

PATIENT PARTICIPATION IN THE DECISION  
TO TREAT CORONARY ARTERY DISEASE

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ABSTRACT

This study was based on the normative argument that patients ought to participate in treatment decisions that could influence the length and quality of their lives. Efforts were made to explore potential errors of judgement that could interfere with the expression of a true preference by a patient. The results of this exploration suggested that people in real decision making situations are affected by framing, they make inconsistent choices, they reverse preferences in situations where preferences are expressed by bids versus choices, and their choices change in situations of potential gain and potential loss.

Participants in the study were willing to pay for an improved position on a waiting list for treatment, but they were very reluctant to sell or trade such a position. An analysis of patients' age and exposure to the health system demonstrated that age was not a predictor of patient choices while pain and disability were contributing factors to patterns of choice. Generally, patient preferences were situation specific.

Recommendations have been made for improving professional sensitivity towards patients whose situation makes them more vulnerable to errors of judgement. Further avenues for research have been sketched.

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## CHAPTER 1

## PATIENT PREFERENCES: The Rationale

1.0 Introduction

The present study was an exploration of patient participation in the choice of a treatment for coronary artery disease. Its emphasis was on two questions. First, what contribution to medical decision making can be made by better knowledge of patient preferences? And, second, how do potential errors in expressing those preferences influence choices? To answer these questions, the study involved patients with heart disease who made choices under simulated conditions. First, patients indicated the value of reductions of: risk, morbidity, and waiting time. Second, questions were posed to evaluate the direction and strength of several potential errors of judgement previously identified and developed by others, in some cases in fields other than health care.

Treatment choices for patients with coronary heart disease were chosen for a number of reasons. First, heart disease is the leading cause of death in Canada, and hospital treatment for heart disease is a major consumer of resources in the health care system. Second, coronary heart disease causes more long-term disability, and economic loss due to time away from productive activity than any other group of diseases in the industrialized nations of the world (Braunwald, 1984). It has been estimated

that each year 200,000 Americans under the age of 65 die from coronary heart disease and an additional 2,000,000 people are afflicted with it. Treating this disease and compensating for the loss of productivity it causes is estimated to cost the American nation \$50 billion each year (Braunwald, 1984). If the cost of treating coronary heart disease in Canada is roughly estimated to be one-tenth of that in the United States, an annual bill of five billion dollars is significant. Quite apart from the dollar cost of this disease, the loss of human life and disability it causes is a compelling reason for exploring the possibility of improving medical decision making for patients with coronary heart disease.

A third important reason for studying actual medical decisions in treating heart disease is that the treatments for this disease carry risks for the patient, as does non-treatment. Current trends in health care, such as the patient's rights movement, indicate that greater participation in treatment choices is being demanded by patients. Moreover, critics of the traditional approach to decision making by physicians are promoting a normative argument that patients 'ought' to participate in the decisions that so obviously affect their lives.

The present study follows the protocol suggested by Keeney (1982). First, a discussion is presented of research that describes the likelihoods of the possible outcomes of each treatment alternative for coronary heart disease. Randomized,

controlled trials offer the best epidemiological evidence of outcome differences, and such studies are reviewed. Second, the method for eliciting patient preferences is described. Third, key studies of patient preferences and common errors of human judgement are reviewed to provide a foundation for the questions posed to patients. Finally, the findings of the study are reported and conclusions are drawn.

The remainder of this chapter provides the background for the study of treatment preferences of patients with coronary heart disease 1. First, the issue of patient participation is addressed as it is evolving in medical decision making. A discussion of traditional physician-patient interaction, autonomy, and informed consent illustrate current attitudes toward patient participation, while a brief review of risk, uncertainty, and the structure of decision trees in medical decision making describe the nature of the decisions physicians and patients make.

This discussion provides the rationale for eliciting patient values for the alternative treatments and health outcomes that affect patients. The alternative treatments and the probabilities of losses and benefits, together with patient values, generate the key items of the tool of medical decision making - the decision tree. The clinical history of coronary heart

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1 Coronary heart disease is also called coronary artery disease and coronary atherosclerosis. These terms are used interchangeably in the literature.

disease, its epidemiology, and economics in the Canadian setting are then examined.

### 1.2. Three Models of Medical Care

Three models of medical care relevant to physician and patient interaction can be identified in the literature. The first is the passive patient model where the physician acts and the patient is acted upon. In this model, 'therapeutic privilege' allows the physician the moral leeway to "set aside the normal duty of disclosure" (Harron et.al., 1983, p. 90). Support for this model comes from Barber (1980, p. 16) who states: "We value full disclosure, so that the ... patient can make a reasoned and prudent decision for himself; but we also value the humane protection of those who are somehow weak or inept - the young, the frightened, the dying."

Some argue that revealing the gravity of an illness to a patient may actually harm the patient. The counter argument states that little clinical evidence supports this and further that the moral obligation to inform the patient overshadows the potential harm the information may cause (Barber, 1980). Most physicians who make unilateral decisions about treatment options for patients base these decisions on maximizing the length of the patient's life (Shephard, 1983). How that life is lengthened, or at what personal cost to the patient, is not considered (Gorovitz, 1982). Seeking patient participation in informed consent

has not been the accepted norm in medical care. Even codes of ethics have been influenced by "the assumption that it is for doctors alone to decide what is right and proper for their patients" (Barber, 1980, p. 29).

"In some of the most critical of life's moments, the average person does not have the requisite knowledge and power to make successful choices in his or her best interests" (Dougherty, 1985, p. 94-95). Patients depend, in these situations, on professional knowledge, and the professional is seen to have the power to make decisions. Special codes of ethics and patient's rights have been developed to protect the dependent person. The duty to uphold these rights rests with the professional who must be influenced in his choices and actions by the interests of the dependent person. In other words, "the professional in a complex society is a fiduciary agent for the maintenance and restoration of practical personal autonomy in the lives of the (persons) whose interests are being served" (Dougherty, 1985, p. 95).

Pressures to move away from this model have come from a broad cultural change where "people challenge authority and ... suspect the motives of many, if not all, professionals (Harron et. al., 1983, p. 91).

The second model is one of patient cooperation where the physician is paternalistic and the patient assumes the role of a juvenile cooperator. "Paternalism ... generally refers to the practise of treating individuals in the way a father treats his

children" (Beauchamp, 1981, p. 137). Two aspects of paternalism are identified in medical care: beneficence, and a primary role as a decision maker. Beneficence, the principle that one 'ought' to do good, is often "invoked as justification for overriding" a patient's autonomy (Gorovitz, 1982, p. 36). Thus, the preferences of the person being treated may neither be sought by the physician nor expressed by the patient (Beauchamp, 1981).

Typical of this model are statements such as: "The request for permission should be presented to the patient in such a way that he feels he has no option to refuse ..it is best to be firm and authoritative, stressing that no other course is possible" (Fisher, 1977, as cited in Barber, 1980, p. 30). The paternalistic physician acts 'on behalf of' or 'for the benefit of' the patient (Collins, 1984). Physicians often believe that in order for a patient to have the courage to accept a treatment it is best not to reveal the uncertainties and risks of the diagnostic procedures or the treatment (Barber, 1980). However, more consumer education and communication has reduced patient tolerance of this paternalism and patients are demanding an active role in decision making in health care (Hoffman, 1985).

The most recent model to emerge, patient participation, describes medical decision making as a joint venture where the patient has the right to be fully informed and to freely give consent to treatment. The shift in the relative importance of patient participation in medical decision making has been due to

less emphasis on the professional "duty to disclose" information and more emphasis on the patient's "right of access" to information (Harron, et.al., 1983, p. 5). This shift was demonstrated by Abram (1982) in a survey that reported that 72% of the public polled wanted to know treatment alternatives and then make a decision jointly with a physician while 88% of physicians polled stated that they believed patients wanted treatment decisions made by a physician. A number of good reasons have been offered by Dougherty (1985) to support the current trend toward more, if somewhat mixed, acceptance of the patient participation model.

The strongest argument for joint decision making as proposed by this model is the protection of patient autonomy. The value of personal autonomy has been a prominent feature of the growing bioethics literature within the past decade (Doudera, 1981). However, the notion of autonomy appears to be less central to physicians or to seriously ill patients, as indicated by the scarcity of references in the medical literature, than it is to philosophers concerned with modern medical practise (White, 1983).

The earliest legal record of a commitment to autonomy as a principle of law was made by Mr. Justice Cardozo of the United States Supreme Court, who stated in 1914: "The root premise is ... that every human being of adult years and sound mind has a right to determine what shall be done with his own body" (White, 1983, p. 76). The qualification added by 'adult years' and

'sound mind' allays the problems created by unqualified commitment to autonomy that may actually hamper good medical care (Abrams, 1982). Full autonomy is not always possible, therefore "...the job of the physician is to help the patient maintain his or her autonomy to the degree possible in the face of the illness" (Cassell, 1983, p. 151). An example of limited autonomy arises in emergency medicine, where injuries to the patient may prevent communication or decision making by anyone other than the physician. In terms of chronic and degenerative diseases, "physicians are consultants to patients, and patients, not physicians, must finally decide upon their own best interests" (Doudera, 1981, p. 106).

"Our ideal of the autonomous person entails that patients have a right to... give or withhold informed consent over all aspects of their care" (Dougherty, 1985, p. 98). To remain autonomous and make reasonable choices, patients have the right to know: what is being done and why, the risk of the proposed actions compared to alternatives, and the outcomes of no treatment.

The increasing role of technological advancement is the second reason for increased patient participation. As more innovations appear in medical care, the potential increases to extend life, control behaviour, and engineer reproduction. Such innovations generate a range of choices dependant on social, personal, and political considerations (Evans, 1985). Humane



medicine in this context will require shared information and participation in decision making by many affected persons.

Third, as the patterns of disease change in developed countries, chronic and degenerative diseases become the major contributors to morbidity and mortality. The treatment of these diseases often require considerable commitment on the part of the patient. This leads to the fourth reason, the finding that mutual participation generates better treatment outcomes. When patients understand their condition they are more easily motivated to try to improve it. Participation in the choice of a treatment increases patient compliance with what may be a lifetime of medication and side-effects.

Finally, three aspects of patient-physician interaction are improved by participation. Satisfaction of physicians tends to be improved by maintaining the human worth of the patient as a decision maker; the physician's professional reputation as a 'healer' is enhanced; and consumer alienation and cynicism is reduced.

### 1.3. Informed Consent

The medical profession has traditionally challenged the concept of autonomy where the individual patient makes the final decision himself, regarding either his own actions or the actions

of others towards him.<sup>2</sup> In some cases, an individual's right to individual decision making is subverted by circumstances, such as a serious accident, or a disabling heart attack. A patient may not be considered fully competent to make a rational choice about treatment when he/she is suffering from pain or mental illness (Forrest, 1984). If a patient is competent, the physician is ethically bound to seek 'informed consent' from the patient for any procedure that carries a risk.<sup>3</sup> The term 'informed consent' derives its meaning from the 'disclosure' required by the word 'informed', and from the 'awareness or assent' required by the word 'consent'.

Informed consent is a procedure that embodies consumer sovereignty or autonomy of choice. Consent is important because: "physicians do the sorts of things to their patients that people in general cannot justifiably do to one another" (Gorovitz, 1982, p. 38). If the patient is informed and consents, then medical intervention is no longer assault, but service. The physician must inform the patient about: what the procedure entails, the alternatives available, the problems that may arise during recovery, the risks of the treatment, and any other

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2 Individual decision making, or autonomy, is what economists call 'consumer sovereignty'.

3 A risk is defined as some probability of a loss. For a patient with heart disease, this loss could be measured as death, continuing disability due to angina, or increased disability causing work loss or lifestyle change.

reasonable information (Grad, 1984). Some physicians argue that a patient is often not capable of truly informed consent because the information provided is too complex, or that truthful or complete information will frighten the patient. However, informed consent, according to the Supreme Court of Canada, is now to be judged by the wishes and preferences of the patient and not the standards of the medical profession (Hoffman, 1985).

An important study by Alfidi (1971) examined the degree to which informed patients refused to undergo a diagnostic procedure (angiography) to evaluate the seriousness of heart disease. Patients who could potentially benefit from this procedure were informed about its risks, discomforts and complications in "straightforward and even harsh" terms (Alfidi, 1971, p. 1325). Overall, 228 out of 232 patients in the study consented to the diagnostic procedure. The study concluded that patients have a desire to know, and 'should' know the risks of a procedure. "The concern that informing the patient of possible complications will result in his refusal of the procedure is now outmoded" (Alfidi, 1971, p. 1329). Barber (1980) cautions against generalizing to other populations and procedures from this one study, but suggests that this is indeed evidence to support the argument in favour of truly informed consent.

Evidence has also been produced to indicate that patients may not want to be informed of 'all' the information available to their physician. In a study of pregnant women receiving a

diagnostic procedure (amniocentesis) to identify birth defects, Berwick et.al. (1985) found that over half of the patients did not want to know the sex of the baby. They wanted it to 'be a surprise'. Similarly, in a study of cancer patients, McIntosh (1976) found that none of the 74 patients in the study wanted to know when the physician expected the patient to die. However, it is important to note here, that patients were asked about withholding information that had little relevance to the treatment decision needed in each case.

In summary, informed consent must be based on a knowledge of the patient's preferences for treatment outcomes, not just in terms of quantity (or additional years) of life, but quality of those years as well. Patients must be allowed to choose a treatment that may, in the opinion of the attending physician, not be the most effective. As Gorovitz (1982, p. 45) has stated: "there is no reason to believe that the prospect for medical success is the only relevant basis, or ought always to be the dominant basis, for exercising choice in medical situations." The normative argument is that patient preferences 'ought' to matter for a number of reasons (Barber, 1980). In practise, they do not always seem to be given primary consideration.

#### 1.4. Attributes of Medical Decision Making

Medical or clinical decision making has been defined as a

way of structuring patient values and probabilities of treatment outcomes so that patient autonomy can be exercised under the guidance of a physician (Pauker, 1976). In this way, risks, benefits, and the probabilities of these occurring become clear to the patient, and are therefore able to improve the patient's decision making (Lusted, 1968; Weinstein et.al., 1979).

A medical (or clinical) decision is generally the result of three components. The first is the value assessment (utility) of a treatment outcome for the patient including relief from symptoms, the prevention of adverse drug or treatment reactions, and the control of cost of care. The second is a determination of three probabilities: that the treatment will improve the health of the patient, that the treatment may cause harm to the patient (including the risk of death), or that the treatment will do nothing (Shapiro, 1977). Third, the interests of the physician shape the choice because of the physician's traditional role in diagnosis as well as treatment (Evans, 1985).

The value assessment component of medical decision making is like the law, which in the British tradition, has been pragmatic. Both disciplines "respond to changing circumstances with a minimum of speculation and theorizing, thereby maintaining a firm rootage in the immediate, concrete human problems under scrutiny" (White, 1983, p. 73).

Law and medicine have been grounded on a consensus of moral and ethical principles, one of which is respect for autonomy.

The Canadian Charter of Rights and Freedoms formalizes autonomy in the right of freedom of beliefs and speech, the right to privacy, the right to self-determination, and the right to decide what will happen to one's own body. The rhetoric of individual rights is sometimes cloudy, but the deliberations of decision making processes aim to clarify the facts, issues and values necessary to make meaningful decisions. In addition, contributions to clinical decisions made by patient's values will likely cause exploration and questioning of assumptions of presumed physician wisdom in matters of life and death (Carlton, 1978). "The wrong decision from a purely medical point of view may ... not be the wrong decision from the broader perspective of the patient's life (Gorovitz, 1982, p. 46).

The second component of medical decision making involves some predictions of outcomes of actions. The purpose of making decisions is to alter and improve outcomes of future events. To make an intelligent or rational choice, one would like to be able to predict the outcomes of those choices (Arrow, 1965). However, in clinical medicine, as in many other decision making situations, the best one can do is offer a prediction in terms of a probability based on evidence of past events that describes the likelihood of some future event. Probability is the mechanism used for quantifying a risk.

When risk is defined as a chance of injury or loss, many of life's activities can be viewed as risky (Childress, 1982;

MacCrimmon and Wehrung, 1985) "In ordinary disclosure, 'risk' refers to the amount of possible loss and the probability of that loss. 'Risk-taking' implies that the actor is aware of the risks and voluntarily assumes them." 'Risk-imposition' "refers to conduct that imposes risk on others." (Childress, 1982, p. 227)<sup>4</sup>

There are a number of probabilities that are important in decision making in health care. First, the probability of a correct diagnosis depends on a doctor's ability to recognize signs or symptoms and interpret diagnostic evidence. Second, the probability that a treatment will alter the course of the disease is less than certainty and this may be influenced by many variables (Shapiro, 1977; Bursztajn and Hamm, 1979).

Bursztajn et.al. (1981) are proponents of a "probabilistic paradigm" that incorporates these uncertainties. However, they suggest that doctors and patients have expectations grounded in the "mechanistic paradigm" first described by Claud Bernard in 1865 in Principles of Experiential Medicine.<sup>5</sup> To change this mechanistic approach, Bursztajn et. al. (1981) have recommended first, that doctors and patients should realize that symptoms may relate to a number of causes with varying effects. Second, diagnostic procedures should be viewed as gambles, not as methods

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4 To give a truly informed consent implies that the patient is risk-taking while the physician is not risk-imposing.

5 Bernard stated that scientific laws are based on certainty, not probability. Scientific laws, and the laws of medicine are derived from the principles of experimentation and determinism in science - a mechanistic approach.

for determining cause. Third, the patient's values, preferences and knowledge are as important in the choice of treatment as the doctor's knowledge and experience. Finally, it should be acknowledged that treatment cannot guarantee elimination of symptoms or the underlying disease and treatment can actually make a patient worse off (Illich, 1974).

The third component, physician preferences, were not a topic of this study. This omission was justified by assuming that if a physician understood a patient's preferences that he/she would provide treatment that would maximize the patient's autonomy and feeling of a satisfactory health outcome. The weaknesses of this assumption have been described by Evans (1984) and in the discussion of the models of patient participation in section 1.2 above.

#### 1.5. Uncertainty in Clinical Medicine: a Component of Risk

When the physician elects to initiate treatment, he/she operates in an environment of uncertainty, part of which is due to "unintentional and potentially hazardous consequences" that can occur every time a doctor makes a move (Israel, 1982, p. 10). In any therapeutic decision there is some uncertainty about the outcomes of alternative modes of treatment. Uncertainty about treatment modes and outcomes in clinical medicine is a combination of uncertainties about: the causes of disease, the mechanism of disease, individual differences in the response to treatment,



and the dangers of drugs to individuals.

There is also uncertainty about the accuracy of a diagnosis in medical care (Elstein, 1976). Physicians generally combine uncertain data from diagnostic tests, weigh conflicting evidence and use informal means to make judgements on a course of action (Gorovitz, 1982). The role of the patient in these judgements may be unclear to both the physician and the patient.

Uncertainty is a part of our daily lives whether we are sick or well. Doctors tend to ignore many aspects of uncertainty in their discussions with patients. They may distort the story not only for the patient, but for themselves as well. If physicians dealt with uncertainty in a way that would maximize the decision making ability of the patient they might employ the following five steps: define and describe the available alternatives for the patient, admit to uncertainties about which is the best treatment choice, elicit patient preferences, try to understand the reasons for those preferences, and make a treatment recommendation to which the physician is not bound (Katz, 1984).

In actual fact, this strategy is seldom practised. Medical advice from a physician is often the most influential factor in a patient's understanding and acceptance of a treatment (Gorovitz, 1982). Physicians state that patients do not want to discuss uncertainty, and that such discussions cause anxiety. They also state that patients cannot possibly understand complex medical problems. Doctors express, instead, certainty about treatment

choice (based on a rigid treatment philosophy) as part of their socialized, paternalistic views about patients and the doctor-patient relationship (Waitzkin and Stoekle, 1972; Katz, 1984).

#### 1.6. Representing Risk in Medical Decision Making

Risk has been defined as the chance of a loss, which is expressed in decision making by a probability (Childress, 1982; Keeny and Raiffa, 1976; MacCrimmon and Wehrung, 1985). Patients have demonstrated the ability to understand and to use probabilities when they indicate preferences based on diagnostic information. For example, Pauker et.al. (1981) have indicated that parents seeking genetic counselling can differentiate the risks associated with bearing a deformed child and the risk of an abortion. When the probability of giving birth to a deformed infant rose, the number of parents choosing an elective abortion also rose.

Throughout this study, probabilities are expressed as a single number wherever possible so as to avoid the problem of ambiguity. Ambiguity, in this context, can be described as a situation where the outcomes of an action (or treatment) are described by a range of probabilities. Ellsberg (1964) showed that if subjects were offered a choice between two gambles - one with an outcome described in terms of risk (a precise outcome) and one with an ambiguous outcome (the probability is given as a range), most subjects will prefer the former even if the proba-

bilities are similar. Ellsberg (1961) called this behaviour ambiguity avoidance. Subjects in decision making situations in health care have been shown to be willing to pay to avoid such ambiguity (Curley et.al., 1985).

Two factors are important in understanding a patient's response to the risk situation in medical care. First, there is the event that gives rise to the potential risk, and, second there is the probability that a treatment or intervention will reduce the risk. The second probability is often called an outcome probability.

Two perspectives of probability are used in medical decision making: objective and subjective. Objective probability is often defined in medical decision making as a probability judgement by an expert. It may be based on epidemiological data from similar populations receiving specified treatments. The calculation of this probability is usually made by a physician combining previous knowledge about similar cases with information on the symptoms and diagnostic test results of the new patient.

Subjective probability in this context is defined as the likelihood of various treatment outcomes made by the patient. This measure may be derived from the patient's understanding of the physician's assessment of the objective probability. In practical terms, it is usually necessary to make an evaluation of the patient's ability or capacity to achieve an adequate level of understanding of the objective probabilities of treatment

outcomes (Gorovitz, 1982).

Two fundamental perspectives of objective probabilities have been expressed. Savage (1954) has stated that there are no objective probabilities, arguing that all decisions are future oriented and there is no record of such events. Israel (1982, p. 82) has conditionally supported Savage's argument by stating: "In some circumstances it is virtually impossible to estimate objective probabilities (based on relative frequencies)." Edwards (1962) has taken the other side of the argument, asserting that established probabilities can easily be compared to probabilities revealed by decisions involving future events. In this way, the outcome of an individual case updates objective (outcome) probabilities collected from all previous cases. In studies of medical decision making, epidemiological records of treatment outcomes are treated as objective probabilities (Pauker, 1976).

The attitude of a patient toward risk-taking or accepting a risky treatment is a function of three judgements the patient must make about his/her situation. First, the patient must make an appraisal of the level of risk (a subjective probability). Tversky (1972) has stated that this appraisal may be biased because his study found that subjects overestimated low objective probabilities and underestimated high ones. Second, the patient must have some internal measure of the anxiety caused by being in the risky situation. Third, the patient must make an estimate of

the effect of the remedial action (Mooney, 1977). This estimation is made difficult by the necessary comparison of vectors of treatment outcomes and the dominance of some aspects of the treatment process. It is the patient, Israel states (1982, p. 82) who must make this estimate, because: "...no two medical cases are alike, considering psychological differences at the outset, whether the disease is evolving rapidly or slowly, and the variable effects of the medication."

Bursztajn et.al. (1981) have stated that objective probabilities are translated into subjective probabilities by comparing the health variables of a statistical population (using actuarial tables) to the health variables of the patient. While the physician is in a position to describe the objective risks, he cannot tell the patient how to weigh the risk of death against a chance of reduced angina pain. Patient preference determines the trade-off between pain and risk of death or other life restrictions. These patient judgements determine the relative importance of one state of health over another. Patients may also demonstrate different levels of anxiety associated with similar levels of objective risk due to inexperience with the risk, or different response mechanisms for dealing with risk. Therefore, one expects different values to be attached to the same treatment outcome by different patients.

For example, if patients state their life expectancy, it can be used as an approximation of the subjective risk patients apply

to the seriousness of their disease and the probability that it will kill them prematurely. To roughly determine the subjective probability a patient places on his/her life expectancy, a ratio can be calculated from the patient's expectancy estimate and the (objective) life expectancy of the patient drawn from actuarial tables (Edwards, 1962). Actuarial tables present some problems due to their representation of the general population and not the population of patients at risk.

A number of experiments on risk taking behaviour have been done with hypothetical situations (Kahneman and Tversky, 1979; Knetsch and Sinden, 1984; Thaler, 1980). Some have been done on subjects using limited money bets as the risk. Studies of patient's responses to risk have been reported for cancer patients (McNeil et.al., 1978) and women receiving diagnostic tests for birth defects (Berwick and Weinstein, 1985). These studies are reviewed in detail in Chapter 3.

In a study of the effect of positive feelings on risk taking among student subjects, Isen and Patrick (1983) used real risk (roulette) and a hypothetical dilemma (job change). The authors found that hypothetical risk was less effected by subject's feelings than risk taking with real resources. In addition, they stated that people "exhibit more bravado when there is little chance of actually losing" (Isen and Patrick, 1983, p. 200).

Jones-Lee (1976) noted three behavioural characteristics of people in a risk-taking situation that are of importance to the

present study of heart disease patients. First, a patient will not bankrupt himself for any reduction in risk other than a complete reduction. Second, if the patient is in a situation where risk is potentially increasing, no amount of compensation is likely to be able to induce the patient to take a larger risk. Third, the marginal value to the patient of a reduction in risk will be positive and increasing as the risk is reduced toward zero. In presenting this argument, Jones-Lee (1974) assumes that a person prefers a low probability of death to a high probability, and that this person would forfeit some of his present wealth to attain the low probability.

Before concluding this section on measuring risk, it is useful to identify briefly the types of risk the study has attempted to measure. A list of eligible risks drawn from Mishan (1971) consists of four basic types: direct, direct-involuntary, financial, and psychic. Direct risks are those people assume voluntarily and can be described in health care as a demand for services that have an inherent risk factor. Direct-involuntary risks are those people bear without a conscious decision, such as radiation or hospital induced infections. A financial risk is a monetary loss (or gain) that is born due to someone's death, while a psychic risk is the sadness experienced at the death or disability of a cherished individual. This study measured the value to a patient of a reduction in the risk of death, a direct risk, which Mishan feels is the only approach that makes sense in

theoretical terms. Direct-involuntary risks are reflected in the objective probabilities of treatment outcomes described in the following section on coronary heart disease in Canada. However, the study did not attempt to measure financial or psychic risk. Financial risk is not an issue in Canada, where health care is publicly supported, and psychic risk was an inappropriate measure for treatment choices the patients made for themselves, rather than for someone else.

#### 1.6. Summary

The present study of patient preferences has been introduced through a discussion of the reasons for greater attention to the protection of patient autonomy and the criteria for informed consent. Evidence has been presented on the use of probabilities to describe the risks of treatment outcomes and the uncertainties inherent in treatment, two important factors in the decision-making process in medical care (Hiatt, 1975).

The following section is devoted to a discussion of the epidemiology, treatment options and costs of treatment of coronary heart disease. It includes: definitions of medical terms in their historical context, a description of the symptoms and treatment protocols, and information on the hospital use attributable to coronary and other types of heart disease in Canada. This information forms the basis for the treatment alternatives available for patients and the objective probabili-



ties that describe the risks associated with the treatments, which are used in concert with patient preferences to make a medical decision.

## SECTION TWO

### CORONARY HEART DISEASE: History, Epidemiology, and Economics

#### 2.0 The Clinical History of Coronary Heart Disease

The history of our current clinical understanding of coronary heart disease began in 1772 at the Royal College of Physicians in London when William Heberden delivered a paper on the chest pain associated with disease of the heart: angina pectoris. He described it as: "a painful and most disagreeable sensation in the breast, which seems as if it would extinguish life if it were to increase or continue" (Grotto, 1985, p.8).

'Angina' comes from the Greek word 'angere' which means to strangle or suffocate (Shillingford, 1981). Angina arises when oxygen demand exceeds the oxygen supplied due to inadequate circulation caused by narrowing of the arteries of the heart. It occurs more frequently with exertion in persons with coronary heart disease and may be relieved by rest. A classical symptom of angina is a tight or squeezing central chest pain, frequently radiating to the left arm, shoulder, or neck.

Severe narrowing of the coronary vessels is generally the cause of death or damage to the heart muscle known as 'myocardial

infarction'. Narrowing of the vessels is termed a 'stenosis'. A myocardial infarction is now believed to be due to the formation of a clot on the wall of a coronary artery where stenosis is present. Pain is not always associated with a myocardial infarction, and damage to the heart muscle can occur as 'silent ischemia' (Shea et.al., 1985).

In 1778 Edward Jenner discovered the relationship between angina pectoris and the underlying cause: disease of the coronary arteries. In 1793 Jenner anatomically defined the diseased areas of the arteries as 'coronary atheroma' during autopsy studies. It was not until the next century that Antonio Scarpa described the pathogenesis of the coronary vessels as a condition of ulceration and degeneration of the arterial lining. Scarpa was correct in thinking that the process took many years. In 1883 Scarpa's description was named 'arteriosclerosis', by Jean-Fredrick Lobstein, a pathologist. This generic term now covers a variety of conditions that cause the artery walls to lose elasticity and thicken or harden.

The term 'atherosclerosis', describing the kind of arteriosclerosis of the inner lining of the artery, was coined by another pathologist, Marchand, in 1904. Atherosclerosis is the result of fatty deposits called 'atheromata' (from Jenner's term atheroma) which cause the artery lining to become irregular and thick.

In 1912 the Journal of the American Medical Association published "Clinical Features of Sudden Obstruction of the Coronary Arteries" by James Herrick. In this article, Herrick is the first to describe how obstruction of the coronary arteries can cause the chest pain we call angina, and myocardial infarction (heart attack) that causes sudden death in some persons (Grotto, 1985).

A number of complex and sometimes interrelated risk factors are believed to influence the development of coronary heart disease. Some of these factors are life-style related: smoking, obesity, sedentary living, and stress. Heredity is also an acknowledged factor as are chronic conditions such as diabetes and hypertension.

## 2.1 Grading the Angina of Coronary Heart Disease

Coronary heart disease is caused by atherosclerosis: a thickening of the interior lining of the arteries. This atherosclerosis of the vessels of the heart is not always symptomatic. If the blood supply to the heart is adequate to maintain sufficient oxygen, no pain is associated with the narrowing of the vessels. However, when the occlusion closes the vessel to 30% of its initial capacity, angina pain may occur.

Angina, or angina pectoris, is only one of a number of common symptoms of coronary heart disease. Other symptoms include shortness of breath and fatigue. Angina can be classi-

fied by a number of systems. The grades listed in Table 1.1 were established by the Canadian Cardiovascular Society (1972) and are recognized by the American National Heart and Lung Institute.

TABLE 1.1

Grading of Angina of Effort by the Canadian Cardiovascular Society

1. "Ordinary physical activity does not cause ... angina", such as walking or climbing stairs. Angina with strenuous or rapid or prolonged exertion at work or recreation.
2. "Slight limitation of ordinary activity." Walking or climbing stairs rapidly, walking uphill, walking or stair climbing after meals, or in cold, or in wind, or under emotional stress, or only during the few hours after awakening. Walking more than two blocks on the level and climbing more than one flight of ordinary stairs at a normal pace and in normal conditions.
3. "Marked limitation of ordinary physical activity." Walking one to two blocks on the level and climbing one flight of stairs in normal conditions and at a normal pace.
4. "Inability to carry on any physical activity without discomfort - anginal syndrome 'may' be present at rest."

SOURCE: Canadian Medical Association Journal (1975, vol.122, p. 522)

## 2.2. The Epidemiology of Coronary Heart Disease

Coronary heart disease is the leading cause of death in Canada and the United States. It is a progressive disease that affects primarily older age groups and frequently affects the

middle aged. In Western countries, it accounts for about 80% of all the sudden deaths and for twice as many deaths as all forms of cancer. Although the incidence of coronary heart disease appears to be on the decline in Canada and the United States, it is one of the major causes of death in the twentieth century (Shillingford, 1981). Statistics Canada reports that for 1982, this type of heart disease was the cause of death for 28,796 men and 20,239 women (Statistics Canada, report 84-203, 1984).

Statistics on hospital separations by diagnosis identify the number of patients treated for heart disease and the average length of stay for Canadian men and women for 1978. Five diagnoses were selected and are summarized in Table 1.2 (using the International Classification of Disease) to indicate the economic importance of treatment for heart disease in this country. Four diagnoses were selected from the Canadian Classification of Disease for 1982 and are presented in summary form in Table 1.3. Hospital data do not indicate separations made due to death, but the mortality associated with a hospital stay for acute myocardial infarction ranges from 20% to 30% of patients in hospital (Acton, 1973). As a result, combining mortality data and hospital separation data will tend to overstate the incidence of heart disease. In addition, it is useful to note that the diagnosis of angina causes utilization of hospital care by about 18,000 patients, but this diagnosis is seldom listed as a cause of death.

TABLE 1.2

Hospital Stays for Canadians with Heart Disease,per 100,000 Population, 1978

(using the International Classification of Disease)

ICDA	DIAGNOSIS	MEN (no.)	DAYS <sup>6</sup>	WOMEN (no.)	DAYS
410	acute myocardial infarction	31,280	15.5	14,379	19.8
411	other forms of ischemic <sup>7</sup> heart disease	8,961	10.2	5,948	13.0
412	chronic heart disease	36,892	14.5	23,741	24.7
413	angina	10,446	7.9	7,453	9.3
427	symptomatic heart disease	25,186	12.8	22,799	15.3

NOTE: Many other diagnoses are listed, only five categories are included in the table as an illustration.

SOURCE: Statistics Canada (1984, Bulletin 84-203, p. 87-89)

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6 Days refers to the average stay in days per patient.

7 Ischemia means damage to the heart muscle caused by inadequate oxygen supply due to constriction of the coronary arteries.

TABLE 1.3

Hospital Stays for Canadians with Heart Disease,  
per 100,000 Population, 1980-1981

(using the Canadian Classification of Disease)

CCL	DIAGNOSIS	MEN (no.)	DAYS	WOMEN (no.)	DAYS
082	hypertensive disease	7,670	14.4	11,771	15.4
083	acute myocardial infarction	32,983	15.1	15,680	20.4
084	other forms of ischemic heart disease	55,816	12.7	36,137	22.5
086	other forms of heart disease	40,543	15.5	34,878	23.1

NOTE: This classification differs from Table 1.2, making comparison by years impossible. Where the diagnoses are consistent, numbers of cases per 100,000 population are similar.

SOURCE: Statistics Canada, Morbidity Report (1984, p. 122-123)

### 2.3 The Progressive Nature of Coronary Artery Disease

Coronary artery disease is considered to be a progressive disease in most patients (Moise and Bourassa, 1985). In a study of the prognostic significance of progression of coronary disease, Moise and Bourassa (1985) examined 313 patients and determined that 139 had progression of the disease, 33 died

during the study period, and 39 suffered an acute myocardial infarction but survived. In total, 211 (63%) patients had more serious (or fatal) disease at the end of the study period.

These authors also stated that the combination of progressive disease and myocardial infarction significantly reduced four year survival of patients with the disease. For example, the probability of four year survival with a myocardial infarction for patients with non-progressive disease was 89% while it was only 73% for patients with progressive disease. When data included patients without a myocardial infarction, the probability of surviving four years for non-progressive disease was 94% while with progressive disease it was 83%.<sup>8</sup>

Moise et. al. (1985) found progression of artery disease in 16 of 31 patients studied with previously identified minimal artery disease. They also identified progression in 3 of 20 patients with normal coronary arteries. Factors associated with the rate of this progression were: the number of diseased segments of the artery, the age of the patient, the smoking status of the patient, and the initial cholesterol level.

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<sup>8</sup> The Gompertz effect is an important contributing factor in the mortality rates stated for persons with coronary heart disease because this specific population is an ageing one. Gompertz (1825) showed that after a certain age the likelihood of dying is more a function of age than disease; ageing itself becomes a critical factor in reported mortality rates.



#### 2.4. The Clinical Background: Medical Therapy

In the following sections on alternative treatments for coronary heart disease, the focus is on angina as a major symptom because it is one of the most important signs of treatment effectiveness. Control of chest pain is a common goal for patients seeking treatment for coronary heart disease and it was a key symptom in the present study.

Angina can often be managed by reducing activities that aggravate it such as smoking, overeating, physical activity and stress. In addition to some lifestyle modification, medical therapy generally involves one or more of three groups of drugs. The first drugs in general use were the nitrate group, of which glyceryl trinitrate is the most common. The nitrates act to relax the coronary arteries and increase the blood supply to the heart, thus reducing pain. Nitrates also dilate normal arteries that supply other areas than the heart reducing blood volume in the heart itself which in turn reduces stretching of the heart and its vessels.

The second group of drugs, beta-blockers, act to regulate heart rate and the force of muscle contraction by blocking the sympathetic nerve transmission to the heart muscle. Patients with angina demonstrate significant improvements in exercise tolerance when they are treated with beta-blockers. The most widely used of this group is propranolol which became available in Canada in 1970 but was not widely used until five years later (Myers, 1985).

The third group is the calcium antagonists (also called calcium channel blockers) which have several cardiac actions including relaxing (dilating) coronary arteries and decreasing the force of heart muscle contraction. They may be used alone or in conjunction with beta-blockers and/or nitrates.

Few studies are available to compare the efficacy of these groups of drugs, either alone or in combination. Those studies that have attempted to compare outcomes have used small sample sizes and therefore cannot detect small differences (Myers, 1985).

Medical treatment can relieve angina for about 70% of patients with coronary heart disease. Some patients are troubled by the side effects of the drugs such as drowsiness, impotence, personality changes and nausea, so patient compliance can be a management problem. Surgical treatment of the blocked vessels in the heart is an alternative for the 30% of patients who do not experience pain relief from, or who are not compliant with drug treatment (Shellingford, 1981).

Califf et. al. (1984) have stated that medical therapy for patients with coronary heart disease may demonstrate a lower survival rate than surgical treatment because more high risk patients are treated medically. These authors reported that "...reasons for selection of non-surgical therapy include patient and physician preference, concomitant illness, and estimated surgical risk" (Califf et.al., 1984, p.1494).

## 2.5. The Clinical Background: Coronary Bypass Surgery

Coronary Artery Bypass Grafting (CABG) is the surgical interposition of a vein graft around coronary arteries blocked by atherosclerosis. The venous homografts are taken from the patient's legs. During this procedure the patient's body temperature is reduced, the heart is arrested and circulation is maintained by a mechanical pump that takes the place of the heart and the lungs. CABG is usually available to low risk patients less than 70 years old with good heart function and no other adverse diseases.

About 80% to 90% of patients who receive a graft have improved angina status (Pauker, 1976; Reeder et. al., 1984). Surgical treatment of angina does not appear to significantly alter the course of atherosclerosis nor is there agreement on whether it alters the subsequent risk of myocardial infarction (Hamilton et.al., 1983). In the case of left main coronary artery stenosis, studies have shown prolonged survival in patients who have had CABG (Alderman, et. al., 1983). Increased survival of patients with triple vessel disease has been demonstrated in the European Coronary Surgery Study Group (1980).

A major clinical trial of coronary artery bypass grafting was completed in 1983. The Coronary Artery Surgery Study (CASS) reported that: "bypass surgery is no more effective than conventional medical management in prolonging survival among patients

with stable ischemic heart disease." (The Medical Post, Nov. 27, 1984, p.8) This study (sponsored by the National Heart, Lung, and Blood Institute) established a registry for 25,000 patients who demonstrated blockage of one or more coronary arteries. The study found the following significant facts: first, the surgical mortality rate of 6630 patients followed in the CASS study from 1975 to 1978 was 2.3% while the rate for patients over 70 years of age rose to 7.9%; second, the three month mortality of patients across institutions performing surgery ranged from 0.3% to 6.4%; third, the five year survival rate was 89%; and fourth, the mortality curves for surgical and medical groups were almost superimposable (Braunwald, 1984). Increased experience of surgical teams with the technique seemed to be related to lower death rates of patients (Pauker, 1976).

The CASS study also determined baseline rates of survival for 586 men who recovered from a myocardial infarction but did not have CABG. Eighty per cent of patients survived 5 years; 61% survived 10 years; and 43% survived 15 years (Braunwald, 1984).

Braunwald (1984) has concluded that a majority of cases selected for CABG in the 1970's had angina of grades three and four. However, the trend for the 1980's has been toward operating on less severe cases. In addition, the average age of patients in this latter group is about 50, approximately half of whom have had a myocardial infarction. As a result of this change in surgical criteria, outcome data from the 1970's is

difficult to compare to that of the 1980's.

Some controversy over the relative merits of coronary bypass grafting has emerged in the medical literature, with long term studies demonstrating either no advantage of the surgical treatment over the medical treatment, or only a slight advantage.

Frick et. al (1983) conducted a prospective study of a randomized series of patients with coronary artery disease. In one group, 36 patients with stable angina pectoris were medically treated while the other group of 42 patients with similar symptoms were surgically treated. After a five-year follow-up 67% of the medical and 69% of the surgically treated patients demonstrated progression of their heart disease. Fewer medically treated patients had complete occlusion of a major vessel than did surgically treated patients.

In another study with similar methodology, Detre et. al. (1984) reported follow-up results of a randomized controlled trial of patients from the Veterans Administration Cooperative Study of CABG. The effects of medical therapy were compared to medical plus surgical therapy for patients with stable angina. This study determined that over a five-year period, therapy had little effect on resting left ventricular function among survivors in either group. A number of patients died of myocardial infarction during the study.

In addition to the controversy over the findings of these studies, controversy exists over the problems created by random-

ized clinical trials. Rahimtoola (1985) has stated that these studies are fraught with problems including: possession of the data by the sponsoring industry, drawing the wrong conclusions from the initial hypothesis, continuous alteration of the hypothesis, exclusion of many of the eligible patients, significant crossover of patients, and sample sizes too small for comparison.

## 2.6. The Clinical Background: Angioplasty

A more recent innovation in the treatment of coronary artery disease is Percutaneous Transluminal Coronary Angioplasty (PTCA). Coronary angioplasty is a non-surgical method of reducing the stenosis in a coronary artery using a dilating catheter equipped with a guide wire and a small inflatable balloon. The balloon is inflated inside a partially blocked coronary artery to dislodge or compress the atherosclerotic plaque in the vessel. The catheter route used is usually femoral (the artery in the patient's leg) but may also be brachial (from the arm).

During the inflation of the balloon, the coronary artery will be completely blocked which may cause severe angina or myocardial infarction. Surgical intervention in the form of CABG is always a possibility for patients who elect angioplasty. The controlled injury to the coronary vessel heals slowly, although the patient can usually return to normal activity within a week.

There are a number of advantages to the shorter hospitalization required for PTCA including improved chances of the patient returning to work.

Amiel et.al. (1984) estimate that 5% to 10% of patients previously treated by CABG can be treated with angioplasty. The treatment is considered to be successful if the stenosis is decreased by 20%.

In a study reported by Greuntzig et.al. (1979), initial success (measured as relief from angina) was 66%, emergency bypass surgery was required for 12% of the patients, and no deaths were attributable to angioplasty. This study followed 33 patients for a mean of 9 months and found 25 had improved (less angina), 6 deteriorated and 2 died (Greuntzig et. al., 1979).

In a National Heart Lung and Blood Institute study, 34 major centres using angioplasty reported a success rate of 59% for 663 treatments on 631 patients (Levi, et. al., 1981). The mortality rate from subsequent surgery due to failed angioplasty was 0.95%. Complications in the method caused failure in 18.5% of the patients.

By 1983, a five year report from the same Institute showed 73 centres reporting on 1,500 patients. The rate of emergency CABG due to occlusion of the coronary artery during PTCA was 6.8% with a mortality rate of 1.1% due to angioplasty itself. The incidence of complications that produced severe myocardial ischemia

or infarction or death was reported to be nearly that of CABG (Greuntzig, 1983).

Braunwald (1984) states that 60% to 80% of cases of PTCA show a successful dilation of the stenosis. In 5% of the cases, the coronary artery occlusion produced by the equipment causes a myocardial infarction. Risk of death for this group can be reduced by doing a CABG immediately. Mortality overall in this procedure is stated as 0.5% to 1%. In about 20% of initially successful cases, restenosis occurs within six months. About two-thirds of this group can have the procedure repeated successfully. It has been estimated that 15% to 30% of patients eligible for CABG may be effectively treated by PTCA (Marquis, 1985). (Note that this is twice as high as the Amiel et.al. estimate)

Angioplasty has a range of risks and results important to the preparation of any tool for eliciting patient preferences for this type of treatment. Research reported above indicates an initial success rate of 60% to 80%. Of this patient group, 80% have long term functional improvement and reduced angina while 15% to 20% have early restenosis. The risks are: 10% of patients have total coronary occlusion, 5% to 10% suffer a myocardial infarction, 5% to 10% must have an emergency bypass when angioplasty fails, and about 2% of patients suffer hospital deaths. These groups are not mutually exclusive.



## 2.7. The Cost of Medical Therapy in Canada

Many patients with angina are treated throughout the remainder of their lives with large doses of a beta-blocker, a calcium-channel blocker and a long-acting nitrate in order to control their symptoms (Waters, 1985). A segment of the Waters (1985) study is reproduced in Table 1.4 to indicate the average cost in Canada for one month of treatment with drugs that prevent angina. A patient using each of the three types of drugs described above could be paying \$145.00 a month for treatment (Waters, 1985). The data represent averages calculated from a national survey of pharmacists and hospitals in 1984.

TABLE 1.4. Average Cost of Antianginal Drugs in Canada  
(1985)

Drug	Dose (mg/d)	Cost per month (\$)
<u>Nitrate</u>		
Isosorbide dinitrate	120	15.92
<u>Beta-blocker</u>		
Propanolol	160	19.84
	320	29.68
Pindolol	20	29.80
<u>Calcium-Channel Blocker</u>		
Verapamil	480	73.15
Nifedipine	80	99.00

SOURCE: Walters (1985) The Canadian Medical Association Journal, vol.171, p. 627

### 8.0 The Cost of Coronary Artery Bypass Grafting

Catastrophic expenditures associated with surgery and hospitalization for the critically ill have been documented by a number of authors (Zook and Moore, 1977). Coronary artery bypass grafting is considered to be among those high cost episodes.

Keon, Menzies and Lay (1985) have investigated the cost of CABG at the Ottawa Heart Institute. In 1984, 750 coronary artery grafts were performed at this Institute and 50 of these were randomly selected for detailed economic analysis using hospital charts. The ratio of males to females was 5 to 1, similar to the Canadian average for incidence of coronary heart disease calculated by Anderson (1973). The mean age was 55.3 with a range of 39 to 73 years, also near the Canadian average for this disease.

The average cost of an episode of care involving coronary artery grafting was \$9595.00 with a range of \$6387.00 to \$18,415.00 (in 1983 dollars). Professional fees were 20% to 30% of the total and hospital costs were 70% to 80% of the total. Indirect costs were not considered, including patient time away from work, travel to the hospital, recovery time at home, and family disruption.

In a recent study of CABG performed in the United States, 191,000 cases were estimated to have been performed in 1983 (Metropolitan Life Insurance Co., 1985). During the early 1980's the average American medical care charges for a coronary bypass operation were \$21,800 with a 228% overall variation by state.

On the average, 71% of the direct cost to the insurer was attributable to hospital costs while 29% was the physician's fee. These fees varied across states from a low of about \$5,000 to a high of about \$10,000.

The Metropolitan (1985) study has contributed a detailed analysis of some indirect costs attributable to CABG in the United States. Between 1974 and 1978, 147 active employees of the company underwent CABG. Half of the cases recorded occurred in 1977 and 1978 and over half (56%) of the patients were under 55 years of age (44% were between 55 and 64).

Two groups of employees emerged in this analysis: those returning to work and those not returning. Ninety-one (62%) employees returned to work after an average of 20 weeks recuperating, accumulating 9,000 sick days. More employees under 55 returned to work than over 55. Of this cohort, only 9 were still at work on January 1, 1984. The 56 employees (38%) who did not return to work accumulated 61,000 sick days.

The wage loss per patient averaged \$68,000 with a range of \$40,000 to \$108,000. Younger employees who did not return to work suffered the greatest wage loss even after sick pay and disability compensation were taken into account. It was clear that the indirect costs to patients and to employers of patients receiving CABG could far exceed the direct costs of the episode of surgical and hospital care related to the bypass operation.

## 2.9. The Cost of Angioplasty

The total health care cost of angioplasty has been estimated to be one-fifth to one-sixth as much as bypass surgery (Amiel et. al., 1984). In a study at the Mayo Clinic, Reeder et. al. (1984) have reported a significant (56.1%) difference between the cost of angioplasty (\$7,508) and coronary bypass surgery (\$13,387) including one year follow-up. The follow-up costs included the cost of coronary bypass surgery for 25% of the angioplasty patients with restenosis. Length of hospital stay was also significantly different: 9.3 days for angioplasty and 13.2 for coronary bypass. Reeder et. al. (1984) estimated an 85% success rate for angioplasty done at the Mayo Clinic after 1984, while the success rate reported in the 1980 study group was only 69%. The increased success rate was acknowledged by the authors to cause a reduction in the cost of care for the angioplasty group.

## 2.10. Conclusions from the Clinical Discussion

This section has outlined the clinical treatment options for patients with coronary heart disease. The objective of each treatment is to reduce the severity of symptoms associated with coronary heart disease and reduce the risk of premature death. The probabilities of success as well as the risks have been summarized. Surgical intervention (CABG) and non-surgical intervention (Angioplasty) offer a higher probability of pain

reduction accompanied by peri-operative mortality while medical treatment has a lower probability of reducing pain but also has a significantly lower risk of early mortality as a result of treatment. Many factors must be considered for an effective decision in the treatment of coronary heart disease. Some of these factors are technical and diagnostic, limiting participation of the patient because of the rationality limitations inherent in medical practice. However, some factors are well within the prerogative of the patient, and these include the willingness to bear risks and the preference for outcomes depending on their probability of occurrence. It is this important contribution of the patient that was addressed in the patient preference study.

The summary in Table 1.5 identifies the opportunities for patients to participate in the decision to treat coronary artery disease. The outcome probabilities are those discussed in this section, and the 'costs' listed represent both economic costs to society and economic as well as personal costs to the patient.

TABLE 1.5. Summary of Treatments and Outcomes in the Decision to Treat Coronary Artery Disease.

STEP 1	ENTRY TO THE HEALTH SYSTEM
	a) The patient enters the treatment phase directly due to symptoms: chest pain, shortness of breath, unwarranted fatigue, or prostration due to a heart attack.

b) The patient enters the treatment phase because of identification of subclinical symptoms by screening or follow-up of other health problems.

#### PATIENT DECISION

The patient decides whether to accept entry to the health system by admitting or by ignoring the effect of symptoms of heart disease.

### STEP 2

#### DIAGNOSIS

Diagnosis of the extent of atherosclerosis or stenosis of the coronary vessels is achieved via case history, electrocardiogram, blood pressure measurement, stress testing and diagnostic imaging such as an angiogram.

#### PATIENT DECISION

The patient decides how much information to reveal in a case history, and decides whether the risks attached to diagnostic tests are compensated by the value of the diagnostic information in choosing an appropriate treatment.

### STEP 3

#### TREATMENT OPTIONS

#### PROBABILITIES of OUTCOMES

- a) medical management ..... 60% to 80% chance of no pain, 20% to 40% chance of same symptoms, likely side effects such as nausea.
- b) coronary bypass ..... 60% chance of no pain, 80% chance of some pain relief, 1% to 10% risk of death, 15% to 25% chance of same pain.
- c) angioplasty ..... undetermined long term outcome, short term: 60% to 80% chance of pain relief, 1% to 5% risk of death, 15% to 20% chance of no relief.
- d) lifestyle change ..... no data available.
- e) do nothing ..... disease progresses, pain likely to remain.

**PATIENT DECISION**

The patient evaluates the probabilities of outcomes and selects the treatment whose outcome most closely meets his/her preferences.

**STEP 4      PHYSICIAN PREFERENCES**

Physicians benefit economically from the initiation of treatment options a, b, and c. The health system reimburses physicians for diagnostic procedures, office visits, and surgical interventions.

**STEP 5      ECONOMIC IMPACT and SOCIAL PREFERENCES****COST TO PATIENT**

a) medical management  
 -drugs \$140.00 per month  
 -side effects of drugs

b) coronary bypass surgery  
 -large work loss  
 -morbidity (10-24 days)  
 -risk of death

c) angioplasty  
 -small work loss  
 -morbidity (4-10 days)  
 -risk of death

d) lifestyle change  
 -personal effort

e) do nothing  
 -uncertainty about  
   future health

**ECONOMIC IMPACT**

-profits for drug companies  
 -costs of physician care

-cost of surgery is \$13,000  
 -costs of physician care

-treatment cost is \$7,000

-reduced tobacco sales,  
 etc.

-premature loss of life

**PATIENT DECISION**

The patient determines whether the personal costs of a treatment alter the step 3 choice of a treatment due the merits of its outcomes in terms of the patient's health.

**SOCIAL CHOICE**

Society determines the proportion of health care resources that will be made available for treatment of coronary artery disease.

### 2.11. The Research Questions

The research questions were based on the premise that patient preferences ought to matter. The options available to most patients have been described and the research questions developed have used the probabilities of outcomes as outlined in this section. The literature reporting previous research findings in the study of patient preferences and decision making behaviour is reviewed in chapters 3 and 4. This literature has shown that when patients are asked to express a preference, this preference is vulnerable to a number of errors of judgement. The literature has also shown that independent variables have some influence over the expression of a preference or choice. The questions explored in this study are defined more completely in later chapters, but are listed here in order to complete the introductory function of this chapter.

The research questions are:

- a) Patients' perception of the information provided is altered by the manner in which the information is presented.
- b) Patients make errors in judging the proportional difference between pairs of outcomes.
- c) The size and probability of a potential gain influences the patient's value of that gain depending on whether the patients must choose between two gains or offer something of value in exchange for those gains.



- d) A patient's willingness to take a treatment with a risk is influenced by whether the patient views the treatment as a gain or a loss.
- e) A 'right' already possessed by a patient will be worth more to the patient than a 'right' he/she may want to possess.
- f) The severity of coronary artery disease is a factor in predicting a patient's willingness to take a treatment risk.
- g) Preferences are influenced by a patient's age, the severity of coronary artery disease, and the previous health care history.

In the following chapter, methods developed to explore patient choices and preferences relating to these research questions are described.

## CHAPTER 2

## MEASURING PATIENT PREFERENCES: Methodology

1.0. Introduction

This chapter deals with the methodology of the study and the use of the questionnaire to elicit patient preferences for outcomes of treatment for coronary heart disease. The methodology reviewed reflects decision making behaviour studied in a variety of settings, with emphasis on those that relate directly to health care. Methods applicable to the purposes of this study include: eliciting preferences for treatments and hospital stays, measuring patients' aversion to surgical or treatment risk, and patients' willingness to pay for treatment as a measure of the value of health care.

Many studies of decision making and individuals' preferences have used college students as subjects. Studies of real and hypothetical risk have been reviewed (McNeil et. al., 1978; Grether and Plott, 1979; Slovic and Lichtenstein, 1983). They suggest that some benefits accrue to a strategy of asking preference questions to patients when we wish to contribute to an understanding of decisions to initiate costly treatments with uncertain outcomes. Support for the study of real decisions comes from Einhorn and Hogarth (1981, p. 81) who state: "The external validity of decision making research that relies on laboratory simulations of real world problems is low."

## 2.0. Structure of the Chapter

This chapter has four main components: a discussion of the sample, comments on the choice of measurement strategies, administration of the questionnaire, and analysis of the results. The discussion of subjects in the study is comprised of four sections. The first section presents sampling strategy, the calibration of subjects, the role of the patient in the study, and patient assurance. The instrument itself appears in Appendix I along with appropriate covering letters used, the application to the university ethics committee and the ethics certificate, patient instructions, and debriefing materials for participants. The visual aids used to assist subjects appear in Appendix II.

Section two of the chapter reviews methods described in the literature that have been shown to produce reliable results in determining patient preferences and demonstrating decision making behaviour. Section three reviews factors important in achieving acceptable rates of response. Interviewer bias and steps taken to reduce its influence are also discussed in this section. The statistical procedures and the rationale for sensitivity analysis of the results comprise the fourth component of the chapter.

## 3.0. Sampling Strategy

Patients with coronary heart disease were selected as subjects for this study because, as stated earlier, heart

disease is the leading cause of death and a major consumer of health care resources in Canada. In addition, involving patients who are seeking medical care provides an opportunity to study decision making in a situation with considerable realism in comparison to the use of subjects making hypothetical choices. A student risking a dollar in a classroom setting may demonstrate very different decision making behaviours than a patient risking his/her own life in the operating room (Knetsch and Sinden, 1984; Vertinsky et.al., 1974).

The research plan involved administering a complete questionnaire to 65 subjects: 15 healthy adults and 50 patients being treated for heart disease by physicians in the Cardiology Division of the Vancouver General Hospital. A more limited questionnaire was answered by 37 hospital administrators in order to include responses by adults who were free from disabling heart disease.

The questionnaire was pretested on 14 subjects. Ten patients with coronary heart disease participated in the pretesting of the questionnaire and four health care professionals evaluated the skills of the researcher by completing the questionnaire. This pretest is discussed in detail in section 7.0. Altogether, 115 subjects completed a full or limited questionnaire. From this total, 49 patients, 15 healthy control subjects and 37 hospital administrators formed the final study group. No pretest questionnaires were used in the data analysis.

The patients with heart disease were recruited by six cardiologists who allowed the patients in their practises to be included in the study over a five month period. Active recruitment of patients by doctors was the method of patient selection. Even with physician participation, considerable difficulty was encountered in achieving the target number of patients. The 50 patients who agreed to participate were drawn from over 670 patients with scheduled appointments in the cardiologists' practises during the five months of the study. During this data collection phase of the project, the researcher was required to be present in the Cardiology Division or in the group cardiology practise every day during office hours, and to be available to interview patients at home.

The healthy subjects were adults between the ages of 40 and 65, an age range typical of patients with heart disease. These subjects were recruited by the researcher using the membership roster of the Alta Lake Sports Club. The membership of this organization included families who were active in outdoor recreation and sports. The hospital administrators participated in a short questionnaire as part of a lecture in medical decision making given at the Pacific Health Forum in Vancouver in September, 1985. From an audience of 52 administrators, 37 completed questionnaires were received.

Many patients who were approached declined for a variety of reasons. Some patients felt they were too ill to participate;

some patients felt the time commitment was too great; one patient didn't like 'research'; and some patients gave no reasons for their refusal to participate.

Several patients agreed to participate, but did not complete the questionnaire. For example, one patient with unstable angina who agreed to participate became anxious during the questionnaire and was advised by the researcher to withdraw. One patient was mentally unable to focus on the questions; for others language was a barrier although they were willing; and one patient was admitted to hospital after agreeing to participate but before commencing. If a questionnaire was not completed, another patient was recruited.

The 50 patients described above formed the heart study group comprising three categories. The 'heart disease control' group consisted of 20 patients with asymptomatic coronary heart disease (disease diagnosed but not showing signs or symptoms), or arrhythmias (irregular rhythm of the heart) treated by medication or a pacemaker, or with valve disease. No patients in this group experienced pain during the time of the study, although some had previously experienced angina pain.

The coronary heart disease patients with angina pain were classified into two groups: the group with 'mild angina' contained 15 patients, and the group with 'severe angina' contained 15 patients, of whom 14 patients completed a usable questionnaire. The unusable questionnaire from this group was not

replaced, as the researcher had determined after the completion of the data collection that this patient should be excluded. The reason for exclusion was that this patient was the only patient interviewed in the Coronary Care Unit of the Vancouver General Hospital. The patient anxiety attributable to the intensive care unit was determined to be a variable that could influence the preferences expressed by this patient in relation to other patients who were interviewed in the doctor's office.

The 'angina' groups were determined using the disability scale of the Canadian Cardiology Institute for heart disease patients with angina (see Chapter 1). Three assessments of disability level were made. First, the patient selected his/her disability level by describing exercise-induced pain and subsequent disability. Second, the researcher made an estimate using the patient history and the disability scale. Finally, the patient's physician stated the disability level. Usually, all three assessments were the same. When there was disagreement, the physician's assessment was used. Patients with disability levels one and two were eligible for the 'mild angina' group, while patients with disability levels three and four were placed in the 'severe angina' group.

The group of 15 healthy adults and 37 hospital administrators acted as controls so that a determination could be made of whether the effects of diagnosis of heart disease and the presence of symptoms influenced decision making behaviour. In

other words, the object was to determine the importance of the nature of the decision in understanding decision making behaviour. Subjects were to make choices in a real situation similar to those in an hypothetical situation.

The 52 healthy control subjects were asked to imagine that their doctor had diagnosed the presence of coronary heart disease. They were then asked to answer the questionnaire imagining that they would experience symptoms sometime in the future, and that they would require treatment in the future. The researcher described what angina pain might be like and how angina could limit normal activities. The description of pain used was taken from Chapter 1. Subjects were given the Canadian Cardiology Institute grading of levels of angina as a reference for the disability caused by angina.

#### 4.0. Pain as a Factor in Decision Making

Patients were selected for this study to represent the spectrum of pain typical of patients with coronary artery disease. Some patients experienced no pain, while others were moderately or severely disabled by chest pain due to angina. In order for a meaningful analysis of the questions relating to preferences for morbidity and treatments accompanied by risk, it was important to have an understanding of how disabled each patient was due to the symptoms of coronary heart disease. Each



patient was asked to describe the onset and duration of pain, the current therapy, and to provide limited demographic data. Each asymptomatic patient described his/her attitudes towards any disability caused by coronary heart disease or other heart disease found in patients in this group.

The experience of pain is an attribute of many disease states. In order to avoid pain comparisons which are not meaningful between patients, pain comparison was made within subjects only (Christensen-Szalanski, 1984). Patients were asked to visualize pain continuing at its current severity, and to visualize one, two and five years without pain.

Twenty-nine of the patients whose questionnaire responses were analysed were experiencing the pain of angina. The possibility of patients violating preferences expressed during a respite from pain, compared to preferences expressed during periods when they experienced pain, was expected (Christensen-Szalanski, 1984). True values may become suspended as a result of the overwhelming need for pain relief (Schelling, 1985). To somewhat compensate for this problem, patients were encouraged to choose treatments whose outcomes would best reflect their needs as they felt them to be during the questionnaire as well as during periods of pain. This strategy was adopted because of Schelling's (1985) finding that people discount the past highly, since the pain they have already suffered doesn't hurt them now. The interesting aspect of angina pain is that patients know it

will be back, and remember well what it is like. This is generally true of most recurring or chronic pain. Understanding behaviour responses to chronic angina pain appears to be based on different criteria than the case of labour pain, which although extreme, is intermittent and self limiting. Research has also shown that people are not consistent in the choices they make even without the added confusion of pain (Arrow, 1971).

Pain, then, can be classified as a disease symptom that may alter true preferences (Christensen-Szalanski, 1984). However, there is an adaptive value to being more sensitive to a state of pain than a state of non-pain or pleasure. The person in pain is motivated to take some action to alleviate the pain by altering the situation that caused it. There remains the dilemma affecting this study of not knowing whether a patient's preference is merely a short-term adaptive response to pain.

#### 5.0. Introducing Subjects to the Questionnaire

At the outset of each interview, demographic variables were collected in a manner similar to a patient history. The questionnaire contained a short form (see Appendix I) asking: age, sex, health history, marital status, number of children, job type, length of symptoms, and lifestyle risk factors. Some patients spent as much as half an hour describing their history.

The reason for asking patients to repeat a history already taken by the physician was to help the patient feel comfortable, to encourage the patient to communicate to the researcher, and to provide information on the kind of pain and disability caused by the patient's heart disease. This history was also important for patients with asymptomatic coronary heart disease because their previous health care experiences provided important data that could have an influence in treatment choices. The treatment seeking behaviour of patients with cardiac arrhythmias, pace-makers, and valve disease was an important factor in reducing disparities between the heart disease control group and the heart disease group with angina pain. The reason for taking a history from all patients was to ensure that data were available to identify similarities and differences between patient and subject groups. It is also methodologically important to have every subject receive the same questionnaire experience.

Patients were not asked to describe their prognosis (the future course of the disease) in order not to cause anxiety. However, subjects were asked to state the number of years they expected to live. This question did cause some anxiety for a few patients.

#### 6.0. The Subject's Role

Subjects are active participants in any experiment. Potential problems that could develop in the course of adminis-

tering the questionnaire were explored by asking: how will the subjects be motivated, how will they perceive this research, and what cues will the patients pick up?

In any experiment of this type, some mutual role expectations become defined, if not at the outset, certainly during the research. Orne (1962) has shown that subjects tend to place themselves under the control of the experimenter, and often do not inquire about the purpose or duration of the experiment. Subjects have been observed to perform meaningless tasks for hours in an effort to be compliant (Orne, 1962, p. 156). Part of this behaviour may be stimulated by the belief that research may make a contribution to knowledge and is therefore important. For this reason, subjects in the present study were debriefed and offered a summary report of findings. Any patients wanting feedback on their preferences were given a verbal summary of the evident decision making behaviours exhibited in the responses.

In terms of demand characteristics of the experiment (cues that convey the purpose of the research), the researcher strived to eliminate bias by explaining the purpose clearly at the outset. When subjects understand the purpose of the research they appear to make every effort to be honest and helpful (Orne, 1962). In addition, the subjects in this study actively worked toward solving the questions, which has been suggested as a normal mechanism for making the research experience more meaningful (Weick, 1967).

A potential source of bias in the attitudes towards risk of patients with pain and patients without pain, could have arisen from the treatment seeking behaviour due to angina pain. In addition, some patients with angina had already undergone bypass surgery which may have altered attitudes towards surgical risk. For example, a patient who has survived surgery with a 10% risk of death may feel that a 10% risk is 'low', while a patient anticipating this risk may believe it is 'high'. To try to reduce the bias that treatment experience could generate, outcomes or treatments were not identified by name. This choice was reinforced by McNeil et. al.'s (1978) finding that many subjects in a study of cancer treatment had an aversion to the words "radiation therapy".

#### 7.0. Interviewer Bias

To evaluate the administration of the questionnaire, two professors experienced in decision research participated in a test of the researcher's ability to conduct a structured interview in a neutral manner. One social worker completed the questionnaire in an interview situation in order to evaluate the researcher's skills in presenting questions to patients who may be anxious. A senior staff physician at the Vancouver General Hospital participated in a structured interview as a 'patient' and assessed the researcher's skills at taking a patient history and answering patient's questions.

The author of the study conducted all the structured interviews (questionnaires). In order to control bias in the administration of the questionnaire the following steps were employed. First, the researcher was introduced to the patient by the physician who recruited the patient. The researcher always wore a white coat and identification tag typical of hospital employees, and used an office identical to those of the physicians. Second, the researcher provided the letter of introduction to each subject and provided a memorized verbal introduction delivered in a friendly manner.

Third, for each item on the questionnaire, a standardized answer for anticipated patient questions was prepared. The researcher provided the same explanation each time a question was raised, and the researcher did not show any signs of approval or disapproval for patient responses, except to nod and say, "that's fine." Patients were reminded that there were no right answers. Finally, consistent use of the visual aids for each question was made, whether or not the patient expressed a need for the aid.

#### 8.0. Patient Assurance

Anxiety is a real phenomenon in medical care and in medical research. This study dealt with patient anxiety by asking patients about their feelings before and after they participated in the questionnaire (Mooney, 1977, p. 132).

Less anxiety was noticed in the healthy subjects than in the heart disease patients. This was expected, based on Mooney's (1977) finding that individuals in a hypothetical situation may not be able to take into account the anxiety associated with a real risk situation.

Patient anxiety was also alleviated with formal assurances. A detailed protocol for patient assurance (a letter telling patients that the research will not interfere with their treatment) was developed for use by the subjects in this study (Thompson, et. al., 1984). The items covered in the letter were adapted from Thompson et.al. (1984) and listed below. The patient assurance document is found in Appendix I.

1. Patients are assured of anonymity and confidentiality.
2. The researcher explains the rationale and importance of the research.
3. The questions are as close to real situations as is feasible.
4. Any purely hypothetical situations are clearly identified.
5. Props such as dice and diagrams are used to explain the questions and how they may be answered.
6. Patients are assured that there are no 'right answers'.
7. Patients are debriefed and asked if answering the questions has made them more anxious about their condition.

The research project, including the complete questionnaire, was subject to the scrutiny of the Ethics Committee of the University of British Columbia. The project was also evaluated

by the Cardiology Division of the Vancouver General Hospital and the Vice President and Director of Research for the hospital. Written permission from these three sources was required before any patients could participate.

Following hospital regulations, patients were requested to give written consent to their physician before the researcher was given the patient's name. The consent form also appears in Appendix I.

#### 9.0. Attributes of Patient Choice

There are many factors relevant to a patient's choice of treatment for coronary heart disease. For the purposes of this study, these have been limited to pain, morbidity, length of hospital stay, and health outcomes. Choices based on real income and net worth measures have been avoided because they have very little influence on a patient's access to health care in Canada.<sup>1</sup> Choice of a treatment that could alter the course of the disease has been excluded because most interventions in coronary heart disease treatment are not able to significantly alter the course of progressive atherosclerosis.

Klein (1983) has stated that people think about only a subset of all relevant attributes when the choices are broad or

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<sup>1</sup> A useful distinction may be made between the costs of surgical treatment for coronary heart disease which are paid by Medicare, and the drug costs of medical therapy for coronary heart disease which are paid by the patient.



varied. For each heart patient, only a few attributes are relevant across the range of treatment options. Many attributes will be evaluated by the physician acting as an agent or advisor to the patient, while a number of attributes will be too difficult for some patients to utilize because of limits on ability to process information.

Some problems may arise due to the choice of outcome attributes. Values close together may demonstrate errors of proportional difference of greater magnitude than values near the extreme points. For example, patients may readily distinguish between two weeks in hospital with pain and two weeks in good health, but they may have difficulty distinguishing between two weeks in hospital recovering from surgery and two weeks as an invalid at home with severe angina pain. So, even if there is a real value difference for the patient between these two states, measurement of this difference may not be possible. To compensate for this difficulty, the questionnaire anchors patient responses to 'very good' and 'very bad' outcomes, and it attempts to offer choices within a range of attributes of treatment outcomes. The process of finding an outcome considered by most subjects to be a 'good outcome', such as no more angina pain; and an outcome considered to be a 'bad outcome' such as death or permanent disability is known as 'anchoring'.

### 10.0. Measuring Utility in the Heart Study

Utility reflects the desirability of an outcome or the value of one outcome as compared to another (Keeny and Raiffa, 1976; Merz, 1983). Its numerical value is attached to the "worth of a consequence" or the outcome of a decision (Lindley, 1976, p. 101). A utility scale is a description of how preferences change as various factors in the environment change. For example, if a patient with cancer of the lung has the lung removed surgically and is otherwise capable of living a normal life, the worth of living with only one lung has a measurable utility. This number is usually expressed as a proportion of the value of living in perfect health.

For patients with coronary heart disease, the treatment utility is made up of a number of components, both positive and negative. Positive components (or outcomes) include: 'cure' of the heart disease, relief from symptoms such as pain, elimination or reduction of dollar costs of hospital treatment or drug therapy, and establishing a firm diagnosis (Berwick and Weinstein, 1985). Negative outcomes include: physical or emotional disability, family disruption, lengthy hospitalization, side effects from drugs, continued or more severe pain, continuing costs, and death (Kassirer, 1976, p. 155).

Stated preferences for a treatment outcome are indices not only of the subjective value of the treatment to the patient but also its value to the patient's family. A number of the study

interviews (10%) included family members who took an active interest in the subject's participation.

Von Neumann and Morgenstern (1944) have offered an example of the estimation of an ordinal value for utility. Briefly, "if an individual prefers A to the 50-50 combination of B and C (while preferring C to A and A to B) then his preference of A over B is greater than the preference of C over A" (Von Neumann and Morgenstern, 1944, p. 20). At least an ordinal placement of A, B and C can result from this choice. The questionnaire developed to elicit patient preferences uses this notion of measurement of utility.

Torrance et.al. (1982) have described a method they used to develop a cardinal ordering of the utility of various health states. Subjects were asked to place arrows corresponding to health states on a 'feeling thermometer'. The spacing between the arrows was the source of data on the relative difference between the value of various health states. Perfect health was listed as 100 and death was listed as zero.

Torrance et. al. (1982) suggested that utilities measure the value of the health state independent of the prognosis of the patient. In other words, even if a heart patient will always live under the threat of a myocardial infarction, life without the threat will have a measurable utility. Using a utility measure allows the combination of many attributes of health into a common denominator, such a 'quality of life years'. This measure

discounts years of sickness or disability so that more disabled years of life are then equivalent to one year of good health. In order to avoid an explanation of probabilities, Torrance et.al. (1982) used a trade-off between living in perfect health for 'x' years and living with ill health for 'x + y' years. The point of indifference between these singular choices yielded a utility measure. As Lusted (1968, p. 154) noted, "relative utilities for an individual are measurable, but absolute utilities are not. The person is free to assign arbitrary utility values, and a utility function is determined as follows: If the decision maker is indifferent between two alternatives, the expected utility of the alternatives is the same."

Components of the available choices are not singular, but are actually vectors of outcomes that may be identified by a prominent attribute. A number of components of such a vector were examined in this study: a hospital stay, convalescence at home, pain, and risk of death. Patients were asked to identify the most prominent attribute of the treatment outcome vector. For example, a patient may have identified 'being able to work in the garden' as the most important attribute of convalescence; or 'being able to play golf' as the most important outcome of pain control.

#### 11.0. Measurement Strategies

In the patient preference study simple measurement stra-

tegies were followed, assuming that, as Beach and Barnes (1983) found, patients would try to describe their preferences regardless of how they were asked to communicate. To help patients understand probabilities of outcomes, the questionnaire was supported by bar graphs and diagrams and the researcher administering the questionnaire answered subjects' questions and demonstrated probabilities with dice and coins. One question was illustrated with four empty pill capsules, each representing a 25% chance of treatment risk. (see Appendix II)

Subjects were asked to describe their preferences for alternative outcomes with attendant benefits and costs (or risks of negative outcomes). They were also asked to state the value of alternative outcomes. Several methods of eliciting patient preferences were chosen for ease of administration of the questionnaire and because more complex methods have not been shown to be significantly better. These methods included: the standard gamble, time-trade-off techniques, scenarios, ranking, and ordering.

#### 11.1. Standard Gamble and Comparisons

The 'standard gamble' method of eliciting personal preferences in a situation of uncertainty has been attributed to Von Neumann and Morgenstern (1944). In this method, subjects are asked to state an equivalent outcome to a 50-50 gamble described in a scenario. They may also be asked to choose between a 50-50

gamble and an intermediate outcome that occurs with certainty. Such an intermediate outcome is called a 'certainty equivalent'. The basic principles of this method were described in more detail above in the discussion of an ordinal scale for utility.

Vertinsky and Wong (1975) evaluated two methods of preference measurement that were useful for the development of the questionnaire. The first method used scenarios to present different alternatives to subjects. The alternative method described the probability of a positive outcome coupled with the probability of a negative outcome (Von Neumann and Morgenstern, 1944). These gambles offered equal chances at either a small or large number of bed rest days due to treatment outcomes for an illness. Subjects were asked to state how many days they would rest in bed for sure rather than take a gamble offering either a long or a short hospital stay.

Each subject's utility was calculated from stated utilities of the alternative bed rest days. The following formula was used:

$$u(x) = 0.50 u(a) + 0.50 u(b)$$

The small number of days of bed rest was set to zero and the large number (up to 15) was set to one. In this way, each choice of a certainty equivalent generated a data point used to create a utility measure.

Subjects in the Vertinsky and Wong (1975) study found the standard gamble method to be 'easier to handle'. Consequently,

this method was adapted to the present study to measure patient's utility for years of life with certainty versus risk of death due to treatment.

The standard gamble technique has been compared to category scaling by Llewellyn-Thomas et.al. (1984). In this study, scenarios were used to describe health states which were evaluated by raters using both techniques above. Consistently higher values were assigned using the standard gamble technique.

McNeil, Weischselbaum, and Pauker (1978) used a scenario method in a study of patient preferences for treatment for carcinoma of the bronchus and lung with demonstrated success. The scenario was separated from the probability of outcomes statement and a diagram was used to assist patients in visualizing the probabilities. Diagrams similar to those developed by McNeil et.al. (1978) were used in the present study for questions using probabilities.

McNeil et.al. (1978) used a 50/50 gamble strategy to develop utility scales for patients expressing an aversion to surgical risk. Their method involved five basic steps. First, patients were asked to choose how many years they would like to live in good health: 10 or 25 years. Second, these patients were asked to think of a 50/50 gamble in terms of a coin toss. If heads appeared they would get the long term survival, if tails appeared they got the alternative, death. Third, these patients were offered a choice between taking the gamble or stating a fixed

period of life equivalent to that gamble. (The lower this certainty equivalent, or guaranteed survival, the more averse a patient was to risk.)

Fourth, the researchers took the certainty equivalent (for example, 5 years) and asked the gamble again, using the new equivalent in place of death (written as zero years of survival). The question was then a choice between a 50/50 gamble of 5 years before death and the choice of 10 or 25 years from step 1 and a certainty equivalent selected by the patient. Finally, step four was repeated using the 50/50 gamble between the certainty equivalent and immediate death, versus a choice of a guaranteed survival.

Patients who were averse to the risk of surgical death, chose less than 3 years of survival rather than take the 50-50 gamble between death and 10 years of good health.

One purpose of the present study was to measure the utility to heart patients of avoiding the risk of surgical death. To accomplish this, changes were made to the McNeil et. al. (1978) method by replacing the certainty equivalent with a sequence of probabilities of outcomes. This adjustment was made because patients in the study pretest group had difficulty dealing with the substitution of each newly generated certainty equivalent. In order to reduce the potential effects of an error in the first answer causing a compound error in all the answers, each question was written as an independent one. Patients experienced less



difficulty and demonstrated a better understanding of the principle behind these questions when the probabilities were altered rather than the certainty equivalent.

#### 11.2. Ranking and Preference Scaling

Beach and Barnes (1983) expanded on the work of Stillwell et. al. (1982) to demonstrate several approximate measures that were useful in eliciting subject preferences. These included a simple ranking method, a seven point preference scale rating, and voting. The study determined that "the simple seven point rating scales yield an ordering that correlates .9 with the ordering derived from the ranking method and .89 with the ordering derived from the points method" (Beach and Barnes, 1983, p.423). The authors recommended against the voting method because it had the lowest correlation with other methods studied. Isen and Patrick (1983) also report the successful use of scaling to demonstrate preferences in an hypothetical risk situation.

Pliskin et. al. (1985) have stated that a patient need not attempt an assessment of choices in order to create a two attribute utility function. Instead, the patient may be presented with pairs of choices and asked to rank the pairs. Ranking was feasible in the Pliskin (1985) study because the outcome measure (the number of radiographs performed per year) was also a decision variable that had influence over the probability of the second attribute (probability of a tooth lesion).

### 11.3. Time-Trade-Off

Time trade-off has been considered to be empirically equivalent to the Von Neumann and Morgenstern standard gamble by Torrance et.al. (1982). In the Torrance study, patients were asked to determine a point of indifference between a lifetime (70 years) with a chronic illness and a shorter but healthy life. The interviewer supplemented the question with visual aids. Since no lotteries were used, the researchers could not evaluate the patient attitudes toward risk, instead they developed a measure of the population mean of health states preferred to death.

Torrance et. al. (1982) recommended that questions asking patients to scale attributes of health states offer the subjects one very bad and one very good outcome. Statistical analysis of the ordered preferences is simplified by this strategy.

An example of the time-trade-off strategy has been reported by Read et. al. (1984), who found that subjects in a study of physician responses to choices of health outcomes stated that 15 years of life with severe angina was worth less than 10 years of life with moderate angina.

### 12.0. Administering the Questionnaire

Administration of the questionnaires to individuals was chosen over groups so that participants would feel more comfortable asking for clarification and offering additional comments.

As stated earlier, the questionnaire was administered in a doctor's office adjacent to a large waiting room in the Cardiology Department of the Vancouver General Hospital, and in an office of a cardiology group practice.

The questionnaire was administered essentially as a structured interview. Structured interviews about health states have demonstrated subject confusion rates of 17% (Kaplan et.al., 1979) while 27% of interviews about health states where participation by the researcher was prohibited were unusable due to indications of subject confusion (Torrance et. al., 1982). Several patients in the present study did not have adequate reading skills to do the questionnaire without help from the researcher, making the structured interview essential.

Torrance et. al. (1982) found 78% of completed interviews in a study of preferences for health states had some usable data (they demonstrated no subject confusion) when the interviewer did not attempt to clarify problems. To increase the number of usable questionnaires in the present study, patients with difficulties in understanding concepts were assisted by the researcher and the prepared visual aids. Usable data was collected from over 95% of respondents. Three patients (4.4%) were unable, or unwilling, to complete several questions. These questionnaires were excluded from the analysis.

Torrance et.al. (1982) found that patient preference questions were well accepted by the general public. A random

sample of subjects generated a 75% response rate in a later study by Sackett and Torrance (1984).

Although, patient preferences based on age of the patient have not been explored in detail, some evidence has been reported on macro-choice differences that appear in older patients. Cassileth et.al. (1980) found differences in choice behaviour and information seeking between younger and older patients. Younger patients wanted to participate in decisions, while many older patients wanted to abdicate and let doctors make decisions.

Curley et.al. (1984) studied 306 outpatients and spouses and found that 33% of older patients wanted to defer decisions to doctors. The study also explored the effect of ambiguity and found that 21% of the subjects refused ambiguous treatment while only 3% refused risky treatment. Pendelton and House (1984) also confirm that older patients with diabetes are less interested in being involved in personal care than younger patients.

Unfortunately, in the present study, even though the questionnaire was administered while the patient's were visiting their physician, (increasing the convenience for the patient), the willingness to participate was very low. Some of this very low rate of response may have been due to the older ages of many of the patients.

### 13.0. The Use of Patient Preferences Over Time

Identifying patient preferences and developing a utility

scale for patient avoidance of treatment risks was a time consuming effort. Indications are, however, that once these preferences are identified they demonstrate stability over time. Torrance et. al. (1982) found that in repeated measures of health state preferences on the same individual, choices remained consistent. This was demonstrated by high correlation coefficients (0.86 to 0.94).

#### 14.0. Statistical Analysis

Several design and environmental constraints limited the use of formal statistical analysis in this study. First, the small sample size prevented division of subjects by factors into groups with enough subjects per cell for meaningful multivariate or stratified analysis.

Analysis of results was conducted using a number of tests for statistical significance. Chi square tests were used to identify significant differences between observed and expected frequencies, and the Mantel chi square was used to test for significant trends (Mantel, 1963). Intra-observer variability was assessed using the Kappa statistic (Spitzer, 1967). Kappa measures how well two observers agree or how well a single observer makes two observations. This statistic takes into account underlying chance agreement that could occur.

A sensitivity analysis was performed on several questionnaire responses by sorting patient choices by a patient's past experi-

ence of a myocardial infarction and by exposure to coronary artery bypass grafting. The rationale for this analysis was based on the possible influence these major health events could have on patient attitudes towards treatment risk.

The difference in risk avoidance between diagnostic groups was measured using the trapezoid rule. The influence of life expectancy on risk aversion was illustrated by a figure rather than a statistic.

#### 15.0. Conclusions

The present study to determine patient preferences for treatment outcomes employed the methods described in this chapter. Efforts were made to ensure subject confidentiality, reduce subject and interviewer bias, and maintain consistency throughout the data collection.

Methods selected were those that directly involved patients in making choices. This strategy was based on the normative argument that patients ought to participate in health care decisions that affect the length and quality of their lives. The study involved patients in stable condition only.

The following two chapters describe the study questions, the subjects' responses, analysis of the responses, and clinical conclusions drawn from the analysis. Chapter three explores potential errors of judgement that could prevent a patient from expressing a true preference. Chapter four evaluates the impact

of independent variables on treatment choices and patients' responses to risk.

## CHAPTER 3

## THE STUDY OF PATIENT PREFERENCES: Errors of Judgement

1.0. Introduction

Two objectives of this study guided the development of the questionnaire used to elicit patient preferences. The first was to study patient preferences under the constraints imposed by pain and the need to make actual choices for therapy for coronary heart disease. Second, the study sought to determine if several previously observed errors of judgement in decision making in other contexts were demonstrated in medical decisions in which outcomes (including the risk of death) were real. Slovic and Lichtenstein (1983, p. 598) have recognized "the importance of motivation and the need to test nonstudent subjects."

A relatively new school of research on decision-making has focused on the influence of errors of judgement in decision making under uncertainty (Slovic and Lichtenstein, 1983; Kahneman and Tversky, 1979; Knetsch and Sinden, 1984; Thaler, 1980; McNeil et.al., 1978). An error of judgement that arises from a violation of the axioms of expected utility theory has also been termed a "decision bias" by Kahneman and Tversky (1979).

One normative construct of expected utility theory is that decision makers follow a "preference order" which implies transitivity, dominance, and invariance. Transitivity describes a situation where if alternative A is preferred to B, and B to C, then A will be preferred to C. Dominance describes the clear



preference of one alternative state over one or more other alternatives or states. Invariance is the condition where small variations in an outcome will not affect choice (Keeny and Raiffa, 1976). Invariance does not refer to the way a decision problem is presented, such as variations in wording.

In this chapter each potential error of judgement is discussed and the questions used to test it are described. The errors described and tested in this study were: the certainty effect, preference reversal, the formulation effect of framing, consistency of choice (the substitution effect), asymmetric choice, willingness to pay, and the endowment effect. The studies reported are those whose methods and questions to subjects were most influential in the development of the patient questionnaire in the study of patients with heart disease.

## 2.0. The Certainty Effect: an Example of Risk Aversion

The theory of expected utility states that the value to an individual of an outcome is weighted by the probability of the occurrence of the outcome. This theory does not allow an event with a high probability outcome or a "sure thing" to have more relative value than outcomes with any other level of probability when these are weighted. Expected utility theory is violated when decision makers place proportionally greater value on a specific outcome that is considered "certain" or "for sure" than they do on an outcome that may occur with reasonable

probability. For example, when asked to choose between a 100% chance of winning \$300.00 and an 80% chance of \$400.00, most subjects choose the \$300.00 for sure, even though the expected value (EV) of the alternative choice is higher (\$320.00). Kahneman and Tversky (1979) call this phenomenon the overweighting of certainty, or "the certainty effect".

A number of studies in cognitive psychology and in clinical medicine have reported that subjects prefer a modest outcome for sure rather than a taking gamble on a very good and a very bad outcome even when the expected value is the same (Kahnemen and Tversky, 1979; McNeil et.al., 1978; Pauker, 1976; Keeny and Raiffa, 1976). Keeny and Raiffa (1976, p. 149) define such a decision maker as "a risk averse person".

Kahneman and Tversky (1979) tested for the certainty effect using 95 student subjects. When they were asked to make a choice, 20% of the subjects chose an 80% chance of \$4,000 (EV=\$3,200) while 80% chose \$3,000 (EV=\$3,000) for sure. The expected value of the first choice was higher, but this was overshadowed by the influence of the certainty of getting \$3,000.

The domination of an outcome with a high probability over an outcome with a lower probability associated with a higher expected value has also been found by McNeil et.al. (1978) in cancer patients. These patients demonstrated a preference for

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1 The expected value of an outcome is calculated by multiplying the probabilities and the values of each component of the outcome. An expected value is identified in the text by the notation 'EV'.

treatment outcomes (radiation) with no risk of early death even though the expected survival time for these patients was less than for the treatment option that had a risk of early death (surgery).

Pauker, Pauker, and McNeil (1981) studied parents' choices under conditions that carried the risk of a negative outcome. This study included 338 prospective parents taking genetic counselling for possible defects in unborn children. These subjects were asked:

"At what chance of a pregnancy's producing a severely deformed child would you prefer an elective abortion to the risk of having a live-born child affected by that deformity?"

Parents were able to state the level of risk of bearing a deformed child that would encourage them to elect to have an abortion. The distribution of acceptable levels of risk was wide with numerous peaks, indicating that these preferences were influenced by personal values as well as by risk.

Attitudes toward treatment risk were explored in the present heart study by asking patients to determine a threshold level of years of pain-free life that compensated for bearing a risk of death from treatment.

In the risk avoidance question patients were expected to demonstrate a preference for a modest outcome for certain. A modest outcome refers to a health state that is intermediate between perfect health and complete disability. If subjects preferred the intermediate outcome, they were asked to determine

the compensation needed to make the alternative treatment (with the risk) as good as the modest outcome (with the certainty effect). Patients who did not select the modest outcome were asked to state the number of additional pain-free months needed to make the rejected option equivalent to the preferred option. The question used was described as a treatment choice.

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Listed below are two treatments with different long term outcomes. These treatments have different risks. Choose one. Assume that if you survive the treatment you live as long as you expect to live, but you will have angina pain.

treatment A: This treatment completely eliminated angina pain for an average of 6 years for 90% of patients, 10% suffered complications and died.

treatment B: This treatment completely eliminated angina pain for an average of 5 years for all patients.

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The rationale for a sensitivity analysis of this question was based on the determination of how much compensation seemed 'fair' to patients when they were exposed to a risk of death of 10%. Patients who asked for compensation may not have realized that treatment A had an expected pain-free time of 5.4 years while treatment B had 5 years of pain-free time. This sensitivity analysis allowed an estimate of the negative value of treatment risk and the positive value of a treatment whose outcome was known 'for sure'.

### 2.1. Results of Questions on the Certainty Effect

In the certainty effect questions, 46 out of 64 subjects (72%) selected five years with no angina pain 'for sure'. These subjects were then asked to state the compensation needed to accept the risky treatment. They asked for an average of 4 more years with a range of one to twenty years additional good health to accept the 10% risk. The expected value of the risky choice was 5.4 years, higher than the certain choice.

The clinical implications of the strong influence of the certainty effect should suggest to physicians that many patients do not value the length of their life above a number of other values, one of these being the certainty of being alive. Patients should, therefore, be offered an opportunity to express a preference for a treatment that may, in the view of the physician, be less effective in prolonging life - if the objective of treatment is to maximize the welfare, or well-being of the patient.

### 3.0. Preference Reversal

Slovic and Lichtenstein (1983, p. 596) stated that "Preference reversals occur when individuals are presented with two gambles, one featuring a high probability of winning a modest sum of money (the P bet), the other featuring a low probability of winning a large amount of money (the \$ bet)." The typical

finding was that people often chose the P bet but assigned a larger monetary value to the \$ bet even though the expected values are the same. This behavior is of interest because it violates the axiom of preference order. A "preference model" is violated "due to the strong dependence of choice and preferences upon information processing considerations" (Slovic and Lichtenstein, 1983, p. 597).

Lichtenstein and Slovic (1971) argued that the way the subjects processed information differed depending on whether the decision was simply a choice or whether the subject was required to set a price (or value) on a gamble. In a later paper, Slovic and Lichtenstein (1983, p. 598) observed that "choices among pairs of gambles appeared to be influenced primarily by probabilities of winning and losing", whereas an attractive outcome for a gamble appeared to encourage a higher bid.

Preference reversal may also be related to a behaviour pattern described by Thaler (1985) in a study of betting behaviour among race track patrons. Thaler showed that patrons frequently placed a small bet on a long shot chance to win a large sum, while they appeared averse to even-money bets independent of their past wins or losses. Kahneman and Tversky (1982) have demonstrated that preference reversal can be induced by the manner in which the information is presented to subjects.

The Slovic and Lichtenstein (1971) study asked subjects to choose between and to bid for the following pairs of gambles:

Pair #1: 9/12 to win \$1.20 and 3/12 to lose \$.10; (P bet)  
 Pair #2: 3/12 to win \$9.20 and 9/12 to lose \$2.00. (\$ bet)  
 EV for Pair #1 = 0.875; EV for Pair #2 = 0.70.

Lichtenstein and Slovic (1971) found that 63% of subjects preferred the 'P bet' to the 'dollar bet' while only 29% of the subjects set a higher value on the 'P bet'. Grether and Plott (1979) found that for subjects who were motivated by real money, 70% of the initial choices of P bets were reversed by the prices given to the \$ bets. The following is one of the pairs of gambles in the Grether and Plott (1979) study. Subjects were asked to bid with real money for, and to choose between, the following pairs of gambles:

Pair #1: 35/36 to win \$4.00 and 1/36 to lose \$1.00; (P bet)  
 Pair #2: 11/36 to win \$16.00 and 25/36 to lose \$1.50. (\$ bet)  
 EV for Pair #1 = \$3.97; EV for Pair #2 = \$3.85.

Throughout the questionnaire used in the present study, the 'P bet' is labelled a "sure bet" and refers to a high probability of a short term health improvement while the '\$ bet' is labelled a "gain bet" and refers to a low probability of a long-term health improvement. The change in terminology was deemed necessary because there were no money bets in the questions developed for the heart study.

The questions used to identify preference reversal behaviour in the present study were adapted from research by Slovic and

Lichtenstein (1971) and from a replication of this work by Grether and Plott (1979). Instead of a money bet, patients in the preference study were asked to 'bet' weeks of hospital treatment in order to 'win' years of relief of angina pain. The graphic demonstrations used to assist patients in understanding the chances of winning and losing were adapted from Grether and Plott and adjusted to represent real probabilities of treatment outcomes. (see Appendix II for the visual aids for the study.)

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In the patient preference questions, patients were first asked to state the number of weeks they would be prepared to stay in hospital to achieve the following outcomes stated as gambles:

Outcome A: 98% chance of 2 years with no angina pain,  
2% chance of pain the same as it is now.  
(EV = 2 years with no pain)

Outcome B: 25% chance of 8 years with no angina pain,  
75% chance of pain the same as it is now.  
(EV = 2 years with no pain)

Later in the questionnaire, patients were asked to state which was the preferred treatment outcome (A or B) from the same pair of gambles.

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An indifference option was included in these questions in order to reduce bias due to what Grether and Plott (1983, p. 626) call "systematic resolution of indifference on the part of



subjects forced to record a preference." Systematic resolution occurs when subjects who may really be indifferent choose the same option (e.g. they always choose 'A') every time they feel indifferent.

To identify how much patients valued the difference between 100% and 98% chance of treatment success, the questionnaire asked patients who chose Treatment A to consider choosing a 100% chance of one year with no angina pain instead of Treatment A. There was considerable resistance among patients and healthy subjects to changing a choice. When the subject did not agree to change, he/she was offered the original year plus additional months up to 11 more months. The results showed that patients and healthy subjects overvalued the 100% chance of one year free of angina pain compared to a 98% chance of two years with no angina pain. This was demonstrated by patients and subjects accepting much less than the expected value of a 98% chance of 2 years free from pain. Many respondents appeared satisfied with a 100% chance of 15 or 18 months.

Patients who selected the 25% chance of eight years with no angina were asked to consider a 50% chance of five years with no angina. The sensitivity analysis of this question was conducted by allowing the probability of the "50% chance of 5 years" to vary at the subject's discretion. The expected value of a "25% chance of 8 years" is two years while the expected value of "50% of 5 years" is 2.5 years. Those who chose the 50% chance of five

years may have anchored on the 50%, or they may have had an understanding of expected value. Those who continued to choose the "25% chance of 8 years" were assumed to focus on the outcome (years) rather than the probability. This sensitivity analysis was the strategy for demonstrating the hypothesis of Slovic and Lichtenstein (1983) stated above.

### 3.1. Results of Preference Reversal Questions

The contribution this study makes to the understanding of preference reversal is not just a demonstration of its presence, but an exploration of the influence of indifference on its appearance. In this study, subjects were permitted to bid the same number of weeks in the hospital for both treatments. They were also able to bid 'no weeks'. When asked to choose between outcomes, subjects could state indifference, although only one subject actually did. Constraints of the original demonstration of preference reversal were relaxed by asking for 'bets' on a non-money gamble, and by allowing indifference.

Table 3.1 summarizes the results for all subjects. The choices are labelled 'A' and 'B', as they are in the questions. Indifference is identified as 'A=B'. Preference reversal appears in the lower left cell in the table, while the opposite of preference reversal (called an inconsistent choice) appears in the upper right cell. Throughout all diagnostic groups, the high

probability outcome is preferred, as shown in the left hand cells of the table.

Table 3.1 Preference Reversal for all Subjects, n=64

		choice		
		A>B	A=B	A<B
bid	A>B	22 (34.4%)	1 (1.6%)	4 (6.3%)
	A=B	9 (14.1%)	0 (0.0%)	5 (7.8%)
	A<B	11 (17.2%)	0 (0.0%)	12 (18.8%)

note: A represents the sure bet  
B represents the gain bet

### 3.2. Discussion

When the results from all subjects were tabulated, only 11 out of 64 (17%) exhibited preference reversal. This finding is counterbalanced by four subjects (6%) who exhibited a decision pattern opposite to preference reversal, termed an "inconsistent choice". An additional 14 subjects (22%) were indifferent between the choices when they bid weeks in hospital for them, but all of these subjects identified a preference between the options when asked to choose one. Only one subject was indifferent between the options when he had to choose between them, although he preferred 'A' when bidding.

The results of these questions demonstrated a trend toward the high probability outcome. In all, 42 subjects (66%) chose 'A' when asked to choose a treatment, although the initial bids for 'A' and 'B' were widely dispersed (from 1 week to 52 weeks).

When diagnostic groups were compared, the patterns of response were most similar between the healthy subjects and the heart disease control patients. The healthy subjects (n=15) exhibited preference reversal 20% of the time, while heart disease controls (n=20) exhibited it 35% of the time. Among those patients with pain and disability, only 7% of patients with mild angina (n=15) demonstrated preference reversal and none of the patients with severe angina (n=14) did. These two groups had the largest proportion of subjects bidding for, and actually choosing, either 'A' or 'B'. This was an unanticipated occurrence that could have been due to the small sample size.

When asked to talk about their choices, patients with severe angina seemed realistic about their future health. One-half of the patients in this group had already received a coronary artery bypass graft. Patients choosing  $A > B$  on both the bid and the choice stated that their focus was on the 'certain' qualities of a 98% chance of no more pain. Those patients choosing  $B > A$  on both the bid and the choice said that an eight year period of pain relief was an attractive gain because it would likely be as long as their expected lifetime.

Several healthy subjects and heart disease control patients who demonstrated preference reversal described their reasons for making a treatment choice stating that they were willing to bid more weeks in hospital for treatment 'B' because if it didn't provide pain relief, they would subsequently take 'A' with the high probability of two years with pain relief. These subjects were reminded that a fall-back position was not available under the constraints of the question.

#### 4.0. Framing: The Formulation Effect

Research studies in several fields of decision making have demonstrated the influence of framing bias. This bias occurs because the wording of a question has the potential to alter a subject's response. Kahneman and Tversky (1984, p. 16) suggest that "A physician ... could influence the decision made by the patient ... merely by the framing of outcomes and contingencies." McNeil et. al. (1982) demonstrated the effects of framing with different scenarios and descriptions of treatment outcomes: first, in terms of percent mortality, and second, as average years of life of survival after treatment. The study by McNeil et. al. (1982) used 238 male patients in an ambulatory setting, 424 radiologists and 491 graduate students in business school as subjects for a framing test. Here is the question from the "mortality frame".

Of 100 people having surgery, 10 will die during treatment, 32 will have died by 1 year, and 66 will have died by 5 years. Of 100 people having radiation therapy, none will die during treatment, 23 will die by 1 year, and 78 will die by 5 years. Which treatment would you prefer?

The alternative way of framing of this question, called the "survival frame", asked subjects to choose a treatment when surgery offered an average life expectancy of 6.1 years and radiation offered an average life expectancy of 4.7 years. Radiation was preferred 42% of the time in the mortality frame, and 25% of the time in the survival (years of life) frame. The majority of subjects in both cases elected surgery. No lung cancer patients participated in this study.

Kahneman and Tversky (1984, p. 343) have described framing questions that violate invariance as follows:

Imagine that the U.S. is preparing for the outbreak of an unusual Asian disease, which is expected to kill 600 people. Two alternative programs to combat the disease have been proposed. Assume that the exact scientific estimates of the consequences of the programs are:

Problem 1: (152 subjects)

If Program A is adopted, 200 people will be saved. [72% chose A]

If Program B is adopted, there is a one-third probability that 600 people will be saved and a two-thirds probability that no people will be saved. [28% chose B]

..The same cover story is followed by a different description of the prospects associated with the two programs:

Problem 2 (155 subjects):

If Program C is adopted 400 people will die. [22% chose C]

If Program D is adopted, there is a one-third probability that nobody will die and a two-thirds probability that 600 people will die. [78% chose D]

Several departures from these reported techniques of demonstrating framing were made in the present study. First, medical terms that could induce preconceptions in patients were avoided. The words surgery, drugs, and angioplasty were not used as identifying terms. The reason for this change was drawn from the McNeil et.al. (1978) finding that patients may have a particular fear of treatment such as radiation and allow their preconceptions to generate avoidance behaviour even if the outcomes were preferred by the patient with an unidentified treatment. Second, the questions were kept as similar as possible, altering only the order of the outcomes. Patients were encouraged to see what the question implied by using visual aids that described the treatment outcome. The same visual aid was used for both questions (see Appendix II).

The reason for such a simple test of the effect of the formulation of the question was to determine whether a small variation could cause subjects to alter their preferences for a treatment. The framing questions were as follows:

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(a) The "wellness frame".

After a treatment for angina, some patients have no pain while some patients have pain twice as often as before the treatment. The numbers below are chances that the treatment will eliminate angina pain for 2 years. Which of these groups would be acceptable to you?

chance of no pain	pain twice as often	yes / no
A. 90%	10%	_____
B. 70%	30%	_____
C. 50%	50%	_____
D. 30%	70%	_____
E. 10%	90%	_____

If A is not a good enough 'chance' for improvement, what chance would be acceptable? \_\_\_\_\_

If E is acceptable, what lower chance is not acceptable?

(b) The "illness frame".

After a treatment for angina, some patients have pain twice as often as before the treatment, while some patients have no more pain. The numbers below are chances that the treatment will cause pain twice as often for some patients. Which of these groups would be acceptable to you?

chance of pain twice as often	no pain	yes / no
A. 10%	90%	_____
B. 30%	70%	_____
C. 50%	50%	_____
D. 70%	30%	_____
E. 90%	10%	_____

#### 4.1. Framing Effects

Framing was considered present when the patient changed his/her choice of a treatment by one level in either direction. That is, if a more conservative treatment was chosen (level B was preferred in the "wellness" frame and level A was preferred in the "illness" frame), framing was considered to be present. Subjects were considered to be consistent if the framing of the question did not influence their choice. Framing was also considered to be present if the illness frame caused a less



conservative choice than the wellness frame. Subjects were also permitted to avoid making a choice by stating that no treatment was "good enough" (offered a high probability of improvement), and to extend the range of treatment outcomes offered by stating an additional probability of pain relief that would be good enough. The questions used in the study of patients with heart disease differ from other framing studies because they allowed patients to continue choosing treatments until they reached a level of unacceptable probabilities of pain relief, as determined by the patient. Other studies have offered subjects two alternatives only.

Table 3.2. Framing Effects for All Heart Study Subjects, n=64

diagnosis/ outcome	framing		same	total
	more	less		
healthy	3	4	8	15
heart control	9	3	8	20
mild angina	6	3	6	15
severe angina	6	5	3	14
TOTAL	24	15	25	64

Note: 25 patients and subjects were consistent in their choices, including 2 patients who were consistent in their refusal to take any treatment.

#### 4.3. Discussion of Framing

Table 3.2 shows that 39 out of 64 patients demonstrated vulnerability to framing: 24 took a more conservative treatment with an "illness frame" than with a "wellness frame" while 15 accepted a less conservative treatment under the same conditions. A detailed evaluation of the questionnaires of the patients not making a choice showed that these patients made comments like: "I would take whichever treatment my doctor wanted me to take." Or, "I can't decide because I don't have any advice."

In previous reports of studies probing the framing bias, subjects were constrained by two choices and evaluation of some of the effects found here could not be made.

#### 4.4. Discussion of Diagnostic Groups

Framing appeared to affect all diagnostic groups to a similar extent. Seven of 15 (47%) healthy subjects exhibited framing effects. Among heart disease control patients, 12 of 20 (60%) exhibited framing while nine patients out of 15 (60%) with mild angina demonstrated it. For patients with severe angina, 11 out of 14 (79%) were influenced by the framing of the question. These differences were not statistically significant although the power to detect a difference was low.

The patients with the most serious pain and disability were the group most vulnerable to the decision bias. Of considerable

interest was the number of patients who remained consistent and appeared not to be influenced by framing. Among healthy subjects, eight of 15 (53%) were consistent. The group of patients who were heart disease controls had seven of 20 (35%) consistent members. Patients with mild angina had six of 15 members consistent while of those 14 patients with severe angina, only two (14%) were consistent. The majority of this last group were influenced by framing. Again, it was difficult to deny that patients with severe pain and disability were not influenced by this decision bias more than healthy or only moderately ill persons.

#### 4.4. Conclusions

The focus of the framing questions in this research was not to demonstrate framing alone, but to demonstrate other peripheral effects of the formulation of a question. It was possible with the format used to demonstrate that the wording of the question caused a number of effects. Would patients and subjects be induced to change their preference for a treatment whose outcome probabilities varied by more than 20%? Only one patient (with severe angina) was so strongly influenced by the wording of the question that he chose a treatment outcome with 'illness framing' 40% above the treatment with 'wellness framing'.

The clinical significance of this demonstration of framing is drawn from the fact that almost twice as many subjects were

vulnerable to framing as were consistent. These subjects also had a visual aid clearly representing the probabilities of improved health in both the wellness frame and the illness frame. Further research into identifying how patients anchor on either the first or last thing a physician says would improve the understanding of framing as a barrier to communication.

#### 5.0. The Substitution Effect

The substitution axiom of utility theory states that if one choice (A) is preferred to a second choice (B), then any change that affects both choices equally should not influence the choice of A in preference to B.

Two questions in the present study attempted to determine whether the substitution effect held for clinical decisions involving risk of death as an outcome. The first question was essentially a replication of the McNeil et.al. (1978) study of preferences for patients with cancer of the lung. Heart disease patients were offered a choice between a moderate outcome with no risk of death and an outcome with greater pain reduction accompanied by a 5% risk of death. To try to demonstrate the influence of the substitution effect, a 10% risk of death was added to both sets of outcomes while simultaneously reducing the other outcomes (pain relief, or no change) to 90% of their former level in order to maintain the total probability of outcomes at 100%. The actual results were rounded to the nearest 5%, to

reduce subject confusion. Rounding small probabilities can cause problems with the formulation of an accurate demonstration of the substitution effect in its strictest sense.<sup>1</sup> In addition, three sets of probabilities were offered to subjects, rather than the common use of two sets. The reason for this choice was due to efforts to make the decision as realistic as possible.

Theory predicts that a person choosing treatment A in the first pair of choices, should choose treatment A\* in the second pair of choices (Savage, 1954). The two series of choices are given below.

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Substitution effect, part one:

Listed below are some hypothetical procedures with risks and benefits listed; which one would you choose? Assume that you cannot have both treatments.

	no angina	same pain	risk of death
treatment A	80%	15%	5%
treatment B	60%	40%	0%

choice: A \_\_\_\_\_ or B \_\_\_\_\_ or no preference

If you chose A, what outcomes would need to be altered and by how much to encourage you to choose B?

If you chose B, what outcomes would need to be altered and by how much to encourage you to choose A?

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<sup>1</sup> The rounding of the probabilities in this example caused the utilities of the outcomes in the examples chosen to vary by .05. Clinical significance and patient understanding was given priority over mathematical equivalence in this question.

## Substitution effect, part two

These treatment groups have different outcomes, which one would you choose?

	no angina	same pain	risk of death
treatment A*	70%	15%	15%
treatment B*	55%	35%	10%

choice: A\* \_\_\_\_\_ or B\* \_\_\_\_\_ or no preference \_\_\_\_\_

What aspects did you focus on to make your choice?

---

The second pair of choices was followed by asking the patient to state which outcome was the determinant of the choice of treatment. Treatment B would likely have significant attraction for those subjects choosing treatment A (risk averse patients) in the first treatment choice, while the presence of the risk of death as an outcome in both options of the second pair of choices may swing the focus onto the pain relief, encouraging patients to alter their choice from A to B\*. In the questionnaire, the A\* and B\* markings were omitted. Some influence of the certainty effect was probably felt by patients who select choice B since the risk of death here was zero.

Option A is a fairly close approximation of the statistical outcome of bypass surgery as reported in the CASS Study reviewed in Chapter 1. Option B is a close approximation of the outcome of medical therapy for coronary artery disease.

The data from these questions were analysed in two groups: healthy subjects for whom the decision was hypothetical, and

patients with heart disease, for whom the decision was realistic. Those subjects who were consistent in their choices are identified in the A,A\* cells and the B,B\* cells on the main diagonal. Subjects who violated the substitution axiom are identified in the B,A\* cells in the lower left cell of each table.

The second question employed a sensitivity analysis to determine a tradeoff point for patients who selected treatment B. Patients were asked how much better treatment A needed to be (in terms of time free from symptoms) in order for them to choose it. This analysis was also used to identify whether there was considerable resistance among patients to assuming a 'risk' after a modest outcome 'for sure' had been chosen.

Table 3.3. Substitution Effect: All Respondents, n=100

		<u>second choice</u>	
<u>first</u>		A*	B*
<u>choice</u>	A	47	8
	B	# 19	26

notes: (a) percents equal counts when count equals 100.  
 (b) # identifies violation of the substitution axiom  
 (c) Kappa of .44 indicates poor intrasubject agreement.

Table 3.4. Substitution Effect: Heart Disease Groups, n=49

		<u>second choice</u>	
<u>first</u>		A*	B*
<u>choice</u>	A	29 (59.2%)	1 (2.0%)
	B	#13 (20.6%)	12 (19.0%)

notes: # identifies violation of the substitution axiom

Table 3.5. Substitution Effect for Healthy Subjects and Hospital Administrators, n=51

		<u>second choice</u>	
<u>first</u>		A*	B*
<u>choice</u>	A	18 (34.6%)	7 (13.5%)
	B	# 9 (17.3%)	17 (32.7%)

note: # identifies violation of the substitution axiom.

### 5.1. Discussion

It is interesting to note that heart disease patients were more consistently risk-seeking than the group of healthy adults and hospital administrators. Both groups demonstrated almost the same rate of violation of the substitution axiom: 21% for the patients, and 17% for the healthy subjects. When the subjects making a consistent choice were compared by health status, no



significant difference ( $p=.64$ ) was found between healthy subjects and heart disease patients.

A noticeable difference between these groups was that 14% of the healthy subjects made an inconsistent choice in the opposite direction to violation of the substitution axiom, while only 2% of the patients with heart disease made this choice.

Comments from this group added to the understanding of these responses. A typical verbal response from a patient with heart disease was "I chose A in the first question because the outcome was better, but I could not choose A\* in the second question because the level of risk was unacceptable." Analysis of comments of healthy subjects and patients suggests that subjects focused on pain relief exclusively when they chose A and A\*, and they focused on risk of death exclusively when they chose B and B\*. Those who violated the substitution axiom seemed to be drawn to do so when their interest in avoiding risk of death was distracted by both treatments having a risk of death (10% and 15%). Some patients claimed that these two levels were "similar". They explained that when the risk of death was similar, they focused on pain relief in order to make a choice. These comments from subjects support the assertion of MacCrimmon (1974) that subjects tend to make choices by comparing pairs of attributes.

#### 6.0. Asymmetric Choice: Choices in the Domain of Gains or Losses

Utility theory states that the value of wealth (or in this study, health) is determined by the final asset position, or final state of health, not by the particular life circumstance of the individual. Observations of actual decision making behaviour do not always support the theory. MacCrimmon (1974, p. 474) states that "risk taking may not be a general personality trait but may be very dependent on the situation the decision maker is in." Therefore, actually facing a loss may place a decision maker in a situation in which risk taking behaviour is demonstrated.

An alternative proposal for understanding risky choice has been called 'prospect theory' (Kahneman and Tversky, 1979). One hypothesis of prospect theory addresses the observation that changes in wealth from some arbitrary reference point determine decisions. In other words, decision makers have a subjective value of a loss or a gain. The utility function appears steeper for losses than gains, describing the more intense feelings associated with a loss than with a gain for the same magnitude. Thaler (1980, p. 42) has summarized the findings of the above studies as follows: "... gains are treated differently than losses. Except for very small probabilities, risk seeking is observed for losses while risk aversion is observed for gains." This generalization is drawn from a number of results including the following two examples from Kahneman and Tversky (1979).

Both examples offer identical final states of wealth.

Problem 1: In addition to whatever you own you have been given \$1,000. You are now asked to choose between:

A: a 50% chance of \$1,000

B: \$500 for sure

In this problem, 70 subjects were tested; 16% chose A and 84% chose B.

Problem 2: In addition to whatever you own, you have been given \$2,000. You are now asked to choose between:

C: a 50% chance of losing \$1,000

D: losing \$500 for sure.

In this problem, 68 subjects were tested; 69% chose C and 31% chose D.

To test whether utility theory described choice behaviour, or whether changes in asset position were more important, patients in the present study were asked to make treatment choices where changes in asset position over either gains or losses could cause different behaviour.

The questions used in the heart study to test patient's subjective value of gains or losses in relation to states of health are set out below.

(a) Choosing between gains.

Choose between the following two treatments:

treatment A: A 50% chance of no angina pain after any amount of exercise, and a 50% chance of pain the same as it is now;

treatment B: Twice as much exercise for sure with no angina pain.

(b) Choosing between losses.

Choose between the following two treatments.

treatment A: A 50% chance of no angina pain after any amount of exercise, and a 50% chance of not being able to exercise at all;

treatment B: A certain loss of 1/2 of your current exercise time before angina pain the same as it is now.

Patients were also asked:

How long can you exercise now before angina pain?

How many blocks can you walk without angina?

---

The study questions were biased in favour of eliciting a choice similar to those described in prospect theory. This theory states that subjects will prefer a modest outcome for sure (and are therefore risk averse) in the domain of gains but prefer a risk in the domain of losses. The loss question was biased by improving the 'gamble' of the loss from a 50/50 chance of the status quo or a loss (as in the Kahneman and Tversky (1979) questions), to a 50/50 chance of a gain or a loss. Should subjects demonstrate risk aversion in the domain of losses, the study results would suggest a demonstration of utility theory rather than prospect theory. If subjects were risk seeking in this domain, prospect theory would not necessarily be supported because the 50/50 gamble in the heart study was somewhat better than the gamble posed in the tests of the theory by Kahneman and Tversky (1979).

Patients and healthy subjects were asked to make two consecutive choices, one replicating the domain of gains and the

other replicating the domain of losses. All patients were reminded of their current level of symptoms while healthy subjects were asked to imagine a level of exercise tolerance of one-half hour. For very ill patients, exercise time was minimal, and for some patients, nonexistent. This factor may have had an influence on the unique pattern of responses found in the group of patients with severe angina.

The choices made in the first question were represented by the 'gainbid' rows, while the choices made on the second question were represented by the 'lossbid' columns.

In Tables 3.6 and 3.7, the first number listed in each cell is the number of subjects making the combined choice. The second number is the proportion of the total number of subjects found in each cell. Row totals and column totals are labelled.

Table 3.6. Asymmetric Choice for All Heart Study Patients, n=49

		<u>lossbid</u>		
		A'	B'	total
<u>gainbid</u>	A	5 10.2%	9 18.4%	14 28.6%
	B	9 18.4%	26 53.1%	35 71.5%
total		14 28.6%	35 71.5%	49 100.0%

Table 3.7. Asymmetric Choice for All Healthy Subjects, n=51

		<u>lossbid</u>		
		A'	B'	total
<u>gainbid</u>	A	14 27.5%	8 15.7%	22 43.2%
	B	15 29.4%	14 27.5%	29 56.9%
total		29 56.9%	22 43.2%	51 100.0%

### 6.1. Discussion

Across all 100 subjects, 36% of subjects were risk-seeking on the first choice (gains), while the majority, 64%, were risk averse. When a comparison was made of risk averse choices (the B,B' choice) among healthy subjects and patients with heart disease, the groups were found to be significantly different ( $p=.016$ ). On the question relating to a loss situation, 57% were risk averse while 43% of the subjects were risk-seeking, less than would be expected with a money question of the same nature. The significant departure from prospect theory is the 57% of subjects who are risk-averse in this situation. In fact, 40% were risk averse in both questions.

Three very interesting trends were established in these data. First, the upper right-hand cell of each table presents

the responses to the two questions as predicted by prospect theory. The healthy subjects and patients represented by this cell have responded in a risk averse way to the first question and in a risk seeking way to the second question. Of the healthy adult subjects ( $n=15$ ), one-third responded in the pattern predicted. In both the heart disease controls ( $n=20$ ) and the patients with mild angina ( $n=15$ ), 20% made a risk-averse choice in the gain question and a risk-seeking choice in the loss question. However, of the 14 very ill patients (those with severe angina,  $n=14$ ), only 14% responded as predicted by prospect theory. This evidence offers some support to the initial question posed by the study that pain and disability influence decision strategies - including errors of judgement. Less than half as many very ill patients as healthy subjects demonstrated the pattern predicted by prospect theory. Previous research on asymmetric choice behaviour has been conducted primarily on young, healthy subjects using money bets. The heart study evidence with subjects demonstrating other demographic characteristics suggests that the accepted theory may not be generalizable especially if choices used are hypothetical.

The second interesting finding is that a different per cent of healthy subjects and patients were risk averse on both choices. This choice is displayed in the lower right-hand cell in Tables 3.6 and 3.7. Among healthy subjects, 28% demonstrated this choice pattern while 53% of heart disease patients exhibited

it. The third interesting finding is that the most severely ill patients are the most consistently risk-seeking over both choices. This group chose the risky outcome 29% of the time while the other groups chose these outcomes only 7% of the time (healthy and mild angina), or not at all (heart disease controls). To understand the thought processes underlying this pattern, an analysis of patient's comments on this question was conducted. A patient with severe angina commented: "I would choose the 50/50 gamble in question (a) because my exercise time is so short now that twice nothing is still really nothing." Similar reasons were apparent for choices on the second question. One patient replied: "I would be glad to risk not being able to exercise at all for a 50% chance of freedom from this pain." The choice that created the biggest difference between the groups was this risk seeking choice by severely ill patients on question (a). It is almost the complete reverse of the pattern demonstrated by healthy subjects. This is a trend worth further investigation.

## 6.2. Conclusions

The data collected from the 64 heart study subjects and 36 hospital administrators in this study did not strongly support the observations of asymmetric choice as it has been described. Only 24% of all respondents (n=100) were risk averse in the domain of gains and risk seeking in the domain of losses. At



least half of every group except hospital administrators were risk averse over both choices; 20% of administrators demonstrated this pattern. The heart study patients generally preferred a modest outcome for sure rather than a 50/50 gamble between a very good and a very poor outcome or a very good outcome and the status quo.

The exception to this general finding was risk seeking over gains and losses by patients with severe angina. Risk-seeking choices may have been encouraged by the pain and disability experienced by patients with angina. For many patients, even the status quo (as it is described in the first question) is a poor outcome because it is based on current pain and disability. Further discussion of the risk seeking behaviour of the very ill patients appears in Chapter 4.

Physicians and other health professionals treating those patients who must make a treatment choice can best meet the needs of the patient by applying strategies similar to those just described that differentiate risk-seeking and risk-averse patients. Although the most seriously ill patients in this study were the most consistently risk-seeking, the difference between patient groups was not statistically significant.

#### 7.0. Willingness to Pay

Efforts have been made by economists to adapt market strategies to understand the value to consumers of health care

consumption in a situation where there is no cost to the patient at the point of service delivery. Mendeloff (1983, p. 575) has stated that " in a market context we expect people to pay more to reduce risks that they do face than risks they do not face." One application of these efforts has been a measure of 'willingness-to-pay' for health care services, especially when those services have been paid for by either private or public insurance. Willingness-to-pay may be viewed as a measure of the value of the service to the consumer or a technique of exploring "individual valuations of probabilities of death" (Evans, 1984, p. 255). Several problems exist with this measure, not the least of which is that consumers may not be the best judges of what and how much health care they should consume (Evans, 1984). Consumption, therefore, is usually dependent on the agent's (usually the doctor's) determination of the patient's need for care which may not reflect the value of health care to the patient.

Problems with willingness-to-pay are also due to the fact that "valuations are not linear" (Evans, 1984, p. 256). A long life appears to have less value than a short one. In addition, these measures are uni-dimensional and do not take into account the value of an individual's life to his/her family and friends.

Generally, willingness-to-pay measures utilize a proportion of income or net worth as a means of establishing the value of a

health care service.<sup>3</sup> Medeloff (1983) cautions that questions asking what people ought to pay for a health program and questions asking people what they will pay lead to different answers. The present study has adopted the latter strategy as a method to try to quantify how much patients value a treatment program.

Thompson et. al. (1984) have explored this issue in arthritis patients and identified a number of constraints. First, a very low response rate (27%) applied to the willingness-to-pay questions posed to patients with chronic arthritis. The researchers suspected that this concept may be a difficult one for patients to grasp. Second, Thompson et. al. (1984) could offer only tentative findings because of limited statistical significance of the results of regressions. They concluded that many patients with less severe arthritis were more influenced by arthritic pain than by disability. The arthritis study found that the patient responses to the willingness-to-pay measure seemed to be affected by what seemed 'fair' rather than by personal variables such as income. In addition, problems with framing and interviewer technique impaired the validity of the questionnaire.

Berwick and Weinstein (1985) reported that patients were willing to pay for diagnostic information for its own sake, not just for its role in medical decision making. Sixty-two patients

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<sup>3</sup> Other research on the value of health care services may be found in Acton (1973, 1976).

in this study were asked to value seven items of information about the status of their health and that of their fetus. The majority of patients wished to know whether the baby was normal and whether their own health was normal. They were also willing to pay, in some circumstances, to have information withheld. For example, in this study, nearly 50% of women eligible for ultrasound diagnosis during pregnancy wished to keep the gender of the baby a surprise. Berwick and Weinstein found that income level had a significant effect on willingness-to-pay, with four very wealthy patients skewing the average willingness to pay from \$430 per patient to \$709 per patient.

Tversky (1967) has explored transactions similar to willingness-to-pay behaviour. In the Tversky study subjects were asked to state a lowest selling price for a gamble in an experiment. Subjects were also asked their maximum buying price for the gamble. The selling price was usually higher than the buying price.

The patient preference questionnaire in the present study avoided the problems of monetary trade-offs for health services by asking patients to trade a per cent of a reasonable sum of money for one year of retirement for an altered waiting status for heart surgery. In this way, it was hoped that the fairness issue would be resolved and all patients could trade a commodity of similar relative value. Evans argued (1984) that valuations should not be biased by individual wealth while they maintain

an individual approach. Therefore, in the analysis of results for this question, the percent of the sum the patient was willing to pay was used. This reduced the bias of large and small retirement 'needs'.

Initially, patients were offered the opportunity to "buy out" of a 5% chance of having a heart attack over a 6 month period. Patients were asked how much they would be willing to pay to get rid of the 5% risk (gamble). Patients were asked to pay for eliminating the risk for 3 months, 5 months, and all but 1 day. The following three questions evaluated patient willingness-to-pay and compensation demanded for changing positions on a hypothetical waiting list for treatment:

---

To determine how many dollars you have for this question, state how much money you need for 1 year of retirement, and make that your annual income. Income = \$ \_\_\_\_\_

You are on a 6 month waiting list for heart surgery. If other positions on the list were available, how much of your income for one year would you be willing to exchange for the positions listed below? If you wait there is a 5% chance you could have a heart attack.

To wait only 3 months I would pay \$ \_\_\_\_\_

To wait only 1 month I would pay \$ \_\_\_\_\_

To not wait at all I would pay \$ \_\_\_\_\_

---

### 7.1. Results of Willingness to Pay

Table 3.8 summarizes the number of subjects who were prepared to pay to reduce a 5% risk of a heart attack.

Table 3.8.

Willingness to Pay for All Patients and Healthy Subjects, n=64

time frame:	3 mo.	5mo.	all but 1 day
number who would not pay:	20	13	8
number who would pay (% income)	44 (39.9%)	51 (46.1%)	56 (56.2%)

### 7.2. Discussion

Subjects in the present study were willing to pay for reducing the risk of a heart attack when the risk could be eliminated sooner rather than later. More subjects refused to pay to reduce a risk they would bear for three months than refused when the risk would last only until tomorrow. When patients were asked how they thought about this risk, a typical reply was that a 5% risk for one day would not likely affect them, while a 5% risk over a period of months might affect them. This thought process may be similar to Tversky's (1974)

finding that subjects tend to overestimate small probabilities while underestimating large ones.

### 7.3. Conclusions

As with previous studies of willingness-to-pay, the present study produced no conclusive evidence that this technique can measure the value of treatment (as a method of reducing risk) to a patient. The data certainly indicated a trend that patients prefer treatment sooner rather than later. However, between 12% and 30% of patients would not pay anything to take a treatment that would reduce the risk of a heart attack, either because they did not feel the risk was significant or they had little confidence in the treatment.

### 8.0. The Endowment Effect

Thaler (1980) introduced the term 'endowment effect' to describe the reluctance of people to part with things (or positions) they already possess. The endowment effect appears to be strong when subjects are asked to state selling prices for goods or rights they already possess and buying prices for the same goods when they have not been owned before. Knetsch, Kahneman and McNeil (1985) demonstrated this effect in a study of compensation demanded by renters who were asked what compensation they would accept in order to move to another apartment. For an

average rent of \$443.00, renters asked for compensations of \$1,000.00 to \$10,000.00.

In the patient preference study, heart patients were asked their willingness to 'sell' top positions on a hypothetical waiting list. The compensation demanded for a top position was a proxy for the value of the position that had already been 'endowed'. If the endowment effect was in operation, this value would be larger than the price a patient would be willing to pay for a position when the patient was told he was on the bottom of the list.

The questions were as follows:

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You are on a 6 month waiting list for heart surgery, and you are first on the list. You have already waited 6 months. Waiting longer has a 5% chance that you could have a heart attack. The same money is available to everyone on the list as is available for you. No one is sicker than you.

Would you give up your place to wait 1 more week? \_\_\_\_\_  
 How much compensation would you want? \$ \_\_\_\_\_

would you give up your place to wait 3 more months? \_\_\_\_\_  
 How much compensation would you want? \$ \_\_\_\_\_

Would you give up your place to wait 6 more months? \_\_\_\_\_  
 How much compensation would you want? \$ \_\_\_\_\_

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#### 8.1. Results of the Endowment Effect Questions

Subjects were expected to ask for more compensation to sell



what was viewed as a positive state than they were willing to pay to acquire it. They were also expected to be reluctant to relinquish a position that would expose them to the risk of a heart attack. Very few subjects were willing to give up first place on the waiting list for any amount of money. Table 3.9 indicates the compensation demanded by those who were willing to give up their position.

Table 3.9. Compensation Demanded, n=64

give up one week	53 subjects (83%) would not sell or trade their positions. 11 subjects would give them up for 38% more income.
give up three months	58 subjects (91%) would not sell or trade their positions. 6 subjects would give them up for 57% more income.
give up six months	60 subjects (94%) would not sell or trade their positions. 4 subjects would give them up for 53% more income.

notes: (i) Compensation is listed as an additional per cent of a stated annual income.

(ii) For subjects who would not accept compensation, the researcher confirmed with each subject that even 100% more income would not encourage the patient to relinquish the position on the waiting list. Most subjects said they would not give up their positions for any amount of money.

When it came to compensation demanded, the majority (53 out of 64, or 83%) of patients would not accept any sum of money to take on a 5% risk of a heart attack by giving up their top position on the waiting list. Those few who agreed to take compensation wanted much more money to accept a risk than they were willing to pay to avoid it once they had it. For example, among patients with mild angina, three were willing to accept compensation from another patient to accept a lower position on the waiting list. Patient #1, would pay nothing to get rid of a 5% risk for 3 months, but he wanted an additional 6% of his annual income to take on the same risk. Patient #2 also refused to pay to get rid of the 5% risk, while he wanted an additional 100% of his annual income to accept such a risk. Similarly, patient #3 was willing to pay 12% of his income to avoid the risk, wanting in return an additional 75% of his income to take it.

Again, the most noticeable difference between groups occurred with patients who had severe angina. This group was the least willing to pay to reduce risk, especially for 3 months. When these patients were asked why they didn't want to pay, a typical response was: "I waited for 3 months for my bypass with a greater risk of a heart attack than 5%. I don't think eliminating that risk (a 5% risk) is worth very much." These patients may also have had some negative feelings towards heart surgery, as noted in Chapter 4. However, they were the least willing to give up a

position on the waiting list once they had it. A clear trend was established across all groups in increased willingness to pay as the risk reduction approaches certainty. It is interesting to note that many patients were willing to pay 100% of their income to have the risk eliminated tomorrow. The constraints of the question prevented them from offering more than 100%, although a number of patients said they would pay all they could in addition to the income allowed in the question.

## 8.2. Conclusions

It is clear from the data in the present study that patients as well as healthy subjects attribute greater value to a position they currently hold than they are willing to pay to acquire such a position. Subjects' choices on questions relating to willingness-to-pay and compensation demanded should be examined simultaneously if patient preferences are to be fully understood. If health professionals are aware of the strength of the endowment effect, and its influence on decisions, patients may be more effectively counselled when a treatment chosen requires the patient to wait or if other circumstances force the patient to wait longer than expected. Waiting lists are a common source of public frustration with the health system. Findings from studies such as this one can illuminate the reasons why public sentiment can be so strong.

### 9.0. Summary of Findings

This chapter has presented the research foundations upon which the study questions relating to errors of judgement were based. Data from subject responses have supplied evidence to support previous demonstrations of the certainty effect, preference reversal, framing, the substitution effect, willingness-to-pay, and compensation demanded. Fewer subjects in the present study demonstrated asymmetric choice in the domain of gains and losses than has been found in other studies of this judgement bias when money bets were used.

The following chapter presents questions exploring the influence of independent variables on subjects' choices. The purpose of the analysis of such variables as patient's age, degree of disability, and previous treatment history, was to determine whether the errors of judgement demonstrated in this chapter were compounded in some groups of patients. Cooperative decision making by health professionals and patients could be improved by a sensitivity toward patients most vulnerable to errors of judgement.

MEDICAL DECISION MAKING: Patient Preferences, Demographic  
Characteristics, and Quality of Life Issues.

1.0 Introduction

This study of the preferences of patients with heart disease has attempted to illuminate some of the issues current health care policy is addressing by identifying preference patterns for treatment among specific groups of patients. For example, considerable attention has been focused on the influence that the ageing of the population will have on health care in Canada (Evans, 1984). The debate has centred around utilization patterns and greater needs for funding due to the increasing proportion of elderly (over 65 years of age) in the population. Evans (1984, p.309) has stated that it is not the actual ageing of the population, it is that "age-sex specific utilization rates are themselves changing, in such a way as to increase substantially the relative utilization of the elderly." Limited attention has been drawn to the actual preferences of older persons for particular types of care or for cessation of heroic interventions.

The approach of the study has been to link independent variables to the patients' treatment choices. The variables selected were diagnosis, age, previous health history, and hospital experience.

The influence of angina on patient choices was explored by asking patients to express their preferences for outcomes that required some period of morbidity, or asked the patient to bear some risk of death directly associated with treatment. The results of these questions are presented as the investment patients were willing to make in their own future health. Three time periods were explored: one year, five years, and the life years expected by each patient. Following this, the risk averseness of patients and healthy subjects is displayed in graphical form and discussed. Data are also presented that summarize patient choices when treatment carried no risk of death.

Two questions guided the analysis of the influence of age on treatment choices. First, did patients over age 65 have different preferences for treatment than younger patients? And second, are these older patients more prone to errors of judgement in decision making than younger patients?

Following the analysis of data regarding older patients is a discussion of three other independent variables: the influence of previous myocardial infarctions on choice patterns, the influence of coronary artery bypass grafting on choice patterns, and the influence of angina on choice patterns.

## 2.0 Investment in Future Health

A new emphasis on preventive health strategies and lifestyle

modification motivated a number of questions to explore patients' willingness to invest in their future health. The study questions asked how much subjects were prepared to spend for future consumption, where consumption was described as good health without symptoms of coronary heart disease. The participants indicated the number of weeks they would be prepared to spend in the hospital now for pain relief later. Although some younger patients and healthy subjects found it difficult to relate to this question when a lifetime of good health was offered to them, older subjects and patients with less than ten years of expected life did not find this question difficult to address. Patients with arrhythmia or valve disease were offered the same outcomes with angina pain replaced by 'your symptoms'. The following question was used to determine patients' willingness to invest in future health:

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In each of these questions you have to trade weeks in the hospital now for eliminating pain later. You will have pain while in the hospital.

To completely eliminate angina pain:

- a) for 1 year, I would spend \_\_\_\_\_ weeks in the hospital.
- b) for 5 years, I would spend \_\_\_\_\_ weeks in the hospital.
- c) to eliminate pain for the rest of my life, I would spend \_\_\_\_\_ weeks in the hospital.

What would you be giving up to spend these weeks in the hospital?

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Table 4.1 summarizes the findings from each group, with the standard deviation of each group included to indicate the range of investments. The graphic representation in Figure 4.1, "Investment in Future Health", indicates the importance of relating the number of weeks each patient group was willing to spend to achieve time without symptoms, to the average life expectancy of the group. The average life expectancy for each diagnostic group was calculated using the patients' subjective statements of their life expectancy.

Table 4.1 Investment in Future Health by Patient Groups

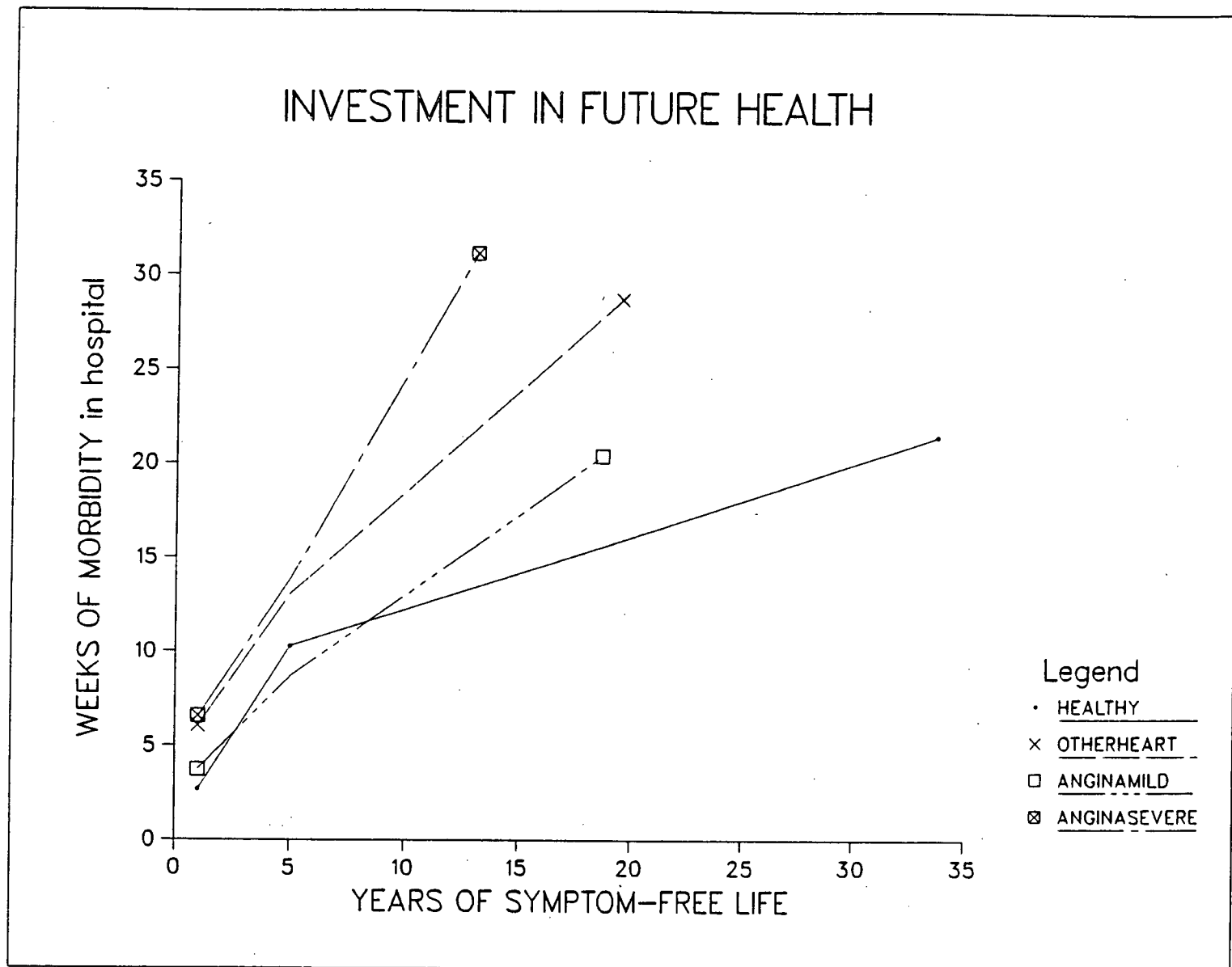
<u>GROUP</u>		<u>TIME PERIOD</u> (number of weeks bid)			
		1 year	5 years	life	perceived life expectancy (in years)
healthy	M	2.7	10.3	21.5	33.7
	SD	2.0	11.8	24.4	13.2
	Med.	3.0	8.0	10.0	35.0
other heart	M	6.1	13.1	28.7	19.5
	SD	11.2	22.6	28.1	11.5
	Med.	2.5	4.0	24.0	15.0
angina mild	M	3.7	8.7	20.4	18.7
	SD	5.9	13.3	25.6	8.8
	Med.	2.0	4.0	12.0	20.0
angina severe	M	6.6	13.9	31.1	13.1
	SD	13.4	25.3	38.8	6.9
	Med.	2.0	5.5	10.0	12.5

Notes: M=mean; SD=standard deviation; Med.=median



Figure 4.1.

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#### 4.1 Discussion

Healthy subjects had the least willingness to invest in future health when the investment was a hospital stay. This group bid an average of 2.7 weeks in the hospital for one year of good health. The patients with mild angina bid 3.7 weeks and those with other forms of heart disease bid 6.1 weeks in the hospital for a year of good health. Patients with severe angina were prepared to invest the most: 6.6 weeks for one year of good health. It was also interesting to note that, even though the seriously ill patients had less than half the life expectancy of the healthy subjects, they were prepared to invest one-third more time to ensure pain free life. These patients bid an average of 31 weeks in the hospital for only 13 years of expected life while healthy subjects bid 21 weeks for 33 years of good health.

Several patients in the study groups stated that they would be prepared to stay in the hospital as long as their doctor said they should in order to achieve a good health outcome. These patients were encouraged to state a preference when the interviewer asked if 52 weeks would be an acceptable stay to achieve one year with no angina pain. When patients realized that they had an upper bound of tolerance for a hospital stay they were prepared to focus on a personally acceptable length of time.

## 2.2. Conclusions

The results in these investment questions supported the belief of the physicians whose patients participated in the study. These physicians stated that patients were the most willing to alter lifestyle behaviours such as smoking when they had recently experienced a heart attack or severe anagina pain. In other words, a patient seemed most willing to invest in future health at a time when he/she was most ill. This finding helps to explain the momentum of the 'curative' rather than 'preventive' approach of medical care most prevalent in some physician behaviour as noted in Chapter 1. It also explains why health education and health promotion may often appear to fall on deaf ears.

## 3.0 Value of Risk Avoidance

The risk avoidance questions tested whether patients with different degrees of disability demonstrated different amounts of aversion to the risk associated with treatment. In the case of patients with coronary heart disease, the relative desirability of pain relief accompanied by treatment risk compared to continuing pain with no risk formed the trade-offs used to develop a utility function.<sup>1</sup>

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<sup>1</sup> A comprehensive discussion of utilities may be found in Arrow (1958, 1963, 1965, 1967, 1971)

Chapter 2 included a review of the method of McNeil et.al. (1978) of using certainty equivalents as points on a utility scale to describe risk aversion for cancer patients. Earlier, Pauker (1976) developed utility functions by analysis of two dimensions of preference: quantity of life and quality of life. Quality was "determined by the presence or absence of disabling angina and by the pain and suffering necessitated by coronary bypass surgery" (Pauker, 1976, p.8). In a subsequent study, McNeil, Weschelbaum and Pauker (1981) demonstrated that a utility function incorporating quality of life was displaced downward from one using only length of life. Subjects in this study were asked to give preferences for surgery or radiation for laryngeal cancer. Surgery offered a longer life expectancy at the expense of the ability to speak while radiation offered shorter survival with the ability to speak intact.

The questions used in determining patients' utility for risk avoidance were developed from the three studies described above. They were as follows:

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For this question use the number of years you expect to live as the years free of angina pain. State how many years of life you would take (with angina like you have now) in order to be indifferent between the years with angina and the following gambles.

Would you agree to take a pill that offered a 98% chance of complete recovery from your heart disease and a 2% risk of death?

yes \_\_\_\_\_ no \_\_\_\_\_

Would you agree to exchange all the years you expect to live with heart disease for one year of perfect health?

yes \_\_\_\_\_ no \_\_\_\_\_

Choice #1: This treatment is a pill that has a 50% chance of completely eliminating angina pain for your lifetime and a 50% chance of immediate death.

Take the pill? yes \_\_\_\_\_ no \_\_\_\_\_  
Take \_\_\_\_\_ years of life for sure.

Choice #2: This treatment is a pill that has a 75% chance of completely eliminating angina pain for your lifetime and a 25% chance of immediate death.

Take the pill? yes \_\_\_\_\_ no \_\_\_\_\_  
Take \_\_\_\_\_ years of life for sure.

Choice #3: This treatment is a pill that has a 25% chance of completely eliminating angina pain for your lifetime and a 75% chance of immediate death.

Take the pill? yes \_\_\_\_\_ no \_\_\_\_\_  
Take \_\_\_\_\_ years of life for sure.

---

This question was administered with the assistance of four differently coloured, empty pill capsules, each representing a 25% chance of treatment failure. Indifference was explained to subject, and for each answer offered by a subject, the researcher asked whether the years for sure were equivalent to the gamble. In other words, would the subject be prepared to take either offer? Was he/she indifferent between the two? This technique helped subjects deal with indifference and the changing probabilities of outcomes.

Patients who were risk averse were expected to take a shorter life with certainty than a longer life accompanied by a risk of death. As the probability of survival decreased from 75% to 50% to 25%, risk aversion was expected to increase more than proportionally. This expectation was based on the results of McNeil et.al. (1978) who found that cancer patients demonstrated aversion to the risk of early death due to surgery.

### 3.1. Results and Discussion

In Table 4.2 the results for each group are listed along with the average perceived life expectancy of the group.

TABLE 4.2. Value of Avoiding Life Risk

GROUP		PER CENT CHANCE OF SURVIVAL			perceived life expectancy (in years)
		25%	50%	75%	
healthy	M	2.9	10.9	18.3	33.7
	SD	2.5	5.7	10.7	13.2
other heart	M	4.4	8.3	14.0	19.5
	SD	4.5	6.1	10.7	11.6
angina mild	M	4.1	7.9	13.4	18.7
	SD	2.3	3.4	6.8	8.8
angina severe	M	2.4	6.6	9.4	13.1
	SD	1.9	3.9	4.5	6.0

Notes: M=mean; SD=standard deviation.

A comparison of the responses of each diagnostic group is presented in Figure 4.2. This figure demonstrates the relatively risk averse preferences of healthy subjects and the more risk seeking preferences of patients with heart disease. Figures 4.3 to 4.6 illustrate the bids made by each diagnostic group. A risk averse individual prefers a certain survival of  $Y$  years to any gamble for survival with expectation  $Y$ . If a subject demonstrated risk neutrality, his/her bids would fall on the diagonal line joining the origin of the graph with the upper right hand corner. Healthy subjects (Figure 4.3) demonstrated the strongest risk aversion as is shown by the steepness of the curve as it departs from the origin. Patients with mild angina (Figure 4.4) and other forms of heart disease (Figure 4.5) were less risk averse, while those with severe angina (Figure 4.6) were almost risk neutral. These subjects were almost indifferent between the gamble offered in the question and certain survival.

The contribution made by this adaptation of the McNeil et.al. (1978) study is the extension of previous understanding of patient preferences by indicating that patients can respond to preference questions with their own life expectancy as the anchor point, rather than a derived standard life expectancy set by the researcher. Data generated by this question also indicated that high levels of pain and disability reduced risk avoidance in patients with coronary heart disease.

Figure 4.2.

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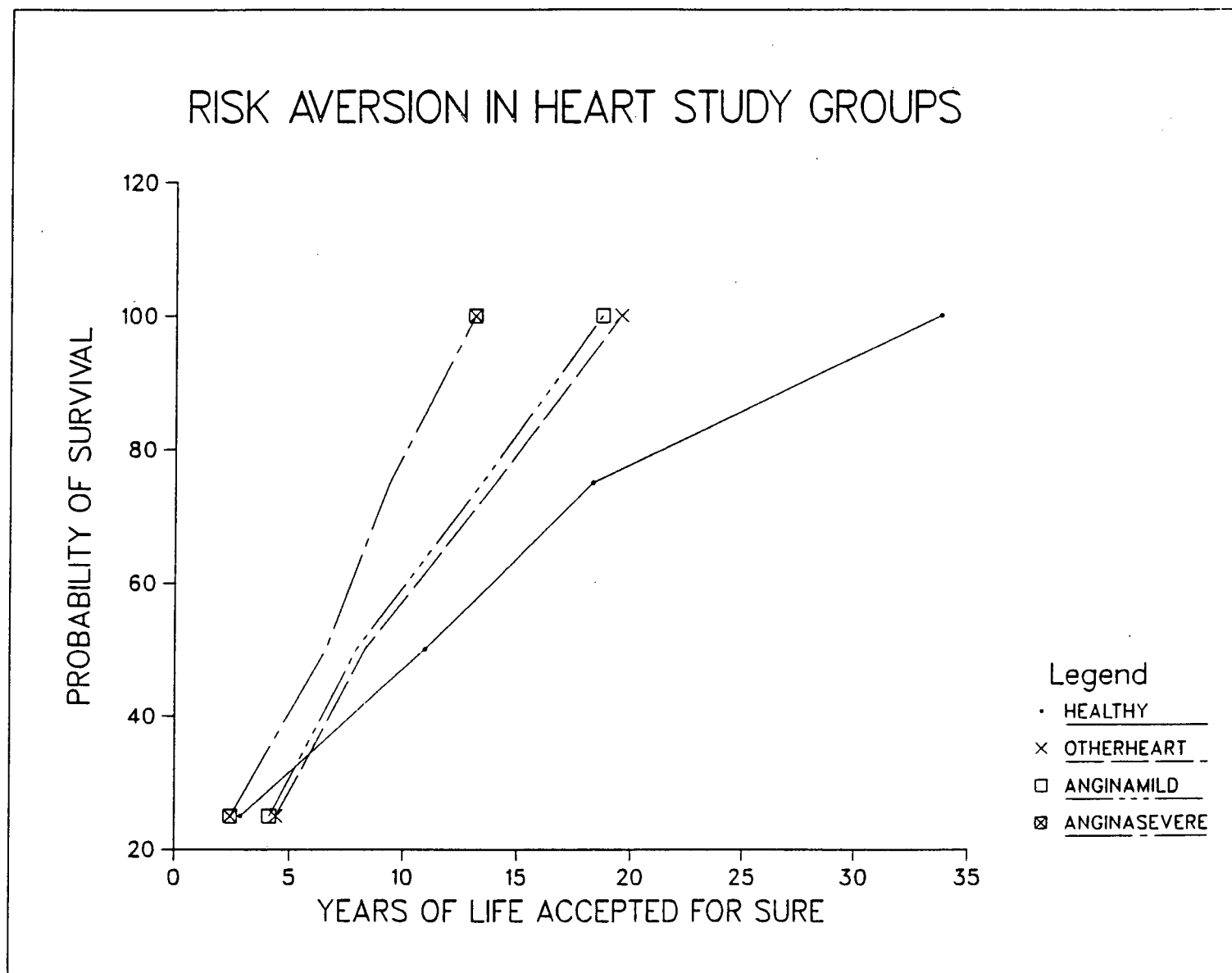




Figure 4.3.

137

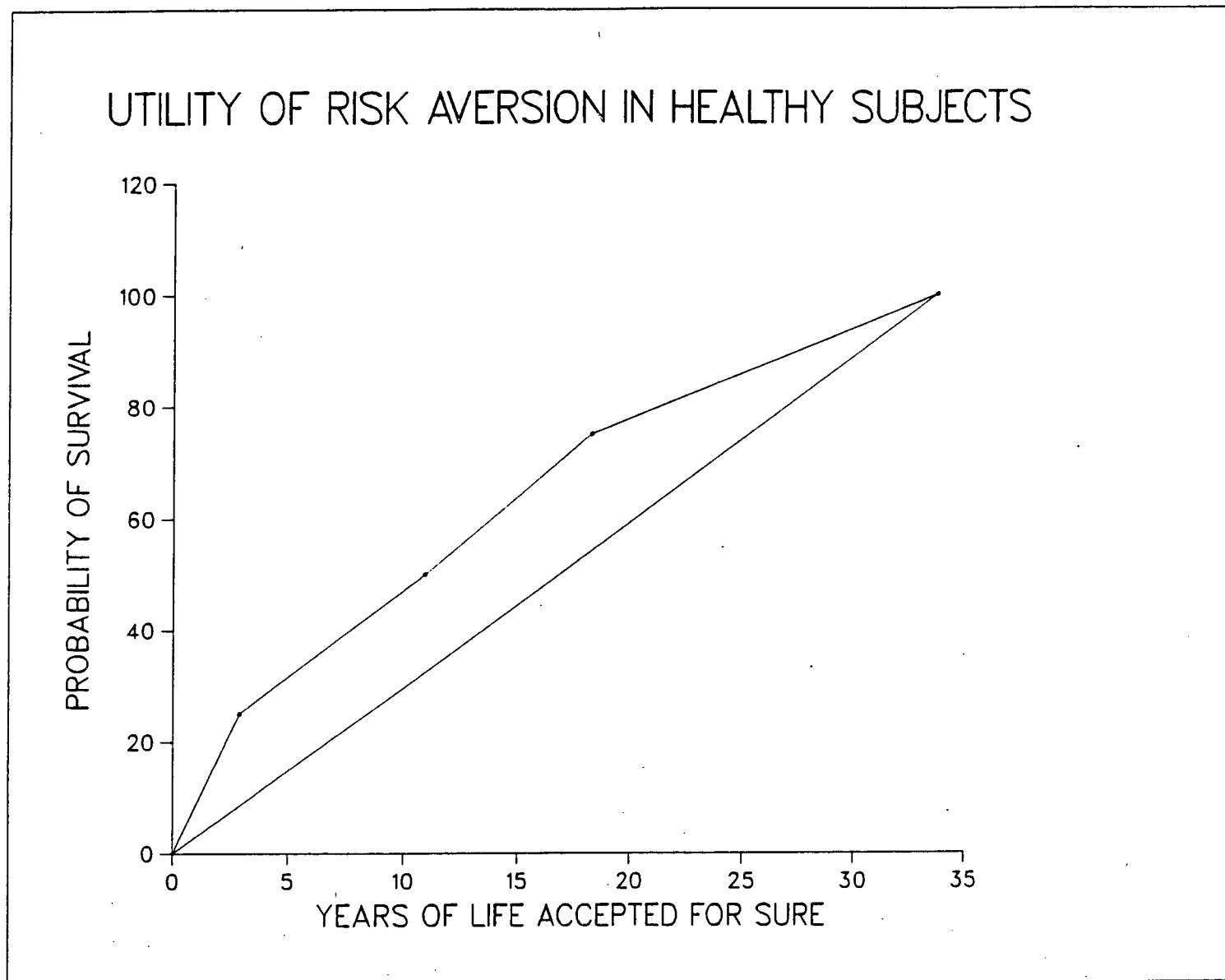


Figure 4.4.

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# UTILITY OF RISK AVERSION IN HEART DISEASE CONTROL PATIENTS

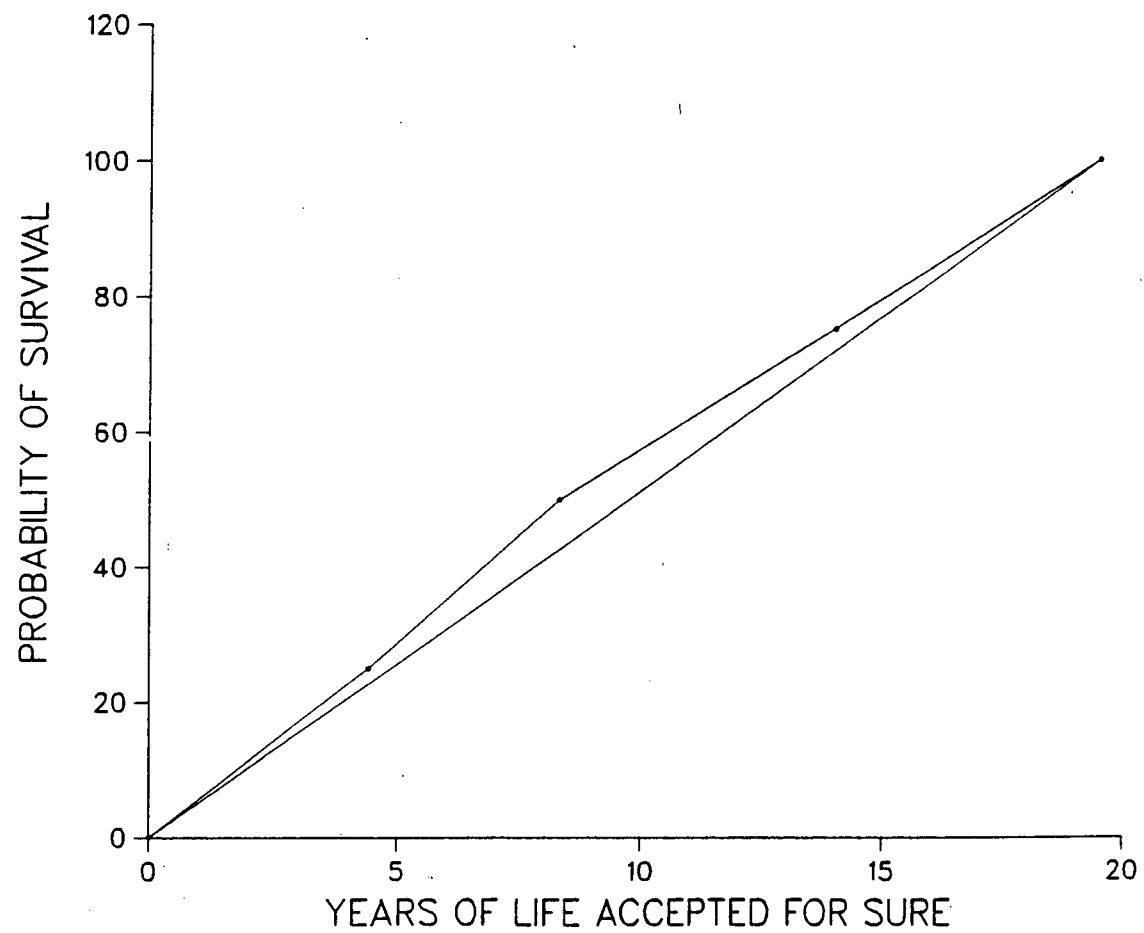


Figure 4.5.

139

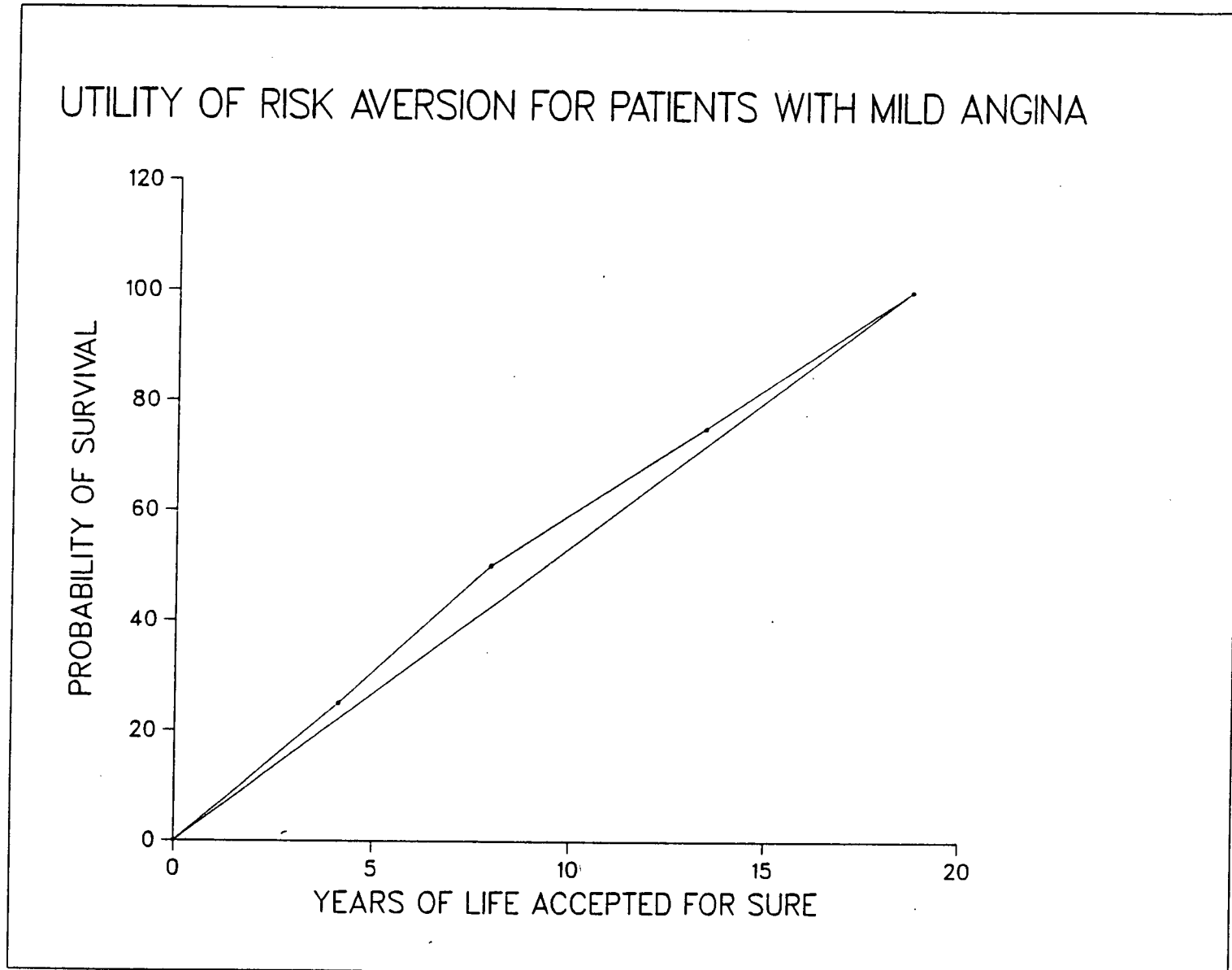
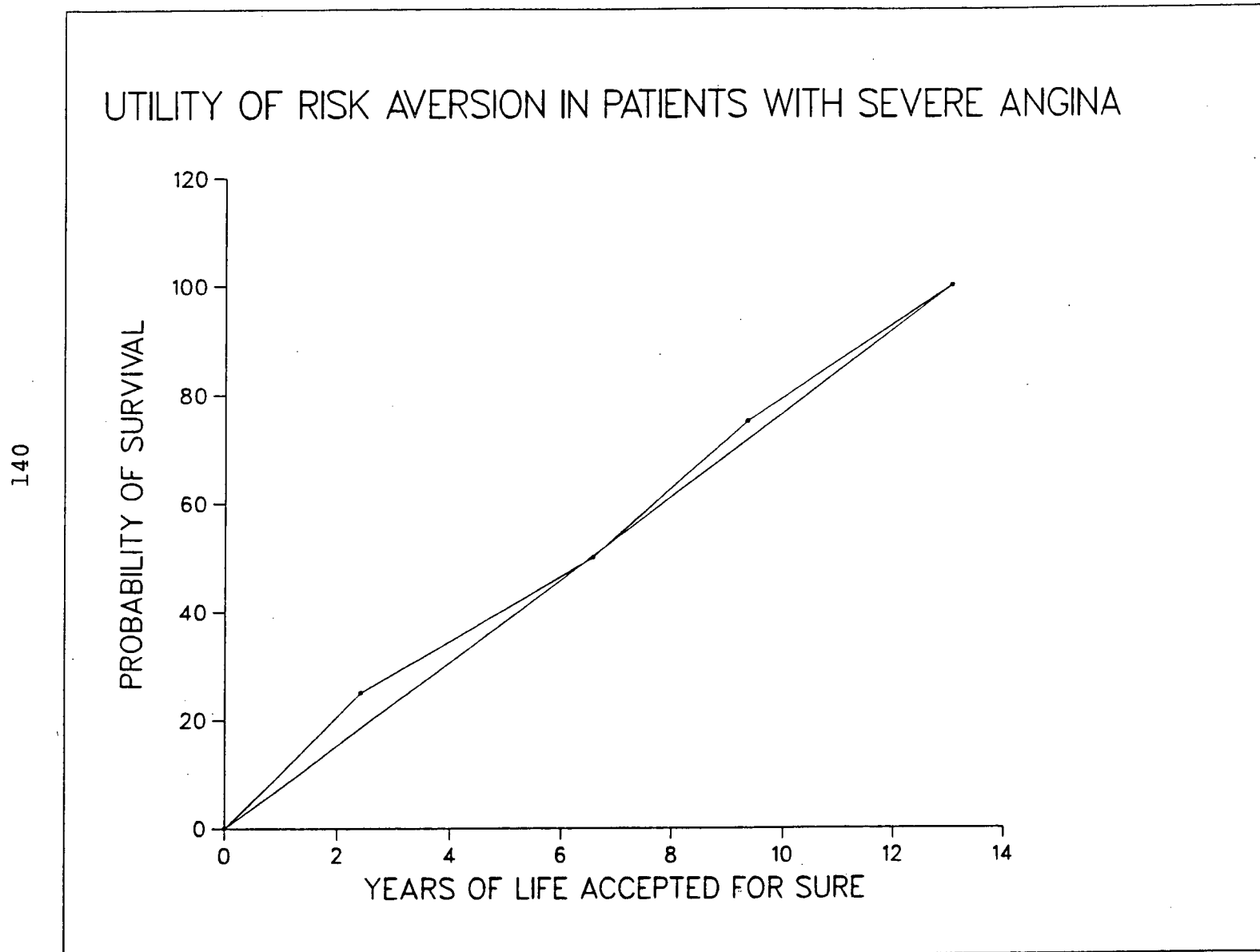


Figure 4.6.



There are a number of plausible reasons why this set of preferences was elicited. First, patients may not have understood the question or been implicitly encouraged by the interviewer to state a number of years higher or lower than the minimum number of years they would accept in return for avoiding the risk. Second, some patients may have preferred the risky choice.

Since patients and subjects were interviewed in the order in which they agreed to participate rather than by diagnostic group, the first alternative would apply to all patients thus biasing all groups equally. The second reason, risk preference, remains a possibility.

When each patient's responses were evaluated, more patients in the heart disease control group (shown as 'other heart' in the figures) elected to take the risk (identified by the 'pill') than in any other group. Five of nineteen (26.3%) preferred the pill. These patients were saying, in effect, that they would prefer a 75% chance of complete recovery and a 25% chance of death over a known life expectancy with heart disease. Among 15 healthy subjects, none asked for the pill, two out of 15 patients with mild angina wanted the pill, while three of 14 patients with severe angina preferred the pill. It appeared that patients with more severe illness were prepared to accept greater risk for the alleviation of symptoms. This behaviour was reasonable,

considering the effect of severe angina on a patient's ability to live a normal life.

### 3.2. Analysis of Utility Curves for Risk Aversion

The utility curves in Figures 4.3 to 4.3 were analysed using the Trapezoidal Rule in order to determine whether a real difference existed between the diagnostic groups. This Rule is a method for determining the area under a curve. For the purposes of this analysis, the results of the calculations have been termed "the risk aversion score". The larger the value of this score, the lower was the willingness of the patient or subject group to accept a treatment risk. If the score was zero, or close to zero, the group was identified as risk neutral while a negative score would imply risk seeking. In the present study a risk neutral patient was prepared to accept whatever risk applied to a treatment that would reduce the pain and disability associated with coronary artery disease.

Table 4.3. Risk Aversion Scores of Diagnostic Groups

GROUP	SCORE
healthy	498.75
heart disease controls	63.75
mild angina	66.25
severe angina	31.35

The scores in Table 4.3 reflect the slope of each utility curve as well as the weighting contributed by the average life expectancy as perceived by the members of each diagnostic group. The high score of the healthy subjects indicates a greater aversion to treatment risk than was demonstrated by patients with severe angina. Patients with mild angina and heart disease controls demonstrated an intermediate level of aversion.

The clinical implications of a utility measure to determine which patients should receive radiation for lung cancer have been described by McNeil et.al. (1978). The contribution of a "risk aversion score" is that it allows a patient's attitudes toward treatment risk and the patient's life expectancy to be combined into one score that could be used to identify those patients most willing to take a treatment whose outcome was uncertain.

The risk aversion score described above is not an orthodox method of describing expected utility. Before it may be considered as a useful measure it should be compared to other more established techniques. This comparison was not made in the present study.

#### 4.0. Preferences for Morbidity with no Risk

In two questions patients were asked to indicate preferred treatments when the probability of success varied but there were no life risks attached to the treatment. As was discussed in the

section on 'framing' in the previous chapter, the influence exerted by framing is powerful enough to impair the ability of the question to accurately determine a difference between patient groups in willingness to tolerate morbidity with no risk. The question was as follows:

---

Would you agree to 2 months of mandatory bed rest at home if your chances of completely eliminating angina pain for 2 years were:  
(answer yes or no)

yes/no

90%	_____
70%	_____
50%	_____
30%	_____
10%	_____
1%	_____

If you have not accepted any of the chances above, why would you not accept bed rest?

---

#### 4.1. Results and Discussion

This question did not significantly differentiate between the patient and healthy subject groups. It is possible to report only that a trend appeared in the group of patients with severe angina. These patients were less willing to accept treatments with a probability of success below 50% than were other patient groups. Of those willing to take treatments at home, the average acceptable probabilities of success were as follows: healthy



subjects, 53%; heart control patients, 51%; patients with mild angina, 44%, and patients with severe angina, 70%. These data suggest that seriously ill patients want to take treatments with a higher probability of success, even if the treatment is non-invasive (such as bed rest at home), than do less ill or healthy subjects.

Not all patients were willing to accept bed rest: one of 15 healthy subjects refused, four of 20 heart control patients refused, four of 15 patients with mild angina refused, and one of 14 patients with severe angina refused. An evaluation of comments provided by respondents indicated that a number of factors other than disability level were significant contributors to willingness to take treatments at home for two months. These included the availability of a caregiver, demands of a job or family, level of restlessness, willingness to do 'whatever the doctor wants', and limited life expectancy (the patient did not want to waste what little life he had left resting in bed).

The following sections explore the results of the questions analysed by the age of the patient and the previous health history of the patient.

#### 5.0 Patient Age as an Independent Variable

Data from patient and subject histories were analysed to determine whether severity of disease was linked to patient age. Patient age was not found to be a predictor of severity of

coronary or other heart disease in the study groups. The average age of patients with valve disease or arrhythmias was 56.4 years, while the average age of groups with mild and severe angina was 59.1 years. The range of ages was also similar among groups. Recall that Chapter 2 reported a study of coronary artery bypass grafting at the Ottawa Heart Institute where the average patient age was 55.3 years with a range of 39 to 73 years, very similar to the patient groups in the present study.

#### 5.1. Vulnerability to the Influence of the Framing Bias

This study has shown that framing exerts a powerful influence over patient preferences as expressed by willingness to participate in a treatment with a less than certain outcome. When the patient responses were classified by age, the 23 patients who exhibited a vulnerability to framing were found to have an average age of 56.7. Of the 24 patients who demonstrated a consistent choice, the average age was found to be 54.7. The difference in average age was not statistically significant, but it must be noted that the study groups were small. These data suggest that framing has a universal influence, and that as many as one-third to one-half of patients will change their choice due to the description of the treatment outcome.

#### 6.0. Previous Health Experience as an Independent Variable

The fear, uncertainty, and pain associated with a myocardial

infarction are feelings that patients in the study could describe clearly, even if the experience had occurred many years before. Since Zook and Moore's (1977) description of the high cost users of health care suggested that patients with heart disease were frequently hospitalized, the study sought to determine whether previous history of a heart attack and subsequent hospitalization had an influence on a patient's attitude toward future hospitalization.

The research question asked was: Would past experience bias current attitudes towards hospitalization? Patients were asked to:

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Choose between the following hospitals offering treatment. Assume that the treatment has side effects that prevent trying another for at least two years. While you wait you bear a 5% risk of having a heart attack.

Hospital A: Waiting time is 6 months (all patients have angina for 6 months), after the treatment all patients are free of angina for 4 years.

Hospital B: No waiting time, after the treatment patients are free of angina for 3 years.

A: wait 6 months \_\_\_\_\_  
 B: no wait \_\_\_\_\_

If you chose hospital A, how long would angina pain have to be eliminated at hospital B to get you to choose hospital B?

\_\_\_\_\_

If you chose hospital B, how long would angina pain have to be eliminated at hospital A to get you to choose hospital A?

\_\_\_\_\_

---

### 6.1. Results and Discussion

Of the 64 subjects interviewed, 21 had suffered a myocardial infarction and 43 had not. Table 4.6 summarizes the waiting choices of these subjects.

TABLE 4.4. Myocardial Infarction and Waiting Choices

	wait	no wait	total
heart attack	10 (47.6%)	11 (52.4%)	21
no heart attack	16 (37.2%)	27 (62.8%)	43
total	26	38	64

Notes:  $p=0.42$

Table 4.4 shows that a greater proportion of patients who have had a heart attack are willing to wait six months for treatment than those, including healthy subjects, who have not (48% versus 37%), although this difference was not significant. This question of willingness to wait has considerable significance in the hospital system because of the possibility of long waits for diagnostic procedures and surgery for patients who survive a heart attack. Health administrators may be able to offer a more sensitive approach to patients required to wait if some ex ante determination could be used to differentiate those willing to wait from those whose anxiety was increased by waiting.

### 7.0. The Influence of a Coronary Artery Bypass on Choices

The waiting questions were also analysed by bypass history to determine if previous experience with surgical intervention altered willingness to wait for treatment. In the study group overall, 26 subjects preferred to wait while 38 did not want to wait for hospital care. Table 4.5 summarizes the preferences of these subjects when bypass experience is considered an independent variable.

TABLE 4.5. The Influence of Coronary Artery Bypass on Waiting

	wait	no wait	total
bypass	7 (58.3%)	5 (41.7%)	12
no bypass	19 (36.5%)	33 (63.5%)	52
total	26	38	64

Notes: Fisher's  $p=.14$

The appearance of a noticeable, but not significant difference between the proportion of bypass patients willing to wait six months for hospital care, compared to the proportion willing to wait who did not have a bypass, suggested that an experience with surgical treatment increased the tolerance for waiting. When these patients were asked to describe why they were willing

were willing to wait, the common replies were: "I had to wait nearly six months for my bypass with a risk of having another heart attack always present; six months isn't a bad wait." and, "I found having a bypass a really unpleasant experience, I don't want another too soon."

One conclusion that could be tentatively drawn from these findings is that people with little exposure to intensive hospital care are more anxious to have care immediately available than people who have been in the system before. In terms of policy considerations, one could suggest that the availability problems identified by non-users may be exaggerated when compared to availability constraints identified by those who have used hospitals.

#### 8.0. Health Experience and Risk Avoidance

How does a personal experience with either a myocardial infarction or a coronary bypass influence a patient's choice of a treatment that carries a risk of death? It appears that exposure to risk of death in the past increases a person's ability to accept risk in the future. The question used has been described in Chapter 3 in the discussion of the certainty effect. The first option described in Table 4.6 is a treatment that offered 5 years of pain relief with no risk of death. The second option offered 6 years of pain relief accompanied by a 10% risk of death. The

expected value of the second treatment option was 0.4 years longer than the first option.

### 8.1. Results and Discussion

Table 4.6 summarizes the findings across five classifications of subjects by previous health experience.

TABLE 4.6. Health Experience and Risk Avoidance

<u>past history</u>	<u>choice</u>		total
	take 5 for sure	take 6 with risk	
no MI & no bypass	39 (92.9%)	3 (7.1%)	42
have had MI	16 (76.2%)	5 (23.8%)	21
have had bypass	10 (76.9%)	3 (23.1%)	13
both MI & bypass	6 (66.6%)	3 (33.3%)	9
all subjects	58 (90.6%)	8 (9.4%)	64

notes: (a) MI = myocardial infarction

(b) In the Mantel test for trend differences,  $p=.027$

What became apparent from the results of the Mantel test for a significant trend in the results of Table 4.6, was that as patients were exposed to the stress of myocardial infarction and

bypass surgery, their willingness to assume risk increased. The proportion of patients willing to opt for the treatment with a 10% risk of death is three times larger for patients with past experience with a myocardial infarction or bypass (23%) than for those without (7%). It is of interest to note that although the expected value is higher for the option of six years with no pain accompanied by a 10% risk of death than it is for the five year option with certainty, the vast majority (90.6%) of subjects were not influenced by the higher expected value of 5.4 years.

An analysis was also conducted to compare a patient's experience with angina pain as an independent variable acting as a predictor of treatment choice when a treatment carried a risk of death of 10%. Patients with previous angina who were classified as heart disease control patients were included in this analysis, along with patients with current angina. In Table 4.7, the risky choice is summarized by level of angina pain, showing that angina increases willingness to bear risk for a higher expected gain, but the increase is only 10%. This difference was not significant.



TABLE 4.7. Angina Pain and Risky Choice

	6 years with risk	5 years for sure	total
angina	4 (21.1%)	15 (78.9%)	19
no angina	4 (11.4%)	31 (88.6%)	35
total	8	46	54

Notes: There was no significant difference between groups.

#### 9.0. Health Experience and Choice of Surgical Treatment

Study subjects were given a question that did not use the words "surgery" or "drug therapy", but the outcomes described in the question matched the probabilities of treatment outcomes offered by these two methods as described in Chapter 1. The research question asked: would patients who had already been treated surgically prefer the treatment whose outcome probabilities matched surgery? All three groups of heart patients contained at least one patient who had received a coronary artery bypass. In the heart disease control group (n=20), the one patient who had a bypass chose surgery in the question. Among patients with mild angina (n=15), five patients had a bypass but only two selected surgery as their optimal choice of treatments, while three selected drug therapy as the optimal treatment. Of some interest, all six patients with severe angina (n=14) who had already had a bypass selected

surgery again as their preferred treatment outcome.

It is important here to reflect back to Chapter 3 and the discussion of preference reversal. In the above discussion of preferences for surgical or drug treatment, patients chose a treatment based on the probability of outcomes. The reliance one may place on the ability of participants in a decision to demonstrate consistency was shown to be misplaced because of the number of patients who were not consistent in their choice when the question asked for a bid for an outcome versus a direct choice.

If some policy suggestions could be drawn from the tentative interpretation of patient preferences for surgical treatment, they might focus on making surgery available for the severely ill patient who demonstrated a strong and consistent preference for surgical outcomes. In the present study, sixty per cent of patients with mild angina who had a bypass demonstrated a preference for drug therapy. This may be an over-treated group. Recall the discussion in Chapter 1 that identified the preferences of physicians and the economic incentives that could encourage treatment rather than non-treatment.

An analysis was also conducted on treatment choices using classification of study groups by diagnosis. The research question asked whether symptoms such as pain acted as an influence on patient choices.

TABLE 4.8. Diagnosis as an Independent Variable

	surgical choice	drug choice	total
healthy subjects	8 (55.3%)	7* (46.7%)	15
other heart	10 (50%)	10 (50%)	20
mild angina	8 (55.3%)	7 (46.7%)	15
severe angina	12 (85.7%)	2 (14.3%)	14

Notes: (a) One patient in the \* group was actually indifferent.  
 (b) The difference between groups was not significant.

A noticeable, but not statistically significant influence of severe angina on treatment choice appeared as 85% of this group chose surgery over drug therapy. There was also no statistically significant difference in the rate of surgical versus medical choices for healthy subjects, patients with other forms of heart disease or patients with mild angina. The clinical implications of this finding suggest that patient preferences may be independent of symptoms except for those with severe pain or disability and should therefore be elicited before the decision to treat is made.

#### 10.0. Summary

This chapter has shown that patient age is not a strong predictor of interest in or willingness to consume health care services associated with coronary artery disease. Pain has

appeared as a variable capable of influencing an increased willingness to seek treatment and to wait for treatment deemed to be of value to the patient. No patients were offered a cure or a lengthened life by taking treatment. Previous experience with the hospital system acted to increase the tolerance of waiting as well as the aversion to surgery among patients who had already had a bypass (CABG). Patients who had no experience with major surgery appeared more anxious to be treated.

The results reported in this chapter suggest that pain and disability may be important variables determining patient preferences for treatment of coronary heart disease.

#### 11.0. Limitations of the Study

The generalizability of the findings of this study has been limited by a number of factors including selection bias, small sample size, and only partial replication of other studies. In Chapter 2, a discussion of selection of subjects identified the low response rate among ambulatory patients receiving treatment in the Cardiology Division of the Vancouver General Hospital. Direct recruiting of preselected patients by hospital cardiologists did not produce response rates as high as those in other studies (Torrance et.al., 1982).

Patients willing to participate in the questionnaire appeared to be more literate than the average patient, introspective, interested in medical decision making, had stable angina or

other heart disease, and had seen their cardiologist more than once. This group of patients demonstrated vulnerability to a number of errors of judgement. Although the study sample was biased by patients with a 'better than average' level of function, it appears likely that patients with unstable angina, a recent myocardial infarction, or a need to make a prompt treatment choice will be just as vulnerable, or even more so. Patients who have been hospitalized for treatment will also have less confidence, more anxiety, and probably more pain; all variables that reduce the likelihood of rational decision making. These patients may have a greater need than ambulatory patients for a structured, sequential method of expressing a treatment preference.

A related sample bias was due to the selection of healthy subjects from a sports club whose members were probably healthier than average. The lifestyle risk factors identified in the subject's medical history were noticeably different between the patients and the healthy subjects. No healthy subject smoked or was overweight, although some stated that their jobs were stressful. Almost all patients with moderate or severe heart disease were currently or had been heavy smokers and many admitted to being 'heavier than they should be'. Since lifestyle risk factors have been shown to play a significant role in the development and severity of coronary heart disease, the use of recreational athletes was considered to be a justifiable choice.

A second limitation of the study was that it did not attempt to replicate previous studies. Several acclaimed and important studies in medical decision making (McNeil et.al., 1978; McNeil et.al., 1982; and Pauker, Pauker, and McNeil, 1981) served as the foundation for a number of preference questions, but no questions were actually replicated. In addition, questions developed by others (Kahneman and Tversky, 1979, 1984; Lichtenstein and Slovic, 1971) using money bets were not appropriate for treatment choices, and a different 'currency' was created to test for the presence of errors of judgement previously demonstrated by choices involving money. As a result of using a 'new currency', reference to terms identifying errors of judgement such as preference reversal may be misplaced. However, the purpose of the study was to identify errors of judgement that could influence a patient's ability to express a true preference. Demonstrating such an error with more general units provided an opportunity to increase the scope of understanding of decision making in cases where dollars were not the appropriate measure.

A third limitation of the study was due to the hypothetical nature of the questions. For example, subjects were asked to state the per cent of their 'retirement income' they would be prepared to exchange for a better position on a waiting list than the position they had been assigned. Subjects were told that waiting carried a 5% risk of heart attack. This question was used, not only as a strategy to probe waiting, but as a strategy

to try to understand response to risk. The study identified patients for whom treatment had a low or even negative value as measured by their willingness to 'pay' to be treated sooner. Patients demonstrated very different responses: the 5% risk completely deterred some patients from waiting, while others felt this risk to be inconsequential. As a result of the ability of these questions to differentiate patients who were willing to bear risk, the hypothetical nature of the questions was felt to be justified.

Finally, the role of the researcher as a non-medical participant in medical decision making was perceived as a potential limitation in the study. Patients and physicians are the usual decision makers. However, as Chapter 1 has shown, some physicians do not involve patients in the choice of a treatment. Thus, the researcher developed a role that was threatening to neither the patient nor the physician. Due to the preliminary nature of the present study this role was supported by the Division of Cardiology and the Ethics Committee of the University of British Columbia. In addition, many patients felt less constrained about 'making a mistake' with a para-medical person than they did with a physician. The researcher was deliberately not informed in advance of any decisions the physician or patient had previously made regarding treatment. Thus the questionnaire was not used to confirm any decisions, but to explore the patient's preferences for future treatments.

## 11.0. Conclusions

Several trends have been identified by the results of the study. First, previously identified errors of judgement have been demonstrated by patients with heart disease and by healthy subjects making a treatment choice 'as if' they had heart disease. These errors included framing (the wording of the question influenced choice), preference reversal (whether the outcome was chosen or bid for influenced preference), asymmetric choice (choices differ when there is a chance to gain or to lose), and violation of the substitution axiom (when a choice was changed by the same factor as a competing choice it was not selected a second time).

Subjects in the study who were healthy exhibited a different pattern of risk aversion than subjects with serious heart disease. These results suggest that considerable merit may accrue to studying decision making in a realistic environment even though such studies may be more difficult and time consuming. Health (and life) risks previously faced by patients demonstrated a positive relationship to the choice of a treatment with an uncertain outcome. For example, patients with diagnosed heart disease were more risk averse than patients with heart disease accompanied by a heart attack. The greatest risk seekers were patients with heart disease, a previous heart attack and a coronary bypass.



Several expected trends were not demonstrated. Older subjects did not exhibit different treatment preferences than younger subjects. Since only one-fifth of the subjects were women, no differences due to sex could be identified. Previous treatment did not appear to influence future choices. For example, less than half of the patients who had received a coronary bypass selected it (based on outcome probabilities) as a preferred future treatment.

Finally, the study has demonstrated that patients can express a preference for treatment. As more is known about errors of judgement, health professionals can improve methods of communicating with patients and assist patients to participate in treatment decisions.

### 13.0. Opportunities for Further Research

The physicians who permitted their patients to participate in the present study have expressed an interest in the development of the questionnaire into a tool capable of actually helping patients express a preference for treatment. In order to create such a tool, refinement of questions and techniques would be required involving patients with unstable as well as stable angina. Ambulatory patients as well as those in hospital would need to participate in testing existing questions. Involvement of the physician in this decision would add to the understanding

of such a tool in furthering patient participation in medical decision making.

Further testing of the questionnaire with larger groups would also be of value. In addition, one would hope to encourage a higher response rate among the patients in a cardiology practice.

The role of the researcher in this study was developed to pose a threat to neither the patients nor the physicians. Evaluating the potential role of a nurse practitioner or other para-medical health professional would also be of interest. The patients in the present study indicated positive feelings towards expressing preferences to a 'neutral' person.

Further work toward understanding errors of judgement would increase the ability of health professionals to avoid situations where such errors could endanger the expression of a patient's true preferences. Although most of the theoretical development of this field is underway in psychology and economics, its application to medicine is significant. One has only to recall that about one-third of every provincial budget is devoted to health care.

Finally, it is important to acknowledge the potential influence of research bias in the delivery of the questionnaire and analysis of data. A researcher setting out to support a theory may be more likely to find such evidence than a researcher setting out to find contradictions to established theory.

Efforts must be made by researchers to interpret evidence without bias, and in the case of competing paradigms, to strive to be objective regarding the ability of each paradigm to offer a model for understanding human behaviour.

#### 14.0 Final Comments

As a case study of medical decision making, this research suffers from a small sample size but compensates for this with a broad spectrum of data collected on each subject. Efforts to understand patient preferences under difficult conditions have been based on previous work in medical decision making as well as other disciplines. Attempts to differentiate the treatment preferences of patient groups did, on a number of occasions, produce statistically significant results. Although the findings did not always support previous reports in the literature, a general conclusion that may be drawn from the study is that preferences are situation specific. However, replication of these questions as well as those with non-significant findings would be useful with larger samples.

The University of British Columbia  
Office of Research Services

B85-081

BEHAVIOURAL SCIENCES SCREENING COMMITTEE FOR RESEARCH  
AND OTHER STUDIES INVOLVING HUMAN SUBJECTS

C E R T I F I C A T E      o f      A P P R O V A L

---

INVESTIGATOR: MacCrimmon, K.R.

UBC DEPT: COMM & BUSINESS ADMIN

TITLE: Patient participation in the decision of  
coronary bypass surgery

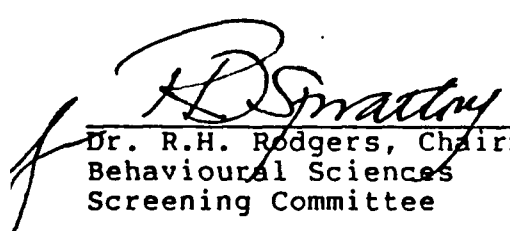
NUMBER: B85-081

CO-INVEST: Vertinsky, I.                      Fulton, M.J.


APPROVED:                      MAY 27 1985

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The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.



Dr. R.H. Rodgers, Chairman  
Behavioural Sciences  
Screening Committee



Dr. R.D. Spratley  
Director, Research Services

THIS CERTIFICATE OF APPROVAL IS VALID FOR THREE YEARS  
FROM THE ABOVE APPROVAL DATE PROVIDED THERE IS NO  
CHANGE IN THE EXPERIMENTAL PROCEDURES

THE UNIVERSITY OF BRITISH COLUMBIA  
FACULTY OF MEDICINE

y F. Mizgala, M.D., F.R.C.P.(C), F.A.C.C.  
essor of Medicine,  
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ARTMENT OF MEDICINE,  
Heather Street,  
ouver, B.C. V5Z 3J5

June 6, 1985

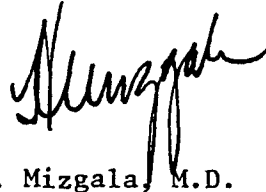
Marian Jane Fulton  
Doctoral Candidate into Disciplinary Studies  
Faculty of Medicine and Faculty of Commerce  
and Business Administration  
The University of British Columbia  
Vancouver, B.C.

Dear Ms Fulton:

Dr. Kerr has submitted to me documentation relating to your project entitled "Patient Participation in the Decision of Coronary Bypass Surgery". I hereby grant you full authorization to carry out this project among outpatients seeing members of the Division of Cardiology on the 3rd Floor of the Doctors' Residence. This approval will be subject to obtaining written approval from the UBC Ethics Committee, as well as from the Vancouver General Hospital Research Committee. I have indicated to Dr. Kerr how this second condition might be fulfilled rapidly without further delaying the start-up of your project.

It will be our pleasure to co-operate with you in this interesting project and we look forward to seeing the results.

Yours sincerely,



H. F. Mizgala, M.D.

c.c. Dr. C. R. Kerr

## INTRODUCTION TO THIS QUESTIONNAIRE

A note to participants:

The purpose of this research project is to gather information that will help doctors to understand how patient's preferences can influence the kind of treatment chosen.

This choice can be very important to heart patients because different treatments have very different effects.

We are asking you to answer the questions we have given you. A researcher will help you with the questions if you wish. If you do not wish to complete the questionnaire, or there are some questions you do not want to answer, that's allright. Since the answers are completely anonymous, no one will know. This confidentiality also allows you to be completely candid about your preferences. Some questions ask you to answer yes or no, some ask you for "how much" of something, and some ask you to choose between two gambles. These questions relate to heart disease generally, they do not apply to you directly. There are no 'right' answers.

We assume that if you answer the questions that you have given us your consent. We will keep your answers confidential by asking you not to write your name on the paper.

When you have finished the questions, the researcher will talk to you about them. It is not uncommon for a few people to feel some anxiety about their own illness after they think about being in hospital or being an invalid for some time. The researcher will answer your questions about this also.

## CONSENT FORM

I, \_\_\_\_\_, authorize  
(name of patient)

Dr. \_\_\_\_\_ to inform Jane Fulton, M.Sc.

that I have heart disease. I understand that my participation  
in the University of British Columbia research project  
"Patient Participation in the Decision to Treat Coronary  
Heart Disease" is voluntary.

\_\_\_\_\_  
(signature of patient)

page 1

## PARTICIPATING IN DECISIONS

INSTRUCTIONS: Please answer the following questions using the visual aids available. The researcher is here to help you with any questions.

## HISTORY:

age \_\_\_\_\_ sex \_\_\_\_\_ date \_\_\_\_\_

Doctor's name \_\_\_\_\_

Doctor's diagnosis \_\_\_\_\_

Angina present \_\_\_\_\_ not present \_\_\_\_\_

Description of symptoms:

-duration \_\_\_\_\_

-onset after exercise \_\_\_\_\_

-duration of relief \_\_\_\_\_

Working status:

health status:

-other chronic illness \_\_\_\_\_

-other hospital stays \_\_\_\_\_

-other family illness \_\_\_\_\_

Family status:

-marital \_\_\_\_\_

-children \_\_\_\_\_

Lifestyle risk factors:

-smoking history    number of years smoked \_\_\_\_\_  
                          do you still smoke \_\_\_\_\_  
                          when did you quit \_\_\_\_\_

-weight \_\_\_\_\_

-stress \_\_\_\_\_



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## THE QUESTIONNAIRE

## NOTES:

1. In some questions you will see the word 'chance' accompanied by a number such as 30%. This can be thought of as 30 people out of 100 people.
2. Some questions state that angina pain may be reduced for 2 years. These 2 years are part of the total number of years that you expect to live.
3. When you are asked to make a choice, try to think of it as being a final choice. If you choose treatment A now, you cannot have treatment B later.

## QUESTIONS:

1. How many years do you expect to live? \_\_\_\_\_ years

2. Please identify how important the following aspects of hospital care are to you. Mark an 'X' on the line below each statement.

a) There is no waiting list for treatment.

very important \\_\_\_\_\_ \\_\_\_\_\_ \\_\_\_\_\_ \\_\_\_\_\_ \not important

b) Treatment in hospital takes longer than 2 weeks.

very important \\_\_\_\_\_ \\_\_\_\_\_ \\_\_\_\_\_ \\_\_\_\_\_ \not important

c) Angina pain is controlled by treatment.

very important \\_\_\_\_\_ \\_\_\_\_\_ \\_\_\_\_\_ \\_\_\_\_\_ \not important

3. Would you agree to 2 months of mandatory bed rest at home if your chances of completely eliminating angina pain for 2 years were: (answer yes or no)

Chance of reducing angina pain for 2 years:  
yes/no

90% \_\_\_\_\_  
70% \_\_\_\_\_  
50% \_\_\_\_\_  
30% \_\_\_\_\_  
10% \_\_\_\_\_  
1% \_\_\_\_\_

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4. After a treatment for angina, some patients have no pain while some patients have pain twice as often as before the treatment. The numbers below are chances that the treatment will eliminate angina pain for 2 years. Which of these groups would be acceptable to you?

chance of no pain	pain twice as often	yes/no
A. 90%	10%	_____
B. 70%	30%	_____
C. 50%	50%	_____
D. 30%	70%	_____
E. 10%	90%	_____

If A is not a good enough 'chance' for improvement, what chance would be acceptable? \_\_\_\_\_

If E is acceptable, what lower chance is not acceptable? \_\_\_\_\_

5. In each of these questions you have to spend weeks in hospital now for eliminating pain later. You will have pain while you are in the hospital.

To completely eliminate angina pain:

for 1 year, I would spend \_\_\_\_\_ weeks

for 5 years, I would spend \_\_\_\_\_ weeks

for the rest of my life, I would spend \_\_\_\_\_ weeks

What would you be giving up in order to spend these weeks in hospital?

\_\_\_\_\_

6. State how many weeks you would be prepared to stay in hospital to achieve the following outcomes:

Outcome A: 98% chance of no angina pain for 2 years  
2% chance of pain the same as it is now for 2 years

A \_\_\_\_\_ weeks

Outcome B: 25% chance of no angina pain for 8 years  
75% chance of pain the same as it is now for 8 years

B \_\_\_\_\_ weeks

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7. Listed below are some hypothetical procedures with risks and benefits listed, which one would you choose? Assume that you cannot have both treatments.

treatment group A: This treatment completely eliminated angina pain for 2 years for 80% of patients; 15% still had pain, and 5% died in hospital.

treatment group B: This treatment completely eliminated angina pain for 2 years for 60% of patients, 40% had the same pain they had before the treatment, no patients died because of the treatment.

	no angina	same pain	risk of death
treatment A	80%	15%	5%
treatment B	60%	40%	0%

A \_\_\_\_\_ or B \_\_\_\_\_ or no preference \_\_\_\_\_

If you chose A, what % of group B would have to have pain relief to get you to join the group? \_\_\_\_\_%

If you chose B, what would the outcome in A have to be to get you to join the group? \_\_\_\_\_

8. These treatment groups have different outcomes, which group do you prefer?

	no angina	same pain	risk of death
treatment A	70%	15%	15%
treatment B	55%	35%	10%

A \_\_\_\_\_ or B \_\_\_\_\_ or no preference \_\_\_\_\_

What outcomes did you focus on in making your choice?

\_\_\_\_\_

page 5

9. Listed below are two treatments with different long term outcomes. These outcomes have different risks. Choose one. Assume that if you survive the treatment you will live as long as you expect, but you will have angina pain.

treatment group A: This treatment completely eliminated angina pain for 6 years for 90% of patients; 10% of the patients suffered complications of treatment and died.

treatment group B: This treatment completely eliminated angina pain for 5 years for all patients.

A \_\_\_\_\_ or B \_\_\_\_\_ or no preference \_\_\_\_\_

If you chose A, then how many more months would B need to get you to choose B?

1 month \_\_\_\_\_  
 2 months \_\_\_\_\_  
 3 months \_\_\_\_\_  
 4 months \_\_\_\_\_  
 5 months \_\_\_\_\_  
 6 months \_\_\_\_\_, more than 6 months? \_\_\_\_\_

If you chose B, how many more months would A need to get you to choose A?

1 month \_\_\_\_\_  
 2 months \_\_\_\_\_  
 3 months \_\_\_\_\_  
 4 months \_\_\_\_\_  
 5 months \_\_\_\_\_  
 6 months \_\_\_\_\_, more than 6 months? \_\_\_\_\_

10. How long can you exercise before angina pain? \_\_\_\_\_  
 How many blocks can you walk without angina? \_\_\_\_\_

Choose between the following two treatments:

treatment A: 50% chance of no angina pain after any amount of exercise, and a 50% chance of pain the same as it is now;

treatment B: twice as much exercise for sure with no angina pain.

A: 50/50 chance \_\_\_\_\_  
 B: twice as much for sure \_\_\_\_\_

page 6

11. Choose between the following two treatments:

treatment A: 50% chance of no angina pain after any amount of exercise, 50% chance of not being able to exercise at all;

treatment B: a certain loss of  $1/2$  your current exercise time before angina pain the same as it is now.

A: 50/50 chance \_\_\_\_\_

B:  $1/2$  loss for sure \_\_\_\_\_

12. For this question use the number of years you expect to live as the years free of angina pain.

State how many years of life you would take (with angina like you have now) in order to be indifferent between the years with angina and the following gambles.

Would you agree to take a pill that offered a 98% chance of complete recovery from your heart disease and a 2% risk of death?

yes \_\_\_\_\_ no \_\_\_\_\_

Would you agree to exchange all the years you expect to live with heart disease for one year of perfect health?

yes \_\_\_\_\_ no \_\_\_\_\_

Choice #1: This treatment is an experimental pill that has a 50% chance of completely eliminating angina pain for your lifetime and a 50% chance of immediate death.

Take \_\_\_\_\_ years of life for sure instead of the pill.

Choice #2: This pill has a 75% chance of complete recovery for your lifetime and a 25% chance of death.

Take \_\_\_\_\_ years of life for sure instead of the pill.

Choice #3: This pill has a 25% chance of complete recovery for your lifetime and a 75% chance of death.

Take \_\_\_\_\_ years of life for sure instead of the pill.

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13. Please choose between the following outcomes of a treatment for your angina. When you finish the treatment assume that you must live your expected life with angina.

Treatment A: 98% chance of 2 years with no angina pain, and a  
2% chance of pain the same as it is now.

Treatment B: 25% chance of 8 years with no angina pain, and a  
75% chance of pain the same as it is now.

A \_\_\_\_\_ or B \_\_\_\_\_ of Indifferent to A or B \_\_\_\_\_

If you chose A, consider the following offer:

Treatment C: 100% chance of no pain for 12 months.

choose A \_\_\_\_\_ or C \_\_\_\_\_

If you chose A, how many months need to be added to C to get you to choose C? \_\_\_\_\_ months

If you chose C, how many months less than 12 would you accept to retain C? \_\_\_\_\_ months

If you chose B, consider the following offer:

Treatment D: 50% chance of 5 years with no angina pain,  
50% chance of pain the same as it is now.

choose B \_\_\_\_\_ or D \_\_\_\_\_

If you chose B, what would the chances in D have to be to get you to choose D? \_\_\_\_\_ %

If you chose D, how would the chances in D have to change to get you to choose B?

14. To determine how many dollars you have for this question, state how much money you need for 1 year of retirement, and make that your annual income. Income = \$ \_\_\_\_\_

You are on a 6 month waiting list for heart surgery. If other positions on the list were available, how much money would you be willing to exchange for the positions listed below. If you wait there is a 5% chance you might have a heart attack.

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To wait 3 months I would trade \$ \_\_\_\_\_ (    %)

To wait 1 month I would trade \$ \_\_\_\_\_ (    %)

To not wait at all I would trade \$ \_\_\_\_\_ (    %)

15. You are on a 6 month waiting list for heart surgery, and you are 1st on the list. Waiting longer has a 5% chance that you will have a heart attack.

The same money is available for everyone on the list as is available for you. No one is sicker than you are.

How much money would you want from the person taking your place if you were to wait 1 week?

\$ \_\_\_\_\_ would you trade? \_\_\_\_\_

If you waited 3 months?

\$ \_\_\_\_\_

If you waited 6 months?

\$ \_\_\_\_\_

16. Choose between the following hospitals offering treatment: (Assume that the treatment has side effects that prevent trying another for at least 2 years) While you wait you bear a 5% risk of a heart attack.

Hospital A: Waiting time is 6 months (all patients have angina for 6 months), after the treatment all patients have no angina pain for 4 years;

Hospital B: No waiting time, patients have no angina for 3 years.

A: wait 6 months \_\_\_\_\_

B: no wait \_\_\_\_\_

If you chose hospital A, how long would angina pain have to be eliminated to get you to choose B? \_\_\_\_\_

If you chose hospital B, how long would angina pain have to be eliminated to get you to choose A? \_\_\_\_\_

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17. After a treatment for angina, some patients have pain twice as often as before the treatment while some patients have no more pain. The numbers below are chances that the treatment will cause angina pain to occur twice as often. Which of these groups would be acceptable to you?

pain twice as often	chance of no pain	yes/no
10%	90%	<input type="checkbox"/> / <input type="checkbox"/>
30%	70%	<input type="checkbox"/> / <input type="checkbox"/>
50%	50%	<input type="checkbox"/> / <input type="checkbox"/>
70%	30%	<input type="checkbox"/> / <input type="checkbox"/>
90%	10%	<input type="checkbox"/> / <input type="checkbox"/>

PATIENT'S COMMENTS:

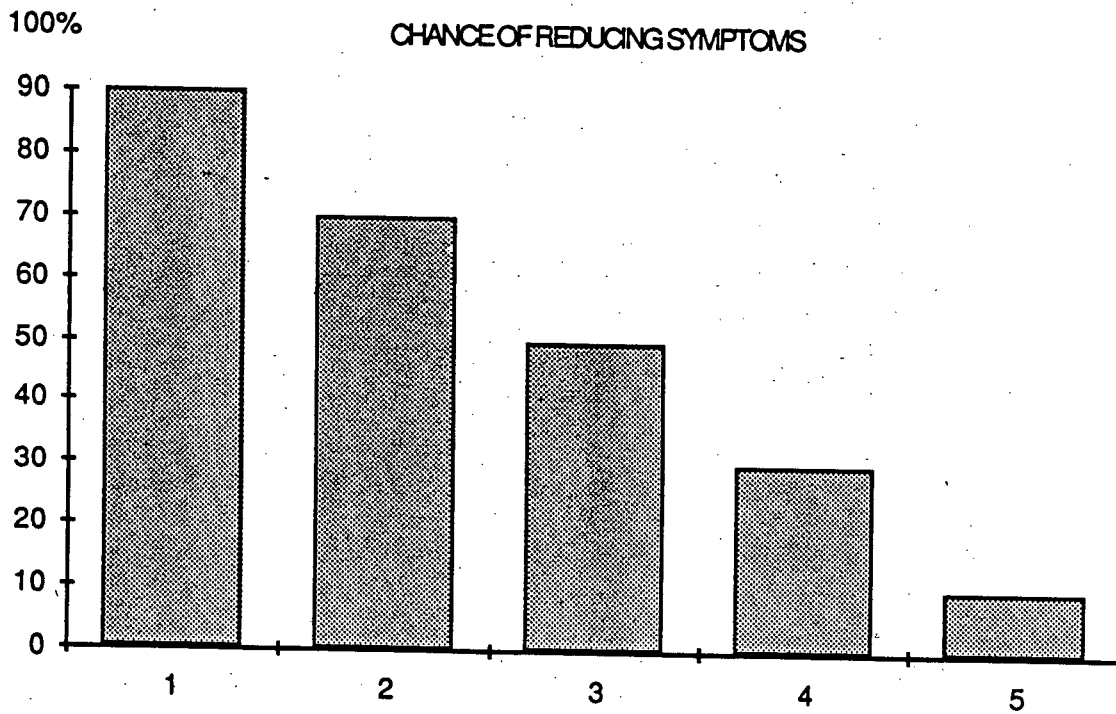


## APPENDIX II

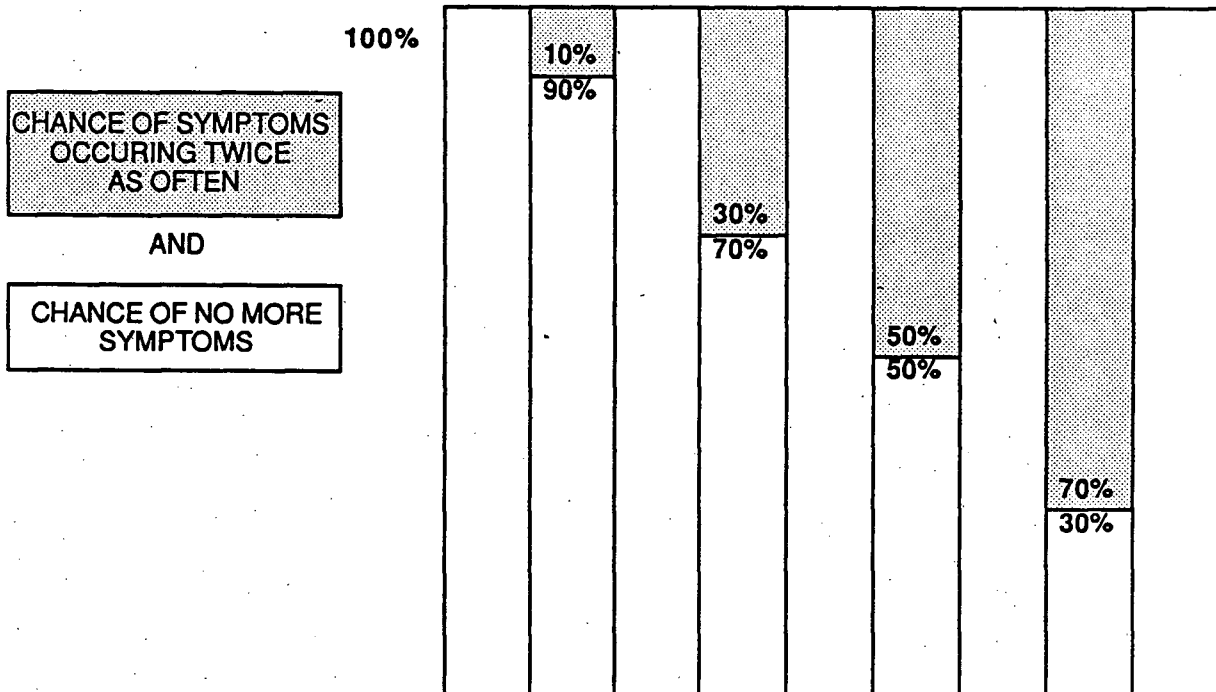
# VISUAL AIDS

for subjects participating in  
the Vancouver General Hospital  
Coronary Heart Disease Study.

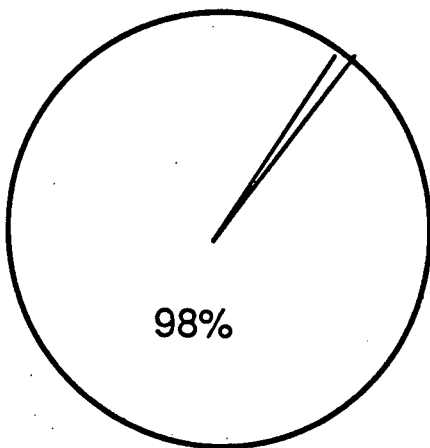
## Question 3



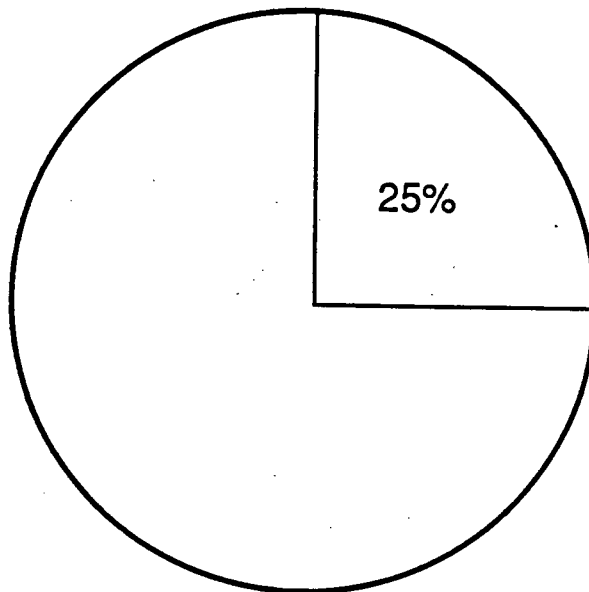
## Question 4 &amp; 17



Question 6 & 13

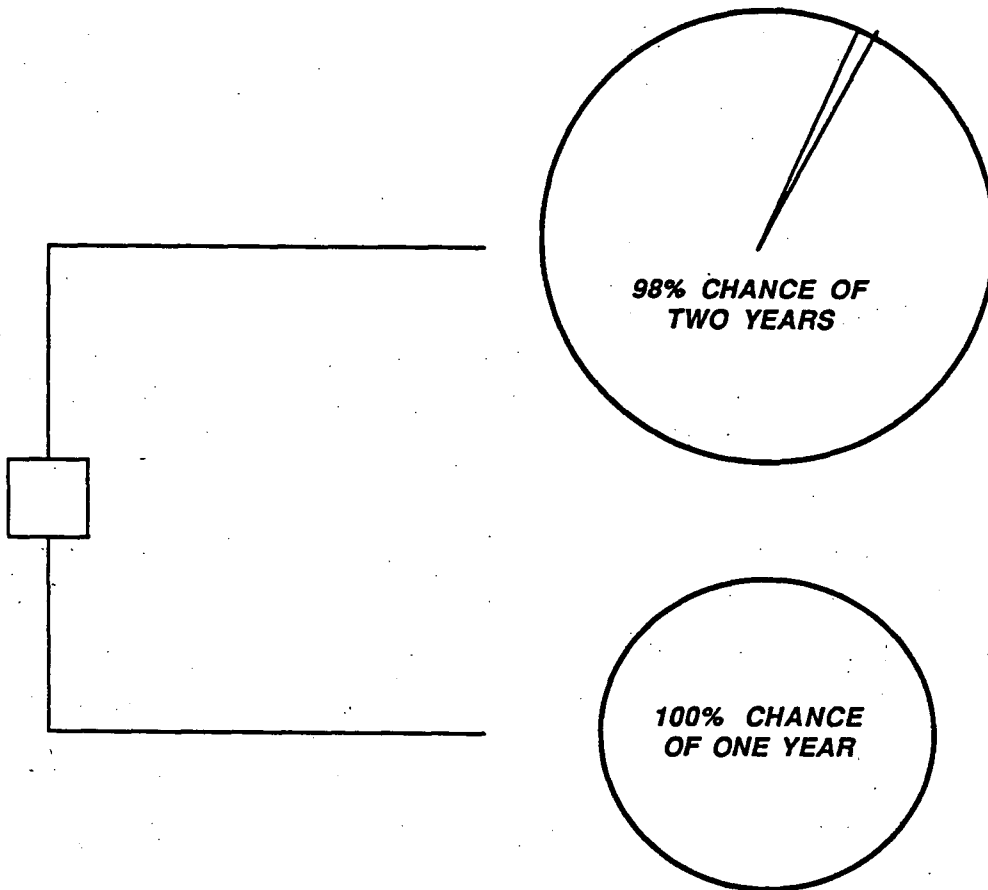


98% CHANCE OF 2 YEARS  
FREE FROM SYMPTOMS

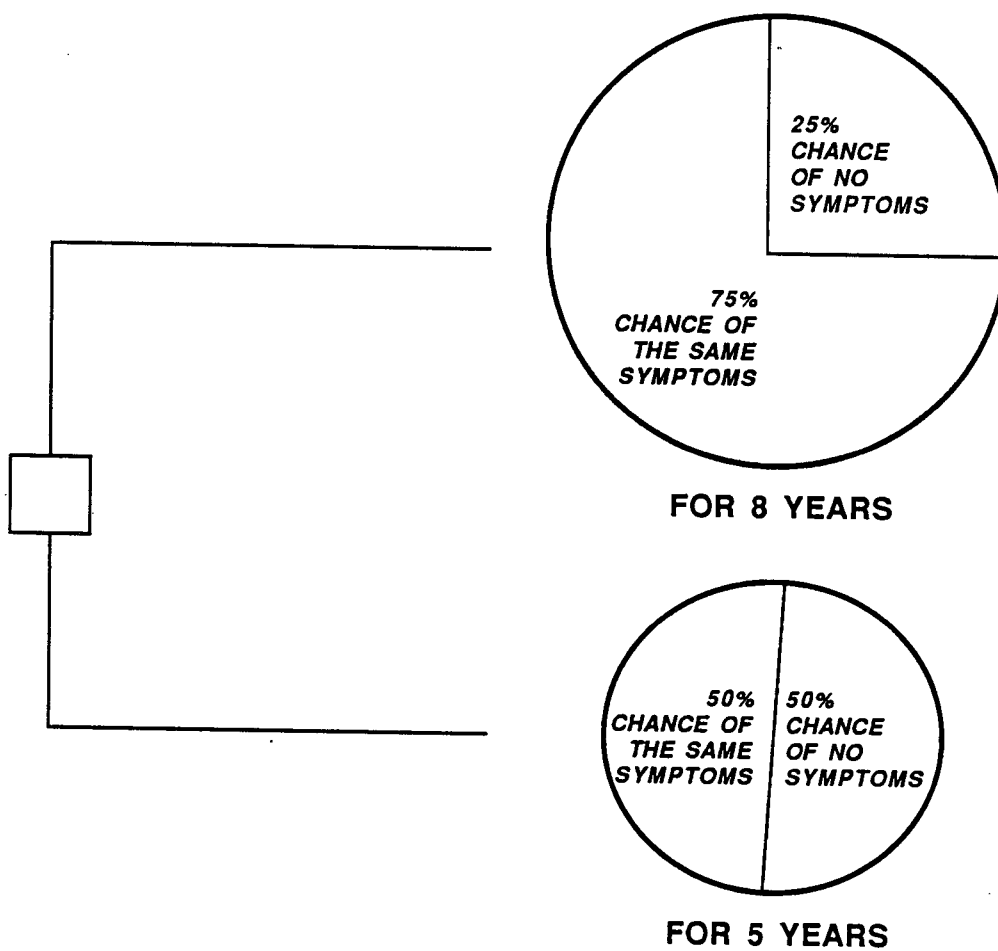


25% CHANCE OF 8 YEARS  
FREE FROM SYMPTOMS

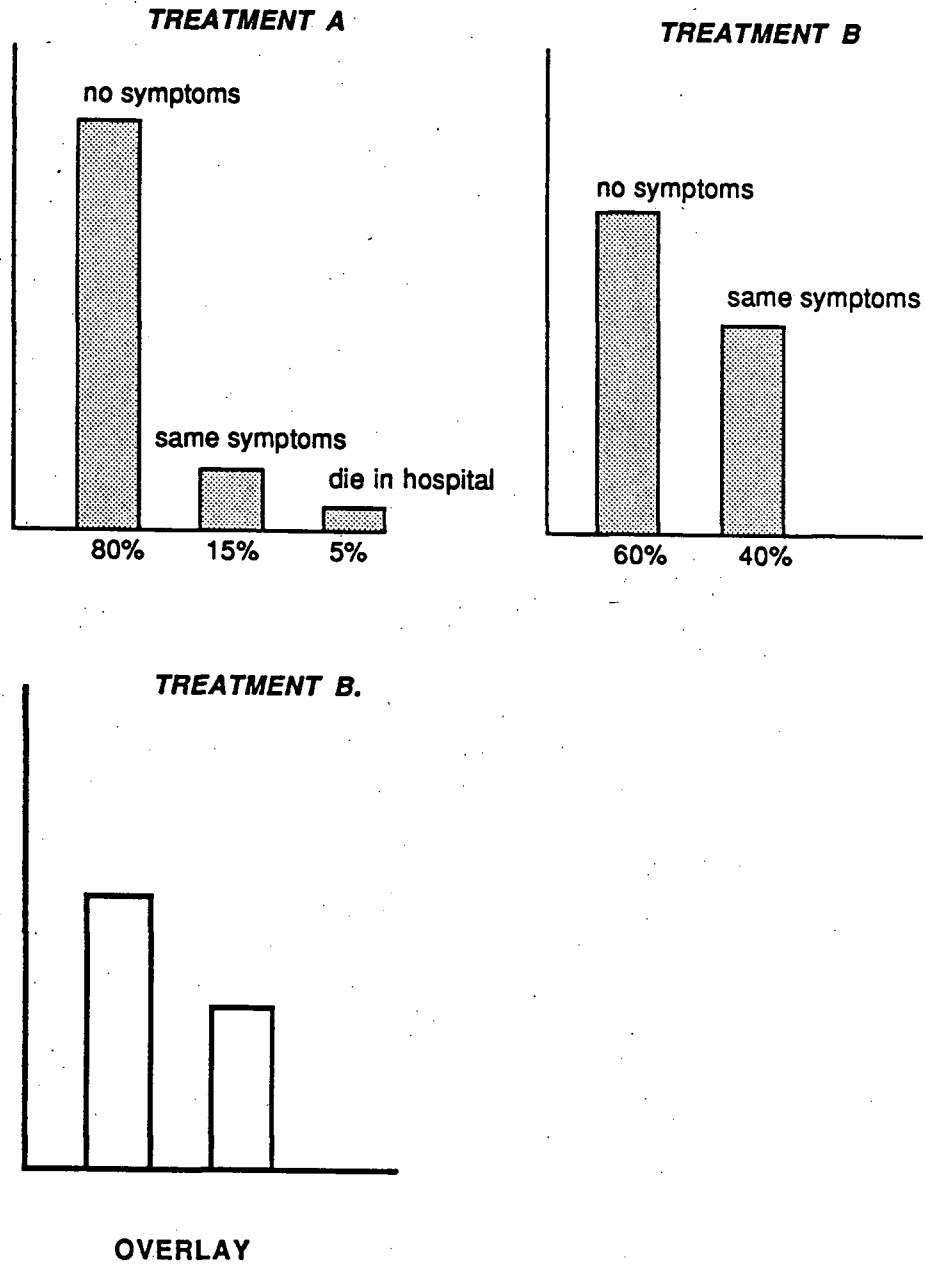
## Sensitivity Analysis for Question 13



## Sensitivity Analysis for Question 13

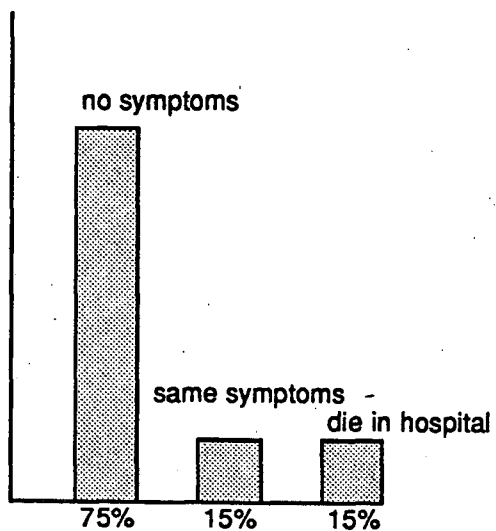
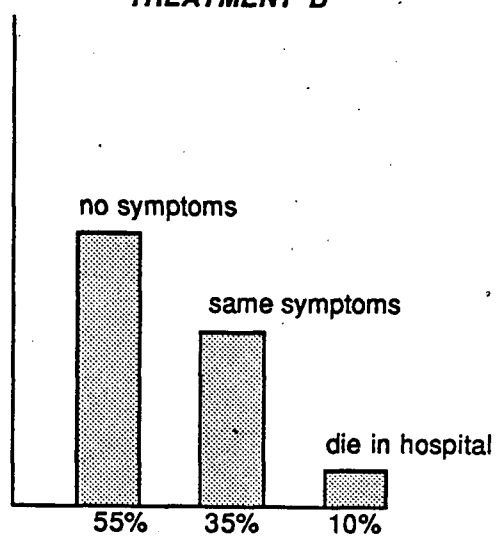
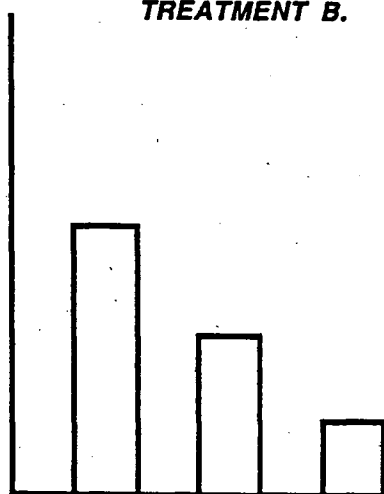


## Question 7



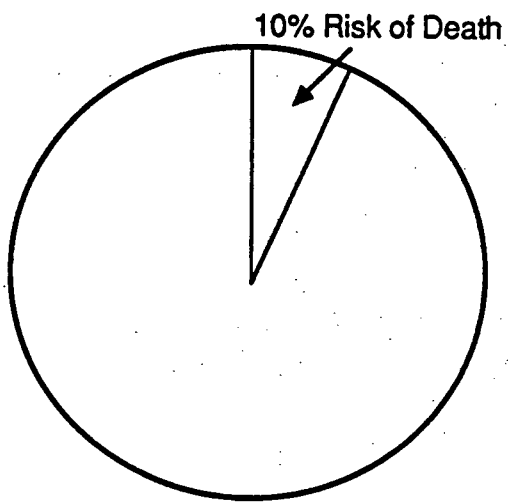


## Question 8

**TREATMENT A****TREATMENT B****TREATMENT B.****OVERLAY**

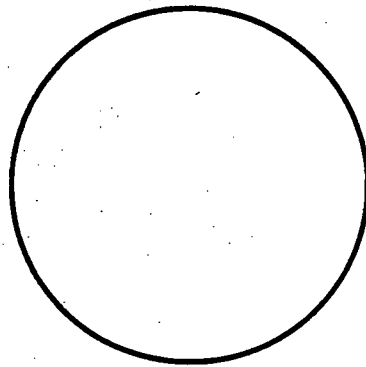
## Question 9

TREATMENT A



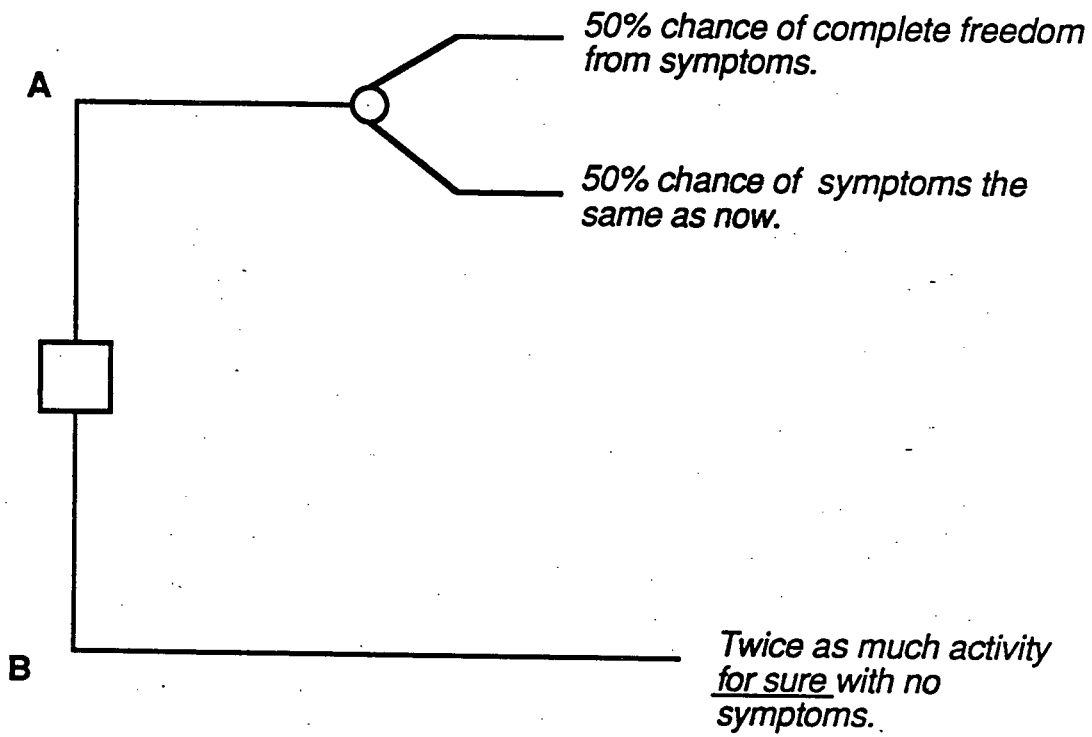
NO MORE SYMPTOMS  
FOR 6 YEARS

TREATMENT B

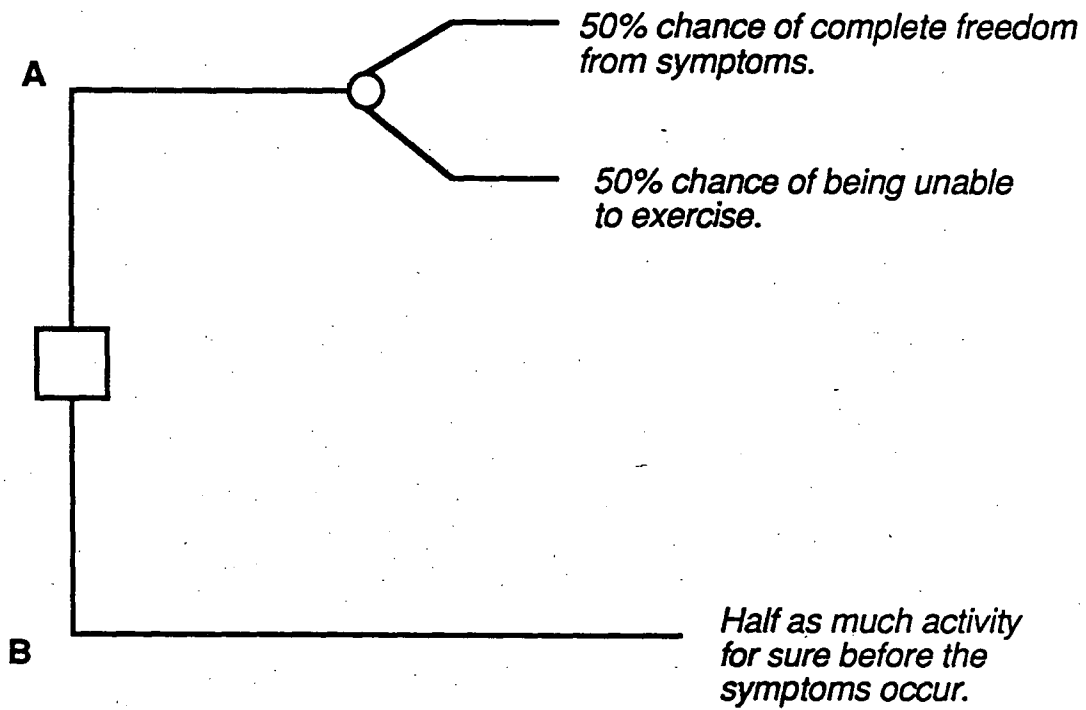


NO MORE SYMPTOMS  
FOR 5 YEARS

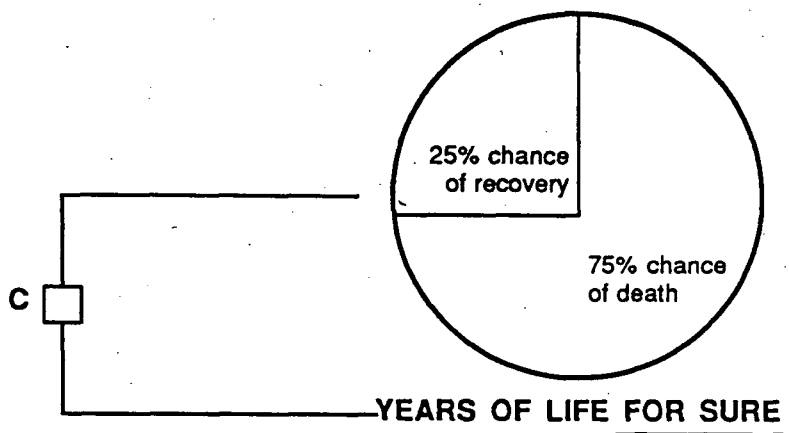
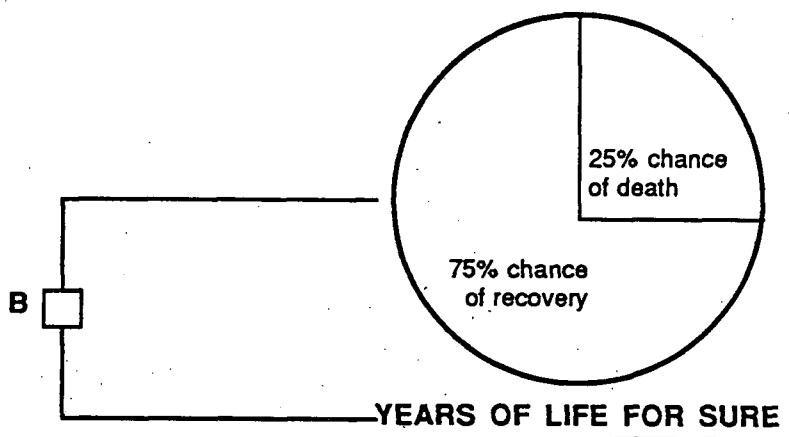
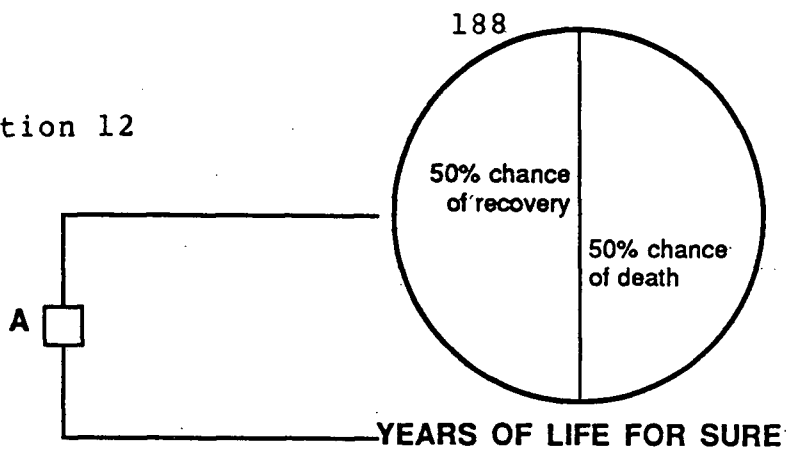
## Question 10



## Question 11



Question 12



## Question 16

## HOSPITAL A

*WAIT  
SIX MONTHS*

*4 YEARS WITH NO SYMPTOMS*

## HOSPITAL B

*3 YEARS WITH NO SYMPTOMS*

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