured... (Patient age 67, with melanoma)

Table 11.3 Representative responses of focus groups

	Responses	
Questions	Patients	Families
1. Principal concerns during the first appointments at the institution	Stage of illness and possibility of cure	Stage of illness
	Possibility of being admitted to the hospital	Cost and duration of treatment Administrative requirements
2. What kind of information did you want to receive?	Information about the illness	Information about care in the home of the patient
	Administrative requirements	Treatment options and their costs The need for information about the illness without the patient being present, “to avoid greater worry for the patient” To receive information they in a language they can understand, without medical terminology To receive an explanation about the diagnostic processes for the illness
3. How long did it take you to understand your diagnosis and the type of treatment you would receive?	Answers varied, but none showed an understanding of the illness Possibility of cure The need for information about the illness and the results of laboratory tests	A continuous process, in which the family needs to ask different questions at different stages of the illness
4. Do you think that there were specific factors that made it easier for you to understand the information you received?	Information provided by the physicians, and information from other patients	Mostly information from other families in the waiting room Information from the physician
5. Do you think, after some time attending the institution, that there is a better way to provide the information you received?	Clear and direct information provided by the physician	Written information
	Information presented on posters	A 24-h telephone hot line
	The cost of hospitalization for surgery	Specific information about patient care, reaction to medications, deterioration or setbacks in health, and prognosis for the course of the illness Options for financial assistance

(continued)

Table 11.3 (continued)

	Responses	
Questions	Patients	Families
6. Are you familiar with the term "informed consent"?	All patients had signed an informed consent form It was a requirement to be admitted to the hospital	It was a part of the administrative process
7. Do you have any additional comments?	Thanking the physicians and the institution A feeling of safety	When anyone in the family has cancer, the whole family suffers

The information requested by patients (question 2) depended on the type of illness. Patients with breast cancer were anxious to have information; patients who had been undergoing treatment for a longer period or time or had spent more time in the hospital wanted more precise information; male patients were worried about their employment, and older patients were most concerned about the possibilities of a cure.

> I have been here for two years, and the treatments change often. I always feel ill after treatment, so… I want to know what is happening to me… (Patient age 20, with leukemia)

Only a few patients had questions about administrative procedures, the cost of treatment, or financial questions. Most patients had received treatment for several months or even years in the hospital.

There was no direct response to the question of how long it took them to understand their diagnosis and treatment options (question 3); all responses related to the possibility of being cured.

> They've given me all the tests, but I don't know anything; no-one has told me anything. They say I have a malignant tumor, but what I really want to know is if I am sick, or what is going to happen to me… (Patient age 63, with head and neck cancer)

> I don't know anything; after two years here I am desperate because I have already had many problems… I don't know what is going on. Somebody tells me something, but in a few days they say something else… (Patient age 60, with cancer of the uterine cervix)

In the initial response to the question about factors which improve patients' understanding about their illness, most patients said that they knew about their illness and that their physician had "clearly" explained the nature of their problem, its prognosis and treatment. On probing more deeply, however, the patients were not able to explain their diseases or the information given by the physician. Of the 32 patients participating in the focus groups, regardless of the knowledge of their disease and treatment options, not one could give specific information about the type of cancer they had, the stage of the disease, treatment options or the possibility of cure.

The following example is typical of the limited information understood by the patients. This patient knew that she had advanced cancer, but, repeating the information given to her by the physician, implied that science could not help her; it was all in the hand of God.

> Yes, I understand my disease. The physician told me that I had advanced cancer. What will happen to me, how long I shall live, I don't know, because the doctor said that we are not gods, and only God knows how this will end… (Patient age 45, with cancer of the uterine cervix)

The patients spoke of their illness as "an obsession", the only item of importance to them at this time.

In reply to question 4, most patients said that written information and videos helped them to understand their disease. They also felt that conversations with other patients were very useful.

All the patients said that they had signed an informed consent form (question 6), although they acknowledged having limited knowledge of its content and objectives. Most patients said that the document was more of a requirement for admission to the hospital.

> It doesn't matter to us what it is for, they told us to sign it and that was enough… (Response from one group of patients)

In response to question 7, which asked for additional comments related to any of the topics discussed, none of the patients had any complaints about their physicians. Instead, the patients were grateful for having been admitted to the hospital, and believed that the quality of care provided by the institution and the physicians was "the best". One 60-year old male patient cried as he said:

> I am thankful to be a patient at INCan…I am thankful for the care they have given me

There was dissatisfaction, however, about the information given to them by the physicians.

Families of patients Family participation in the focus groups was extremely valuable. These sessions lasted longer and revealed three major concerns: (1) the diagnosis and stage of the disease; (2) the cost of treatment, and (3) payment options. The financial aspects were most important for the families.

According to the families, the information provided by the hospital was confusing and insufficient in several ways. Most families wanted more information about how to care for the patient at home (Table 11.3), the need for an explanation about the diagnosis and procedures, and the treatment options and costs during the illness.

Some families said that the information given to them was often overwhelming, including explanations of the disease, treatments, and administrative procedures all at the same time. All families interviewed agreed on the necessity of being given information about the disease without the patient being present "so as not to worry them more". Some responses were:

> We have had to wait hours while the physician received the patient, asked a lot of questions and checked the papers we brought. Then he asked my father why he waited so long to see a doctor. Later, the nurse spoke to us about payments, appointments, and necessary tests; we waited quietly and, when the physician told my father that he had cancer, neither he nor I understood anything… (Daughter of a patient age 75 with lung cancer)

Most family members said that the words and language used by the physicians were difficult to understand – terms such as palliative treatment, cardiac toxicity, analgesic, adjuvant, chemotherapy, neoadjuvant chemotherapy, disseminated disease, and incurable disease. They also said that it takes time to really understand the disease. They emphasized the importance of continuous communication between physicians and families to increase their knowledge and help them understand the information. They added that very useful information was gained in the waiting rooms from talking with the families of other patients.

Focus group participants asked for the availability of written information. Almost all the families had questions about the treatment process, and wanted more information about what to expect as treatment was given. They also wanted to know where they could find support or a guide to living with a patient with cancer.

> When my son had chemotherapy for testicular cancer, I made him eat some hot chicken soup. Afterwards, I felt very guilty - nobody had told me that he had an ulcerated esophagus. I made him suffer… (Mother age 40, son age 19)

All the families said that although the patients had signed "consent" papers, the patients themselves had not made the decisions about their treatment.

> I do not believe that my wife was able to decide her treatment; the doctor told her that she had breast cancer and that they would give her medicine for three months to make the tumor smaller, after that they would remove her breast…

Several relatives did not understand the concept of chronic disease and said that their worries about money increased with time. In many cases they talked about loans and asking for money from other relatives. They often spoke of the duty of the family to care for someone who was sick.

Family members were convinced of the importance of family support to patients, which explains their interest in understanding the patient's diagnosis, treatment options, and responses and/or reactions to therapy. They felt that the patient's only concern should be to be cured, while the family would take care of the monetary issues.

> Each new appointment you must be prepared for bad news and the request for a new treatment, and each time the medicines are more expensive… (Members of one of the focus group with patients' relatives)

Economic concerns and responses about the continuously escalating cost of medications explains the high number of INCan patients who participate in clinical trials, for many of them participation in the trial is the only means to obtain treatment. In Mexico, the price of many medications for cancer is out of the reach for most of the population, certainly for patients eligible for care at INCan.

11.4 Discussion

Study results provide a clear picture of the Mexican people who receive care in the public hospitals, and raise questions about the manner in which physicians explain the diagnoses, prognoses, and treatment options to patients and their families. Approximately 80 % of industry-sponsored clinical trials are conducted in public hospitals. A diagnosis of cancer is itself very stressful and can influence the process of informed consent (Alexander 1990; Doyal and Tobias 2001). For this reason, it is necessary to better understand the factors which influence decision-making by patients and their families. There is a need to implement significant changes in the process of informing patients about their illness and its consequences, the chronic nature of cancer, the available treatment options, and what each of these imply. This study has shown that at present patients do not clearly understand these issues.

Poor communication between physicians and patients leads us to question if the patients are taking their medication in accordance with the physician's wishes. Since many INCan patients take part in clinical trials, not following the treatment regimen can distort the trial data for the treatment.

11.4.1 The Role of the Family in Decision-Making

Most INCan patients (74 %) are either unemployed or work without salary, and therefore depend heavily on their family. Consequently, relatives have a part in decision-making, almost always influenced by the economic situation of the family while trying to obtain the best care possible for the patient. In Mexican society, affection, solidarity and care are an integral part of daily family interaction.

When a family member is ill, it is common to see various relatives accompanying the patient to physician appointments. The same applies when the patient is admitted for treatment; sometimes it is difficult to differentiate the patient, as an individual, from his family. In Mexico (and other societies), the physician will confer with the family before talking to the patient. The family and the physician will frequently decide the strategy for telling the patient about the diagnosis (Chan 2004).

Any patient who receives a diagnosis of cancer experiences a sudden turning point in their life. Readjustment during the grief process includes the loss of their previous autonomy and perception of self, and eventually leads to a re-interpretation of self-identity and the recovery of individual autonomy. The loss of autonomy affects the capacity of the individual to make decisions (Calinas Correia 1998). In these circumstances, unlike the situation in other countries where patients are the primary subject by tradition and law (Moazam 2000; Younge et al. 1997), in Mexico there is a preference for decisions by the family (Fan 1997).

It is the family which most frequently questions medical decisions, complains about the small amount of information they receive, gives news to other family members, and assumes financial responsibility for the patient. During the focus groups it was clear that the relatives were concerned about the health of the patient, but their major anxiety related to money. For this reason, it is more than possible that it is the family who encourages the patient to participate in a clinical trial.

11.4.2 Who Decides?

During the interviews it was clear that the only concern of the patients was their illness and its consequences – their preoccupation with physical pain and expectation of life; none showed active interest in treatment decisions, financial arrangements, or long-term socio-economic consequences for themselves or their families.

The right to self-determination, based on respect for patient autonomy in Anglo-American applied ethics, should be adapted to the Mexican context. Public hospital physicians must remember that valid informed consent requires meeting three essential conditions – information, ability to understand, and voluntary consent (Younge et al. 1997). Physicians must keep in mind the socio-economic circumstances of the INCan patients and their families (little formal education and poverty), and be sure that the patients have understood the information and explanations they have been given (Clará et al 2004). Otherwise, one of the essential factors for valid informed consent is missing. Few physicians remember that most of their patients have a limited understanding, or recall only a fraction of the information they have received (Parker 2000), including instructions about how to take medication.

When asking for informed consent for clinical trials, more time could be given to ensure that the information has been understood. The complexity of the information provided by the health personnel and the poverty of the population treated in public medical centers leads patients to consent in order to access free treatment and better care.

Health services cannot be separate from cultural and sociopolitical norms (Nutbeam 2000), which, in Mexico, include the role of the family in making decisions. The paradigm of autonomy, which in many societies has superseded the paradigm of social context (Schäfer et al. 2006), may not be the best for the Mexican population. We feel that the administrators of the health institutions of Mexico (and possibly other countries in the region) must recognize the difficulties patients have in understanding a clinical environment and providers with a health-illness paradigm, and develop ways to improve doctor-patient communication. It is necessary to study further the role of families in the decision-making process.

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