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LAY REASONING AND DECISION MAKING RELATED TO HEALTH AND ILLNESS

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A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Doctor of Philosophy

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ABSTRACT

Research in decision making has identified the importance of prior knowledge and heuristics on decision making behaviour. These develop with experience in a fashion similar to how domain experts develop specialized knowledge structures and heuristic reasoning patterns. This research is extended to the domain of health and lay decision making in a series of studies characterizing conceptualizations of health and illness, information-seeking strategies, and the impact of medical information on lay decision making. Lay subjects included those with diabetes, heart disease, and no identified ongoing medical diagnosis.

Semi-structured interviews and think aloud methodology were employed. Interviews focused on understanding of health and illness, prior knowledge and beliefs, and decision making. In Study One, subjects were presented with health-related problem scenarios and instructed to think aloud as they reasoned through them to make decisions. In Study Two, subjects (lay and medical) were presented with a telecommunications device and scenarios of data to enter into the system. All data were audiorecorded, transcribed, and analyzed for factors and strategies related to information-seeking and decision making behaviours.

Lay understanding of health and illness was characterized as feeling well and functioning in everyday life. The knowledge used in making decisions was based on experience and socio-cultural tradition. Knowledge about disease was found to be decoupled from decisions to act related to illness. Additional information was sought using four criteria grounded in common experience: accessibility, familiarity, complexity, and credibility. These characteristics influenced interactions between lay people and domain experts, such as health care providers, and with technology designed by experts for lay users.

Both technical and lay people make decisions with incomplete information and uncertain outcomes. For lay people making decisions about health-related issues, this incomplete knowledge is filled in based on everyday life rather than medical and scientific facts.

RESUMÉ

La recherche sur le processus de décision a identifié l'importance des connaissances acquises et des apprentissages quotidiens sur le comportement de prise de décision. Ceux-ci se développent avec l'expérience de manière similaire à celle d'experts de domaines techniques. Ces techniciens appliquent des schèmes de pensées spécifiques à leurs connaissances spécialisées ainsi que des raisonnements heuristiques. La présente recherche s'étend au domaine de la santé et à celui du processus décisionnel en une série d'études sur des concepts tels la santé et de la maladie, les stratégies de recherche d'information et l'impact de l'information médicale sur le processus commun de prise de décision. Les cas étudiés comprennent des individus atteints de diabète, de maladie du cœur ou des individus n'ayant pas à ce jour de diagnostic médical déterminé.

La méthodologie utilisée comprend des entrevues semi-structurées et la présentation de cas problèmes. Les concepts communs sur la santé et la maladie, les croyances antérieures et la prise de décision sont au centre de ces entrevues. Dans la première étude, des cas problèmes reliés à la santé ont été présentés aux individus étudiés. Ils devaient suivre une directive précise soit celle de penser tout haut et d'exprimer leurs raisonnements afin d'en arriver à une décision. Dans la deuxième étude, les sujets (le public ou le corps médical) doivent compléter dans un système informatique un scénario en y inscrivant eux-mêmes des données. Tous les sujets ont fait l'objet d'un enregistrement. Les données recueillies ont été transcrites et analysées en vue d'étudier les facteurs et les stratégies déterminants dans les comportements de prise de décision et de recherche d'information.

Les concepts communs sur la santé et la maladie étaient essentiellement caractérisés par les sentiments de se sentir bien au quotidien, par l'expérience et les habitudes socioculturelles qui ont un impact sur la connaissance et sur le processus décisionnel. Dans les faits, la connaissance des symptômes inhérents à une maladie n'influe pas sur la prise de décisions potentielles pour le traitement desdits symptômes. La recherche d'informations additionnelles est basée sur quatre (4) critères particuliers dans l'expérience du public en général. L'accessibilité de cette information, son caractère familier, sa complexité et sa crédibilité. Ces critères influencent les interactions du public avec les experts, tels les spécialistes en soins de la santé et celles du public qui utilise des technologies développées par des experts.

Que ce soit des techniciens spécialisés ou le public en général, ils prennent des décisions basées sur une information incomplète et dont les résultats sont incertains. Pour le public, prendre des décisions concernants des problèmes de santé s'appuie surtout sur la compréhension de se sentir bien au quotidien plutôt que sur des facteurs connaissances scientifiques et médicales.

STATEMENT OF ORIGINAL CONTRIBUTION

The research reported in this thesis contributes to psychology theory by providing insight into the process by which lay people make decisions about health-related problems in their daily life. Previous research has suggested the importance of heuristics and prior knowledge in decision making. In the studies presented here, this is expanded to the domain of lay health, illness, and health care, where prior knowledge and everyday experience with health and illness are shown to dominate the decision making process about pathological disease. Lay conceptualizations of health and illness, shown to be characterized in relation to the ability to carry out daily activities, do not necessarily lead to the required decision outcomes but rather interfere with knowledge of disease so that knowledge and decisions are decoupled. Information provided by experts, in this case by health care providers to lay people, remains isolated from the lay decision making structure and is implicated in reasoning only when it has become integrated within the structure of prior knowledge.

Changing health-related behaviours becomes more and more important as lifestyle is increasingly implicated in illness and disease. Yet attempts to change healthrelated actions have proven only marginally successful, particularly when the attempt is population wide. The findings reported here provide an explanation for the relative ineffectiveness of programs attempting to improve peoples' knowledge, since people make decisions based on what they understand, information that is integrated within their

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structures of prior knowledge. This makes the assessment of prior knowledge and their understanding based on this knowledge important in communication with health care providers and in their compliance with therapeutic regimens.

LIST OF PUBLICATIONS

Parts of the work presented in this thesis have been reported in the following:

Cytryn, K. N. & Patel, V. L. (1998). Reasoning about diabetes and its relationship to the use of telecommunication technology by patients and physicians. <u>International</u> Journal of Medical Informatics, 51, 137-151.

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STATEMENT OF AUTHORSHIP

Research is not an isolated endeavor but rather is the product of exchange and discussion among researchers. In this context, each of the papers presented in this dissertation is the work of more than one researcher. I am primarily responsible for the conceptualization, development, organization, execution, analysis, and reporting of the research projects presented here. Dr. Vimla Patel is my supervisor and, in that context, guided my progress through these projects contributing her expertise and experience to the work. Dr. James Cimino contributed medical and informatics expertise to the project reported in Chapter Three as well as editorial support. Dr. Charles Safran provided the motivation and resources for the study reported in Appendix One as well as access to the ambulatory primary care unit of the Beth Israel Deaconess Medical Center in Boston, MA and Dr. Edward Shortliffe participated in the refinement and reorganization of the manuscript.

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CHAPTER ONE

INTRODUCTION

Research into disease causes, treatment, and prevention has suggested ways that people can make changes to their lifestyles so that they will be healthier. If disease is present, there is frequently an arsenal of treatments available to health care providers, ranging from as simple as a daily pill to as complex and intrusive as surgery and kidney dialysis. We know how to prevent and treat many diseases. Yet people knowingly continue to make choices that are potentially dangerous to their health. Health care delivery often involves the co-operation of the patient, often in the form of taking a medication or carrying out a lifestyle regimen such as dietary or exercise changes. Patients leave their providers' offices with the best of intentions, yet fail to carry out these intentions at home. Educational programs targeting health-related behaviour change have similarly not had the desired long-term effects on actions. Many reasons have been proposed to explain why people make questionable choices, ranging from lifestyle issues such as competing priorities to difficulties in understanding and carrying out instructions. A common thread is the question: Why do people make these choices and how can they be encouraged or educated to choose better options?

This question is the focus of decision making research, which examines how people evaluate options and choose among them. Decision making research has shown

that, in general, decisions are made using tactics such as heuristic strategies (Tversky & Kahneman, 1974) that simplify decision making by selectively directing attention to certain factors or aspects of information and neglecting others (Payne, Bettmen, & Johnson, 1993), thereby reducing the amount of cognitive processing necessary to make a decision. There is ample evidence for the use of such heuristic strategies in the domain of medicine and health (Patel & Groen, 1986; Redelmeier, Rozin, & Kahneman, 1993).

People make decisions about their health using strategies based on lay knowledge of health and disease and conceptualization developed without formal training, a framework grounded in social and cultural experience Making decisions about health and illness is often framed in terms of scientific information and reasoning, since most of the research is carried out by health care providers and scientists who have health-related scientific knowledge. However, non-scientifically trained lay people do not view the world or reason about science in the same way as trained scientists (Carey, 1986; Kuhn, 1996). Expert physicians make decisions about health and illness using pattern recognition and forward or data-based reasoning (Patel, Kaufman, & Arocha, 2000) rather than turning to logical reconsideration of biomedical pathophysiological pathways with each decision that is made. When confronted with anomalous or unfamiliar information, expert physicians engage in backward or hypothesis-based reasoning. When an underlying knowledge of pathophysiology is necessary for lay people to make decisions about health and illness, they use non-scientific knowledge since they do not have technical or biomedical knowledge (Kuhn, 1989).

The variety of cognitive mechanisms related to health care decision making described above suggest that lay decision making shares features with expert reasoning

while also including processes that are complex and unique. The reasoning of lay people about health and illness is of both theoretical and practical importance. Modifying health-related behaviours occupies much of health care and often involves patient compliance with medical plans, which can be very difficult to achieve. A large body of research has developed examining why compliance is so problematic, yet the problem remains a major roadblock to achieving health in both the healthy population and those with illnesses. The findings described above yield some clues as to why this may be so. Informational materials tend to provide numerical frequencies and percentages to describe risk, yet this type of quantitative information is converted into qualitative concepts by lay people (Patel, Arocha, & Kushniruk, in press). Explanations are provided based on causality and instructions are given in the context of physiological importance. Yet this is not consistent with the cognitive processes by which decisions are ultimately made (Redelmeier et al., 1993). The practice of medicine is grounded in scientific theories and health care providers are trained to think in this way. Incompatibility between the two frameworks may in part explain poor patient compliance with health care regimens. It is therefore critical that the lay framework of health and illness be understood.

The effect of prior knowledge and differences in knowledge structures and reasoning also has implications for how lay people interact with health care providers and the educational materials generated by these providers (Patel et al., 2000). When they interact with health care information or providers, such as when seeking information or medical advice, they interface with a scientific/medical framework. Health care providers trained to reason in a different manner develop information and education

programs aimed at modifying lay health behaviours. This results in educational and informational tools that are not structured in a way that is consistent with the target audience, patients and the lay public. Many types of educational materials, both low-tech (e.g. pamphlets, verbal instruction) and high-tech (e.g. Internet, CD-ROM), are aimed at providing information to health care consumers. The manner in which consumers use this information is frequently not as intended by the designers, however (Wright, 1999). Consequently, they may not have the anticipated effect. Even communication between provider and patient dyads in an office visit context is affected in this way. People's models of health, illness, and the medium of information transmission itself (such as pamphlets or technology) impact on their interactions with the educational information and how they understand, retain, and use the content. Understanding of instructional materials can be improved by tailoring them to fit with the models of the consumers, but first these informal models must be understood so that new technologies targeting lay consumers can be designed to match the way they will be understood and used.

Compliance research has isolated variables that affect what patients do and has developed models of reasoning processes that contribute to actions. Differences between physicians and patients on a variety of factors, including psychosocial issues and health beliefs, have been identified as a source of difficulty and the importance of communication and negotiation in order to promote compliance with medical regimens has been highlighted (DiMatteo & Lepper, 1998). The importance of considering the cognitive constructs of illness has been suggested (Dunbar-Jacob, Dwyer, & Dunning, 1991) and the role of cognitive processes has been explored (Gould, 1999).

Health care consumers are playing an increasingly important role in determining their own health care and making their own health-related choices. Participation by patients in decisions that affect their health and illness management requires that patients play an integral role in decision making and in carrying out treatment plans. This level of collaboration requires efficient communication and some level of shared understanding among those involved in making decisions (Orasanu & Salas, 1993), i.e. between the team, frequently localized in a health care centre, and the patient, who is at home. The different conceptualizations of health, illness, and disease of physicians and of patients have created difficulties and blocks to communication. This has implications for the negotiative process and compliance of patients with medical directives.

Several theoretical and practical issues have been raised in this discussion. Focal areas for further examination are:

- Characterization of health care consumers' reasoning about health and disease,
- (2) Identification of the critical factors (e.g. knowledge and information, fear, daily life, social influence) in how lay people make decisions about health and illness,
- (3) Description of the nature and use of information sources and resources that are employed in making decisions,
- (4) Investigation of the user/designer problem when lay people are users of health related technology designed by health care providers, engineers, computer scientists, and other technology experts.

Understanding these factors and the nature of strategies used by people to develop their knowledge and make their decisions can guide the development of educational material that influence behaviour change for health promotion and maintenance as well as disease prevention. Such programs and materials will provide the knowledge on which the lay public can base judgements about general lifestyle issues as well as day-to-day decisions. This comprehension of how consumers make their decisions and what factors are important to them will also encourage a collaborative negotiation process between lay and health care provider groups. In this way, the health of the public can be supported in a manner that is consistent with their thought processes, goals, and priorities. Incorporation of these elements a priori in the development of the patient care plan is expected to have beneficial effects in improving patient compliance by producing a plan that is more consistent with what they want to do, what they feel they can do, and what they are willing to do in promoting their health.

This thesis is based on two studies, one reported in publication and one in a manuscript submitted for publication. Chapter Two provides an overview of the research relevant to reasoning, particularly about science and health, by experts and lay people. Chapter Three focuses on how lay people think about health and illness, how they inform these understandings, and how knowledge and heuristics impact on the decisions they make. Chapter Four describes research examining lay decision making about healthrelated issues by subjects with diabetes, reasoning by physicians, and how this affects their interactions with telecommunications. This is followed by Chapter Five, a discussion of the implications of these findings for cognitive theory and for health care

delivery. Also included is a third study (Appendix One) that further explores the different frameworks of doctors, nurses, and patients and how this might affect their ability to communicate effectively.

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CHAPTER TWO

LITERATURE REVIEW

Lay reasoning about health and illness involves reasoning about a number of areas, including general decision making skills, reasoning about science, and reasoning specifically relating to information about health and illness from lay and health care sources. This chapter describes the areas of research related to people making decisions about health-related issues. It begins by outlining general decision making research as the basis for subsequent, more directed studies relating basic research to decisions about health and illness (Cho, Keller, & Cooper, 1999; Redelmeier, Rozin, & Kahneman, 1993). It then proceeds to a brief discussion of the study of decision making about science by lay people and expert scientists. This is followed by a summary of decision making about disease by experts in that area, i.e. physicians. These discussions the form the basis for examination of decision making by lay people with respect to issues of health and illness.

2.1 Classical Decision Making Research

Decision making research was initially based on the assumption that these processes were rational as determined by the rules of logic. This normative approach is best exemplified by the theories of rational choice (Becker, 1976), which have formed the basis for much of economic thought (Mellers, Schwartz, & Cooke, 1998; Shafir & Tversky, 1995). For example, the Theory of Expected Utility (von Neumann & Morgenstern, 1944) assigns utility values and probabilities to expected outcomes and proposes that decisions are based on manipulations of these variables. Discounted Utility Theory proposes that temporal discounting, or the exchange between the value of an outcome and the discounting due to a temporal delay in achieving the outcome, is the same for all outcomes (Fishburn & Rubinstein, 1982; Loewenstein, 1987). Bayesian theory focuses on the inclusion of baseline probabilities in determining normative decisions (Savage, 1954). These models require extensive knowledge of all available possibilities, understanding of each, and subsequent evaluation of every alternative (Richardson, 1998). Yet observation of human behavior in empirical investigations and in the real world suggested that these normative approaches do not explain actual decision making (Mellers et al., 1998; Shafir & Tversky, 1995).

In their landmark research, Tversky and Kahneman (Kahneman, Slovic, & Tversky, 1982; Tversky & Kahneman, 1974) examined reasoning and decision making about probabilities by presenting subjects with situations involving judgements about probabilities. The responses of their subjects revealed violations to the rules of logic. Based on these findings, they proposed three heuristics, or rules of thumb: representativeness (the extent to which a person, event, or item is representative of other items in the same category), availability (the probability of a person, event, or item being estimated by the readiness with which an example comes to mind), and anchoring (estimating a probability using a particular quantitative probability as a starting point and adjusting based on that starting point) (Kahneman et al., 1982; Tversky & Kahneman,

1974). More recently, they introduced Prospect Theory to describe choices in circumstances of risk and uncertainty (Kahneman & Tversky, 1979; Tversky & Kahneman, 1992), proposing that: (1) people make choices based on gains and losses rather than absolute values, (2) the effect on choosing is greater for losses than gains, termed *loss aversion*, and (3) choices between positive options are made with emphasis on making safe choices rather than lucrative choices, called *risk aversive*. Yet when selecting between two negative outcomes, *risk seeking* behaviour predominates, called the *reflection effect*. This effect has been shown to be influenced by experience and learning (March, 1996) and is reduced if the effects are observed over time (Kahneman & Lovallo, 1993; Thaler, Tversky, Kahneman, & Schwartz, 1997). Evaluation of risk is more consistent when the risk is determined by the subjects and not by experimental hypothesis (Weber & Milliman, 1997).

The manner in which a problem is presented has also been shown to affect the choices made. If a problem is presented as a choice between two positive alternatives, risk aversion is seen. Alternatively, choices presented as negative are made based on risk seeking. This is referred to as the *framing effect* (Tversky & Kał. eman, 1986). When individuals are presented with options, the manner in which the choice is presented has a great deal of impact on which option is selected. Choices that are compatible with the phrasing or the situation and with other options provided are preferred over those that are not (Tversky, Sattath, & Slovic, 1988).

Much of this research is based in economics and therefore was done using numerical values and probabilities or monetary values. While this has the advantage of presenting subjects with quantified problems with clear solutions, attempts to generalize

from studies presenting quantitative options to examination non-monetary, nonquantitative choices in which the comparative value of options is less clear have shown a much smaller framing effect (Slovic, Griffin, & Tversky, 1990). Furthermore, people have a preference for certain attributes and outcomes over others, and this too affects the choices they make. For example, human life is valued above monetary costs, environment versus human safety, and so on. When independent choices about the value of non-monetary attributes versus monetary costs are required, subjects chose based on their preferences. However, when the non-monetary issues are directly compared, the same choices were reversed (Tversky et al., 1988).

Additional information may change the decision or affect the probability that a decision will be made at all. For example a clear choice, i.e. a low conflict situation, is more easily made than a choice in which the options are similar (Tversky & Shafir, 1992). An additional option that focuses the chooser on a particular characteristic will similarly affect the decision made (Huber, Payne, & Puto, 1982). Adding alternatives may highlight specific characteristics and therefore make an item seem more attractive by comparison (Simonson & Tversky, 1992). Alternatively, adding more options decreases the impact of any one alternative on the final choice (Weber, Anderson, & Birnbaum, 1992).

The research of Tversky and Kahneman described above illustrates the manner in which normative rules are routinely violated and the complexity of the decision making process. Their findings have been challenged (Gigerenzer & Hoffrage, 1995) based on improvement in judgement when questions are presented as frequencies rather than probabilities. This may also be attributed to the effect of framing (Harman, 1995;

Tversky & Kahneman, 1981), with cognitions based on frequencies, with which people are more familiar, being more accurate than those based on probabilities. It has also been suggested that information is present in the environment in terms of frequencies rather than probabilities and that humans have evolved to attend to and incorporate information as frequencies (Cosmides & Tooby, 1996; Gigerenzer et al., 1989). They are therefore much better at using frequencies in making judgments (Gigerenzer & Hoffrage, 1995; Hoffrage & Gigerenzer, 1998).

These findings have implications for decisions about health and health care. Does loss aversion lead people to make decisions based on aversion to reduction in health, making choices based on safety, on not loosing, rather than maximizing potential gain? Patients making decisions may do so in favour of maintaining their current lifestyle rather than risk interfering with it. Do people make negative choices based on seeking out risk? What are the implications of that decision making pattern when choosing between medical versus surgical management of a pathology?

The influence of context and consistency may explain changes in people's intent between the doctor's office, where issues are presented in one manner and contextualized as disease-remedy, to the community context, in which issues are much broader and more complex. The reduction of this effect when information is presented in non-numerical, qualitative fashion suggests how health care providers might structure their discussions with patients in order to increase consistency in intent and, more importantly, in followthrough of patients with medical plans. In terms of health care choices by patients, this may explain why choices made in the doctor's office, dominated by the medical model, are accepted in that framework yet are not followed through when the patient returns to

their home environment in which other characteristics are emphasized. In addition, medical choices are often presented in terms of quantitative probabilities of success and sometimes include relative costs of treatment. Based on the research described above, these choices are frequently made based on framing and compatibility of options, rather than the *best* choice. Changing the framing may lead to a change in the perceived best option. Choices made in the doctor's office are reframed at home, redefined by returning to the real world and discussion with other lay people. The outcome of this redefinition might explain changes in decisions as well as non-compliance with medical regimens.

In making decisions about health care, this additional information might contribute to the changes in intention seen as non-compliance when patients agree to a plan and then, once presented with additional options not considered in the doctor's office, fail to follow it. An example would be a diabetic who agrees to a diet with a dietician while sitting in the office but is presented with additional factors, such as social pressures, when actually making the choices. It may also contribute to the growth in popularity of alternative medicine which highlights particular features for comparison with conventional medicine that people find appealing, such as natural, safe, effective, and so on. Other features, such as scientific basis and established treatment effectiveness, are not strongly represented. In this way, alternative medicine is made more attractive by guiding the comparison.

The discussion thus far suggests that cognition does not commonly consist of deduction but rather is based on induction. Understanding of these processes has major implications for choices about health and illness. Perhaps one of the most basic concept is that of *bounded rationality*, in which problem solving occurs within a subset of

possible solutions or decisions (Newell & Simon, 1972; Simon, 1955). It is not possible for human beings with limited cognitive resources to consider all facts and all possibilities. In order to reduce the amount of information considered in a real world filled with incomplete and uncertain data, people attend to only a portion of available possibilities and states of the problem, referred to as the *problem space*. Simon introduced the concept of *satisficing* (Simon, 1955; Simon, 1979), in which the number of possible options to be considered is reduced to conform with the limits of bounded rationality and selected according to a threshold of acceptability, rather than being guided by the criterion of maximum utility dictated by models such as the Expected Utility Model. Satisficing involves making decisions in a real world of poorly defined problems. incomplete information, uncertain and changing outcomes, and limited cognitive resources. Factors that affect decision making include task complexity, encompassing number of alternatives, number of dimensions, and time pressure, each of which affect the quality of the final decision (Richardson, 1998).

The concepts of bounded rationality and satisficing suggest pathways by which decisions about health are made. People make their choices based on the subset of available choices, not ALL available choices. They then choose the first one that is acceptable, not necessarily the best one. The determination of which option is acceptable may change, subject to mechanisms such as the heuristics described previously in Kahneman and Tversky's work. This highlights the importance of understanding the cognitive mechanisms by which decisions are made in order to facilitate the real world process to achieve the best possible outcome.
Newell and Simon (1972) introduced strategies used in solving problems. The simplest of these is random choice, or guessing, used when the decision-maker has no strategy or idea of what to choose. Difference-reduction, or hill-climbing involves identification of the next step that will bring the problem closest to the goal state. This can be problematic if detours are required in solving the problem, as in a maze where the shortest distance to the goal is not a straight line. An alternative, more complex strategy is a means-end analysis, a strategy that incorporates the development of subgoals in which differences between the current state and the goal state are identified. When impediments are encountered in solving the problem, circumventing these blocks becomes a goal in itself, generating subgoals to the final goal state. Operators necessary to achieve the subgoal are identified and implemented until the final goal state is achieved. Subjects have been shown to shift strategies when necessary to achieve the goal state. For example, Kotovsky, Hayes, and Simon (1985) found that subjects initially approached the Tower of Hanoi problem using a difference-reduction strategy, followed by means-end analysis with the development of subgoals when the simpler strategy failed.

Analogical reasoning is a frequently-used strategy in the search for solutions to problems (Gentner & Holyoak, 1997; Gick & Holyoak, 1980), involving retrieval of situations with features that are similar to the problem situation, mapping these features between the source and the target situations, matching features and extrapolating inferences. Analogies provide a means by which reasoning can change problem spaces from one to another (Dunbar, 1998) (which might be viewed as thinking out of the box). It has been suggested that similarity between the source and target, levels of structure

(superficial, deep), and the purpose in drawing the analogy are principle constraints on their use (Holyoak & Thagard, 1997). When implementing analogy as a strategy, subjects tended to recognize only superficially similar features unless they were explicitly instructed otherwise (Gick & Holyoak, 1980; Reed, 1987). When solving complex problems, exposure of subjects to a priming source problem before being given a target problem also facilitated implementation of analogy as a search strategy (Schunn & Dunbar, 1996). Subjects were not aware of this effect, however, and did not report it in either responses to a questionnaire or in their verbal protocols. More recent investigation in more realistic situations suggests that when subjects generate their own analogies, they make greater use of deeper structural similarities (Blanchette & Dunbar, 2000; Dunbar, in press).

It has been suggested that the reasoning patterns described above are in fact quite reasonable (Gigerenzer & Todd, 1999) given the unmanageable amount of information and cognitive processing necessary to make truly informed, rational decisions. The heuristics described above, such as framing, suggest that decisions are not made about isolated pieces of information but include other contextual features. Skill at making good real world decisions is related to specific areas and evolves through adaptation and usefulness (Cosmides & Tooby, 1996; Gigerenzer et al., 1989; Gigerenzer & Todd, 1999), rather than being based on logical principles which can be unwieldy and impractical. Within the complex context of the real world, the data on which decisions must be made are frequently contradictory, requiring that people be able to manage lack of consistency and information in making decisions (Hammond, 1996).

A wide range of heuristics and strategies has been implicated in decision making. Mastery of all of these processes implies a level of expertise in everyday reasoning. This introduces the concept of the lay expert. The discussion therefore now examines the reasoning of identified experts more closely.

2.2 Expert Reasoning

Research on expert reasoning suggests that satisficing, heuristics, and pattern recognition (Chase & Simon, 1973; Simon & Chase, 1973) are hallmarks of expert reasoning as well as general lay reasoning. What distinguishes experts from novices is the speed and accuracy with which they determine the solution. Experts do not seek the best solution from all possible alternatives, but rather as described above, they satisfice, quickly identifying and accepting the best available option.

Experts have been shown to use forward, data-driven reasoning in many fields (Chi, Feltovich, & Glaser, 1981; Patel & Groen, 1986). Novices reason in a backward, hypothetico-deductive manner (Arocha & Patel, 1995), developing forward reasoning with training and education (Arocha, Patel, & Patel, 1993). In order to reason in a forward direction, experts must know which of the many pathways available to them, i.e. which solution components, will contribute to an accurate solution. This requires the ability to assess a problem and the data that is relevant, recognize patterns suggested by that data, and develop associations between inferences and problem patterns. This process is achieved through extensive experience (Saariluoma, 1992; Simon & Simon, 1978).

The experience through which expertise is developed is not random but rather must include clear tasks at a level of difficulty that is challenging but not unduly so, based on the level of the learner. Feedback that is useful in learning is necessary, as is the opportunity for repetition of error. This is termed deliberate practice and is required to master the fields in which expertise is sought (Charness, Krampe, & Mayr, 1996; Ericsson, Krampe, & Tesch-Römer, 1993), building the necessary knowledge base and the ability to recognize and retrieve patterns when needed (Chase & Simon, 1973). This inescapably results in expertise that is specific to the domain rather than being generalizable to other fields (Voss, Greene, Post, & Penner, 1983).

This suggests that one characteristic of experts is the way that they organize and access their knowledge. Experts have been shown to organize information and represent problems differently compared with novices, categorizing problems based on underlying principles rather than based on superficial features as demonstrated by novices (Charness, 1989; Chase & Simon, 1973; Chi et al., 1981; Lesgold et al., 1988). They remember data related to their area better than novices (de Groot, 1978; Ericsson & Polson, 1988; McKeithen, Reitman, Reuter, & Hirtle, 1981; Simon & Chase, 1973), demonstrating increased domain-specific short-term and long-term memory capacity. This increased memory capacity of experts for domain-specific data has been found to apply to data and patterns commonly found within the domain but not to nonsense patterns such as chess pieces in a random arrangement (Chase & Simon, 1973). The improved memory of experts has been attributed in part to the development of long-term working memory retrieval and coding strategies related to domain-specific knowledge and decision making (Charness, 1976; Ericsson & Kintsch, 1995). Experts have extensive networks of related

knowledge coded to facilitate retrieval. Retrieval of the necessary data becomes increasingly problematic as the amount of information increases. Anderson (1990) identified this as the paradox of the expert, in which experts match incoming problem data to an increasingly large knowledge base and do so quickly, using well-developed strategies that compensate for increased time required as the size of the search increases.

The problem solving pattern is also different in that experts collect more information and assess the situation prior to making a decision while novices react more quickly and superficially to individual pieces of information, resulting in superficial and ineffective solutions (Charness, 1989; Dörner & Schölkopf, 1991; Kellogg, 1997). Overall, experts search less, apply more efficient search strategies, and use less information but more knowledge (Camerer & Johnson, 1991).

The key goal in developing expertise is to assure superior performance through deliberate practice, relevant experience, a well-organized knowledge base, improved memory and information retrieval strategies, and more effective problem solving strategies. This is particularly true of domains that are well-defined with well-developed underlying theoretical reasoning (Ericsson & Lehmann, 1996). Examination of the performance of experts has not always borne this out thus far, however. Studies comparing expert decision making against that of non-experts and against statistical models have not always supported the superior performance and expertise of 'experts' (Camerer & Johnson, 1991; Dawes, Faust, & Meehl, 1989; Meehl, 1954; Shanteau & Stewart, 1992). There is some indication that experts have more insight as to the accuracy of their decisions compared with novices, though studies are not consistent (Camerer & Johnson, 1991).

The erratic results in research attempting to show superior expert performance may be due to difficulties in creating truly representative scenarios and situations in which expert performance can be accurately tested, given the high degree of specialization of most experts (Bonner & Pennington, 1991). Another contributing factor may be that not enough is known about characteristics of expert performance to create tasks that precisely evaluate differences between expert and novice performance (Ericsson & Lehmann, 1996). Defining experts as those with experience in the field also creates ambiguity, since it is known that experience alone is not related to the development of expertise (Ericsson et al., 1993). Studying subjects with experience as representative of those with actual expertise may have contributed the variability in the findings of studies of expert reasoning. One solution is to focus on reproducible expert performance and identify common features to the reasoning of identified experts (Ericsson & Lehmann, 1996). Use of representative tasks has produced reliably expert performance in laboratory studies (Ericsson & Charness, 1994). Another is to study experts in their natural environments, solving real world problems in their real world settings. One example based on such research is the Recognition Primed Decision Making Model (Klein, 1993), which proposes that experts initially select a solution, conduct a mental simulation to evaluate its probable outcome, and if this is satisfactory, follow through on that solution. They do not evaluate all possible solutions. This is consistent with classic decision making research described above in that it supports the contention that experts, either in an identified domain or in dealing with everyday life (lay people), use heuristics and satisficing in making decisions. When situations are created in an experimental laboratory setting, experts may use strategies that they do not

use in real world decisions, such as backward reasoning. Presenting difficult decisions to which they respond accurately has suggested a decoupling, or disconnection, between knowledge and action (Leprohon & Patel, 1995). Alternatively, it is also possible that the coupling is based on heuristics and strategies that are not tapped into by experimental methods.

These possibilities have implications for the study of lay reasoning. Both experts and lay people have been found to reason using heuristics and pattern recognition, based on knowledge structures organized through experience over time. Methods used in the elicitation of expert reasoning patterns have been useful in understanding how experts make decisions. These methods are similarly helpful when applied to lay reasoning. Further investigation is therefore indicated.

2.3 Reasoning About Science

Everyday reasoning requires an understanding of the world, including scientific principles. The discussion of principles of lay and expert reasoning thus far suggests the use of heuristics by both lay and expert reasoners. Through extensive training and deliberate practice, the strategies of experts are refined and decisions are based on a larger, differently organized knowledge base. Closer examination of the reasoning processes specific to expert scientists and of lay reasoners about science provides additional insights into how these principles are incorporated into decisions.

2.3.1 Expert Reasoning About Science

Key tasks of scientific discovery include evaluation of scientific information and data, and development of new scientific theory and knowledge (Brewer & Mishra, 1998). Examination of historically significant theories reveals that they have greater explanatory coherence (Thagard, 1992) and are therefore more useful in explaining and predicting outcomes (Patel, Kaufman, & Arocha, 2000). Expert scientists, like experts in other fields, are able to develop experimental research designs rapidly and accurately in their own fields, i.e. the domain in which they have a well established knowledge structure and mental model (Schraggen, 1993). Based on his historical examination of the process of scientific decision making, Holmes (1996) suggests that scientific expertise, like that in other fields, develops over approximately ten years of deliberate practice and is not transferable from one domain to another.

Evaluation of the data produced by the experiments is a crucial component of the scientific process. When this data is consistent with expectations, it substantiates the hypotheses being tested. When data is unexpected however, it has been suggested that scientists respond in one of seven ways: ignore, reject, doubt, or exclude the data, hold the data in abeyance, reinterpret the theory, make peripheral changes to the theory, or change the theory (Chinn & Brewer, 1998). Contradictory findings that are inconsistent with the hypothesis being tested were found to be important in the determination of the direction of subsequent reasoning (Alberdi, Sleeman, & Korpi, 2000; Dunbar, 1999). Analogies are also an important mechanism in the reasoning and discussion of scientific teams (Dunbar, 1995). These team discussions were found to contribute significantly to the scientific process in that input from each individual team member contributed to the

final decisions made (Dunbar, 1995) through distributed reasoning (Dunbar, 1999; Salomon, 1993).

Principles of scientific reasoning suggest how lay people might develop their ideas about science and how they reason about it. Chinn and Brewer's (1998) categories of responses to data may be applicable to responses to all types of data and information, including medical information and information from one's own body in the form of symptoms. An example would be ignoring symptoms until disease progression is sufficiently advanced that they can no longer be denied. The coherence of knowledge structures and of the new data with those pre-existing knowledge structures is as critical for lay people as it is for scientists (Patel et al., 2000; Thagard, 1989). Consultation with others, as seen between scientists, is consistent with how people consult with each other in formulating ideas and making decisions. This provides a basis for the understanding of how lay people reason about science.

2.3.2 Lay Reasoning about Science

Early research examining how lay people reason about science viewed them as intuitive scientists (Kuhn, 1989). This has been challenged, however (Carey & Smith, 1993; Kuhn, 1989). Decision making in the real world is usually more complex, less clear, and less certain (Tetlock, 1992) compared with a scientific context. Scientific training involves developing logical methods of thinking developed over years of rigorous training. Kuhn (1989) proposed that the development of lay thinking processes about science is a progressive one that includes both strategic and meta-cognitive levels of thought. According to this view, contrasting the reasoning of scientists with that of lay

people shows that lay people do not strictly adhere to the rules of logic required for rigorous scientific evaluation but rather engage in very different cognitive processes when thinking about science (Kuhn, 1996). An alternative view proposes that students begin with an everyday, common sense model of science in the world around them (Carey & Smith, 1993), a model that includes misconceptions (Confrey, 1990). Causation may be of a teleological nature, in which causality is explained in terms of a purpose or goal (Carey, 1995; Hatano & Inagaki, 1996; Richardson, 1990). In order to understand scientific principles in a manner that renders them useful in everyday life however, such principles must be integrated into the pre-existing framework of the individual (Carey, 1986). It has been suggested that misconceptions are also embedded within this framework of prior knowledge (Vosniadou, 1994), becoming part of subsequent reasoning processes that incorporate these inaccuracies. One view of lay frameworks of science is that they consist of loosely connected, fragmented ideas (diSessa, 1993) that may or may not be valid (Spiro, Feltovich, Coulson, & Anderson, 1989). Successful lay scientific reasoning has been characterized as the development of associations between lay and scientific frameworks of causality based on processes in which theory and evidence are differentiated and coordinated, leading to inductive inferences (Kuhn, 1996; Kuhn, Schauble, & Garcia-Mila, 1992). This cannot be done by confronting intuitive knowledge that is culturally based, coherent, and has proven useful in an attempt to replace it with a more rigorous scientific one (diSessa, 1993; Songer & Mintzes, 1994). A more productive approach might be to build on the pre-existing knowledge base and strategies which have served both the individual and the culture well in the past (diSessa, 1993).

When learning about science, students employ strategies that preserve lay theory by eliminating the influence of the data or reinterpreting the theory (Chinn & Brewer, 1998). In his classic experimental study of the reasoning involved in subjects' search for an explanatory theory, Wason (1960) proposed that lay subjects generated data consistent with their hypotheses, making choices that confirmed their hypotheses rather than attempting to validate through disconfirmation. Subjects' first goal in explaining scientific phenomena was to attend to evidence consistent with their hypotheses, a strategy which interfered with goals such as explaining unexpected findings (Dunbar, 1993). Changing the goal of the subjects altered the manner in which unexpected findings were used, suggesting that the goal and the treatment of anomalous findings affected the final determination. Subjects were more successful however, when attention was focused on explanation of unexpected findings, as was seen in the reasoning of expert scientists (Alberdi et al., 2000; Dunbar, 1999). First and second grade students correctly identified conclusive tests when presented with two sets of two conflicting hypotheses and asked to generate tests to decide between them (Sodian, Zaitchik, & Carey, 1991), exhibiting differentiation between evidence and theory within a precisely defined context. Fifth and sixth grade students were less successful in developing theories to explain causality relating car design and speed, making invalid judgements based on invalid heuristics that reinforced prior beliefs (Schauble, 1996). Use of valid strategies improved with practice and was more effective in determining causality (Schauble, 1996). They were then used to understand other, related phenomena. These strategies, once developed, are added to the reasoning repertoire of the individual (Kuhn, 1995). They are necessary but not sufficient for successful scientific reasoning in that

they must be employed in conjunction with adequate domain knowledge (Schauble, 1996; Schauble, Glaser, Raghavan, & Reiner, 1992). Perkins and Simmons (1988) suggest multiple levels of knowledge, with flaws in each having the potential to result in misunderstanding and misconception.

These findings may be implicated when lay people are asked to understand and make decisions based on scientific information. Health care providers and information designed by them frequently provide domain knowledge without attending to the strategies required to make effective use of it. Lay people are then left to make decisions with scientific knowledge and lay strategies, without familiarity with scientific decision making strategies. When provided with new information, the first reaction is therefore to try to reinforce the pre-existing, culturally determined model of illness. Successful decisions are made when this initial goal is modified to focus on and include explanation of new data as well as strategies as to its use. The importance of the goal in determining the outcome of the discovery process is also suggestive of how goals might impact on decision making about health, i.e. the goal affects the decision.

Health care data are also frequently presented in terms of probabilities, another concept with which lay people have difficulty. Heuristics identified in the beginning of this review such as representativeness, availability, and anchoring (Kahneman et al., 1982) negatively affect the ability to use probabilities to make accurate decisions. Such basic flaws in the understanding of the concept of probability have been demonstrated with university students who, when given such information, converted it into causal terms (Konold, 1989). As discussed earlier, presentation of information as frequencies rather than probabilities reduces the negative effect of heuristics on decision making

(Gigerenzer & Hoffrage, 1995; Hoffrage & Gigerenzer, 1998). This raises the issue of how the concept of "good" decisions is defined. As discussed earlier, expert lay decision making under the constraints of real world uncertainty is not always synonymous with expert scientific decision making, with its well-defined processes and characterization of evidence. Lay reasoning about science suggests that, like experts in other domains, lay people develop knowledge and heuristics through experience, applying them in a utilitarian fashion to explain their world and make decisions within it.

2.4 Reasoning About Health, Illness, and Disease

This discussion has thus far explored studies of cognitive decision making research in general, followed by elaboration of scientific reasoning in particular. The focus now turns to research concentrating on decisions related to health, illness, and disease, beginning with an examination of expert medical reasoning as a counterpoint to an elaboration of lay reasoning, which follows.

2.4.1 Expert Medical Reasoning

Expert physicians show reasoning patterns consistent with those of experts described earlier. Like decision making research discussed previously, research examining medical decision making began with the assumption of logic as the basis for good decision making, exemplified by the Subjective Expected Utility Model (Weinstein, 1980). Discounted Utility Theory has also been applied to medical decision making, with mixed results (Redelmeier & Heller, 1993). Hypothetico-deductive reasoning was then proposed as a mechanism by which physicians make decisions (Elstein, Shulman, & Sprafka, 1978). The use of the availability (Nisbett, Borgida, Crandall, & Reed, 1982) and representativeness (Eddy, 1982) heuristics by medical experts is documented as well.

Expert physicians do not reason using absolute probabilities but rather categorize levels of probability (Elstein, Holzman, Belzer, & Ellis, 1992; Kuipers, Moskowitz, & Kassirer, 1988; McNeil, Pauker, Sox, & Tversky, 1982). The number of alternatives presented (Redelmeier & Shafir, 1995) and the degree to which probabilities are expressed explicitly (Support Theory) (Redelmeier, Koehler, Liberman, & Tversky, 1995) have both been shown to affect medical decision-making as does the manner in which the choice is framed (McNeil et al., 1982). Provision of additional information also affected physicians' decisions (Redelmeier & Shafir, 1995). Orthopedists were presented with a situation in which they had the choice of giving a patient an antiinflammatory medication or not, a low conflict situation. Under these circumstances, they generally chose to give it. However, when they were given a choice between two inflammatory medications, a high conflict situation, they were more likely to choose not to give any medication at all. The use of natural frequencies rather than probabilities reduced the influence of these heuristics in medical reasoning (Hoffrage & Gigerenzer, 1998), similar to the finding in research exploring lay heuristics reported in Section 2.1. As seen above in studies of other types of experts, physicians' performance was shown to be unrelated to expertise. Improving estimates of diagnostic probability of the likelihood of an infectious process did not improve doctors' treatment choices in the form of reducing prescription of antibiotics (Poses, Cebul, & Wigton, 1995). While expert cardiologists judged risk of cardiac procedures more accurately than internists (Poses et

al., 1997a), emergency physicians were far less accurate in predicting outcomes in terms of survival of patients with congestive heart failure (Poses et al., 1997b).

Physicians reason in a forward direction (fact-driven), generating networks in which observable facts lead from one to the next through intervening explanations, leading to a final diagnosis (Patel & Groen, 1986; Patel, Kaufman, & Magder, 1991). They do not consider multiple options but rather base their decisions on pattern recognition developed through clinical experience. Nor do they routinely make use of biomedical and patholophysiological knowledge and causation in diagnosing clinical cases (Patel et al., 2000). This reasoning pattern has been shown to develop with medical training and education (Arocha & Patel, 1995; Arocha et al., 1993). Backward reasoning, or reasoning in the reverse direction (hypothesis-driven or hypothetico-deductive), has been demonstrated by medical experts when the problem is difficult or anomalous (Patel, Groen, & Arocha, 1990b) or when data remains that is not explained by the main hypothesis (Joseph & Patel, 1990; Patel, Arocha, & Kaufman, 1994). Such shifts in strategies in the face of difficult problems have been demonstrated previously in basic decision making research (Kotovsky et al., 1985).

The knowledge structures that guide expert medical reasoning are constructed of clinical experiences and information related to possible diagnostic pathways (Boshuizen & Schmidt, 1992; Lemieux & Bordage, 1992; Patel et al., 1994). The structures are based on an underlying framework of biomedical knowledge to which physicians no longer refer in making their decisions. As seen in other experts, physicians too demonstrate superior memory for clinical information (Ericsson & Kintsch, 1995; Hassebrock, Johnson, Bullemer, Fox, & Moller, 1993). This increased capacity is not

directly related to level of expertise (Patel & Groen, 1991) but is related to diagnostic reasoning in that critical information is retained (Groen & Patel, 1988) and summarized (Boshuizen & Schmidt, 1992). Mental models are integrated representations of clinical experience (Lesgold et al., 1988) capable of incorporating additional relevant information (Norman, Brooks, Coblentz, & Babcook, 1992). Search processes used by experts in decision making are more efficient and accurate than those of novices (Lesgold et al., 1988; Myles-Worsley, Johnson, & Simons, 1988). Forward-directed reasoning is a highly automated reasoning pattern based on an efficient organization of clinical information developed through extensive clinical experience. Once a reasonable diagnosis is made, expert physicians employ the satisficing heuristic and accept the diagnosis (Joseph & Patel, 1990). This is typified by the well-known maxim "If you hear hoof beats, look for a horse, not a zebra." These differences have been shown to result in differences in performance of expert versus novice physicians in making predictions about survival of intensive care patients (Winkler & Poses, 1993) and in making difficult diagnostic decisions (Norman, Trott, Brooks, & Smith, 1994; Wolf et al., 1994). The reliability of these judgements has been questioned, however (Poses et al., 1997a; Poses et al., 1997b). Backward reasoning has been identified (Elstein et al., 1978) and characterized in intermediate physicians and expert physicians when confronted with a problem outside of their area, with which they are unfamiliar (Elstein & Schwartz, 2000; Patel et al., 1994).

Developing physicians, i.e. students and resident trainees, maintain many misconceptions and have difficulty integrating the biomedical and clinical knowledge bases (Feltovich, Spiro, & Coulson, 1989; Patel et al., 1991), resulting in knowledge that

is not used in clinical decision making. When confronted with biomedical information and asked to use it in clinical problem solving scenarios, the resulting explanations became incoherent and fragmented, with unreliable accuracy (Patel, Evans, & Groen, 1989). Under the medical education paradigm in which basic science is taught in isolation and students are then introduced into clinical settings where they are to apply the biomedical knowledge acquired earlier (referred to as the conventional curriculum), students were shown to use little biomedical knowledge in routine clinical problemsolving with little integration of the biomedical and clinical knowledge bases (Patel, Groen, & Norman, 1993). Closer examination (Patel et al., 1993) revealed that, when biomedical knowledge was provided first, it remained isolated from clinical knowledge. When the reverse order was followed, the clinical knowledge provided a framework into which the biomedical information was then integrated. However the two frameworks became enmeshed so that students provided not only relevant information but also additional, unrelated information. Furthermore, different aspects of the biomedical knowledge base were accessed to explain analogous problems, suggesting that the frameworks were inextricably linked and the biomedical knowledge could not be differentiated from the clinical problem in which it was learnt. It has been shown that learning through problem solving may interfere with adequate learning of abstract concepts, such as those learned in basic science instruction (Sweller, 1988), suggesting that the difficulties of students learning clinical and biomedical knowledge simultaneously stems from the attempt at premature integration of the two conceptual frameworks (Patel et al., 2000). The reasoning pathways of senior students and physicians trained in curricula in which they acquired biomedical knowledge early and in isolation relied more on clinical concepts and generally reasoned in a forward direction while those acquiring both biomedical and clinical concepts simultaneously used more biomedical concepts and reasoned in a backward direction (Patel et al., 1993). It has been suggested that the development of medical expertise is a stage-based process through which biomedical and clinical structures are built in interactive stages that develop and integrate into the cohesive knowledge structures of the expert physician (Schmidt, Norman, & Boshuizen, 1990). Others disagree with so orderly a progression on both practical and theoretical grounds (Patel et al., 2000), pointing out that biomedical knowledge is rarely used when experts solve familiar problems, that the knowledge structure of biomedical knowledge and the inquiry skill of clinical reasoning are very different and their acquisition involves two tasks that may compete for cognitive resources, and that students receive relatively little exposure to biomedical knowledge during their training.

The complexity of the acquisition of advanced medical knowledge suggested by the discussion thus far has been described as the progressive development of mental models, which are knowledge structures that are used to explain experience and in turn, predict and reason about the world (Kaufman & Patel, 1999; White, 1993; White & Frederiksen, 1990). Running these models is referred to as mental simulation, a process by which the model can be applied in a forward direction based on current states to hypothesize about potential future outcomes and in a backward direction to explain current states and infer causality (Patel et al., 2000). Through medical training, students organize the large body of biomedical and clinical knowledge necessary to understand the practice of medicine into the knowledge structure that is used to make clinical decisions

(Boshuizen & Schmidt, 1992; Boshuizen & Schmidt, 2000). Should any misconceptions be incorporated into these mental models, either as part of the prior knowledge structure or through faulty knowledge acquisition, these errors would interact with each other in the further development of the mental models, becoming robust and increasingly applied to erroneous explanations of new phenomena (Feltovich et al., 1989).

As with decision making in general, one process by which mental models of medical concepts are constructed, elaborated, and utilized is that of analogical reasoning (Patel et al., 2000), in which prior knowledge is applied to the understanding of new situations. Analogies can be useful in learning (Brown, 1994) and in medical practice (Kaufman, Patel, & Magder, 1996), or counterproductive (Spiro et al., 1989), leading to solidification of errors within the knowledge structures. For analogies to be successful there must be adequate knowledge of the target domain so that mappings from the knowledge representation to the target domain will be accurate. If this knowledge is insufficient the analogies will be similarly unproductive or inaccurate, potentially leading to propagation of misconception within the knowledge structure. Analogies can be useful in developing knowledge if they are accurate and if they are based on the pre-existing knowledge base, contributing to increasingly sophisticated and complete mental models (White & Frederiksen, 1990).

In summary, expert physicians have been found to reason in a forward direction, based largely on pattern recognition. This clinical knowledge is based on years of experience. Biomedical knowledge develops through rigorous training programs. However it is frequently not well integrated with clinical knowledge and in some cases may actually interfere with clinical decision making. Nor is it used or even needed for

accurate decision making (Leprohon & Patel, 1995; Patel et al., 1989). Expert physicians reason using heuristics and hone their heuristic repertoire and the skill in using them through extensive training and experience.

These findings have implications for how lay people accumulate and use biomedical knowledge, and how they interact with physicians. Training programs in which students are expected to develop clinical and biomedical knowledge simultaneously result in backward reasoning and lead to difficulties in separating biomedical information from the situation in which it was learnt. Yet when lay people are taught by health care professionals, teaching usually includes both clinical and biomedical information at the same time. Inaccurate information may be propagated through the lay mental model of the disorder or illness leading to poor decisions. If lay people require biomedical knowledge, then it might be better to provide it in isolation prior to incorporating it into the decision making process. The other issue raised by the examination of medical decision making is its basis on clinical knowledge and pattern recognition rather than biomedical principles. Perhaps it is not necessary for lay people to struggle with the unfamiliar biomedical knowledge that does not fit with their framework of illness if they can be provided with an alternative means to make their decisions.

The striking differences in cognitive processes between students and expert physicians and the difficulty with which they are acquired also have implications for how experts interact with those who have not undergone this rigorous process, i.e. lay people. Communication requires some shared mental model and shared goals to serve as the basis for interaction. Yet it appears that doctors and patients have very different frameworks,

knowledge structures, and goals. Could this be partly responsible for the difficulties in compliance of patients with medical recommendations? Perhaps one reason might be that physicians comply poorly with patients' plans.

2.4.2. Lay Reasoning about Health and Illness

Lay reasoning about health, like lay scientific reasoning, is guided by processes similar to those of experts in these fields, but the knowledge structures and the precise nature of the pathways are different. Processes such as satisficing and heuristics have developed, as described earlier, to allow people to make sense out of the world and to make decisions in a context in which the rigorous constraints of expert scientific and medical reasoning cannot be maintained. It has been argued that what normative theories interpreted as violations of rational decision making are in fact cognitive mechanisms that have evolved to permit decisions to be made in a world of incomplete information, changing contexts, conflicting goals, time limitations, and uncertainty (Cosmides & Tooby, 1996; Gigerenzer et al., 1989; Hammond, 1996). Research suggests that these lay mechanisms follow certain consistent pathways based on 'common sense' (Diefenbach & Leventhal, 1996; Leventhal, Diefenbach, & Leventhal, 1992), introducing the concept of expert lay reasoners (Patel et al., 2000).

Scientists are trained to reason with rigorous attention to the rules of logic. Lay people have been shown to reason very differently. They may not acquire or evaluate knowledge and evidence in the same way that scientists do, possibly resulting in differences in the use of inference and hypothesis testing (Kuhn, 1989; Kuhn, 1995; Schauble, 1996). These differences may lead to deficiencies in the conclusions of lay

people, with resultant effects on the decisions they make (Perkins & Simmons, 1988). However, the opportunistic and practical nature of lay reasoning does allow people to function in everyday life, making decisions that, while they might not be of the calibre of a trained scientists, also do not require the same investment of training, time, and rigour; resources that lay people do not have.

Many models have been proposed in attempts to describe lay reasoning about health. The well-known Health Beliefs Model (Becker & Maiman, 1975; Rosenstock, 1974a; Rosenstock, 1974b) identifies psychosocial, perceptive, and demographic variables that impact on decisions and the interactions between them, with variable predictive validity (Harrison, Mullen, & Green, 1992). Normative decision making theories such as the Theory of Reasoned Action concentrate on beliefs and attitudes in decision making (Ajzen & Fishbein, 1980). It has been applied to health-related decision (Fishbein & Middlestadt, 1989), though its veracity in the domain of health has been challenged (de Weerdt, Visser, & van der Veen, 1989; Sutton, 1987). Subjective Expected Utility Theory (Edwards, 1954) focuses on the evaluation of desirability and likelihood of expected outcomes and has been studied with respect to health related decisions (Furby & Beyth-Marom, 1992). Discounted Utility Theory assigns values to delays in achieving outcomes (Loewenstein, 1987) and has also been applied to healthrelated issues (Chapman & Elstein, 1995). Social Cognitive Theory focuses on cognitive and self-regulatory mechanisms, particularly self-efficacy, as they affect behaviour (Bandura, 1986). Prospect Theory (Kahneman & Tversky, 1979), which was discussed earlier, has also been applied to decisions related to health and illness (Pierce, 1993;

Redelmeier et al., 1993). Each of these characterizes components of lay decisions and decision making.

Cognitive theory has provided some insight into the reasoning processes by which lay people make decisions about health and illness, determining that actions are based on representations of symptoms (Cameron, Leventhal, & Leventhal, 1993; Diefenbach & Leventhal, 1996; Leventhal et al., 1992). Intentions are implicated in determining behaviour, with a well-formulated strategy having more impact on behaviour than a vague, unspecified plan (Gollwitzer, Heckhausen, & Ratajczak, 1990; Orbell, Hodgkins, & Sheeran, 1997). Knowledge also plays a critical role, though it must be coherent to have significant impact on behaviour (Leventhal et al., 1992; Thagard, 1989). This has been found to be problematic.

Maasai mothers living in rural and urban Kenya and Ethiopia interpreted scientific, quantitative instructions within the pre-existing framework of knowledge by translating them into qualitative estimations of the original instruction (Eisemon & Patel, 1989; Patel, Eisemon, & Arocha, 1990a). This is not unique to African cultures but was found to be true of North American subjects as well (Hurd & Butkovich, 1986; Kendrick & Baynes, 1982). Examination of the knowledge structure and concepts of causality of disease of lay people in Kenya (Eisemon, Patel, & Ole-Sena, 1987; Patel, Eisemon, & Arocha, 1988), India (Sivaramakrishnan & Patel, 1993a), and Indian mothers in Western society (Sivaramakrishnan & Patel, 1993b) showed that those with only the traditional knowledge base about health had a detailed, coherent structure. However those with additional education showed fragmentation and incoherence of explanation. Their conceptualization of causality of disease incorporated concepts from both their cultural,

traditional model and the biomedical information introduced in school, resulting in an inaccurate and disjointed representation that combined but did not integrate the two frameworks. Concepts from either structure were recruited to explain a given situation in an opportunistic fashion leading to explanations that lacked the internal consistency of descriptions based on a single knowledge structure. This was exemplified by the finding that Indian mothers in Canada used biomedical concepts more to communicate with members of Western society than as the basis for decisions making (Sivaramakrishnan & Patel, 1993b), with the interpretation of health-related concepts remaining remarkably resilient to change by exposure to Western biomedical concepts.

This resilience of the traditional conceptualization and the lack of integration of biomedical knowledge into the traditional knowledge structure may be due in part to the different manner in which the two structures are acquired (Patel et al., 2000). Traditional knowledge is socially acquired over time and is based on observation and practical application (Carey & Smith, 1993). Biomedical concepts are typically obtained in abstract form, in a classroom isolated from everyday life or through various media. By the very nature of their abstraction, biomedical concepts are not always validated in everyday life while cultural knowledge is, since that is the original basis for its development. An example is the explanation of cold temperatures and wet feet as causing upper respiratory tract infections based on the coincidence of the winter season in which these three phenomena tend to co-exist. Viruses, though the true cause of the cold symptoms, are not visible. Nor is transmission of these microscopic particles through close contact. Cold weather and wet feet are readily observable and correlate with the pre-

existing framework does not make science available for successful decision making (Carey, 1986; Kuhn et al., 1992). Knowledge alone, though necessary for decision making, has therefore not been found to increase compliance with medical instructions (Jones, Arthurs, Sturman, & Bellis, 1996; Taira, 1991).

Examination of decision making by novice medical students suggests the impact and pervasiveness of prior knowledge. These are students who have accumulated at least a college level of scientific knowledge and training. Yet when asked to explain case scenarios of illness, the accuracy of their problem solving was negatively affected by the provision of biomedical information in the form of medical textbooks (Patel et al., 1993). Explanations were not integrated but rather included "loose ends," factual errors, and misconceptions. This might be similar to the manner in which biomedical education interfered with Massai and Indian mothers' reasoning. In addition, knowledge and skills acquired through traditional means do not necessarily transfer to understanding of academic principles. Brazilian school children were shown to have developed a high level of expertise in the mathematical operations required to make change while working in the streets as street vendors (Carraher, Carraher, & Schliemann, 1985). These principles did not assist them, however, in solving pen and paper problems. Traditionally acquired knowledge did not transfer to classroom skills. Singley and Anderson (1989) suggest that such transfers are seen when the underlying logical principles of two sets of skills are similar, rather than when superficial features are alike.

Classroom learning from examples and self-explanation has been shown to be both preferred over lecture instruction (Chi, de Leeuw, Chiu, & LaVancher, 1994) and more effective in achieving learning (Carroll, 1994; Cooper & Sweller, 1987; Zhu &

Simon, 1987). This may reflect the manner in which lay knowledge structures are constructed. People learn from experience and associations in a narrative fashion. Learning from examples mimics this type of learning, with the importance of selfexplanation suggestive of the creation of a narrative knowledge structure that can support reasoning.

This hypothesis suggests that the difficulties that lay people have in understanding and working with scientific medical knowledge may be due to fundamental differences in the underlying structure and reasoning processes by which medical knowledge is developed and applied. The problems look similar superficially in that both are dealing with health-related issues, but the underlying knowledge structures are different. Without coherence in the representation guiding behaviour, there can be little lasting effect resulting from attempts to modify behaviour (Leventhal et al., 1992; Thagard, 1989). Lay people therefore make their decisions based on the coherent component of their knowledge, i.e. prior knowledge based on personal experience (Meyer, Russo, & Talbot, 1995; Pierce, 1996).

These findings have implications for the delivery of health care. This discordance and lack of integration between the culturally acquired traditional frameworks and the biomedical, scientific concepts introduced through formal education contributes to the failure of modern health care in attempting to change health-related practices (Eisemon & Patel, 1990). Patel, Eisemon, and Arocha (1988) suggest that adult education be more considerate of traditional belief systems and practices, a suggestion that is applicable to Western cultures as well. Western health-related instruction tends to be couched in terms of biomedical concepts based on quantitative probabilities. Yet research has shown that this is not how people think about health and illness, nor is it how they make decisions.

Comparison of medical expertise and its acquisition with the lay framework of health and illness is suggestive of how the current situation in health care has developed, a situation in which those providing health care and those receiving it have such discordant views. There is little shared understanding to serve as a basis for communication and goal setting, resulting in conflicting goals and little meaningful interaction.

Health care has made great strides in curing and preventing disease, yet a major difficulty remains changing health related practices of patients as well as of the general public. Non-compliance with medical regimens remains a major roadblock in maintaining, promoting, and restoring health (Barnard, Akhtar, & Nicholson, 1995; Leventhal, Leventhal, Robitaille, & Brownlee, 1999; Mehta, Moore, & Graham, 1997; Schmier & Leidy, 1998). People express dissatisfaction with health care and seek out alternative medicine as a way of obtaining the type of care they require. Research examining how people reason, in particular how they reason about health and illness, reveals that such reasoning is based on a loosely connected framework of knowledge rooted in socio-cultural tradition. Lay cognitive processes are not logical but are based on heuristics. Yet health care is delivered based on scientific principles and health care information is provided based on science and probabilities, in spite of evidence suggesting that (a) people do not reason this way, (b) physicians themselves do not actually reason this way, (c) integration of scientific knowledge into the pre-existing traditional knowledge base and decision making processes is difficult and cannot be done

by simply providing scientific information, and (d) other issues such as personality traits and social issues are important in lay decision making. Effective delivery of health care and the lasting changes in behaviour required for health promotion and preservation may be impeded by these contradictions.

Throughout the review of related research above, potential implications of the cognitive processes described are detailed for effects on how health care decisions might be made, suggesting that such decisions are based on domain-specific heuristics rather than principles of absolute logic. Reliance on knowledge structures that are constructed differently, the use of different heuristics, and different priorities and goals might also impact on interactions between trained health care professionals and lay people. Lastly, the divergent frameworks of professionals and designers who develop educational programs and tools for use by lay people may affect how these tools are used, influencing their efficacy in changing behaviour.

In order to meet the health care needs of the public, more must be known about how health and illness are understood and how decisions about health-related issues are made. This knowledge can then be translated into development of teaching methods and communication tools that are effective in changing behaviours of the intended targets, the lay public.

This thesis presents two studies, including one based on a published article and one article submitted for publication. The initial study targeted understanding of health and illness in detail. Three lay samples (subjects with no current medical diagnosis or treatment, subjects with insulin dependent diabetes, and subjects with a history of cardiac disease) were evaluated for how they describe health and illness, how they seek out

knowledge, what they learn, and how it is implemented in their decision making. Semistructured interviews were conducted, including presentation of scenarios to generate think aloud problem solving protocols. Analysis was based on identification of concepts and semantic network analyses. The three sample groups represent varying degrees of experience with illness and with the health care system. In this way, comparisons could be carried out as to the effects of experience and prior knowledge on the models of cognitive processes, in this case models of health and illness. For example, does experience with illness affect its conceptualization? Does increased contact with the health care system affect where people go to for information? Does it make them more likely to go to a physician for information? How do they decide where to go? Does teaching by health care professionals affect how they respond to decision making situations? These issues are addressed in Study One, reported in Chapter Three.

The second study addresses some of these questions in more detail, examining the cognitive processes involved in decision making by subjects with insulin dependent diabetes and physicians. The population of people with diabetes was chosen because of the salience of the illness and treatment regimen in their everyday lives. Semi-structured interviews were conducted, concepts identified, and semantic network analysis carried out to identify the factors that were relevant to subjects in making their decisions and how they were inter-related. The effect of varying frameworks of providers/designers and patients/users of a technological communication tool was then addressed. It was hypothesized that the differing models of the two groups would affect how they used the system, i.e. that the tool, a telecommunications device designed by physicians, would be understood differently and therefore used differently by physicians and by patients.

Subjects included physicians and insulin-dependent diabetics, who were asked to enter and retrieve data from the telecommunication system designed for patient use. Their interactions with the system were videorecorded and analyzed. Both studies are reported in Chapter Four.

A portion of a third study examines how varying mental models affect resulting actions. The content discussed by people during discourse reflects their underlying models (Kintsch, 1998). The discourse represented by a provider-patient interaction as seen in regular clinic office visits was therefore examined. It was hypothesized that the differing frameworks of doctors, nurses, and patients would affect the topics addressed in their interactions. If their understanding of health, illness, and disease is different, it would be expected that this would be reflected in the concepts they would discuss in their interactions. Provider-patient interviews were audiotaped and analyzed based on the concepts identified in Study One as important to patients. This research is reported in Appendix One.

This series of studies provides insights into how prior experience and knowledge affect mental models, and in turn, how these models affect decisions and actions. This is carried out within a health care context, examining lay models of health and illness, how lay people reason about health and illness, how they inform themselves about it, what they know, how they use what they know, and how their conceptualizations impact on the use of technology designed by providers on their interactions with health care providers. This thread, its implications for health care and for affecting health-related behaviour of patients and the lay public, are discussed in Chapter Five, General Discussion, Conclusions, and Implications.

2.5 Methodology Framework

The methodology employed in these studies was designed to identify conceptualizations and their use in cognitive decision making processes. Subjects were recruited to represent a range of experience with illness and health care, providing a broad view of reasoning related to health and illness. Three groups of subjects were delineated. One group, examined in both Studies One (Chapter Three) and Two (Chapter Four), was made up of patients coming to see their endocrinologist at the Medical Day Centre of the Royal Victoria Hospital, a tertiary care in Montreal, Quebec, Canada. Clinic nurses assisted in the identification of patients with insulin-dependent diabetes mellitus. A second group, included in Study One, consisted of patients recruited from the clinic of a cardiac intensive care physician. Only patients with cardiac diagnoses including Coronary Artery Disease, Congestive Heart Failure, Angina, or a history of myocardial infarction were included in the study. Subjects with both diabetes and cardiac diagnoses were excluded from the study. The third group of Study One consisted of people who had no medical diagnosis at the time of the study. The presence of any current or ongoing chronic diagnosis resulted in the elimination subjects from this group. These subjects were volunteers recruited from students and staff of McGill University and the Royal Victoria Hospital. Fluency in either English or French was required for participation in the study.

Data was collected using semi-structured interviews and scenarios that generated think aloud protocols (Fitten, Lusky, & Harmann, 1990). Probes for the semi-structured interviews were developed based on the literature identifying discussed previously concepts of importance in lay reasoning. The interviews began by addressing how lay

people understand health and illness in general and, for those subjects with specific diagnoses, the knowledge and understanding of their illness in particular. How subjects make decisions related to health promotion, disease prevention and treatment was explored with all groups. Subjects were given specific explanation tasks as well were included in order to elicit reasoning about health-related issues. An example of this type of probe would be asking a diabetic subject why (s)he might eat a piece of cake one day and not the next. Sources of information were determined, including why each source would be used. Probes in the interview in Study One (Chapter Three) also examined subjects' knowledge of heart attack. Scenarios related to heart attack (Study One, Chapter Three) were realistic and consistent with literature describing the clinical phenomena depicted (Gillium, Fortmann, Prineas, & Kottke, 1984). Their validity was verified in consultation with a critical care physician. The scenarios related to diabetes given to physicians and patients in Study Two (Chapter Four) were also verified by an expert endocrinologist. This design combined features of both controlled experimental studies and real world environments.

The procedure began with explanation of the study to subjects and obtaining their informed consent to participate in the study. The semi-structured interview was then administered. This was followed in Study One by presentation of scenarios depicting varying levels of uncertainly and ambiguity related to cardiac symptoms and in Study Two by presentation of data in scenario form to enter into a telecommunications system. Subjects were given no instruction when responding to the scenarios in order to determine their responses based on prior knowledge and conceptualizations only, rather than responses influenced by modifications introduced by instructions grounded in the

biomedical model of physicians and the system designers. This also allowed examination of learning of the system originating from a naïve understanding unaffected by instruction. In clinical practice, a telemedicine device such as the one used here, as well as any other piece of equipment, would require training before patients would be given the tool in their homes. However the goal in this study was to assess their prior knowledge and understanding of the device before receiving information from health care providers.

Elicitation of verbal think aloud protocols is an established and valid method to capture decision making processes (Ericsson & Simon, 1993). It is a well-developed method for identifying and characterizing the nature and types of concepts that has been used previously in studies by this group of researchers. Techniques for analysis were drawn from (1) discourse analysis, in which complex verbal data generated by subjects is analyzed, and (2) propositional analysis, in which concepts are identified from verbal protocols (Olson & Biolsi, 1991; Sivaramakrishnan & Patel, 1993a; Sivaramakrishnan & Patel, 1993b; van Dijk & Kintsch, 1983). Propositional representations explicitly represent ideas and their interrelationships (Patel & Arocha, 1995). The occurrence of concepts was identified and percent frequencies calculated. Relations among propositions were then represented as semantic networks, which allow identification of directionality and coherence of reasoning processes (Patel & Arocha, 1995; Sowa, 1984). When biomedical concepts were being evaluated, subjects' responses were compared with reference models (AMI and diabetes) based on information from the literature and experts in the respective fields.

Ethical approval was obtained for all three studies. Studies One and Two were authorized by the Institutional Review Board of McGill University, Department of Medicine. Study Three (Appendix One) was sanctioned by the Institutional Review Board of the Beth Israel Hospital in Boston, MA.

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CHAPTER THREE

LAY CONCEPTIONS OF HEALTH AND ILLNESS RELATED TO ACUTE MYOCARDIAL INFARCTION: A COGNITIVE ANALYSIS

3.1 Abstract

Objective: Rapid recognition and action in response to symptoms of Acute Myocardial Infarction (AMI) is critical for initiation of life-saving treatment. Delay in action has been tied closely to patients' conceptualization and biases about their own health. This study investigates lay understanding about health and illness and its implications for development of technological support for effective intervention.

Design: Subjects represented three levels of experience with heart disease and health care: subjects with pre-existing cardiac disease, with insulin dependent diabetes, and without any ongoing medical diagnosis. Subjects were interviewed and were then instructed to evaluate scenarios representing symptoms of AMI, using think aloud protocols to describe decisions about actions.

Measurements: Data were audiotaped, transcribed, and analyzed for concepts related to health and illness, knowledge, and the relationship between these concepts for making decisions.

Results: Concepts related to health and illness centred on feeling well and carrying out daily activities. These concepts did not change as a function of experience with illness, showing remarkable stability. When seeking health related information, subjects' choice of sources was grounded in everyday patterns based on accessibility, familiarity, complexity, and credibility. Knowledge of AMI appeared to be decoupled from decisions to act. Rather lay people used heuristics and demonstrated bias in dealing with their problems.

Conclusion: Understanding about peoples' choices, decisions and actions are prerequisite to developing adequate technological support for rapid access to accurate, relevant information when needed.

Keywords: Patient Education, Medical Informatics, Internet, AMI, Physician-Patient Relations

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3.2 Introduction

Heart attack claims many lives every year. Rapid recognition of the onset of symptoms of acute myocardial infarction (AMI) followed by immediate action can make the difference between survival and death as well as significantly improving the outcome after AMI in terms of survival of heart muscle and thereby quality of life. Yet during this period, individuals experiencing these symptoms frequently do not realize the importance of what they are experiencing and may delay taking decisive action. Reducing this delay would have major impact on both morbidity and mortality following heart attack. Information technology has been used to improve the recognition and action in response to acute symptoms for diabetic patients (Meneghini, Albisser, Goldberg, & Mintz, 1998). This suggests its potential to provide valuable information about how to recognize heart attack symptoms, how to differentiate them from other, more benign symptomatologies, and how to decide what to do more quickly (Cimino et al., 1998). Recent research has examined the comprehension of health care teaching materials by lay people and found that understanding of information is often incomplete or it is misunderstood and can be applied incorrectly or inadequately (Wright, 1999). For technology to have the greatest impact on the actions of patients at risk for AMI, it must be tailoured to the needs of the intended users, how they think and make decisions, what they understand of the information provided by health care system sources, and how they use that information (Patel & Kushniruk, 1998).

3.3 Theoretical Framework

Most decisions about health and illness are made by lay people in the community: decisions such as how to relieve a headache, is the backache sufficiently severe to warrant intervention and what kind, and so on. One such decision is when to contact health care services. This is particularly important when the decision is about AMI, a decision that can affect mortality, long-term morbidity, and quality of life. Symptoms frequently appear in a community setting rather than a health care context and it is often up to members of the lay population (the person, family, friends) to decide what to do. In recognition of this reality, educational programs have been implemented to provide information to those who need it, the lay public, in an attempt to reduce the amount of time taken to make the decision for an AMI patient to go to a hospital. These programs have not had the expected results in terms of reduction of the delay to receiving treatment (Blohm, Hartford, Karlson, Luepker, & Herlitz, 1996). Reasons for continuing delay include misinterpretation of symptoms (Meischke, Ho, Eisenberg, Schaeffer, & Larsen, 1995), choosing an ineffective action (Meischke et al., 1995), and mistaken beliefs about heart disease and the efficacy of its treatment (Bleeker et al., 1995). The source of the information underlying these decisions is health care providers, however they are not the only resource. Friends, relatives, television, and print media (James, James, Davies, Harvey, & Tweddle, 1999; Meischke & Johnson, 1995) are each alternative sources of health related information. The choice of where to go to for information is influenced by a number of factors, including the credibility and accessibility of the source (Meischke & Johnson, 1995), personal experience with the problem (Meischke & Johnson, 1995), and the purpose and circumstances for which the information is being sought (James et al.,

1999). Information from this multitude of sources is synthesized into an underlying framework of beliefs that guide behaviour. Unfortunately, this framework has been ineffective in generating the response to AMI, i.e. people do not respond quickly enough. The new tool of technology has the potential to be more effective, however it must be seen as useful and approachable as determined by these criteria.

Individual psychological processes as well as social and cultural influences contribute significantly to the decisions made and actions taken by patients, and there have been suggestions that these must be incorporated into any intervention for it to be effective (Bleeker et al., 1995; Meischke et al., 1995). An understanding of the cognitive mechanisms involved in making the decision to seek treatment, or not to, can provide a cohesive framework guiding the development of technology that will assist in making an appropriate decision with respect to accessing emergency services. Cognitive psychology is uniquely suited to address these process oriented questions. Interventions aimed at changing thinking and action, such as technologically based educational programs, must address the issues that are important to the lay reasoners who are actually making these decisions and the processes they use. Before programs can be tailored to their needs, these needs and processes must be identified.

Cognitive-psychological research has shown that lay decision making is based on observation, on associationistic and correlational evidence acquired through social and cultural exposure (Eisemon, Patel, & Ole-Sena, 1987; Kuhn, 1995; Patel, Kaufman, & Arocha, 2000). Prior knowledge structures developed in this way, usually based on cultural models developed informally, influence reasoning about health and illness more strongly than formal learning from schools and the health care system (Sivaramakrishnan

& Patel, 1993). Attempts to integrate new, scientific evidence with pre-existing, traditional knowledge results in a combined knowledge structure that is incoherent and contains internal contradictions (Sivaramakrishnan & Patel, 1993). When novice medical students are presented with data contradicting a pre-existing hypothesis, they tend to ignore or reinterpret the new information to maintain the original concept (Arocha & Patel, 1995). These characteristics of lay reasoning point to the difficulty of modifying longstanding beliefs. Furthermore, scientific evidence furnished by health care providers tends to be in quantitative form. Yet when confronted with quantitative information, lay reasoners were found to translate numbers into qualitative approximations using general heuristics (Eisemon et al., 1987; Patel, Eisemon, & Arocha, 1988). This has the potential to create miscommunication when lay reasoners convert such quantitative information.

The role and resilience of prior knowledge in lay decision making has implications for how lay people interact with health care materials (Patel et al., 2000), including technology. Many types of educational materials, both low-tech and high-tech, are aimed at providing information to health care consumers. The manner in which consumers use this information is frequently not as intended by the designers, however (Davis et al., 1998; Wright, 1999), frequently due to user-designer mismatch (Cytryn & Patel, 1998). Simple incompatibility between the literacy level of the consumer and the level required to understand teaching materials has been shown to be problematic in printed materials (Estey, Musseau, & Keehn, 1994) and on the World Wide Web (Graber, Roller, & Kaeble, 1999). Graphics have been found to improve learning comprehension (Davis et al., 1998) yet information is frequently presented in text-based form. Examination of the impact of users' models of the health, illness, and technology on how telecommunication technology is applied exposed discrepancies between the intentions of the designers and the implementation by the users, with potentially negative outcomes (Cytryn & Patel, 1998; Patel, Arocha, & Kushniruk, in press; Zhang, in press). Cardiac patients continue to delay in taking action (Blohm et al., 1996) in spite of the availability of on-line information that includes recommendations of what actions to take (Dracup, 1997). People are willing to use the Web as a resource (James et al., 1999), however their models of health, illness, and of the technology itself impact on their interactions with computer systems (Cytryn & Patel, 1998). Understanding of instructional materials can be improved by tailoring them to fit with the models of the consumers (Eisemon et al., 1987), increasing the appeal, availability, and credibility of technological and Internet resources. Before this can be put into practice, however, these informal models must be understood so that new technologies targeting lay consumers can be designed to match the way they will understand and use it.

Research is needed in order to answer these questions. Focal areas for further examination are:

- (1) How health care consumers reason about health and disease with respect to familiar and unfamiliar health related events, such as the appearance of symptoms.
- (2) What actions lay people take based on how they reason, particularly the relationship between perception and action. Current evidence suggests that these are decoupled. Can technology strengthen the connection between information and action, supporting better decisions? Or, if knowledge is not

the basis for decisions, how can technology address the mechanism that *is* used and support good decisions through that mechanism?

- (3) How lay people manage anomalous data. Can technology affect this response, either by reducing the perception of data as anomalous or presenting appropriate alternative responses to the data, available on a just-in-time basis, directing better actions?
- (4) How people determine where to go for information and how technology can be tailoured to meet these criteria.

In this study, we examine the conceptual understanding of health, illness, and the health care system by patients with cardiac diagnoses, patients with insulin dependent diabetes mellitus, and people with no current medical diagnosis. The relationship of this understanding to their decisions about intervening when confronted with cardiac symptoms is then explored.

3.4 Methods

3.4.1 Subjects

Three groups of 10 subjects (N=30) were recruited, representing a range of experience with cardiac disease and with the health care system. Patients with histories of cardiac illness (high experience with cardiac disease and health care) and patients with insulin-dependent diabetes mellitus (low experience with cardiac disease, high experience with health care) were recruited from the Royal Victoria Hospital, a tertiary care McGill teaching hospital, with the assistance of a critical care physician, an endocrinologist, and endocrinology nurses respectively. Patients were approached, the study explained and

their participation requested. Subjects with no current medical diagnosis (low experience with cardiac disease and with health care) were drawn from volunteers from the general population of university and hospital personnel. While an effort was made to match the groups, it was felt that it was more important that the sample be realistically representative rather than unrealistically equivalent. This study was based in the natural clinical environment and reflects the composition of the patient population present at the time the data were collected.

Based on demographic data collected during interviews and summarized in Table 3.1, the sample was found to be predominantly female (67%) due to a preponderance of women in the diabetic group (90%), though this difference was not statistically different. Data were also collected describing subjects' level of education, which was fairly normally distributed over the entire group, ranging from elementary school to postgraduate education. The cardiac subjects had significantly less formal education compared with the younger diabetic and healthy groups. Subjects' ages ranged from 19 to 86 years, with the cardiac group being significantly older than the other two groups.

3.4.2 Materials

Interview: In the Background above, several factors that play a role in lay decision making about health and illness in general and AMI in particular were identified. A semi-structured interview was developed based on those factors known to create delays in people seeking emergency assistance for AMI (Appendix 3.1). Interview items or probes focused on conceptualizations of health and illness, knowledge about AMI, and information sources about AMI and about health and illness in general.

Table 3.1. Demographic Characteristics (Age, Sex, Education) of the Subject

Groups: those with no medical diagnoses, with diabetes mellitus, and with cardiac diagnoses.

Demographic Variables		Subject Grou	p
	No Medical	Diabetes	Cardiac
	Diagnosis	Mellitus	Diagnosis
	(n = 10)	(n = 10)	(n = 10)
Age (years)			
Mean	35	44	71***
Standard Deviation	12	16	12
Sex (percent)		· · · · · ·	
Female	60	90	50
Male	40	10	50
Education (percent)			
College or less	30	60	100**
University – Undergraduate Level	40	20	0
University – Graduate Level	30	20	0

*** $F_{2,27} = 20.35$, $p \le 0.001$ ** $\chi^2_8 = 21.4$, $p \le 0.01$ N.B. χ^2 analysis was carried out rather than ANOVA due to the ordinal nature of this data.

Scenarios: Three scenarios (Table 3.2) were developed with progressively increasing familiarity of symptoms of AMI, representing decreasing levels of anomalous symptoms as data. Symptoms ranged from unrelated to the heart to severe, sudden chest pain. The representativeness and accuracy of these scenarios was verified by a critical care physician who acted as a consultant physician. The familiarity of the symptoms presented was verified by asking subjects what they knew about AMI symptoms during the interview and matching symptoms reported with those presented in the scenarios. Responses to the exploration of symptoms in the interview also provided the baseline prior knowledge on which subjects founded their decisions in the scenarios.

3.4.3 Procedure

Subjects were recruited into the study in the clinical and community areas described above. The study was explained and their informed consent obtained. Interviews were carried out in the clinical settings for subjects recruited from the patient populations and in the research laboratory or subjects' homes for subjects recruited from the community. Immediately following the interview, subjects were presented with the three scenarios. Subjects were instructed to provide an uninterrupted, unedited stream of their thoughts as they reasoned through the situation, thinking aloud as they read through the scenario and reasoned about the patient as they understood them. This method has been shown to provide an accurate representation of the cognitive reasoning processes used by subjects in working through a situation (Ericsson & Simon, 1993). All interviews were audiorecorded for analysis.

Scenario One: Symptoms unrelated to heart attack:

You are walking along the street with your friend, a 50-year-old gentleman, who tells you that he is having terrible stomach cramps and that he has been vomiting. He is not feeling well. What would you do? How did you make that decision, what did you base your decision on?

Scenario Two: Less clear symptoms of heart attack:

You are walking along the street with another 50-year-old gentleman and he tells you that he has some indigestion, is feeling anxious and is having some difficulty breathing. You notice that he is also perspiring (sweating). What would you do? How did you make that decision, what did you base your decision on?

Scenario Three: Clear symptoms of heart attack:

You are once again walking along the street with a friend and this time, your 50year-old friend suddenly interrupts you and tells you that he has a pressing sensation in his chest and is having difficulty breathing. What would you do? How did you make that decision, what did you base your decision on? A coding scheme was developed based on the issues identified in the Background and highlighted in the interview (Table 3.3). Concepts related to health and illness were based on literature identifying everyday socio-cultural influences as salient in determining health-related behaviour (Eisemon et al., 1987; Kuhn, 1995; Patel et al., 2000; Sivaramakrishnan & Patel, 1993). Knowledge of symptoms of AMI was coded based on the most common presenting symptoms (Gillium et al., 1984). Categories of sources of information were developed from the literature identifying where people go to for material (James et al., 1999; Meischke & Johnson, 1995). Responses to the scenarios presenting symptoms of AMI were categorized based on actions, both appropriate and inappropriate, identified above.

Verbally generated protocols were transcribed and analyzed according to the categories of the coding scheme. This was carried out by two researchers, both experienced in this type of analysis. The coding scheme was reviewed and sample transcripts were coded in conjunction by both researchers to verify agreement and understanding of the categories. Uncertainty and disagreements were discussed until resolution was achieved. Inter-rater reliability was determined by comparing the scores obtained for each category and was 92%. Cohen's Kappa was 90. Concepts were identified within the protocols and recorded as frequencies of occurrence. These raw frequencies were standardized by conversion to percentage scores for each subject within each concept group, thereby reducing the effect of speaking patterns such as verbosity or excessive brevity on the analysis. The groups' scores were compared using multiple

Table 3.3. Coding Scheme Categories of Concepts Related to Health, Illness, Knowledge of Symptoms of AMI, Actions in Response to Scenarios, and Information Sources about Health, Illness, and AMI. Additional detail is provided in Appendix 3.1.

Concepts Related to Understanding of Health

Daily Activities	Absence of Illness	No Medication/Doctors		
Feeling Well, Energetic	No Specific Sympto	ms		

Concepts Related to Understanding of Illness

Decreased Daily Activities	Specific Symptoms	Dependency, Fearfulness		
Feeling Ill	Medication, Health C	Care		

Knowledge about symptoms of AMI (Gillium, Fortmann, Prineas, & Kottke, 1984)

Chest Pain	Diaphoresis	Anxiety
Arm / Jaw Pain	Gastro-Intestinal	Symptoms
Dyspnea	Syncope / Vertig	0

Actions in Response to Scenarios

Passive	Accessing Health Care
Active	Accessing Emergency Services

Sources of Information

Health Care Services	Media – Print
Lay People	Media – Audiovisual
Technology	

analysis of variance. The Wilks' Lambda statistic was used, with post hoc comparisons made using Tukey's Honestly Significant Difference.

An additional, more detailed analysis was carried out examining relationships between concept categories characterizing sources of information using an analysis of semantic relations (Cytryn & Patel, 1998; Sivaramakrishnan & Patel, 1993). An illustration of the analysis an following excerpt from a subject's response to an interview probe exploring information-seeking behaviour is presented:

Excerpt: "I wouldn't know where to turn in terms of journals. If was looking for something about lung cancer, probably I would get information from a physician first, (of the) person involved. If not I would be able to search more directly for resources on the internet, about, say, lung cancer than I could journals."

Key concepts in this excerpt are 'journals', 'lung cancer', 'physician', and

'Internet'. The categories in which these concepts fall are Media – Print, Search Topic,

Health Care Provider, and Technology. Attributes of these concepts are:

Media – Print (Journals)

- Familiar (Negative): "I wouldn't know where to turn"
- Accessible (Negative): "I would be able to search more directly
 - ... than I could journals"

Health Care Provider (Physician)

- Primary Source: "first"
- Personal Information: "of the person involved"

Technology (Internet)

 Accessible: "I would be able to search more directly for resources on the Internet"

This subject would consider the physician to be the primary source of information, partly because of a personal attribute. She would consider technology because of its accessibility. She would not use journals because they are unfamiliar to her and less accessible compared with the Internet. This is represented diagrammatically:



3.5 Results

3.5.1 Conceptualization of Health and Illness

Responses to interview probes eliciting conceptualizations of health and illness are reported in Table 3.4, showing the mean percent frequency of concepts identified by subjects. In each of the three groups, health (Table 3.4A) was predominantly described as feeling well ($F_{4,9} = 9.29$, $p \le 0.05$) and able to carry out daily activities ($F_{4,9} = 11.50$, $p \le 0.05$). There were no differences between feeling well and carrying out daily

 Table 3.4. Conceptualizations of Health and Illness. Mean percent frequency of

 concepts identified by subjects in their descriptions of health. Results are presented for

 each group individually.

Categories of Responses	Subject Group							
Conceptualizations	No Medical Diagnosis (n = 10)		Diabetes Mellitus (n = 10)		Cardiac Diagnosis (n = 10)		Total Sample (n = 30)	
	Mean	S	Mean	S	Mean	S	Mean	S
A) Health			<u>, , ,, , , , , , , , , , , , , , , , ,</u>					<u></u>
Daily Activities*	34.8	26.4	32.7	24.1	40.2	36.4	35.9	28.6
Feeling Well, Energetic*	37.6	16.4	31.8	33.5	40.4	33.5	36.6	28.2
Absence of Illness	8.4	9.1	16.4	19.0	7.1	12.4	10.6	14.2
No Specific Symptoms	14.5	18.8	14.5	15.1	12.5	24.6	13.8	19.2
No Medication / Doctors	4.9	10.5	4.6	10.1	0	0	3.2	8.4
B) Illness					<u> </u>			
Reduced Daily Activities*	52.3	33.3	31.4	32.5	40.4	40.5	41.4	35.5
Feeling Ill	11.7	16.2	0	0	15.6	18.3	9.1	15.2
Specific Symptoms	32.0	30.4	44.2	35.1	23.6	36.4	33.3	34.0
Medication, Health Care	3.3	10.4	2.7	8.5	7.9	16.2	4.6	12.0
Dependency, Fearfulness	0.6	1.9	4.6	14.5	2.5	8.0	2.6	9.4

MANOVA Design: Intercept + Group

* denotes difference between concepts identified with the asterisk and those not identified with the asterisk, $p \le 0.05$
activities. There were also no significant differences in concepts identified between the three groups.

In contrast, Table 3.4B shows the conceptualization of illness. Reduction in daily activities was identified significantly more frequently compared with the other concept categories ($F_{56,49} = 1.72$, $p \le 0.05$). As in the understanding of health, there was no significant difference between the three groups. The presence of specific symptoms also appeared to be important in thinking about illness, however the difference was not statistically significant. Feeling ill did not carry the same emphasis in illness as feeling well did in health, with no significant impact identified compared with ability to carry out daily activities.

Health was expressed in interview data as the ability to live ones' life as one would wish, while illness was identified as a reduction in that ability. Comparison of the three groups suggests that neither experience with illness or with the health care system affected this understanding. Experience with illness and the health care system (comparison of the group with no diagnosis versus the two groups with diagnoses) did not affect the identification of concepts, suggesting that these experiences had no impact on their view of health.

3.5.2 Knowledge about Symptoms of AMI

Decision making is based on underlying conceptualization and on prior knowledge. In order to examine decision making about AMI, the prior knowledge of subjects about the symptoms of AMI was assessed based on transcribed interview data. To better develop an intervention aimed at cardiac patients, a more detailed description of

what they knew about cardiac symptoms and interventions was undertaken. Analysis of responses to interview probes identifying subjects' knowledge about symptoms of AMI is reported in Table 3.5.

No significant differences were seen between the three groups in their identification of symptoms of AMI. All groups identified chest pain and dyspnea more often than the other symptoms. Curiously, left arm pain accounted for only 14% of the symptoms described by subjects. This is worrisome since radiating left arm pain or heaviness is frequently a presenting symptom of AMI (Gillium et al., 1984). A high degree of variability in subjects' responses is noted.

All subjects had some knowledge of the symptoms of AMI, however awareness of symptoms was incomplete. Even the cardiac subjects, who had experienced heartrelated symptoms and health care, did not describe symptoms more accurately than other subjects did. Again, the resilience of the underlying framework is seen by the stability of the responses across groups, reinforcing its importance in system development.

3.5.3 Decisions Related to Symptoms of Acute Myocardial Infarction

Having established both conceptualizations of health and illness and prior knowledge about AMI, the next step in the decision making process is that of responding to stimuli related to AMI. In the investigation of prior knowledge just reported, it was established that chest pain and shortness of breath were the most generally recognized symptoms of AMI. These symptoms were included in Scenario Three. Other symptoms were far less well known, and are represented in Scenario Two. Scenario One describes

Categories of Responses	Subject Group								
Symptoms of Acute Myocardial Infarction	No Medical Diagnosis (n = 10)		Diabetes Mellitus (n = 10)		Cardiac Diagnosis (n = 10)		Total Sample (n = 30)		
	Mean	S	Mean	S	Mean	S	Mean	s	
Chest Pain ***	29.9	18.0	41.6	24.7	52.6	28.7	41.4	21.2	
Arm / Jaw Pain	12.6	17.9	19.0	18.1	11.5	15.9	14.4	17.0	
Dyspnea ***	26.0	40.1	11.4	17.6	24.1	19.4	20.6	27.4	
Diaphoresis	4.8	10.7	10.5	15.3	0	0	5.1	11.3	
Gastro-Intestinal Symptoms	19.0	26.0	9.3	19.7	9.1	14.8	12.5	20.5	
Syncope / Vertigo	5.8	12.4	8.1	17.7	0	0	4.6	12.5	
Anxiety	0	0	0	0	2.5	7.9	0.8	4.6	
MANOVA Design: Inter	cept + 'Che	st Pain' +	· 'Dyspnea'	+ ('Chest	t Pain' x 'D	yspnea')			

frequencies of symptoms identified by subjects.

MANOVA Design: Intercept + 'Chest Pain' + 'Dyspnea' + ('Chest Pain' x 'Dyspnea' Chest Pain: $F_{36,35} = 18.4, p \le 0.001$ Dyspnea: $F_{20,31} = 27.7, p \le 0.001$ Chest Pain = Durante Interaction F = 424.0 m < 0.001

Chest Pain x Dyspnea Interaction: $F_{4.9} = 424.9$, $p \le 0.001$

symptoms that, while being urgent, are unrelated to AMI. Following the interviews, subjects were presented with these three scenarios (Table 3.2), and asked to think out loud as they determined what actions they would take. Table 3.6 shows the mean percent frequencies with which they projected what they would do in response to the scenarios, categorized as passive, active, health care related, and emergency responses.



Table 3.6. Categories of Response Types for Three Situations. Mean percent

frequencies of types of responses made by subjects in response to scenarios representing

varying degrees of familiarity with respect to AMI.

Categories of Responses:

Passive: Being sympathetic, making recommendations

Active: Calling someone (non-medical), taking person home

Accessing Health Care: Calling or contacting a health care provider or service

Accessing Emergency Services: Hospital / Emergency Department / 911

Categories of Responses	Subject Group								
Actions Reported in Response to Scenarios	No Medical Diagnosis (n = 10)		Diabetes Mellitus (n = 10)		Cardiac Diagnosis (n = 10)		Total Sampie (n = 30)		
, . <u>.</u> , , , , , , , , , , , , , , , , , , ,	Mean	S	Mean	S	Mean	S	Mean	s	
Scenario One*									
Passive	59.1**	36.1	36.1	46.7	3.3**	10.4	32.8	40.7	
Active	9.0	19.1	16.4	29.6	13.3	32.2	12.9	26.8	
Health Care	27.5	34.3	15.6	34.5	21.2	30.8	21.4	32.4	
Emergency Services	4.4***	10.6	31.9	39.7	62.1***	38.2	32.8	39.4	
Scenario Two									
Passive	50.6*	42.5	27.4	37.0	8.3*	26.2	28.8	38.8	
Active	8.3	18.0	17.5	32.9	2.0	6.3	9.3	22.2	
Health Care	5.3	11.6	17.3	31.5	12.3	20.2	11.6	22.4	
Emergency Services	35.7	41.5	37.8	42.6	77.4	31.6	50.3	42.2	

Table 3.6 (Continued)

Categories of Responses		Subject Group									
Actions Reported in Response to Scenarios	No Medical Diagnosis (n = 10)		Diabetes Mellitus (n = 10)		Cardiac Diagnosis (n = 10)		Total Sample (n = 30)				
	Mean	S	Mean	S	Mean	S	Mean	S			
Scenario Three	;	<u> </u>									
Passive	34.0*	40.9	13.0	32.0	0*	0	15.7	32.2			
Active	2.0	6.3	9.3	17.7	9.3	20.6	6.9	15.9			
Health Care	4.0	12.6	6.7	16.1	11.7	254	7.5	18.3			
Emergency Services	60.0	45.9	71.0	34.5	79.0	36.0	70.0	38.6			
MANOVA Design: Intercept + Group Scenario 1: $F_{8,48} = 2.76$, $p \le 0.05$ Scenario 2: Not Significant				* p	# 0.05 diffe # 0.01 diffe	rence betw rence betw	veen cells ind	dicated			

Scenario 3: Not Significant

******* p # 0.001 difference between cells indicated

The frequency of responses involving urgent action (accessing a hospital, Emergency Department, or 911) increased as the symptoms of AMI became more familiar and conversely the prevalence of passive responses decreased as situation severity became clearer. Responses in the first scenario were diverse, with subjects responding in a wide variety of ways. This variability decreased as the symptoms became more familiar.

When the symptoms presented were unrelated to AMI, cardiac subjects were significantly more likely than healthy subjects to report that they would contact emergency services (Tukey's HSD = 57.7, $p \le 0.001$). This difference is also seen when the symptoms of AMI were unfamiliar, approaching though not quite reaching

significance (Tukey's HSD = 41.7, p = 0.06). Healthy subjects were more likely to be passive than the cardiac group in all three scenarios (Scenario One: Tukey's HSD = 55.8, $p \le 0.01$; Scenario Two: Tukey's HSD = 42.3, $p \le 0.05$; Scenario Three: Tukey's HSD = 34.0, $p \le 0.05$). However, as the symptoms became more familiar, the difference between healthy and cardiac subjects in frequency of accessing emergency services disappeared as all three groups took urgent action.

The preponderance of passive actions by healthy subjects is illustrated in the following transcript excerpt:

Response to Scenario One, Symptoms Unrelated to AMI:

"Go see a doctor. ... They should get it checked out by some medical person."

Response to Scenario Two, Unfamiliar Symptoms of AMI:

"I would have him get medical attention, because that sounds like he may be having a heart problem. I would tell him to get it checked out."

Response to Scenario Three, Familiar Symptoms of AMI:

"Tell him to go see the doctor. ... It could be a heart problem ... like a myocardial infarction."

Symptoms of AMI:

"From what I understand, they would be a tingling on the left side, your left arm. Shortness of breath, chest paints and possible perspiration." Response to AMI:

"Call 911."

Explanation of Discrepancy:

"Because none of those ... seemed to be terribly pressing, although if I thought somebody were having a heart attack or were having serious problems that couldn't wait, I would certainly call 911. ... I thought of that actually as you were giving me the scenarios, about calling 911, but as I said, it didn't sound as though any of those were as urgent as somebody just having a heart attack. It sounded, they may be having a problem, an irregular heart beat, for instance. But they wouldn't necessarily need immediate medical attention."

Even when this subject identified the symptoms in Scenario Three as potentially being that of AMI, the response was still passive, i.e. "tell him to go see the doctor". Decoupling between knowledge and action is clearly illustrated. The subject recognized the symptoms of AMI but still responded passively.

The relationship between the knowledge reported by subjects and the actions they described in their problem solving protocols was examined by comparing the symptoms described in Scenarios Two and Three (Table 3.6) and subjects' knowledge about those specific symptoms (Table 3.5). Subjects' responses to Scenario Two were evaluated based on their levels of knowledge about the symptoms of AMI presented in that scenario (symptoms of gastric irritations, anxiety, dyspnea, and diaphoresis). There was no relationship between knowledge of any symptom and actions reported. The same analysis was carried out for chest pain and dyspnea and responses to Scenario Three with similar results. This verifies the decoupling characterized in the previous analysis.

Subjects reported appropriate actions to some degree in the situations, but this was inadequate for effective response. Cardiac subjects relied heavily on emergency services while healthy subjects were more passive. When presented with "typical" symptoms of AMI, subjects in each of the three groups reacted to the emergency. However, when the symptoms were unfamiliar, healthy subjects tended to be passive while subjects with illness were likely to choose a more active response. Here we begin to see an effect of differences in experience with cardiac illness on reported responses to symptoms. Cardiac subjects had experienced cardiac illness and had therefore integrated that experience and information into their pre-existing knowledge structures, which they then applied in the form of choosing emergency services more than subjects with no ongoing illness.

3.5.4 Sources of Information about Health and Illness

The analysis thus far indicates that health and illness are conceptualized in terms of everyday life, knowledge about AMI is spotty, and this knowledge is decoupled from actions that subjects report in response to symptoms of AMI. An argument was made previously that (1) knowledge structures are built through experience, observation, and socio-cultural influences, and (2) additional information, in order to be effective in changing behaviour, must be incorporated into this structure or remain separate and decoupled. It was therefore of interest to determine the sources used by subjects in informing themselves about health, illness, and AMI. Subjects were asked to identify their information sources during the interview. Table 3.7 reports the mean percent frequencies of sources of information identified by subjects. Physicians were of prime

 Table 3.7. Sources of Information about Health. Mean percent frequency of sources

 of information identified by subjects, separated by sample group. "*" and "#" denote

 statistically significant differences.

Categories of Responses	Subject Group								
Sources of Information	No Medical Diagnosis (n = 10)		Diabetes Mellitus (n = 10)		Cardiac Diagnosis (n = 10)		Total Sample (n = 30)		
	Mean	S	Mean	S	Mean	S	Mean	S	
Health Care Services	28.5*	20.5	55.3	33.8	64.5*	32.7	49.4	32.5	
Lay People	19.3	21.1	14.1	15.4	18.0	18.0	17.1	17.8	
Media – Print	18.0	9.0	12.0	14.1	15.3	25.5	15.1	17.2	
Media – Television	18.1	18.1	14.3	24.6	1.1	3.5	11.2	1 8 .7	
Technology	16.4*	12.4	4.2* #	9.5	1.1* #	3.5	7.2	11.1	

MANOVA Design: Intercept + Group

• $p \le 0.05$ difference between cells indicated

* # identifies a pair of cells significantly different from the other cell within the same category

importance to both cardiac and diabetic subjects. Printed material and the media were also consulted, as were friends and family. Accessing computers was reported relatively rarely. Healthy subjects relied less on physicians compared with cardiac subjects (Tukey's HSD = 36.0, $p \le 0.05$) and more on informal sources. They were also the only group that reported significant use of technology (Healthy x Diabetic Tukey's HSD = 12.2, $p \le 0.05$; Healthy x Cardiac Tukey's HSD = 15.3, $p \le 0.01$).

The predominance of the two patient groups reporting going to health care providers for information and of those with little health care contact using technology suggests that information is sought from sources that are accessible. A more in-depth

analysis was undertaken in order to examine how decisions about sources are made. A semantic analysis of the verbal protocols generated by subjects in describing where they reported seeking out information was carried out. An analysis of the three semantic networks generated by two subjects is presented (Figure 3.1), one with illness, one without illness. Examination reveals that they accessed sources with which they were familiar, to which they had access, that they considered credible, and that they could understand. Figure 3.1A, the network of a 64-year-old patient, describes the importance of a sense of *being understood*. It also shows an identification by the subject of the value of information from health care professionals (a retired nurse with a friend who is a physician), with the implication that such a friend was not only accessible and familiar but also had the added value of possessing professional knowledge and was therefore credible. A healthy subject (Figure 3.1B) emphasized sources of information that were less personal, largely print media in the form of books. In this second network, a distinction can be seen among information sources based on both *familiarity* with the problem and its frequency, such as having books on hand with details about familiar and frequently experienced sports injuries for this sports-oriented subject. The *complexity* of the information source was also identified as a factor in choosing the Internet over journals, which this subject identified as unfamiliar. The two networks developed from this subject show how different sources are utilized for three problems. For two familiar and usually innocuous problems (general health and sports injuries), a general, credible reference in the form of books was kept on hand and considered adequate. When the problem was more serious, a physician was identified as the primary source, with the Web used based on its ease of access.

The two groups with illnesses both would not approach technology as an information source, with a cardiac subject stating that "I don't use computers. I'm an old-fashioned old lady." The subject described in Figure 3.1A provided additional detail, confirming that she feels too old for computers, as well as identifying its limits for her. Subjects with no diagnoses did identify technology as a source of information, as seen in Figure 3.1B.

Multiple source of information are identified, with patient subjects trusting physicians while subjects with no ongoing medical diagnoses turned to other sources as well, including technology. The target population, those with cardiac illness, relied largely on physicians and the media for information about health and was reluctant to approach computer technology, accessing sources that were part of their everyday life



Figure 3.1A. Semantic network of a 64-year-old patient with experience with health care.

Problems 1 & 2: General Health, Sports Injuries.



Figure 3.1B. Semantic network of a 26 year old subject with no current medical diagnoses

Figure 3.1. Sources of Information. Semantic networks generated from the verbal protocol of subjects describing their information sources related to health care issues.

and eschewing those that were not. The sample with no diagnoses did report use of computers, however. Major factors in the choice of information sources include (1) ease of access, (2) familiarity, (3) credibility, and (4) a match between the level of complexity of information, complexity of the problem, and the abilities of the information-seeker.

3.6 Discussion and Conclusions

Three groups of subjects (subjects with cardiac diagnoses, insulin-dependent diabetes, and with no current diagnoses) represented varying levels of experience with illness and with health care. A semi-structured interview was developed focusing on conceptualizations of health and illness, knowledge of symptoms of heart attack, and what their information sources were. Subjects were interviewed and then presented with scenarios giving (1) symptoms unrelated to AMI, (2) symptoms of AMI that were unfamiliar, and (3) symptoms of AMI that were familiar. They were instructed to think aloud as they reasoned through the three scenarios, generating verbal protocols. All data were transcribed and analyzed.

These analyses suggest that lay conceptualizations of health and illness are based on feeling well and being able to carry out daily activities. These views were found to be stable across the three groups of subjects, suggesting that neither experience with illness nor contact with health care providers had any significant impact on the culturally based models developed through experience and association. Furthermore, these concepts were retained and dominated the input of health care providers.

Given that lay people (with and without medical diagnoses) are influenced very strongly by their prior knowledge and concepts of health and illness, it is important that these understandings are taken into account when developing technology that support their decision making about both disease management and prevention. If the underlying framework is not considered, there is likely to be little resultant behaviour change. Since people develop explanations for their experiences and base their actions on what they consider to be satisfactory explanations, they are more likely to act if the prescriptions

and recommendations are in agreement with what they believe. Beliefs about health and illness centre on being able to carry out daily activities and feeling well. Technological support systems must therefore similarly be based on these concepts. Interventions that target maintenance or return of normal functioning are more likely to be followed than those that emphasize control of pathophysiology.

All subjects had some knowledge about AMI, predominantly chest pain and shortness of breath. This shows the poor outcomes of simply giving people information. Success in providing information using technology has been achieved (Leaffer & Gonda, 2000) and provides a direction for improving knowledge for cardiac patients and for public education about AMI. The ability to modify information based on the patients' medical records (Jones et al., 1999) and to tailour the form (text, graphic, on demand, etc.) and rate with which it is provided has proven effective in improving knowledge of health-related issues (Goldsmith & Safran, 1999; Tetzlaff, 1997).

Examination of the actions reported by subjects in response to the scenarios reveals a decoupling between the symptoms they identified as symptomatic of AMI and the actions they would take when faced with these symptoms. Furthermore, the actions chosen were sometimes inadequate and potentially dangerous. It is not that they did not know what to do but rather that sensitivity to the symptoms and perception of their severity was insufficient to provoke action. Previous studies have shown that decisions made by physicians under conditions of urgency and ambiguity are complex and more likely to be inaccurate (Patel et al., 2000). The pattern observed in these findings suggests that lay subjects made poor decisions in ambiguous situations, resorting to heuristics based on their experiences with illness. Subjects with little experience with

illness tended to react passively, based on a heuristic that states "Wait it out, it will pass". Subjects with more experience with cardiac disease, a situation that could rapidly deteriorate and become critical, reported the intent to access emergency services more frequently than the other two groups in all situations, possibly following a heuristic stating "When in doubt, get to a hospital". These heuristics, based on experience, dominated the knowledge and recognition of symptoms of AMI.

This difference between the actions reported by the group who had experience with cardiac illness and the group with little experience with illness further suggests that knowledge is not the sole or even the major determiner of projected action. While conceptualizations of health and illness and knowledge of symptoms of AMI are consistent across the three groups, actions reported in response to symptoms are different. The heuristic of the cardiac group has been refined by experience to generate a more effective and safer rule of thumb. It is in this creation of a pattern of action rather than a knowledge-based reasoning pattern that the physicians' admonitions to "get to a hospital!" may echo. The decoupling between knowledge and action and the finding that experience does change behaviour suggests that not only must technology be designed to provide information, as suggested above, but it must also be designed to attend to how the information relates to action. Lay people assimilate knowledge through observation and experience, which then becomes heuristics that guide action. Computer education systems can capitalize on this by presenting video clips and virtual simulations (Lehmann, 1999), allowing users to learn in a manner that it consistent with their normal learning patterns thereby coupling knowledge and action by developing a pattern that users will come to recognize. Computers are uniquely able to simulate experience,

strengthening the connection between symptoms of AMI and the desired actions, allowing repetition and examination of scenarios at a rate determined by the user thereby strengthening the desired heuristic.

These findings suggest that health-related behaviour is determined not by isolated information but by the richness of experience in the real world environment. Subjects sought out information from sources that were incorporate within this fabric. In order to effect change in health-related behaviours, material must be delivered to lay people in a manner and form that is compatible with the way that they assimilate, understand, and process not only information but also experience in their everyday life (Tetzlaff, 1997). It must also come from sources that are part of that familiar experience. Computer technology provides a method by which lay people can be exposed to situations that include important information in a context that encompasses the common learning environment, the real world with its complexities and uncertainties. Using scenarios (Maaske, 1999) and virtual reality software simulations (Richards, Colman, & Hollingsworth, 1998) of AMI could expose people to situations presenting AMI symptoms, allowing them to see and practice appropriate reactions until those reaction become incorporated into their heuristic repertoire, expediting prompt action should the situation of AMI actually arise. Virtual reality simulation, which is possible only with technology, would also provide the visceral component that is an integral part of such situations, allowing subjects to become familiar with the cognitive and emotional components of this decision making process. Lehmann (1999) capitalizes on the lay practice of consulting with other, lay people by creating a virtual diabetic patient. Technology also allows the user to control the influx of information so that, while one of

the common complaints about the Internet is an overwhelming amount of information, the range of data and the flexibility to click on only those components that are of interest is advantageous. Additional flexibility is provided by the opportunity to take away printouts, providing an additional medium as an effective educational tool that can also be tailoured to the individual (Tang & Newcomb, 1998). In addition, the findings also suggest that, since people talk to other people and ask for advice from family and friends, interventions should also include group discussions in working through scenarios.

To be effective, technology must be accessed by the target population. Over half of the American population has access to the Internet and would be willing to use it as a source of information (Goldsmith & Safran, 1999; Horton, Garland, & Fishman, 2000). Our results suggest that cardiac patients do not use technology as an information source because it is not part of their normal lives. They do, however, rely on physicians and the media. Technology could be made part of everyday life by introducing its power and accessibility through other common and trusted sources such as the media, physicians' offices (Helwig, Lovelle, Guse, & Gottlieb, 1999), clinics, and community settings, making it more familiar and less intimidating. This is seen with increasing frequency in television and print media, in which Web sites are often identified and their usefulness and ease of use promoted, supporting the incorporation of technology and making it more familiar and acceptable.

This discussion has suggested that people rely on heuristics to make decisions about AMI rather than using medical knowledge. These heuristics are based on experience. Our understanding of the cognitive processes involved in interpreting the symptoms and making the decision to act suggests that technology can provide a

powerful tool in developing and modifying effective, experience-based heuristics that will expedite swift reaction to symptoms of AMI.

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Concepts Related to Understanding of Health

Daily Activities

References to functioning on a day-to-day basis, carrying out daily activities.

Excerpt: "Me being able to move, play, work and do as I want."

Feeling Well, Energetic

Statements describing generally positive affect.

Excerpt: "To have energy and not to have difficulty getting up and going to work ... I mean easily. Not in a rush, being happy to go to work. Feeling full of energy, it's not just being."

Absence of Illness

Description of health as the opposite of illness.

Excerpt: "I've been well all my life. ... I was never sick."

No Specific Symptoms

Reference to the absence specific symptoms or abnormalities.

Excerpt: "Let's say you have arthritis, you don't have to wake up feeling that arthritis in your hands. It's being to a point where you don't feel your normal aches or pains."

No Medication / Doctors

Identification of health as independence from health care.

Excerpt: "Not having to go see a doctor for anything. Or dentist, that's included too."

Concepts Related to Understanding of Illness

Decreased Daily Activities

Statements referring to reduction in daily activities.

- Excerpt: "Your daily life or your daily routine is pretty much compromised, to the point where you can't function normally, and you have to take a break."
- Excerpt: "Everything was a chore. Everything just seemed much harder to actually accomplish."

Feeling III

Any reference to a generalized feeling of discomfort, non-specific symptoms, feelings expressed in a negative manner.

Excerpt: "It's being weak. Powerless, not having energy, being tired all the time, not being able to do what you would like to do. Losing interest in things you were interested in before."

Specific Symptoms

Identification of individual, precisely named symptoms.

Excerpt: "A really bad sore throat and a cough or something like that."

Medication, Health Care

Any statement identifying the need for health care or medications as an indicator of illness. This does not include statements referring to needing medication for an illness but rather to medication as part of the concept of illness.

Excerpt: "I don't want to become dependent on medication, unless there was a good reason."

Dependency, Fearfulness

Expressions of dependency on others, fear of illness or sequelae of illness.

Excerpt: "Being dependent. I think that might be the worst thing. Being dependent on others."

Knowledge about symptoms of AMI (Gillium et al., 1984)

Chest Pain

Any reference to sensations of discomfort in the chest.

Excerpt: "Chest pains ... but it doesn't have to be severe, just some light chest pains

... especially if it's on the left side ... the heart is on the left side."

Arm / Jaw Pain

Description of sensations radiating to areas other than the chest, particularly the left arm and jaw.

Excerpt: "Tingling or numbness or pain in your left arm."

Dyspnea

Any reference to difficulty breathing or shortness of breath.

Excerpt: "breathing problems ... he can't breath"

Diaphoresis

Any reference to sweating, perspiration, or wetness.

Excerpt: "sweating"

Gastro-Intestinal Symptoms

Any reference to gastric or epigastric pain or discomfort, nausea, vomiting, or

indigestion.

Excerpt: "Indigestion's another sign of heart trouble."

Syncope / Vertigo

Identification of dizziness, faintness, any indication of change in level of

consciousness.

Excerpt: "Feeling faint."

Anxiety

Statements reflecting negative affect preceding AMI within a short time period.

Excerpt: "They're feeling anxious."

Actions in Response to Scenarios

Passive

Being sympathetic, making recommendations.

Excerpt: "I would sit by his side and watch him. ... If he's feeling uncomfortable, then just try to make him feel comfortable for that time"

Excerpt: "I would probably stupidly ask other questions. Any blood or something like that. Have you eaten anything? And I would recommend calling a CLSC (Community Clinic) or going to a CLSC."

Active

Calling someone (non-medical), taking person home.

Excerpt: "Hopefully I can get a way to get him home."

Accessing Health Care

Calling or contacting a health care provider or service other than a tertiary care

hospital or emergency services.

Excerpt: "We might go only to a clinic and then the doctor at the clinic might refer it to the hospital."

Accessing Emergency Services

Going to a hospital, Emergency Department, or calling 911.

Excerpt: "Definitely dial 911 right there. If not I'd try my best to get him to a hospital."

Sources of Information

Health Care Services

Identification of any health care provider, including physicians, nurses, dieticians,

physiotherapists, occupational therapists, and so on. Alternative care was not

included in this category.

Excerpt: "Based on what my endocrinologist had told me."

Lay People

Any individual or group of individuals without professional, formally recognized training. This included family, friends, co-workers and experiences, both personal and of others.

Excerpt: "I might ask for some information from my sister or my brother."

Media – Print

All ink and paper resources were included in this category, such as books (including reference and textbooks), newspapers, magazines, pamphlets.

Excerpt: "I'd say magazines or books that are put out on general health."

Media – Audiovisual

This category was made up of radio and television. It included information programming as well as other types of programming that included information about health and illness, such as weekly dramas and comedies.

- Excerpt: "Sometimes Pulse (news), the Medical Report, they'll indicate some symptoms of a heart attack."
- Excerpt: "Like television, whenever somebody has a heart attack they go (gestures: gasps for breath and clenches chest) so you sort of assume it must be pain there."

Technology

Reference to the use of any form of technology, including CD-ROMs and the Internet in any form (Web sites, e-mail, chat rooms).

Excerpt: "I went on internet to get some information."

N. B.: A category was initially included for alternative care providers, however none of the subjects reported consulting with an alternative care provider. Vitamins were not considered as medication, and no other alternative therapies were mentioned in the protocols.



In the previous study, conceptualizations of health and illness were examined, information-seeking strategies were elaborated, and the relationship between knowledge and decisions characterized. In the next chapter, the role of prior knowledge in decisionmaking processes was examined more closely. Factors related to decision making were identified and a decision making network developed identifying the impact of prior and scientific knowledge on decisions.

Technology has been suggested as a means by which decision making and behaviours can be modified. In Chapter Two, the literature describing lay and medical models of health, illness, and disease and variations between these models were discussed. In Chapter Four, the effect of differing models of health-related technology on its use is investigated. Interactions of both physicians and diabetic subjects with a data entry system were analyzed for differences based on different models of health, illness, and technology.

The chapter presented here is based on an article published in the International Journal of Medical Informatics in 1998. The results presented in Figures 4.1 and 4.2 have been expanded to include 16 subjects, and the text modified to include this additional data. The original article is included in Appendix One.

CHAPTER FOUR

REASONING ABOUT DIABETES AND ITS RELATIONSHIP TO THE USE OF TELECOMMUNICATION TECHNOLOGY BY PATIENTS AND PHYSICIANS

4.1 Abstract

Health care is moving toward a team effort, with patients as partners. This requires effective communication between physicians and patients, who have different understandings of health and illness. These understandings in turn guide their decisions about management of health and illness. With the introduction of home-based technology, which provides an efficient way for doctors and patients to communicate, the question of the effectiveness of the decisions being made must be addressed. In this study, we assess the conceptualizations of health and illness related to diabetes and the relationship to the use of communication technology by patients and physicians. *Methods:* The subjects were interviewed using a semi-structured questionnaire and were then asked to enter information into a telephone-based telecommunications system. Data were audiotaped, transcribed, and analyzed to characterize models of health and illness and for the factors that influence the decision making about diabetes management. Interactions with the system were then examined relative to these findings.

Results: Patients used lay concepts in providing explanations of their illness, whereas physicians used biomedical concepts. Use of these differing concepts influenced interactions with telecommunication technology, with more errors in the communication of information being made by patients than by physicians. Examination of the organization of information required by the system showed it to be incongruent with the way patients normally reason, but in agreement with the way physicians reason. The paper discusses the implications of these findings for (a) the nature of evidence used by patients and physicians and (b) the design of technology to maximize effective doctor-patient communication.

Keywords: Decision Making, Diabetes Mellitus, Telecommunications, Physician-Patient Relations, Evidence-Based Medicine

This chapter is based on an article appearing as Cytryn, K.N. and Patel, V.L. (1998). Reasoning about diabetes and its relationship to the use of telecommunication technology by patients and physicians. *International Journal of Medical Informatics*, *51*, 137-151. (see Appendix Two).

4.2 Introduction

Health care consumers are playing an increasingly important role in determining their own health care and making their own health-related choices. Participation by patients in decisions that affect their health and illness management, while remaining controversial (Deber, 1994), requires that patients play an integral role in decision making and in carrying out treatment plans. This level of collaboration requires efficient communication and some level of shared understanding among those involved in making decisions (Cytryn, Patel, Jones, & Safran, 1997; Gaba, 1992; Orasanu & Salas, 1993), i.e. between the team, frequently localized in a health care centre, and the patient, who is at home. The understandings, or conceptualizations, of health, illness, and disease of physicians and of patients have been found to be different however, creating difficulties and blocks to communication (Patel, Arocha, & Kushniruk, in press; Zhang, in press).

One solution to the dilemmas of geographical separation and scarce resources has been to make better use of communication technology, such as telemedicine. The value of technology in facilitating communication has been demonstrated in terms of cost effectiveness and increased access to care. These benefits include efficiency in communication, closer monitoring of patients' status while reducing office visits, and the savings of scarce health care resources these visits consume (Jones, 1997). However, the extent and variety of uses to which these novel technologies are being put requires that they be evaluated prior to their widespread acceptance and implementation. In order to assure efficiency, effectiveness, and safety of system users with different frameworks, the users themselves must be participants in system design, providing feedback in an iterative fashion so that the ultimate use of the technology is consistent with the original purposes

for which it was designed (Kushniruk & Patel, 1995). This is critical in order to assure that the effects are as planned, and that no unintended outcome compromises patient care.

4.3 Theoretical Framework

Studies of collaboration have shown that for effective communication to occur, team members must share an understanding of goals, resources, tasks, and responsibilities (Safran et al., 1998; Shortliffe, Patel, Cimino, Barnett, & Greenes, 1998). Communication is a fundamental process of collaborative team functioning, serving both as the medium of team development and of team functioning. In health care, it is generally accepted that patients and physicians must collaborate as a team in order to achieve an optimal level of health for the patient (Golin, DiMatteo, & Gelberg, 1996). When patients and physicians communicate, however, differences in their goals and in their understanding of the nature of health, illness, and disease compromise effective communication patterns (Ong, de Haes, Hoos, & Lammes, 1995; Patel et al., in press; Williams & Wood, 1986). This has been shown to be the result of differences in the way that lay people comprehend health and illness (symptoms experienced by the patient, effects on activities of daily living) as opposed to physicians' understanding of disease (pathophysiology). Here, lay people are defined as having a common sense, everyday functional knowledge of the domain while physicians have biomedical and clinical knowledge. Thus, the nature of knowledge possessed by the two groups is epistemologically and functionally different.

Previous research has shown that lay reasoning differs significantly from scientific reasoning (Kuhn, 1989). This extends to physicians and lay people's

abstractions of health, illness, and disease, which similarly deviate (Sivaramakrishnan & Patel, 1993a). Physicians have been shown to use biomedical knowledge as evidence, which is based on scientifically-established, logically consistent information (Patel, Groen, & Scott, 1988b; Perkins & Simmons, 1988). Lay decision making processes and the types of evidence used have also been examined (Eisemon, Patel, & Ole-Sena, 1987; Patel et al., in press) and found to be based on observation, on associationistic and correlational evidence (Kuhn, 1989; Rogoff & Lave, 1984). This evidence is acquired through social and cultural exposure (Sivaramakrishnan & Patel, 1993a). Such different understandings, based on different types of evidence, are likely to serve as the basis for subsequent decisions to be made about health, illness, and disease. For example, lay people do not normally like to calculate quantitative information. When quantitative pharmaceutical instructions were presented to mothers in Kenya, Ethiopia, and Canada, all were found to draw inferences from this quantitative information, translating them into qualitative approximations using general heuristics (Patel, Eisemon, & Arocha, 1988a).

Pre-existing traditional knowledge about health and illness is remarkably stable and resistant to change. Examination of the effect of formal education on the reasoning about childhood nutritional deficiencies of Indian mothers living in India and in Canada showed that explanations varied with the level of education of the mothers, with more educated mothers incorporating more biomedical concepts (Sivaramakrishnan & Patel, 1993a; Sivaramakrishnan & Patel, 1993b). However, the authors showed that the explanations of these concepts continued to be based on traditional theories learned through community consensus and personal knowledge, with biological concepts added superficially. The structure of the resulting combination was incoherent (Patel et al., 1988a).

There is sufficient evidence in the research literature examining prior knowledge and its influence on behaviour to establish that patients have prior knowledge about health and illness, and that this prior knowledge influences how they interact with health care materials (Patel, Kaufman, & Arocha, 2000), including technology. We are interested in patients' understanding of: (1) the concepts of health and illness, (2) diabetes and its management (monitoring and treatment), and (3) the influence of prior understanding on interactions with telecommunication technology.

We have chosen diabetes as the patient problem. Diabetes affects almost every aspect of the diabetics' lives. In addition, telecommunication systems have been developed in the area of diabetes mellitus in an attempt to improve the efficiency and effectiveness of its management (Edmonds et al., 1998; Lehmann & Deutsch, 1995a; Lehmann & Deutsch, 1995b). The two groups involved in its treatment, patients and physicians, are likely to have different expectations of how the new methods of communication will be used and what will be achieved, creating the possibility for misunderstanding and miscommunication of information and generating treatment difficulties. An example of this is the introduction of blood glucose monitoring devices to be used by diabetics, which may result in inaccurate readings by patients due to improper use of the technology. If such errors do arise, they can be corrected immediately during the face-to-face communication of a doctor's office visit. However, through asynchronous communication methods such as technology, this kind of feedback is not always possible and errors may go unnoticed.

The absence of immediate verification of the accuracy of the data being transmitted by this method of communication requires consideration of the effort required in learning to use it. Patients are frequently trained in the use of new techniques and are sent home to implement them. As anyone who has taken home a new stereo, VCR, or computer can attest, once home many questions arise. This puts patients in the position of learning a new process, the use of the new technology, at the same time that they are trying to cope with the content (eg: blood glucose levels). This is not trivial and creates a cognitive load that can be disruptive to successful completion of the task (Sweller, 1988), leading to errors in communication.

In this study, we examine the conceptual understanding of illness by insulindependent diabetic patients and its relationship to their decisions about their diabetes management. The patients' models are then compared with the framework of physicians and how they make decisions about their diabetic patients. We next follow patients and physicians as they interact with a home care telecommunications system (Edmonds et al., 1998). The errors generated in the use of telephone technology in both groups are then characterized to examine the relation between prior understanding and the nature of errors generated in using the system.

4.4 Methods

4.4.1 Subjects

Patients: Subjects were patients with insulin-dependent diabetes mellitus recruited from the Metabolic Day Centre of the Royal Victoria Hospital, a large tertiary care hospital in Montreal, Canada. Each subject had interacted frequently with the health
care team and had received instruction about diabetes. All had been diabetic for at least 10 years.

Physicians: Senior physicians affiliated with McGill University were recruited for participation in the study.

4.4.2 Interview

Patients: In reviewing the literature, a number of factors were identified that appear to be important in lay decision making about health and illness. A semi-structured interview was developed based on this literature. Questions or probes focused on: the model of illness of the subject, the meaning of illness, actions related to illness, the effect of diabetes on daily life and on relationships, and on factors contributing to decision making related to illness.

Physicians: A typical patient scenario was developed by a nurse with expertise in diabetes and knowledge of patient profiles based on detailed study of diabetic clinics and management centres. Subjects were given the scenario and were asked to think aloud as they went through the process of evaluating the patient, generating verbal protocols (Ericsson & Simon, 1993). The interviews were audio-recorded, then transcribed and analyzed for concepts related to the explanations of health and illness, and for factors affecting decisions about diabetes.

4.4.3 Use of Technology

The System: The communication technology used in this study was the Diabetes Home Monitoring Module (Edmonds et al., 1998). It consisted of a central database at

the University of Western Ontario, into which subjects could enter data about their diabetes. This data consisted of their glucose levels, changes in diet, activity, stress, hypoglycemic reactions, and insulin doses. The system was able to provide feedback in the form of averages and ranges of glucose levels entered. An expert system that would provide more in-depth information to patients was planned but was not yet in place. The input device was a Vista 350 telephone, a Northern Telecom Canada telephone that was generally available. A major advantage of this type of device was that it did not require expensive equipment (such as a computer) or connections (such as a server). A display screen allowed more information to be transmitted in both directions than was possible with a basic telephone, and a variety of keys supported more flexible entry of data than phones with only a number keypad.

The Scenarios: A scenario was developed to represent a typical day for a diabetic patient. It included glucose levels at various times, a change in insulin dose, a hypoglycemic reaction, working and week-end days, and changes in all aspects of daily life addressed by the system (diet, activity, stress).

The Procedure: Each subject (patients and physicians) was given the scenario and was instructed to enter this data into the telephone system, thinking out loud as they did so. The interactions were audiotaped and videotaped, including video recording of the telephone screen itself, showing the subjects' input and the system's responses. Subjects were given no training as to use of the system, providing a more sensitive evaluation of the learning process involved in the assimilation of new technology. Audio recordings were then transcribed for analysis.

4.4.4 Analysis

A coding scheme was developed based on the categories of concepts addressed in the patient interview. Verbally generated protocols were transcribed and analyzed using the coding scheme. Each of these categories was identified in the protocols and the data were recorded as frequency of occurrence. The relationships between the categories were determined using analysis of semantic relations (Sivaramakrishnan & Patel, 1993a). An example of the analysis is illustrated with an excerpt from a patient's transcript:

Patient: "I was very depressed and I didn't want to follow my diet and I just went off keel (ate what I wanted)."

'Depressed', 'diet', and 'going off keel' are concepts, and the categories are AFFECT, REGIMEN, and DECISION/ACTION.

Coding: "I got very depressed AFFECT and I didn't want to follow my diet REGIMEN and I just went off keel DECISION."

The patient's frame of mind affects the way (s)he feels about the regimen (s)he has been told to follow, which leads to the action of non-compliance. This is represented diagrammatically below, with concept categories identified and the directionality of reasoning indicated by the direction of the arrows. In this example, reasoning is conditional, i.e. one concept conditional on the previous concept in the chain of reasoning, with both positive and negative conditional influences shown.





Videoanalysis: Videotapes were analyzed with the aid of transcripts made of the audio recordings. Key concepts and difficulties related to utilization of the technology were identified. These occurrences were noted on the transcripts using software (CVideo) that allowed precise localization of the events on the videotape. The time taken by subjects to complete data entry tasks was time stamped using CVideo. The method used is based on techniques modified and refined at the Centre for Medical Education, McGill University, by Kushniruk et al. (1997).

4.5 Results and Discussion

4.5.1 Factors in Decision Making

Lay Reasoning: Figure 4.1 shows the percent frequencies of the concepts used by subjects in describing their illness. The description of the categories is provided in Appendix 4.1. A striking feature of Figure 4.1 is the dearth of biomedical concepts (1%) in subjects' narrations. The major contributing factor to lay explanations of diabetes and diabetes-related decision making was that of the more loosely structured, associationistic/opportunistic type of Lay Knowledge (37%). The diabetic Medical Regimen (22%) and Information from the Health Care Team (15%) were also identified. These findings suggest that knowledge and information were the most important factors

in determining what patients did about their illness (74%). Of the types of knowledge identified, the body of lay knowledge incorporated within the subjects' prior knowledge base was the most important while that from the health care team was less salient. Fear and other affective factors accounted for 13% of the concepts identified while Daily Functioning and Social Impact described 12% of documented concepts



Figure 4.1. Patients' Use of Concepts in Explanations of their Decisions About Diabetes.

These results suggest that patients used lay knowledge to generate an understanding of illness. They were less concerned with underlying pathophysiological changes than with how to maintain their health status by following the diabetic regimen, assisted with information from health care providers. Having some knowledge about the relationships between glucose levels, insulin, diet, exercise, and stress (physical and emotional) helped them decide what actions to take. When patients were asked to explain the relationship between factors, for example the relationship between exercise and diabetes given below, their explanations consisted of simple associations, with exercise and diabetes revolving around insulin. There was no biomedical justification.

Patient: "Exercise helps you to secrete more insulin."

This is in sharp contrast to the results from the transcripts generated by the physician interviews in describing how they would make decisions about the patient in the scenario.

Medical Reasoning: The data show that each physician walked through a process whereby patient data was highlighted and evaluated for relevance to the hypothesis that the patient was diabetic. Alternative diagnoses were considered as well, however the scenario made the diagnosis clear and other diagnoses were unlikely.

Physician: "First of all she's obviously diabetic."

Unlike patients, when physicians were challenged for explanations and justifications of their interpretations, they all turned to underlying biomedical knowledge of diabetes. The explanation was given in terms of pathophysiology. Other factors were rarely mentioned (one or two per subject).

Physician: "The polyuria is produced because the sugar gets in the urine and it acts as an osmotic diuretic, prevents the body the kidney from reabsorbing water from the urine."

There was a clear difference in the nature of the information that physicians and patients consider important or relevant in making decisions about diabetes. Therefore when making decisions, patients and physicians used a different nature of information as evidence.

4.5.2 Schematic Relationships in Decision Making

Lay Reasoning: A schematic network of concepts reported by patients in the interview transcripts about decision making related to diabetes was developed (Figure 4.2). Factors identified by patients as important are shown, the relationships between them are indicated by arrows (representing directionality of influence), and the percent frequency of those relationships represented by the thickness of the lines.

The results reveal the relationships among the major factors affecting decision making identified in Figure 4.2, both directly and indirectly. Decisions were made based on an interacting web of the major concepts identified in Figure 4.1. The diabetic regimen (22%) played a central role in determining decisions people made about their diabetes. Lay knowledge, which accounted for 37% of all concepts identified (Fig. 4.1), interacted with the regimen, each contributing to the implementation of the other.



Figure 4.2. Schematic representation of factors affecting decision making by diabetic patients.

Information from health care providers impacted on the regimen in a unidirectional manner (15%), suggesting that doctors' orders contribute to decision making through the diabetic regimen, but in a manner more isolated than the bi-directional interaction with lay knowledge. Interestingly, health care information did interact bi-directionally with Affect (8%). Affect (8%) and Fear (5%) were involved in several pathways, including influence through Social Impact (6%). An example would be health care information leading to the regimen, but also influencing Affect, leading to Fear (either due to additional restrictions, risk of complications, or other potential difficulties). Both general Affect and Fear led to social impact, both real and potential, which then in turn influenced compliance with the regimen. Daily Functioning (7%) was also identified as a factor, isolated through its influence on the regimen, affecting decisions through interference with daily life.

Medical Reasoning: Turning now to physicians, doctors were presented with a diabetic case scenario and were asked to verbalize their thoughts as they assessed the patient. In clinical settings, physicians usually see patients presenting with complaints (signs and symptoms), and their task is to explain the findings. The resulting train of thought is illustrated in the following transcript excerpt:

Physician: "A fasting blood sugar of 160 I think pretty much says that she's diabetic. The postprandial is 200 also tells us she's diabetic. So either one of those by themselves I think meets criteria for diabetes."

During the interviews, the sequence of their explanations begins with descriptions of the signs and symptoms, followed by a diagnosis.

This has implications for compliance of patients with medical advice. With such varying frameworks, using such differing types of information, with such different goals and priorities in dealing with their disease (for example normal blood glucose levels versus normal lifestyle), it is little wonder that they do not listen to each other and frequently seem to be speaking different languages. In reality, they are. Physicians tend to provide clinical and biomedical information to patients, *the why*, with the goal of returning the patient to physiological normalcy or as close to it as possible. Patients want to know what to do, *the what*, but are also influenced greatly by their own emotional responses, the responses and impact of others, and the goal of returning their lives to their pre-disease state or as close to it as possible. They do not want their lives to be ruled by their illness and fear of it, nor do they want to be identified as socially deviant.

4.5.3 Communication Technology

The Diabetes Home Monitoring Module, described briefly earlier and in more depth in Edmonds et al. (1998), is a telecommunication system that allows diabetic patients to send information to their physicians, improving the level of monitoring and consequently diabetic control. The accuracy of the information that is transmitted is critical to successful communication. Through analysis of the videotaped interactions between the subjects and the system, the data entered by the subjects were compared against the data provided in the scenarios. Only 73% of the data entered were found to be accurate. It should be noted that this is not an indicator of the overall accuracy with which patients transmit data to their doctors using this system as it includes entries made with no training or knowledge of the system. Nevertheless, this indicates that errors do occur, that learning is required, and that, under the stresses and pressures of everyday life, errors will occur.

Figure 4.3 shows that both patients and physicians correctly entered the blood glucose values fairly well (86% and 92% correct respectively). However, none of the changes in insulin doses were entered by patients and only 33% of the hypoglycemic reactions were entered. Comparison of the accuracy of the entries of patients and of physicians shows a higher frequency of correct entries by physicians than by patients. No relationship was found between accuracy rates, experience with technology (from little experience to an informatician), and education level achieved (high school to MD).





The most common error made during the process of data entry was that of entering information on the wrong date. Eighty-three per cent of the six subjects entered values for one date initially, but did not change to the second date when required to. Closer examination of this error in light of the findings discussed thus far reveals a possible explanation.

The task involved entering four glucose levels, two on one date, and two on another. After entering each level, the system issued the following prompts: Verbal Instruction: If you would like to record another blood glucose level, press Yes. If not, press No.

Would you like to record another blood sugar entry? Screen Instruction: Would you like to record another glucose level for this date?

Each subject, when given this information, focused on entering the glucose level without considering that they had not changed the date. Replying 'No' as instructed would have returned them to the Main Menu. They would then be required to select 'Glucose' again, enter the new date, and then enter the glucose level and any other information about diet, activity level, or stress level they intended to provide.

Exclusion of information in the transmission to physicians has major clinical implications for medical decision making in that these are critical indicators of patients' status. That physicians were more accurate in entering information into the system is not unexpected given the previous discussion of the differences in understandings of the two groups. The error related to entry of the date suggests that subjects focused on the glucose levels and not the date, and the prompts to change the date were inadequate to overcome the shift in focus away from date and toward glucose level. Patients were required to learn to use the technology, as its framework was not consistent with their own intuitive model of diabetes.

Learning to Use Technology: The analysis of the videotape data of patients and physicians learning to use the telephone technology revealed two components to the initial use of the system. Since no prior instructions or demonstrations were given,

subjects were required to learn to use the system and to enter the required content simultaneously. This proved to be a difficult task.

The amount of time subjects took to enter the first blood glucose level was compared with the time taken to make the last entry to determine if experience with the system had a positive impact on accuracy. Figure 4.4 shows that this was indeed the case. Entering the first glucose value took an average of 107 seconds while entering the last glucose value took only 33 seconds. It is of interest to note that patients accomplished the task more quickly initially. This can be attributed to the level of experience of the subjects with technology. Subjects, both patient and physician, who reported experience with computer technology required a mean of 49 seconds to enter the first blood glucose level. Subjects reporting little or no such experience required 164 seconds. This difference disappeared on the last glucose entry.

These findings suggest that, while initial use of the system is based on procedural knowledge, such knowledge was quickly gained through practice with the system. It can therefore be concluded that learning did indeed take place, and that it facilitated the accurate entry of information into the system. Facilitation of the learning process by (a) the provision of aids to memory and (b) the development of input processes that are consistent with the processes used by the patients in thinking about their illness would reduce the effort and cognitive load required to enter data and manipulate the system simultaneously, reducing the risk of error and miscommunication.



Figure 4.4. Comparison of Mean Time (seconds) Required by Patients and Physicians to Enter Blood Glucose Values on the First and Last Attempts.

4.5.4 Reasoning Patterns

Lay Reasoning: The errors that subjects made when entering data into the system suggest that they were guided by something other than the system itself during the data entry procedure. The relationship between glucose and diabetic control was clear to all subjects. However, they did not organize the concepts related to daily life based solely on the effect of these factors on glucose levels. An example from Appendix 4.1 illustrates this point. This subject described the relationship between blood glucose level and what she ate, describing it as a causal association. Patient: "Well let's say if I'll eat a pound of candies my sugar will go sky high and it might even cause a stroke!"

In the diagrammatic representation below, it can be seen that the concepts considered, represented by boxes, were carbohydrate intake, blood glucose level, and complication. The links were positive, causal relationships (CAU), represented by arrows. This was a temporal sequence of events.

Patient's Narrative, Temporal Sequence:



Medical Reasoning: Physicians were found to organize their framework in terms of the patients and their illnesses. The most important indicator was the blood glucose level. The observation of changes in glucose levels is made and an explanation for the finding was sought. In the following example, the remedy for diabetes was weight loss and this was the aspect of importance to the physician. Analysis of the previous excerpts of a physician's transcripts illustrate this organization:

Physician: "A fasting blood sugar of 160 I think pretty much says that she's diabetic. The postprandial is 200 also tells us she's diabetic. So either one of those by themselves I think meets criteria for diabetes."

Physician: "So she's overweight. ... So that's already got me thinking that if she is insulin resistant, then I might be able to improve that by having her lose weight at some point if we can manage that."

The physician's sequence is represented as:



COND: Directional Conditionality
: Concept

The decision made by the physician was to address the problem of obesity, which was directly related to diabetes. This is not compatible with the goals of patients, who are more motivated to maintain their lifestyles even if doing so contributes to their illness.

Telecommunications System: Turning to identification of how the telecommunications system used by subjects in this study processes information, it was found that the input sequence began with the date, then the blood glucose level, followed by a selection of factors that might have influenced the glucose level, as shown below:

Telecommunication System's Sequence



COND: Directional Conditionality
: Concept

In addition to blood glucose values, patients were given the options of entering information about the following categories:

- Unusual events that have occurred prior to the glucose level being entered
 - carbohydrate intake
 - activity level
 - stress level
- Changes in insulin dose
- Insulin reactions

When being used by lay people, the system forced them to make predictive inference, which they do not normally do. Patients structure their accounts of illness in a narrative form (Patel et al., in press). In order to enter the information into the system, they were required to reorganize its structure in a way that was not natural to them, creating increased cognitive load and increased risk of error.

The input structure also did not consider the issues of importance to the patient, such as the relationship between glucose level and complications. Patients were required to address a number of factors and categorize them to fit the system interface. The structure of the system related more to the thinking processes of physicians, focusing on problem indicators required by doctors to make their decisions. The question that arises is: How can categories be developed that meet the information needs of the physicians while assuring that patients understand them sufficiently well to provide accurate information? Such categories can be generated through detailed characterization of the nature of lay reasoning about diabetes (quantification from qualitative data).

Analysis of the way that patients and physicians used the system (Figures 4.3 and 4.4) and an examination of the processes guiding this use are consistent with the arguments made earlier that lay actions are guided by lay conceptualizations. Incompatibility between the lay frameworks and the input structure of the technology resulted in inaccuracy and miscommunication. Subjects interacted with the system based on how they saw the world. Studies examining the nature and effects of the errors patients made in using the telecommunications systems will guide system design so that errors with the potential to seriously compromise the patient are identified and minimized. Conflict between the patients' and physicians' models increased the effort required to learn to use the technology, increasing the level of frustration involved in using it which in turn increased the risk that it would be used improperly or not at all. Introducing technology for patients to implement in their homes requires that they learn the skills required to interact with the system, skills which improve with practice. It must be considered however, that skills that improve with practice will also deteriorate with disuse. A patient going away for a month long vacation might be "rusty" on returning. Daily life, with its time pressures, stress, and illness, may also lead to reduced performance. Development of interfaces that allow the patient to tell their story in their way increase the probability that the story will be told and that it will be told as accurately as possible.

Research on lay conceputalizations discussed earlier suggests that these findings are not restricted to diabetic patients, nor are they restricted to only the system examined here. Interactions between users of technology, with one conceptualization, and the designers, with another, are likely to experience the same phenomena demonstrated in this study. For example, designers of Internet World Wide Web pages may have similar difficulties in reaching and meeting the needs of their intended audience and obtaining required information from them.

4.6 Conclusions

This study examined the role of prior conceptualizations in lay decision making and in interactions of lay people with technology. The data show that the nature of information that patients use as evidence in making decisions is based on their personal knowledge, which is validated in everyday experiences. These understandings are different from those reported in investigations of medical decisions making, in which use of biomedical and clinical knowledge as evidence predominates.

These discrepancies in the nature of evidence used by the two groups create mismatches in the use of communication technologies that oblige patients to categorize information into the evidence that doctors require to make medical decisions about disease management. This categorization is not consistent with that of lay people. Successful communication is based on congruence of the communicators and of the method of communication. Potential mismatches between the meaning of information for the patients and for the physicians do not disappear when the information is transmitted through technology. Data transmitted by patients to doctors must include the

facts that the doctors need to make decisions about diagnosis and management of disease. Technology must be designed so that it is efficient, however if the information that is transmitted is not accurate, then technology becomes an ineffective and potentially dangerous tool. The system described in this study, the Diabetes Home Monitoring Module (Edmonds et al., 1998), is designed for physicians to have efficient and effective access to patient data. But the value of the data input will be questionable if consideration is not given to how the patients view the system and how they interpret the input categories.

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Lay Knowledge About Diabetes

Description of factual knowledge about relationships between concepts related to

diabetes without expression of underlying pathophysiological mechanisms.

<u>Patient</u>: "Well let's say if I'll eat a pound of candies my sugar will go sky high and it might even cause a stroke!"

Biomedical Knowledge

Description of underlying patholophysiological mechanisms identifying causal links.

<u>Physician</u>: "The polyuria is produced because the sugar gets in the urine and it acts as an osmotic diuretic, prevents the body the kidney from reabsorbing water from the urine."

Patient: "Exercise helps you to secrete more insulin." (Inaccurate)

Health Care Team input

Statement of information, instruction, or direction from a member or members of the health care team.

<u>Patient</u>: "They (*nurses*) know an awful lot about diabetes and they know their clientele very well."

Regimen, Rigidity

Specific reference to the diabetic treatment regimen associated with reference to inflexibility.

<u>Patient;</u> "The constant testing, the constant watching what you eat and wanting to eat chocolate and wanting to eat this and that."

Functioning in Daily Life (Daily Activities)

Reference to restrictive decisions made about daily activities due to limitations

imposed by diabetes other than those related to the treatment regimen.

<u>Patient</u>: "I'd (*patient's husband*) love to go on kilometre runs, biking all day but I don't think you can do it."

Social Impact (Positive / Negative (Stigma))

Statement of influence from individuals, family, and/or community.

Patient: "I will ask my children to help me."

Affect

Reference to mood, sense of well-being (positive or negative).

<u>Patient</u>: "I have a very bad depression. Because you lost your eye, you lost your job, and we can't have a baby, you know. It was a very bad period."

Fear

Expectation of negative outcomes related to diabetes, such as social stigmatization,

complications, impaired functioning, or fears of others.

- Patient: "He told me I'm not a good girl because I don't do anything."
- <u>Patient</u>: "It's because of that *(unstable blood glucose levels)* I have problem with my eyes and my kidney and like that."
- Patient: "I don't want to be like my father when he died. Well he was eighty-one, practically an invalid."

CHAPTER FIVE

GENERAL DISCUSSION, CONCLUSIONS, AND IMPLICATIONS

5.1 Summary of Results and Discussion

The research reported in this series of studies characterizes the role of prior knowledge in decision making, particularly related to how lay people conceptualize health and illness, how they make decisions about it, and how they interact with health care materials and providers. The first study (Chapter Three) began by focusing on how lay people view health and illness, discovering that their concept of health emphasized lifestyle maintenance, particularly feeling well and carrying out activities of daily living. Concepts related to the absence of illness or of specific symptoms were not strongly represented. This finding was remarkably stable across the three groups. Resilience of the description of health across groups with varying experiences with it suggests that these are fundamental components to the structure of this concept.

The understanding of illness also reflected an emphasis on daily activities, being defined by subjects as interference with the ability to carry out usual responsibilities. This perception was slightly though not significantly more common in the subjects who had not experienced chronic illness, however. The presence of specific symptoms was also identified as a component of being ill. While feeling well was incorporated within the concept of health, feeling ill was not a part of the concept of illness. indicating that

illness was conceptualized as affecting daily life, including the specific symptom that caused that effect. As with the description of health, all three groups, regardless of their experience of illness, reported a consistent pattern. Interestingly, health was not conceptualized as "not sick", nor was illness seen as "not healthy".

These findings identify health as feeling well and able to live life, while illness is seen as less able to do so. The concepts of health and illness are strongly based in everyday experience and everyday life. Commonplace experiences also inform lay knowledge-seeking strategies for information. When asked how they sought out information about health and illness, subjects in all three groups reported many different sources, most frequently health care providers, followed by the media, and then family members and other lay sources. Subjects with cardiac diagnoses had access to and were familiar with their physician and reported consulting their doctor based on the credibility of the physician role, doing so significantly more than subjects not being followed for any illness did. Subjects with no illness reported adjusting their sources based on the problem at hand and used technology significantly more than either of the two groups with ongoing access to health care providers. Sources were chosen based on four criteria: 1) accessibility, 2) familiarity, 3) credibility, and 4) comprehensibility. These criteria suggest an information-seeking heuristic, allowing lay people to obtain useful information efficiently using a minimum of resources. Use of heuristics has been identified as a hallmark of expert reasoning (Ericsson & Lehmann, 1996). The formation of such a strategy suggests that lay people may reason at an expert level, though based on a different understanding from that of physicians. This supports the concept of the expert lay reasoner (Patel, Kaufman, & Arocha, 2000a), with expertise at making decisions

based on extensive general experience and culturally acquired knowledge, thereby maximizing available cognitive and information resources to arrive at the best possible decision within those constraints (Ericsson & Lehmann, 1996).

Each of the three groups of subjects had varying experience with cardiac illness and cardiac information. The cardiac group had had the most extensive contact with health care providers about cardiac disorders. Yet there was no significant difference between their knowledge of the symptoms of AMI and that of the other two groups. This supports the argument for the salience of prior knowledge gained through lay sources, with medical knowledge being isolated from the working knowledge structures. In Chapter Two, an argument is made that learning of new concepts is based on building on the pre-existing knowledge structure (Carey, 1986). It is also asserted that scientific knowledge is superimposed onto the pre-existing, informal lay knowledge structure (Sivaramakrishnan & Patel, 1993). That the three groups are not significantly different in their descriptions of the symptoms of heart attack suggests that their knowledge came from the sources that they all had access to, i.e. lay sources producing lay knowledge. The dramatic image of a man clutching his chest and gasping for breath is a staple of media education and entertainment and is consistent with the model of heart attack reported by these subjects. This supports the information-seeking heuristic suggested above and the existence of lay knowledge as separate from scientific and medical information (Carey, 1986; Sivaramakrishnan & Patel, 1993).

The impact of this lay model of the symptoms of AMI on action chosen when confronted with those symptoms was examined by presenting subjects with three scenarios of equal severity of symptoms but varying familiarity. The dominant response

to recognized symptoms of AMI was to involve emergency services, the only appropriate response in these circumstances. Other responses were seen however, including taking no action at all. In all three scenarios, subjects with no ongoing medical problems were significantly more likely than subjects in the cardiac group not to take any action. The group with diabetes tended to fall in between these two groups in their responses. That the group with no diagnoses had identified chest pain and dyspnea as symptoms of heart attack and yet responded passively suggests a decoupling between knowledge and action. This decoupling has been documented previously in expert nursing decision making in an emergency triage context (Leprohon & Patel, 1995), introducing the possibility that the decoupling seen in Scenario Three is also related to the urgency of the situation. The strong tendency of the cardiac subjects to seek emergency assistance in all three scenarios suggests a heuristic that states: "If you're not sure, get expert help and get it fast." Alternatively, those with little experience with illness have different anchors, or baseline rates for their assessment of the urgency of the situation. In their case, there is less serious illness in their environment. The availability heuristic (Tversky & Kahneman, 1974) would suggest that the probability of an emergency is low, and so they are less likely to act urgently. Their heuristic might be "If you're not sure, wait and see. It will probably pass." This was particularly clear in the excerpt of the subject with no diagnoses presented in Chapter Three. Given the pervasiveness of maintenance of daily activities in the lay conceptualization of health, the supremacy of the concept of health in those with no illness may dominate to the exclusion of other alternatives, such as a serious and immediate health risk.

While the prevalent response to familiar symptoms of AMI was the appropriate one, the variability in responses overall suggests that the effectiveness of current education practices is questionable. Lay decisions are based on lay knowledge and heuristics, suggesting that increasing the amount of biomedical information couched in probability terms is not an effective solution, a contention that is supported by the variability seen in the cardiac group, a group that has received additional exposure to information as part of their medical intervention. Technology offers a unique tool for tailouring information to the way that lay people make decisions, particularly since the group with the poorest performance, the group with no diagnoses, is also the group that identified computers as a source of information about health and illness. Computer virtual reality is able to simulate exposure to real world situations safely while including the visceral component of such high-stress decisions.

A more detailed examination of the process by which decisions are made about health and illness is reported in Chapter Four. In this study, decision making by diabetic subjects about their diabetes was examined using in-depth qualitative analysis. The analysis identified knowledge and information as the most salient determiners of diabetes-related decision and action. Lay knowledge predominated, followed by the procedural knowledge represented by the diabetic regimen. The health care team was also identified as important in determining subjects' actions, consistent with the result in Chapter Three that subjects with access to experts considered them to be major sources of information and guidance. Affective factors were also shown to be important, followed by daily activities and social factors. Reports of biomedical knowledge were negligible.

Examination of the network of concepts involved in lay decision making identified the regimen as central, interacting with lay knowledge to determine action. Information from the health care team informed the regimen but did not interact with it, nor did this information interact with lay knowledge. This level of isolation is not surprising given the separation of the lay understanding from both scientific information (Carey, 1995) and information obtained through formal education (Sivaramakrishnan & Patel, 1993) discussed in Chapter Two. Lay people have been found to base their decisions on an underlying framework of prior knowledge (Carey, 1995). Information from health care providers is superimposed and remains as a separate structure from this prior knowledge base. In addition, this study demonstrates that, when patients did acquire information from the health care team, it still remained isolated from the general path of decision making. The concepts of fear and affect interacted with both lay knowledge and health care information as well as with social factors. The strongest link in the network was the interaction between affect and the regimen, providing an indication of the importance of emotion in making decisions with respect to the regimen and vice versa. Carrying out daily activities was isolated, which is particularly interesting given its importance in the conceptualization of health described earlier.

Neither lay people nor physicians (Patel, Arocha, & Kaufman, 1994) make decisions based on scientific knowledge and yet both succeed in making good decisions nonetheless, based on prior knowledge developed through experience. This suggests that the differing frameworks of patients and physicians (Patel, Arocha, & Kushniruk, in press) will result in different decisions, leading to variations in actions chosen. The second part of the study reported in Chapter Three verifies that the frameworks are

indeed different and this does affect how lay people interact with technology developed by designers with medical and technologically oriented backgrounds. Results demonstrate that these differences are linked with variation in how technological tools developed by one group with one framework are implemented by members of another group with a dissimilar framework. This supports the hypothesis that the nature of the knowledge used by both lay people and physicians is not the same. Does it matter that patients don't use biomedical concepts or think about health and illness in the same way as physicians? Are their decisions different from those of physicians in any important ways? The impact demonstrated here is unanticipated, unintended, and potentially harmful.

It is clear that health care providers and lay people conceptualize health, illness, and disease differently and that these differences impact on their knowledge structures and how they interact with health-related tools, in this case technology. Shared models serve as a basis for effective communication (Orasanu & Salas, 1993). Given this, the nature of the interactions between these two disparate groups was examined. A component of a third study (Appendix One) analyzed clinical interactions between doctors or nurses with patients based on the issues identified in Study Two (Chapter Four) as important in lay decision making. Topics discussed by the doctors and nurses centered on biomedical concepts and the treatment plan, or interventions. Little evidence was seen of discussion of information in lay terms or of emotional or social issues, nor is there framing of explanations in lay terms. Interviews were conducted in the biomedical "language" of the dominant group, the providers, a "language" that the lay patients do not speak or understand. Communication is based on the model of the communicators. The disparity between the underlying frameworks of physicians and lay people is sufficiently great that effective communication does not occur (Patel et al., in press). The topics discussed are not those of concern to the patients. Physicians have been shown to expect that patients will do as they are told, and treat patients differently based on whether they are expected to comply or not (Greenberg, Eisenthal, & Stoeckle, 1984). This suggests a source of the high rates of non-compliance of patients with medical treatment plans: The plans are not consistent with the goals and concerns of the patients and are developed without their input. Alternatively, this might be viewed as the health care providers not complying with the priorities and plans of the patients. From either perspective, the result is one of ineffective communication, with the two groups seemingly talking past each other.

Different understandings result in different approaches to tools, demonstrating that the underlying framework does indeed impact on action. In addition, the lack of a shared mental model impedes the ability of people with contrasting conceptualizations to communicate effectively and work in a collaborative context. The outcome when the issues are those of health and health care is widespread non-compliance. Information is provided to lay people in a manner that is not meaningful to them. Issues addressed are those of importance to providers rather than those emphasized by patients. Lay people are therefore left with little information and fewer strategies that are useful to them in resolving health-related issues, forcing them to rely on prior lay knowledge and heuristics.

The discussion thus far has suggested that lay reasoning is based on knowledge structures that are different from those of physicians, developed and evaluated

differently. The current practice of trying to teach lay people to reason like physicians, a process that takes many years of intensive training, has contributed to patient noncompliance and dissatisfaction with traditional healthcare. Characterization of the interactions between the two groups (Appendix One) suggests that a more effective means might be to include the lay patient as a contributing member of the team, acknowledging the contribution of a different type of input.

This thesis presented a series of studies examining the cognitive processes by which conceptualization is translated into action. The methodology employed has certain limitations by its very nature. Think aloud and semi-structured interviews provide insight into what people are aware of thinking. Ericsson and Simon (1993) identify procedures by which the amount of information retrieved is maximized, including instructing subjects as to how to give think aloud reports. Subjects are not usually accustomed to thinking aloud when solving problems. While this introduces some artifact, it has been shown to capture the underlying thought processes with little adverse effects (Ericsson & Simon, 1993). This method also produces massive amounts of verbal data and thus requires the proper use of probes such as specific interview questions.

Interviews are also subject to individual differences between interviewers and between interviews conducted with each subject. This is both a strength and a weakness in that the interviewer is free to follow the reasoning path of the subject and expand on those components that are of interest, however it can introduce some differences that might affect standardization and therefore experimental control. Unfortunately, this is a tradeoff made in conducting quasi-experimental real life studies.

Another tradeoff in real world studies is in sampling from real world populations. This is seen in the nature of the sample composition in Study One (Chapter Three), in which the group with cardiac diagnoses is significantly older and with less education than the other two comparison groups. It has been argued in this discussion that the tendency of the cardiac subjects to contact emergency services is due to their experience with cardiac illness and their physicians instructions to go to the hospital in case of cardiac symptoms. This argument is based on the theories identifying prior knowledge and experience as critical in determining decisions and actions. However, it is also possible that other factors might explain this finding. Older people have been found to be more likely to surrender agency to physicians, choosing to defer decision making to an authority if one is available (Calhoun & Hutchison, 1981; Curley, Eraker, & Yates, 1984). Under the conditions of ambiguity presented in the scenarios in Study One, the older subjects may have chosen to refer to medical agents rather than make the decision themselves. Education too may have played a role, however it is difficult to separate age and education as contributing variables since they are so highly correlated, with older people being less educated due to changing practices regarding formal education. The effect of age and education on decision making about AMI might be evaluated through samples of subjects with no medical diagnosis and with cardiac diagnoses that were better matched on these variables. This would not be representative of the real world situation however, in which cardiac patients are older than those without cardiac disease. It must therefore be considered that the tendency to relinquish agency may also play a role in decision making by older, cardiac subjects. This again suggests that decision
making is based on a multiplicity of interconnected factors. This thesis has attempted to identify some of these variables and the interrelationships between them.

5.2 Conclusions and Implications

This series of studies attempts to characterize the connection between the understanding of health and illness, related knowledge, and decision making about health-related problems. Lay concepts of health and illness are based on peoples' everyday experiences. Information from other sources, such as health care providers, is not necessarily implicated in their actual decision making but rather may be decoupled from it, as seen when subjects reported symptoms of AMI yet did not report appropriate responses when presented with those symptoms in a scenario. Any information from experts that is used in decision making is incorporated into the lay framework, and its origins no longer retained. Otherwise it is superimposed onto the lay decision making pattern and can be reported but is not actually used in decision making. The choice of decision strategy is built on and influenced by personal experience.

Everyday experience also dominates the sources that people approach when seeking out information, using sources that they learn about and have contact with in the course of their everyday experience and that are readily available to them. The choice of resource is based on four criteria: 1) accessibility, 2) familiarity, 3) credibility, and 4) comprehensibility, each generated from relevance and availability in everyday life.

People view health as feeling well and being able to live their lives. They learn how to do this from what they see around them, building knowledge structures and strategies that guide their behaviour. Expert physicians and scientists have extensive

knowledge developed over years of intensive training and experience. Lay people do not have access to such in-depth medical expertise. This suggests that the scientifically naïve processes by which people make decisions about health are grounded in knowledge of the real world in which they live. Rather than trying to reconstruct this lay knowledge to match the medical pattern, expert health care providers might be more effective by supporting it, providing additional information and strategies that will assist the lay reasoner in everyday functioning. A truly collaborative paradigm in which the public is seen as expert at everyday living, the physician as expert in pathophysiology, and the nurse as intermediary between the two disparate frameworks might be more effective than the current model in which medical knowledge reigns supreme but is too dissimilar from the world of consumers to be integrated in a form that is useful to them. Such a model would change the medically oriented emphasis in patient-provider interactions from compliance or adherence with medical plans and instructions to one of collaboration and negotiation between groups with expertise in different fields. A collaborative approach between health care providers and consumers would result in plans for behaviour change being negotiated between experts (physician and consumer) and in tools targeting consumers being tailoured to their framework, goals, and needs. Such an approach holds promise for capitalization on scientific and medical discoveries to be reflected in the health of the public. In today's climate of increasing participation of consumers in their own health care, it is critical that the expertise of lay people be acknowledged and respected.

Variations in conceptualization, knowledge, and trained reasoning processes, as seen in lay people and expert physicians, impact on communication, with people seeming

to speak two different languages. Users with one framework (patients) use materials developed by designers with a different framework (medical-technological) in unexpected ways. Health care providers and consumers currently conceptualize health and illness differently, as seen by the topics discussed in provider-patient interactions (Appendix One) compared with the conceptualizations of health and illness identified in Chapter Three and health related decision making factors in Chapter Four. This results in tools developed by providers being incompatible with the framework of the intended user, the consumer. When the lay user then attempts to understand the material or tool based on their own perspective, the mismatch results in errors both in the incorporation of information and in the use of tools and equipment. A new and powerful tool in the form of technology has great potential for health-related education and communication. This thesis suggests that for this potential to be realized, systems and programs must be designed to be compatible with lay reasoning processes and priorities. People learn through experience. Computer simulations and virtual reality can simulate experience, thereby integrating information into the lay learning style so that it will be incorporated into their knowledge base in a way that is useful in decision making rather than being superimposed upon it. It can also incorporate the emotional aspects, producing the visceral element of health-related situations as well as the cognitive component. Technology is sufficiently flexible that materials can to be tailored to the individual by the individual, allowing information to be integrated in the manner best suited to the user.

Research usually answers some questions and raises many others. Further processing of the data reported here using semantic network analyses and pragmatics may be undertaken to characterize in more depth how lay people reason. Expertise is a

generic phenomenon with specific characteristics attached to it. Lay people who consider themselves "experts" share these characteristics. They can be labeled as "lay experts" as opposed to technical experts. They reason in a forward direction about familiar problem and use lay knowledge of illness to explain the problem when uncertain. The think aloud protocols collected in response to the scenarios presented to subjects in these studies could be analyzed to determine what pathways and knowledge this group of lay people used to make their decisions.

Lay people use analogies to explain the problems of health and illness and to communicate about them. A detailed characterization of how the analogies are used in descriptions of knowledge about diabetes and heart disease and in decision making would allow generalizations to be made to lay reasoning about health and illness.

Previously in this discussion, technology was proposed as a method to provide information to lay people, producing desired behaviour changes. It was concluded that use of technology varied based on the underlying framework and that differences in the frameworks of lay people and physicians/designers resulted in potentially dangerous uses of this tool. An understanding of how those involved in the design and use of computer systems think about technology, education and informing of lay people, and health and illness would inform safer, more effective designs. This analysis would also add to our comprehension of both individual understandings of these concepts and how these differences interact. Technology also has an effect on the reasoning of those who use it (Patel, Kushniuruk, Yang, & Yale, 2000b). Lay use of technology could be examined for this effect as well. Are these changes beneficial or detrimental? This may be true for other users as well.

The studies reported in this dissertation have provided insight into how lay people reason about health and illness and potential areas for strengthening their ability to make better decisions. They have also provided the basis for a continuing research program into lay reasoning: conceptualizations, knowledge structures, decision making strategies, and the relationships between them. An understanding of how people make decisions in general and how they make decisions about health and illness in particular will add to the theoretical cognitive research characterizing reasoning processes as well as providing guidance into the development of programs and technology that will support better health.

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Appendix One

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RESEARCH BASIC TO MEDICAL EDUCATION

The Collaborative Health Care Team: The Role of Individual and Group Expertise

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Background: Increasing costs of health care and rapid knowledge growth have led to collaboration among health care professionals to share knowledge and skills. **Purposes:** To characterize the qualitative nature of team interaction and its relation to training health professionals, drawing on theoretical and analytical frameworks from the sociocognitive sciences.

Methods: Activities in a primary care unit were monitored using observational field notes, hospital documents, and audio recordings of interviews and clinical interactions. **Results:** The demarcation of responsibilities and roles of personnel within the team became fuzzy in practice. Continuous care was provided by primary care providers and specialized care by intermittent consultants. The nature of individual expertise required was a function of the patient problem and the interaction goal. These team characteristics contributed to the reduction of unnecessary and redundant interactions.

Conclusions: Distributed responsibilities allow the team to process massive amounts of patient information, reducing the cognitive load on individuals. The uniqueness of individual professional expertise as it contributes to the accomplishment of team goals is highlighted, suggesting emphasis on conceptual competence in the development of individual professional education programs.

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The explosion of knowledge and skills, together with the growing need to use limited resources more efficiently, has posed a considerable challenge to researchers and professionals alike, producing substantial changes within science and professional practice. Combining the strengths of individuals into teams has been one key response to these challenges, facilitating the achievement of goals that may be beyond the range of a single individual.¹

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It is generally assumed that health care teams function in a collaborative manner and deliver health care efficiently and effectively.2-4 This type of collaboration requires interaction, which has led to an increased focus on the subject of communication skills.⁵ Indeed, when questioned about the attributes they would consider most important in role models^{6,7} and career choices,⁸ medical students and residents consistently refer to interpersonal skills and good relationships with patients. These findings have led to recommendations that academic faculties should improve the teaching of skills in these areas, so that they may meet the needs of students more effectively.⁵ Such suggestions are made with the acknowledgment that their implementation would require (and has in the past required) a major reallocation of resources.

With the introduction of problem-based curricula into medical education, a trend can already be observed away from a focus on individual competence and toward a focus on group processes.^{9,10} However, this shift has not occurred without costs.¹¹ Specifically, as a result of their intuitive appeal, alternative curricular designs have been implemented with insufficient empirical evaluation leading to a variety of unexpected outcomes, some of which may be harmful to the quality of medical education.¹²⁻¹⁸ There is a similar paucity of empirical evidence with respect to widely held assumptions about the types of skills necessary for competent functioning in collaborative health care teams, although such investigation has begun in several fields. including health care. 19-24 Indeed, a number of authors have expressed concern that focusing on the acquisition of skills that support teamwork¹⁹ may be at the expense of training practitioners to achieve individual conceptual and technical competence.14,17 Therefore, although it is undeniably important that physicians be equipped to communicate effectively with patients and fellow team members, a wholesale redirection of scarce resources needs to be carefully evaluated. We may be shortchanging the most important of resources----the individual conceptual developments that underlie the acquisition of communication skills.^{24,25}

The implications of collaborative health care need to be identified so that medical curricula can be designed to reflect the practices of health care providers, both individually and in teams. In other words, an understanding of collaborative processes in health care teams can provide a theoretical basis for curricular reform in medical education and training. The study reported in this article explores one teamwork environment (a primary care ambulatory clinic within a large tertiary teaching hospital) in which general internists, nurses, psychiatrists, and social workers deliver primary health care, identifying and characterizing basic features of the collaborative effort that is required.

Background: Conceptual Framework

The evaluation of a primary care unit was undertaken with two major objectives: (a) to characterize individual roles and patterns of interaction within the health care team, and (b) to examine the role of communication in understanding conceptual (knowledge) and procedural (planning) aspects of health care delivery necessary for effective management. The role of individual expertise in the team was also explored.

Extensive research has been conducted into the nature of individual expertise.²⁶⁻²⁹ According to this research, experts (such as internists) recognize patterns based on prior experiences, screen out irrelevant information, and employ reasoning strategies to arrive at solutions to problems quickly and effectively. In the clinical context, studies of medical diagnostic reasoning summarized by Patel et al.³⁰ have shown that expert physicians solving familiar problems use predominantly data-driven diagnostic reasoning, making inferences from given information (patient signs and symptoms) to the unknown (diagnosis). In contrast, when dealing with complex or ambiguous situations, expert reasoning tends to be hypothesis driven, using a tentative hypothesis to explain the given information and to guide the search for additional data. Owing to the complexity of internal medicine, which generally includes problems with features of both familiar and complex problems, internist decision-making frequently includes a mix of both data-driven and hypothesis-driven diagnostic strategies.

Laboratory-based studies of problem solving have not been able to completely account for how physicians solve problems and make decisions in complex, real-world situations. Recent investigations into decision making have included the study of group decision making in real environments with different limitations and situational variables. 19,20,21,23,30 A special type of coordinated group activity is that of collaboration, in which individuals with different areas of knowledge and skill work together to perform tasks and carry out activities necessary for achieving a shared goal.² In the medical context, collaborative planning and activity involve interactions among team members to manage the complexity of clinical practice. The health care literature abounds with examples of successful multidisciplinary teams with praise for this type of delivery system in many different domains, including primary care,3 geriatrics,32 diabetes,33 cardiovascular medicine,⁴ head and neck surgical oncology,³⁴ endovascular surgery,35 anesthesiology,20 and psychiatry.³⁶ In each of these domains, physicians, nurses, dieticians, physiotherapists, social workers, and other health care support staff each bring different domain knowledge and coordinated activity to health care decision making (though unfortunately usually excluding the patient who is the focus of the interaction). How

does this coordinated activity work, given that the team members have very specific knowledge and skills?

Patel et al.¹⁹ examined team interactions within an Intensive Care Unit team, where they identified individuals possessing different types of expertise with roles that are clearly and formally defined. This led to the identification of properties that emerged in the collaborative setting. Nurses were found to be responsible for the gathering of observations and reporting on those that they judged to be significant. Residents then synthesized and organized these observations, as well as data that they collected themselves, generating a set of organ-specific conclusions (e.g., gastrointestinal bleed). The attending expert then generated appropriate plans based on consideration of the patient as a whole. The complexity of medical analysis increased at each level in the hierarchy, whereas information management tasks decreased in intensity. The attending physician engaged in synthesizing information and planning future courses of action, dealing only with highly relevant findings.

Multiple streams of information were processed in a hierarchical manner using two types of strategies. Under conditions of high urgency, reasoning was data driven toward action rather than based on consideration of underlying justifications and a high degree of knowledge organization. Under less urgent conditions, causally directed reasoning was used to explain relevant patient information. In both cases, the overall goal of individual and collective reasoning was to find a reasonable explanation for a particular aspect of a patient's condition so that appropriate actions could be taken. Once an explanation was found to be reasonable and acceptable, it was accepted without further deliberation over alternative courses of action. This result is consistent with the findings in a study of decision making during telephone triage by nurses involving calls to a 911 system,³⁷ in which nurses were found to rely on heuristics to make accurate decisions in high-urgency situations.

The analysis of a high-urgency medical description setting is contrasted with the processes in the InterMed Collaboratory, a scientific collaboration in medical informatics involving lower urgency levels. Examination of this team has provided us with general insight into processes that occur among groups of individuals engaged in common coordinated activities.^{38,39} The InterMed Collaboratory consisted of five groups of medical informatics researchers from geographically distant participating institutions, collaborating in the development of shared medical software, tools, and system components to support further applications. Sources of data for this analysis included audiotapes of meetings, conference calls, and workshops, as well as e-mail, electronic interviews, progress reports, papers, presentations, proposals, and the InterMed Web sites and associated access statistics. Communication was important for bridging differences, leading to shared products and understanding. The preferred mode of communication was found to vary with the purpose of the interaction—planning tended to take place during conference calls and face-to-face meetings, whereas technical issues were emphasized in e-mail communication. As tasks were clarified and a shared commitment was developed over time, the pattern of communication became more focused, showing greater degrees of integration. At the same time, the development of communication depended on each individual's contributions (in terms of expertise) to the team effort.

Each of the two collaborations described previously (an Intensive Care Unit and a scientific collaboratory) imposes its own constraints on decision making, particularly in terms of time pressures and urgency. In this study, we borrow from the theoretical and methodological frameworks developed in the Intensive Care Unit study¹⁹ and the InterMed project³⁸ to characterize team decision making processes in an ambulatory care setting, where different constraints are operative. Our analysis focuses on the structure of the team and on communication patterns among team members in relation to individual knowledge and expertise.

Methods

Overview of the Setting

The sample clinical team examined in this article was from an ambulatory primary health care unit at a major United States teaching hospital. The mission statement of this unit stated that it aimed to provide comprehensive and integrated general primary care, maintain health, implement preventive measures, and treat illness in partnership with patients, families, and communities. Like most health care practices within university teaching hospitals, personnel included medical, nursing, and mental health professionals, as well as support staff. All were employed by the hospital and assigned to the primary care unit. Expertise in specific areas was available from the hospital through consultation and specific outpatient services such as diabetes and gerontology.

Participants

Team members were determined from unit documentation, and included representatives of each profession making up the core of the Primary Care Practice's health care team. The participant sample included three primary care physicians, a psychiatrist, two medical residents, two nurse practitioners, a clinical nurse (triage for patients concerns and issues), a social worker, an HIV case manager (coordinates community and hospital resources for HIV positive patients), a community resource specialist, and two administrators.

Data Collection

Health care providers were followed as they went about their daily activities, allowing team members to become habituated to the observer's presence, thereby reducing the possibility of introducing artificial influence that would affect the representativeness of the model produced.⁴⁰ The observation period ranged from a half day to a full day per person being observed, based on the availability of the person. The study was conducted within a time period of 11 weeks.

Interactions with other team members, outside providers, and patients were identified as providers went about their daily work during the observation period. These interactions were noted (role of individuals involved in interaction, method of communication, subject of interaction) and audiotaped when possible. Audiotaping was used to capture details of team interactions for systematic analyses of interactive processes and decisions. Semi-structured interviews (audiotaped) were also conducted with participant providers, using probes designed to elicit information-identifying patterns of team interactions.

All audiotapes were transcribed and analyzed. Observations of interactions through telephones and e-mail were also included in the analysis.

Analysis

The data analysis was based on methods emerging from the cognitive and social sciences, providing a framework for the analysis and modeling of human performance in complex real-world environments, particularly related to team decision making and social interactions.^{23,38,41–43}

Team Interactions

Examination of team member interactions was based on the professional roles described previously. Interactions between health care professional dyads were identified in the transcribed data and field notes (interactions between providers and between providers and patients).

Each interaction bounded by a block of time before and after was coded as a single interaction. The frequency with which professionals in each category interacted with other team members during the period of data collection was calculated and a diagrammatic pattern of the raw frequency of these interactions was developed using sociometric analyses, providing graphical representations of interactions within the group. This type of analysis provides both quantitative and qualitative features of communication patterns.³⁸

A limitation of this method is that interactions about a single topic or issue that were interrupted were coded as multiple interactions. This was chosen over other methods because of its simplicity and clarity. Delineating the limits of repeated communication episodes about a single issue, when it began and when it ended, so that measures such as duration of interaction about that issue could be measured, would create ambiguity as well.

One of the goals in the development of the primary care unit was that the needs of the patient should play a major role in determining the care provided. We therefore examined collaborative patterns in the management of different patient problems. Representative patient cases were identified based on the frequency of specific problems seen on the unit. Sociometric representations of the interactions between providers relative to patients with the specified diagnoses were developed.

Topics of Discussion

The topics of discussions among health care team providers were determined by analyzing transcribed communication episodes. Topics were divided into two major categories: direct patient care and unit organization. Patient care categories were subdivided based on a problem-oriented system of patient care documentation.^{44,45} Organization was subdivided into patient flow, administrative issues, and one provider's determining the activities of other providers involved with specific patients. The coding scheme is shown in detail in Table 1.

It was also of interest to determine topics of discussion relative to the interests of the patients. A coding scheme developed to capture factors determined to contribute to lay decision making was therefore used as well,⁴⁶ as shown in Table 2.

Transcripts were then coded by student research assistants according to these categories and percent frequencies of each category determined. Disagreements among raters were discussed in group meetings and clarified for common consensus until general agreement was reached.

Mode of Interaction

Transcripts of audiotaped interactions and field notes were analyzed to determine modes of interaction: face-to-face contact, telephone, pager, voice mail, paper, e-mail, electronic medical record (EMR), and **Table 1.** Content Categories of Health Care Provider Interactions^{44,45}

Category	Description			
Patient Data	Information describing the patients' conditions: patients' reports, observations, tests			
Assessment	Identification of problem or issue (e.g., medical diagnosis)			
Plan	Treatment plan for identified issue (what is to be done)			
Intervention	Actions taken with respect to identified issue, determined by the plan			
Evaluation	Determination of outcome of plan and intervention (was desired outcome attained?)			
Assistance With Procedure	One staff member assisting another with a procedure			
Patient Flow	Issues related to the movement of patients through the unit and the hospital			
Administration	Issues related to the functioning of the unit			
Monitoring Team Activity	Determining observations, assessments, plans, and interventions of other providers			

an intermediary team member acting as a messenger.³⁹ The frequencies were also analyzed in terms of percent frequencies of synchronous (face-to-face, telephone, pager) and asynchronous (e-mail, voice mail, paper, EMR, intermediary) communication modes.

Results

Team Participants and Health Care Unit Organization

The organization and roles of the team members in the primary care unit are given in Table 3. Health care delivery was found to be organized according to individual roles within the team. A wide variety of personnel were involved, including faculty physicians, psychiatrists, medical fellows, residents, psychiatric residents, interns, nurse practitioners, clinical triage nurses, social workers, and community resource specialists—HIV case managers, practice assistants and secretaries. Analysis of interview responses and utterances within interactions describing provider roles revealed the organization of team roles, responsibilities, and personnel as summarized in Column A of Table 3.

This organization revolved around three domains of care: medicine, mental health, and nursing. Analysis of interview and observational data of team interactions showed that each of the three domains was organized hi-

Table 2. Categories of Concepts Related to Lay Decision Making About Illness"

ay Knowledge About Illness
Description of factual knowledge about relationships between concepts related to illness without expression of underlying
pathophysiological mechanisms
Patient: "Well, let's say if I'll eat a pound of candies my sugar will go sky high and it might even cause a stroke!"
Nomedical Knowledge
Description of underlying patholophysiological mechanisms identifying causal links
Physician: "The polyuria is produced because the sugar gets in the urine and it acts as an osmotic diuretic, prevents the kidney from reabsorbing water from the urine."
Patient: "Exercise helps you to secrete more insulin." (Insccurate)
lealth Care Team Input
Statement of information, instruction, or direction from a member or members of the health care team
Patient: "They (nurses) know an awful lot about diabetes, and they know their clientele very well."
terimen, Ristility
Specific reference to the treatment regimen associated with reference to inflexibility
Patient. "The constant testing, the constant watching what you eat and wanting to eat chocolate and wanting to eat this and that."
anctioning in Daily Life (Daily Activities)
Reference to restrictive decisions made about daily activities due to limitations imposed by illness other than those related to the treatmen regimen
Patient: "I'd (patient's husband) love to go on kilometer runs, biking all day, but I don't think you can do it."
iectal Support
Statement of positive influence from individuals, family, and/or community
Patient "I will ask my children to belp me."
Vifect
Reference to mood, sense of well-being (positive or negative)
Patient: "I have a very bad depression. Because you lost your eye, you lost your job, and we can't have a baby, you know. It was a very b period."
Rear .
Experience of or expectation of negative outcomes related to diabetes, such as social stigmatization, complications, or impaired functions
Patient: "He told me I'm not a good girl because I don't do anything."
Patient: "It's because of that (unstable blood glucose levels) I have problem with my eyes and my kidney and like that."
Patient: "I don't want to be like my father when he died. Well, he was eighty-one, practically an invalid."

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Table 3.	The Organiz	ation and Roles	of the Health	Care Team in the	Priman	Care Ambulator	v Unit
*				COMP C & COMPANY ON PARTY			,

(A) Hierarchical Organization of Participants	(B) Responsibilities	(C) Presence, Availability	(D) Unit of Focus
Medical Care			
Director: General Medicine and Primary Care	Collect patient data, formulate diagnoses, plan interventions, and evaluate outcomes	Intermittent	Patient
Medical Director	•		
Faculty Physician			
Research Feilow			
Resident			
Intern			
Nursing Care			
Director: Ambulatory Nursing	Collect patient data, formulate diagnoses, and	Continuous	Patient
Nurse Manager	develop treatment plans in conjunction with		
Nurse Practitioner	the physician. Monitor patient status and		
Clinical Nurse	provide continuity of care		
Mental Health Care: Psychiatry			
Director: Psychiatry	Collect patient data related to mental health,		
Psychiatrist	formulate diagnoses, plan and implement,		
Psychiatric Resident	and evaluate interventions including psychopharmacological care		
Mental Health Care: Social Services			
Director: Social Work	Collect patient data, identify level of	Continuous	Patient, family
Chief Social Worker	functioning related to psychosocial issues,		•
Psychiatric Social Worker	develop, implement, and evaluate plan		
Mental Health Care: Community		Continuous	Community
Resources			•
HIV Case Manager	Initiate and coordinate hospital and		
Community Resource Specialist	community resources		

erarchically, based on level of expertise and education. This is illustrated in the following excerpt in which a senior resident is consulting with a faculty physician.

Resident: I had a guy who says he acutely got this lump on his hand. It looks like a cyst or something. Physician: What hand?

Resident: It's in a funny location, over the radial artery.

Physician: Is it hard or soft? What does it feel like?

Resident: Kind of squishy.

Physician: Yeah, that's good. Does it hurt? Resident: Once in a while, not that often.

Physician: Yeah, well, then that's probably what

it is [a cyst].

Resident: Probably just have him get it checked out if he wants to.

Physician: Yeah, I think that that's certainly something I would do. I would send him to the hand clinic here. Particularly since it's right over the armory in the neuro there. It's a very good center. I think that the people who do it here are actually through plastic surgery. A. B. and C. D. are the two guys that I know of who do hand work. But they're more into plastic surgery. Resident: Okay. Great.

The resident provides a tentative diagnosis and the clinical data justifying the diagnosis. The physician

then requests additional data, confirms the resident's diagnosis, and suggests a treatment plan.

Interview responses substantiated administrative responsibility and accountability as implicit, flowing from those higher in the hierarchy to those below them. For example, the medical hierarchy ranged from the Director of General Medicine and Primary Care to the medical directors to the faculty physicians to the research fellows, residents, and interns.

This hierarchical structure, however, did not apply between different domains—for example, between medicine, nursing, and mental health. For issues requiring the clinical expertise of individuals in domains other than their own, a pattern surfaced in which each professional functioned at a level approaching equality in providing input into team decisions and was respected for his or her knowledge and expertise. For example, physicians were observed to call on nurses for monitoring and continuity of care, as in the following excerpt from a transcript of a faculty physician talking to a patient:

I don't have the set up for myself to be the one to see you frequently. So, the nurses do it, and I think they generally do a good job.

Nurse practitioners consulted with physicians regarding pathophysiological issues, as in the case in which a nurse was faced with an anatomical abnormality resulting from a surgical procedure in which the patient's eardrum had been removed. She was not familiar with this procedure and so asked a physician to advise her as to how to care for the patient.

A nurse practitioner also reported consulting with a community resource specialist (HIV Case Manager) when dealing with an issue related to community resources, as illustrated in the following interview response:

If it is one of my HIV patients and they need something, if they have a problem in terms of transportation or getting nutritional supplements or if there is a problem with insurance coverage that is going to impact on the care pretty immediately, I will go to the community resource person, either page them or walk around the corner to their office during the visit and try and hook the patient up with that person during the visit. So, often I do interact with other members of the team.

This was consistent with a team approach to the provision of health care seen in the Intensive Care setting.¹⁹

Roles of Team Members, Expertise, Responsibilities, and Tasks

Further characterization of the unit in terms of the types and levels of expertise, responsibilities, and tasks is illustrated in Table 3 (Column B) based on the analysis of roles described previously. Roles were differentiated relative to three different dimensions of health care delivery: (a) domain knowledge, expertise, and responsibilities (Table 3, Column B); (b) availability on the unit (Table 3, Column C); and (c) the area of focus (individual vs. group; Table 3, Column D).

Providers in each of the three domains collected data from the patient, developed diagnoses, and formulated plans for patient management specific to their area of expertise. Analysis of the data showed that both physicians and nurses collected information that was related to patients' health and illness. Figure 1 identifies issues frequently discussed within provider-patient interviews. Both ordered diagnostic procedures, but physicians emphasized biomedical and clinical information. They also addressed issues related to patient education, though largely in the form of questions about need for knowledge rather than information itself. Nurse practitioners discussed issues related to interventions and how the patients were feeling (affect) as well as providing information. The focus of the physicians was on disease and resolving problems related to the disease process, whereas nurses focused on monitoring (as demonstrated in the previous excerpt and Figure 1), on emotional issues, and on health maintenance and promotion. Tasks related to care by mental health providers were similarly partitioned.



Figure 1. Comparison of topics of discussions by physicians and nurse practitioners during patient interviews. Phrases were categorized in transcripts of provider-patient interviews. This figure represents the percentage frequencies with which the categories of concepts were discussed by physicians and nurses in the context of a patient interviews.

The responsibilities and tasks of each group of personnel reflected their expertise. Although both groups addressed psychosocial and biomedical aspects of patient problems, one aspect more than the other was emphasized by each group, operationalizing differences in training by focusing on different tasks and responsibilities. Both groups addressed lifestyle issues; however, physicians emphasized their diagnostic value and physiological implications. Nurses discussed the overlap of lifestyle and interventions as well. Nurse practitioners, with more specific education and experience, followed their own caseloads and were responsible for assessing and monitoring their patients. Clinical Triage Nurses, with less training, were primarily responsible for screening and directing contacts from patients and determining the most appropriate action for the patients' problems. This included directing and/or contacting the provider whose skills most closely fit the needs expressed by the patient. Variations in expertise were accommodated by the amount of supervision provided, with junior staff being supervised much more closely. In this way, tasks were distributed efficiently, so that there was less room for duplication or omission, as reflected in the following statement made by a clinical triage nurse during an interview:

I have been like a mediator from the patient to the physician. It is a big role for collaborating because if I can get a sufficient amount of information from the patient, then walk around the corner to A.B.'s office and talk with her for maybe three minutes about the patient, that is certainly time saving for a lot of people involved.

The presence of the different categories of personnel in the unit varied (Table 3, Column C). Physicians, concerned with the biomedical aspects of patient problems (disease model), were available intermittently. Their commitment to the unit was in specific blocks of time, such as a morning, an afternoon, or a specific day. Given that changes in patient status could occur at any time, a mechanism was required to assure continuity and availability of patient care. This was provided by cross-coverage, that is, by physicians seeing each other's patients when the situation was urgent, and by nurse practitioners, who were available on a continuous basis, alerting physicians if a problem required immediate intervention. Nurse practitioners and clinical triage nurses were present at all times. Social workers were available on demand, as were community resource specialists. Nurse practitioners and social workers both delved into ongoing health and illness concerns, such as lifestyle questions and coping with illness, allotting more time than physicians for each patient. Their continuous presence on the unit thereby provided continuity of medical care, as well as health and illness care. Specialists in particular areas of health, illness, and disease were consulted as determined by the primary care team, based on the assessment of particular patient problems.

Physicians and psychiatrists were present on the unit intermittently, whereas nurses and social workers were present on a more continuous basis. Intermittent care was related to domains that concentrated on disease (physicians and, to some extent, nurses) and continuous care was related to domains that concentrated on health and illness (nurses and social workers). This led to an efficient distribution of resources, because physicians were on site only when required, whereas continuous monitoring of patients was maintained by others. These shared and distributed tasks and responsibilities provided a way for the team to jointly process the massive amounts of information involved in caring for patients in a global, holistic manner and thus reduced cognitive load on individual team members.

The three types of providers also differed in terms of their unit of focus at the individual, family, and community levels (Table 3, Column D). Physicians tended to concentrate on the individual patient, with some attention to the family. Nurses exhibited a broader range, contacting outside community agencies and resources. Social workers were more family and community oriented, with the role of the community resource specialists defined as assisting patients in accessing community resources. This is reflected in the excerpt in the previous section, in which the nurse practitioner discussed community resource specialist for additional intervention.

Summary. There was a demarcation of task responsibilities of each group of personnel within the health care team, showing that roles were well defined, including specific tasks and areas of responsibility. Within this demarcation, the structure and roles of professionals were organized so that there was less opporrunity for duplication and omission of care, minimizing the occurrence of patients "falling through the cracks." Professionals were present as needed, with continuous care provided by the primary health care team and specialized care by the intermittent intervention of specialists and consultants. In this way, team members worked together to provide health promotion and monitoring, including illness and disease management, as part of primary care.

Communication Patterns and the Process of Interaction

Frequency of interactions. The pattern of interaction among the team members is shown in Figure 2, which represents the total number of interactions observed over the period of data collection. Most of the interaction was concentrated among the physicians and nurses (73% of all interactions). Communications in which at least one of the participants was either a nurse or a physician accounted for 88% of all communications. Sixty percent of the interactions by mental health care professionals (including psychiatrists and psychiatric residents, social workers, HIV case managers, and community resource specialists) were with nurses and physicians and 40% were within their own group. This suggests that the primary care physicians and nurse practitioners played central roles in team communication, and probably in overall team coordination.

The characterization of the organization and roles of the health care team in the primary care unit under study (Table 3) shows interdependency in the responsibilities and tasks of physicians and nurses. This suggests the possibility that the concentration of communication within the medical-nursing group seen in Figure 2 was the result of this overlap and interdependency between physicians and nurses in their roles. The high frequency of communication by community resource specialists with physicians and nurses resulted from the central roles of the primary care physician and nurse practitioner, who frequently referred patients for community assistance. Because the roles of the psychiatrists and psychiatric social workers were well circumscribed and delineated, they required fewer interactions with the rest of the team to deliver mental health care. Social workers supervised the community resource specialists, resulting in a greater frequency of communication. It is of interest to note that the trainces in the sample, that is, the medical interns and residents, communicated less with team members than did the faculty physicians in the group. One possible explanation for this is that they had not yet developed the same level of expertise in providing care in a team context. Another potential factor is

COLLABORATIVE HEALTH CARE TEAM



Figure 2. Pattern of interactions between health care providers. Each cell represents a professional role within the unit. Domains of practice are differentiated by shape, with rounded squares representing the medical professions, octagons representing nursing care, and ovals representing mental health care. The lines joining the cells represent communication episodes between members of the cells, with the raw frequency of these episodes observed over a 2-week period represented by the thickness of the lines, as shown in the legend. The core providers, as determined by the highest relative rates of communication, are indicated by the center oval, highlighting medical and nurse practitioners.

that they were simply less familiar with the other team members because their tenure in the unit was short lived and they were therefore less likely to approach team members, favoring people at their own level.

Summary. There were frequent interactions among team members, with faculty physicians and nurse practitioners coordinating services and therefore communicating more. Providers in these two roles, medicine and nursing, also attended to patient issues that overlapped, such as medications, symptoms, health, illness, and disease. They therefore communicated more frequently with each other than with team members whose roles were more distinct, such as mental health care providers. The roles of all of the health care professionals within the unit specifically matched their areas of expertise; for example, those attending to social issues were those who had training and experience in that area, that is, social workers. Each type of professional addressed specific areas of health care, and each communicated with the others for the purpose of providing more comprehensive care. Each communicated with other team members based on his or her responsibilities, tasks, and areas of specialization. Specific professionals, such as the clinical triage nurse, coordinated and facilitated the entire process of communication by assessing patients' needs when they called into the unit and directing the communication to the provider whose expertise best suited the needs expressed by the patient. Junior team members, being parachuted in as part of a training program, communicated less with the team compared to more expert providers. This is a function of adherence to their group's culture, norms, and values. Unfortunately, this isolation is counterproductive to the goal of medical education to assimilate trainces into the setting for which they are being trained. The breakdown of these barriers is encouraged, though this is easier said than done.

Interactions Constrained by Patient Problem

Table 4 gives the pattern of health care team communication as a function of the patient problem. The data show that each patient was attended to by a different subset of team members and that this subset was determined by the needs of the patient. A primary care physician saw all patients, determined what additional health care services were required, and initiated arrangements to obtain the necessary services for the patients. Many were also seen by a nurse practitioner, particularly those with cardiac difficulties and AIDS, illnesses requiring the type of comprehensive, frequent follow-up provided by the nurses. However, only patients whose needs required additional consultation were seen by medical consultants, such as those with gastrointestinal, urological, and gynecological difficulties, and only patients with cardiac diseases were seen by a cardiologist. Several of the examples describing team members' actions also describe situations in which they consulted with other providers within the primary care unit, such as physicians consulting with nurses for monitoring and nurses consulting with community resource specialists for situations in the community. The patient problem dictated which members of the team interacted.

Examination of the role descriptions of members of the team revealed that determining and meeting the

Table 4. Patterns of Interactions Between Health Care Providers as Constrained by Patient Diagnosis

	Types of Medical Diagnoses					
Provider/Consultant	Cardiac*	Gynecological*	Gastrolatestinal*	Urology"	AIDS'	Weight
Physician	7	5	4	4	3	4
Nurse Practitioner	6	I		1	2	
Cardiologist	2					
Gynecologist		4				
Gestroenterologist			2			
Urologist				3		
Infectious Diseases					1	
Nutritionist						1

Note: Patient diagnoses that were seen frequently in the clinic were identified, and the health care providers seen by patients with those diagnoses were determined.

 $n_n = 7$, $n_n = 5$, $n_n = 4$, $n_n = 4$, $n_n = 3$, $n_n = 4$.

needs of patients was the central organizational commonality of the team. The primary care physician and nurse practitioner coordinated the potential myriad of specialists and providers, assuring that the plans and actions of each provider and consultant did not overlap or conflict. The overall organization of the collaborative process is illustrated in Figure 3, emphasizing the nature of interactions between the three main groups of providers. The primary caregivers played a central role in coordinating the multitude of individual experts available. They did not provide all of the care required by each patient, but they were critical in assuring that all necessary care was provided.

Different team members involved in providing patient care differed in their orientation, domain expertise (medicine, nursing, social work, etc.) and methods (skills and techniques required to achieve goals). However, professional health care teams have a shared understanding of their practice, 19,23 so that the team functioned with less redundancy (tasks being repeated by one or more individuals), less inefficiency (wasted time of busy clinicians), and fewer omissions (goals not being achieved, aspects of patient care missed) in completion of tasks necessary to achieve the overall goal of comprehensive patient care. It should be noted that complete elimination of redundancy could result in increased omissions, suggesting that there is a balance struck between the interests of efficiency and safety. In response to an interview probe, one nurse practitioner described assessing the level of understanding of a patient's problem required to deal with a particular issue. If the problem was simple, she could contact any available physician. If it was complex, she contacted the physician or resident already familiar with the patient:

In terms of discussing issues with other providers, if it is a complicated patient and I know the resident—say if it is a resident's patient or a faculty's patient and it is a complicated issue and I know if I bring it to the preceptor that they will—not knowing the patient and being very complicated—they will have a very difficult time making some recommendations in terms of what to do about a problem. I will page the [patient's own] provider during the visit to come up with some answers to questions I have. If it is very forward and the patient is not particularly complicated, but I need a little guidance in terms of where to go from there, I will bring it to the preceptor.

I have gone to some physicians precepting who recommend doing something and I may not think that is the best thing to do, so I will kind of hold off and wait to speak to the patient's own physician, if I don't think that is the right thing to do.

Summary. Team interactions were based on meeting the needs of the patients, which was the identified goal of the team as enunciated in the mission statement. The choice of participants in communication interactions was based on the goal of the interaction and the expertise of the individuals (e.g., physicians, nurses) required to achieve those goals. This expertise included not only domain expertise required by the patient prob-



Figure 3. The health care collaboration. Providers can be seen as making up three groups: Biomedical and Clinical Care, Mental Health Care, and Consultants with particular domain expertise. The physicians and nurses form the fulcrum, acting as the central organizing body, coordinating the activities of the other two teams.

lem but also expertise with the specific patient—that is, the shared understanding of the individual patient and how to manage that patient's problems built through experience with the patient and with the other team members. Thus, the team capitalized on individual expertise with an optimal level of redundancy and omissions, promoting efficient and safe use of the skills of team members and their experience with individual patients as well as their professional expertise. In this way, sufficient redundancy is maintained to act as a check on patient care, reducing the risk of omission and error.⁴⁷ Next, we examine the content and nature of the communication in interactions between team members.

The Nature of Communication

Focus of team communication (content). The topics of team interactions are shown in Figure 4. Content directly related to care of specific patients predominated, with administrative issues, coordination of patients' movements around the clinic, and activities of other team members related to specific patients being observed with less frequency. Evaluation of treatments and previous interventions was part of the ongoing cycle of assessment, monitoring, and treatment, but was seldom explicitly addressed. The preponderance of discussions of patient symptoms, plans, and action as topics for interaction reveals that the majority of topics (78%) around which health care team collaborators interacted were directly related to the identified goals of the team, that is, caring for patients' concerns.

A notable proportion of the interactions (22%) was concerned with team functioning and organizational issues. Collaboration is required to capitalize on the availability of multiple domains of expertise, thus contributing to the added value of the individual expertise of particular individuals within the team (person plus).



Figure 4. Percent frequency of categories used during communication by professionals. This illustrates the percent frequency with which unit team members discussed specified topics of interaction. Topics are divided into goal-related and team-related content categories.

Summary. The content of team communication focused on specific patient-related problems. Other issues, such as moving patients through the clinic and hospital efficiently, coordinating team activities, and other administrative issues were also discussed as needed to assure that the needs of the patients were met. The next analysis in the examination of team interactions reports on the means of communication used by professionals in carrying out these interchanges.

Mode of Provider Interactions

The interaction episodes identified in earlier analyses were examined to characterize the mode of team interactions and the success of each interaction implemented. Mode of communication was determined from field notes and transcripts, from which the providers' method of interaction was identified. For example, a communication episode in which a physician spoke with a nurse using a telephone was coded as such (telephone communication).

Success was defined as an interaction in which the goal to communicate was met. For face-to-face communication, seeking out and then achieving face-to-face contact was considered successful. The quality of the communication or progress toward the actual goal leading to the interaction was not considered for these purposes. Dialing a phone number hoping to speak with someone and reaching a voice mailbox was considered an unsuccessful episode of telephone use. Given the lack of any method of validation, we assumed that if a message was left, the recipient would at some time pick it up, making it a successful use of voice mail. However, there was no direct way of validating this assumption. The same assumption was made of e-mail messages. Each time a provider logged on to the system, such as when accessing patient records (the EMR), a notice was given on the main screen as to the number of e-mail messages in the provider's inbox. Team members were therefore forced to maintain an awareness of the volume of messages at the very least. This made it more difficult and therefore less likely that they would ignore e-mail messages for any length of time.

The most common form of communication was found to be face-to-face verbal communication (Figure 5), followed by telephone and e-mail interactions.⁴⁸ Communication was effective 93% of the time. The telephone was used frequently but succeeded only 81% of the time and accounted for 38% of all failed communication attempts. Verbal communication, e-mail, and voice mail were the most effective means of communication (99–100%). Paper (5%) was used most frequently for recording telephone messages and was successful 86% of the time. The pager (5%) seemed to improve on the immediacy of the telephone but with a low success rate, accounting for 33% of all failed messages.

Synchronous communication methods (face-to-face, telephone, pager) were found to predominate when issues were patient related, whereas asynchronous modes (e-mail, voice mail, paper, EMR, intermediary) were more commonly used for less urgent issues ($\chi_1^2 = 8.12$, p < .01). As shown in Figure 6, topics directly related to patient care were more likely (57–100%) to be discussed using synchronous forms of communication. When discussing organizational issues, asynchronous forms of communication predominated (50–60%).

Each communication mode offered advantages and disadvantages, with team members choosing the mode that best met their goals.³⁹ For example, face-to-face communication allowed for immediate response and rapid exchange of information and ideas, whereas e-mail and voice mail permitted information to be transmitted so that others could receive it at their convenience.⁴⁸ Synchronous modes, particularly the tele-



Figure 5. Percent frequency of modes of interaction. This figure illustrates the percentage frequency with which team members used



Figure 6. Percent frequency of synchronous and asynchronous modes of communication, contrasting interactions directly related to patient issues versus those indirectly related to direct patient care. Interaction content related to patient care is shown on a white background: content indirectly related is within the dashed box.

phone, were often used even though frequently unsuccessful because of their familiarity, ease of use, and the possibility of highly effective communication. The use of synchronous communication methods for patient-related issues and asynchronous methods for other issues substantiates the hypothesis that the choice of mode was related to the goal and time constraints of the communication. In general, a balance was struck between the efficiency of asynchronous modes and the effectiveness of synchronous modes, as illustrated by the following statement made during an interview with a nurse practitioner:

The nurse practitioners that I interact most often with are nurse practitioners with a heavy HIV caseload, and they are down in the last pod. So if I want an answer right away, I will take a walk down. Usually, when they are seeing patients, they may not always answer their telephones, so if I were to call them to get an answer right away, I would get their voice mail. I don't like to page people, so I will usually take a walk down, knock on their door, sometimes you will see them wandering out of their room or sometimes I will catch them in the work room."

Summary. The mode of communication was directly related to the purpose of the interaction. The timely communication among individual members assured the coordination of activities, reducing redundancies and unnecessary interactions. Face-to-face and telephone interactions were the most frequently used modes of communication, offering an immediacy of response and the opportunity for exchange of information and ideas.

Discussion

This study was undertaken to examine collaboration in professional teamwork and its relation to efficient and effective delivery of health care. The provision of continuous and intermittent patient care in collaborative health care practice by primary care providers and specialized care consultants, respectively, makes possible the management of broad health issues and the provision of care for specific medical and psychosocial problems. This combination of continuously and intermittently present providers lends to efficient care, because the expertise of each is available when necessary but freed from attending to other unrelated responsibilities. The nature of the patient problem guides the type of expertise and thereby the type of expert required at the point of care. The determination of who participates in the care of a particular patient problem is not a trivial issue. By the very nature of the primary health care team, the efficient manner in which selected providers are introduced into an integrated patient-specific team tailored to the patient's needs is remarkable. These team characteristics reduce unnecessary and redundant interactions and communications yet retain sufficient redundancy to assure that omissions are minimized. This selection process is achieved by emphasis on the expertise of the individual professional within the health care team.

Coupled with both a theoretical rationale and our previously described findings characterizing scientific and clinical collaboration, 19,20,36 this study emphasizes the importance of definitions of roles and the delineation of tasks and responsibilities. This clarity is particularly important when there is a potential overlap based on professional definitions. Examples would include delineation of when a primary care physician should consider a consultant, when a nurse practitioner should consult a physician and vice versa, and when a social worker or a psychiatrist should be called in. The critical aspect suggested by the structure observed in the unit studied in this report is that for each domain to perform its tasks and responsibilities optimally, each must have the requisite authority and autonomy within the team. The hierarchy within each domain is necessary for (a) supervision, (b) continuing evaluation, (c) maintenance of quality of care, and (d) administrative purposes of the individual domains. However, these functions break down if they are interfered with by a hierarchical structure between domains. This highlights the importance of recognizing the uniqueness of each professional area as it contributes to the accomplishment of team goals.

The individuals who make up the team are coordinated through communication among team members toward accomplishing the goal of managing patient care. Effective and efficient communication is necessary in a practice composed of busy clinicians from several departments who are intermittently present on site (which describes most, if not all, such practices). Different communication modes are appropriate depending on the purpose of the interaction and the level of urgency, and providers capitalize on these differences. Synchronous modes (telephone and face-to-face conversations) most often were used for issues related directly to patient care, whereas asynchronous modes (voice mail, e-mail) were used effectively for administrative issues. Thus, the providers' easy access to telephones, voice mail, and particularly e-mail terminals appears to be important in such team settings. In addition, mechanisms need to be in place to assure that team members can meet personally, because face-to-face communication is important in developing and maintaining a shared understanding of team goals and in maintaining trust. For example, in this study the providers frequently walked over to speak with each other. even when other methods of communication were available. Geographical isolation, such as when team members are located in different areas of large hospitals, could impede this team process.

This is described in detail in Vicente⁴⁹ and is consistent with Hutchins's²² study, in which knowledge and information processing are distributed across individuals and artifacts as functions of a particular culture. In a workplace, workers frequently accomplish tasks and goals, not in isolation through information processing but as a functional team through mutual coordination of their actions. As a result, team communication plays a very important role in the workplace design. In Hutchins's²² cockpit study, the redundancy achieved by having multiple people involved in performing a task has added value in creating a robust mechanism for error detentions and correction. When one worker makes an error, it is frequently noticed by another because team members have access to each others' actions and communications. In the health care team studied here, communication as well as redundancy assured that omissions were discovered and corrected. This begs the question: Does efficient management of professional health care activities lead to more effective and safe delivery of care for the patient? Response to this question is beyond the scope of this study.⁵⁰

In recognition of the importance of communication skills, pressure has been placed on the medical education system to acknowledge their significance and devote resources to teaching them.⁶⁻⁴ Although our results emphasize the prominence of communication in team functioning, they also highlight the conceptual basis of communication related to the development of individual expertise, making team communication an added value to already existing conceptual competence in this domain. We observed that expert providers in this primary care clinic quickly determined the most effective methods for communicating with each other based on the purpose of the interaction being sought. It has been suggested that it is the very nature of the practice itself that promotes acquisition of tacit knowledge and skills.^{51,52} Our finding that junior members new to the team (i.e., students) communicate less suggests that they will be exposed less to environments in which such tacit learning can take place. It is likely that some aspects of communication skills are also tacitly acquired and that explicit instruction alone may not be sufficient to develop such skills. The exclusion of junior members from active teamwork will shortchange their training program.50

That health care providers collaborate is not a new observation. Their ability to work as members of a team, develop shared mental models, and build trust with other members of the team has been identified in the literature as a necessary skill for functioning in the new work environment.⁵³ However, it is only the generic cognitive skills acquired by individuals within the group interactions that are more readily transferable from the situation in which they are learned to other, different, situations.¹³ Knowledge and skills specific to any group functioning, whether in medicine or in other

domains, are heavily contextualized, making them difficult to transfer.^{13,15,17} Thus, although communication skills are developed by individuals in the context of collaborative practice, research on development of expertise has shown that it is the general strategies (skills and ways of doing things common to most situations) that can be transferred effectively. 13,15,19 Because the ability to transfer knowledge and skills from one situation to another has been shown to be one of the indicators of learning,^{13,15} the teaching of general cognitive skills (e.g., problem solving, communication) is likely to be especially important and effective. Such individual competence in general skills related to knowledge and communication is a prerequisite for specialization. However, there is no need for all health care professionals to have equally detailed levels of expertise because this would create redundancy. Physicians' specialization is ideally suited for prevention, diagnosis, and treatment of patient pathology, with other health professions, particularly nursing, sharing domain-related knowledge. In contrast, although all health care providers must have the capacity to interact effectively with the public, the training and experience of nurses and social workers have traditionally emphasized interpersonal skills and psychosocial awareness, topics that are typically less emphasized in medical education. This does not mean that physicians need not be able to communicate with their patients, as reflected in the large body of literature establishing the importance of communication skills in terms of patient outcomes and patient satisfaction.⁵⁴ However, this does not and need not include areas in which physicians have little specialized expertise, areas such as supporting patients and families in coping with illness, teaching about health and illness, and assisting with the management of social problems in the home.

Health care delivery is moving toward collaboration among diverse health care professionals who provide comprehensive patient care.^{2-4,19,34-36} Providers in each domain concentrate on delivering care, optimizing the use of their expertise. Our results show that a physician's practice generally concentrates on disease-related care and a nurse's on illness-related issues. In a team interaction, both physicians and nurses provide their expertise and make decisions about patient care in conjunction with the patient, through a process of negotiation and distributed effort (often termed "distributed cognition").²⁴

The growth of collaboration among health workers has raised several issues regarding the optimal distribution of educational and health care resources. For example, one controversial issue is that of the relationship between primary care physicians and nurse practitioners, with the suggestion made that nurses trained as practitioners can provide primary care of at least the same quality as physicians^{55–58} and at lower cost.^{59,60} Others question the wisdom of this direction,^{61,62} typically arguing that the complexity of medical problem solving, even in primary care settings, often requires the detailed training of a physician.63 The results reported here and elsewhere³⁷ suggest that although there may be interdependency in tasks, physicians have the depth of pathophysiological knowledge necessary to interpret complex cases properly, whereas nurses have special expertise in assisting patients in coping with concerns of health and illness, following patients' status, 19 and assessing common disease-related issues. 57,63 including contextualization of observations, pattern recognition, and monitoring.⁶⁴ We suggest that our health care delivery system capitalize on individual differences in expertise and, at the same time, gain added value by evolving new knowledge and skills through collective decision making. Thus, the development of individual conceptual competency, including conceptual aspects of communication skills, will need to be a focus of training for physicians and other health professionals in our technologically advanced societies.

An evolving educational focus is particularly needed because simple tasks that require lower level cognitive skills will increasingly be accomplished through the use of technology, particularly as a source of information and a means for communication.65 Individuals interact with technology to augment the higher cognitive processes that characterize expert performance.66 Even though computers can provide information and expert systems can suggest treatment plans, it remains the purview of the practitioner to filter through the information provided, to distinguish relevant from irrelevant information, and ultimately to choose among treatment options. 30,67 Cognitive studies of expertise have established the importance of prior knowledge in shaping performance and learning.66 This body of prior knowledge can only develop within the context of individual learning, which is then distributed within a group through team communication. Hence, the basis of collaborative functioning by the team remains predominantly dependent on the expertise of the individual, which is then combined with that of other individuals to provide a whole that is greater than the sum of its parts.22,24,25

We accordingly argue for capitalizing on one of the most powerful resources we have—the human mind by keeping our focus on the development of *conceptual aspects* of individual expertise and competence in the times when we are busy teaching much needed specific group-related skills. This approach also recognizes and nurtures the differences in knowledge, skills and orientation among the various members (e.g., nurses, doctors, social workers) of the health care team.

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Appendix Two

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Reasoning about diabetes and its relationship to the use of telecommunication technology by patients and physicians

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Abstract

Health care is moving toward a team effort, with patients as partners. This requires effective communication between physicians and patients, who have different understandings of health and illness. These understandings in turn guide their decisions about management of health and illness. With the introduction of home-based technology, which provides an efficient way for doctors and patients to communicate, the question of the effectiveness of the decisions being made must be addressed. In this study, we assess the conceptualizations of health and illness related to diabetes and the relationship to the use of communication technology by patients and physicians. Methods: The subjects were interviewed using a semi-structured questionnaire and were then asked to enter information into a telephone-based telecommunications system. Data were audiotaped, transcribed, and analyzed to characterize models of health and illness and for the factors that influence the decision making about diabetes management. Interactions with the system were then examined relative to these findings. Results: Patients used lav concepts in providing explanations of their illness, whereas physicians used biomedical concepts. Use of these differing concepts influenced the use of telecommunication technology, with more errors in the communication of information being made by patients than by physicians. Examination of the organization of information required by the system showed it to be incongruent with the way patients normally reason, but in agreement with the way physicians reason. The paper discusses the implications of these findings for: (a) the nature of evidence used by patients and physicians; and (b) the design of technology to maximize effective doctor-patient communication. © 1998 Elsevier Science Ireland Ltd. All rights reserved.

Keywords: Decision Making: Diabetes Mellitus: Telecommunications: Physician-patient relations: Evidence-based medicine

1. Introduction

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Health care consumers are playing an increasingly important role in determining their

1386-5056 98-519.00 © 1998 Elsevier Science Ireland Ltd. All rights reserved. *PII* \$1386-5056(98)00111-7 own health care and making their own health-related choices. Participation by patients in decisions that affect their health and illness management, while remaining controversial [1], requires that patients play an integral role in decision-making and in carrying out treatment plans. This level of collaboration requires efficient communication and some level of shared understanding among those involved in making decisions [2-4], i.e. between the team, frequently localized in a health care centre, and the patient, who is at home. The understandings, or conceptualizations, of health, illness, and disease of physicians and of patients have been found to be different however, creating difficulties and blocks to communication [5].

One solution to the dilemmas of geographical separation and scarce resources has been to make better use of communication technology, such as telemedicine. The value of technology in facilitating communication has been demonstrated in terms of cost effectiveness and increased access to care. These benefits include efficiency in communication, closer monitoring of patients' status while reducing office visits, and the savings of scarce health care resources these visits consume [6]. However, the extent and variety of uses to which these novel technologies are being put requires that they be evaluated prior to their widespread acceptance and use. In order to assure efficiency, effectiveness, and safety of system users with different frameworks, the users themselves must be participants in system design, providing feedback in an iterative fashion so that ultimate use of the technology is consistent with the original purposes for which it was designed [7]. This is critical in order to assure that the effects are as planned, and that no unintended outcome compromises patient care.

2. Theoretical framework

Studies of collaboration have shown that for effective communication to occur. team members must share an understanding of goals, resources, tasks, and responsibilities [8.9]. Communication is a fundamental process of collaborative team functioning, serving both as the medium of team development and of team functioning. In health care, it is generally accepted that patients and physicians must collaborate as a team in order to achieve an optimal level of health for the patient [10]. When patients and physicians communicate, however, differences in their goals and in their understanding of the nature of health, illness, and disease comproeffective communication mise patterns [5,11,12]. This has been shown to be the result of differences in the way that lay people comprehend health and illness (symptoms experienced by the patient, effects on activities of daily living), as opposed to physicians' understanding of disease (pathophysiology). Here, lay people are defined as having common sense, everyday functional knowledge of the domain while physicians have biomedical and clinical knowledge. Thus, the nature of knowledge possessed by the two groups is epistemologically and functionally different.

Previous research has shown that lay reasoning differs significantly from scientific reasoning [13]. This extends to physicians, and lay people's abstractions of health, illness, and disease, which similarly deviate [14]. Physicians have been shown to use biomedical knowledge as evidence, which is based on scientifically-established, logically consistent information [15,16]. Lay decision-making processes and the types of evidence used have also been examined [5,17] and found to be based on observation, on associationistic and correlational evidence [13,18]. This evidence is acquired through social and cultural exposure [14]. Such different understandings. based on different types of evidence, are likely to serve as the basis for subsequent decisions to be made about health, illness, and disease. For example, lay people do not normally like to calculate quantitative information. When quantitative pharmaceutical instructions were presented to mothers in Kenya. Ethiopia. and Canada. all were found to draw inferences from this quantitative information, translating them into qualitative approximations using general heuristics [19.20].

Pre-existing traditional knowledge about health and illness is remarkably stable and resistant to change. Examination of the effect of formal education on the reasoning of Indian mothers living in India and in Canada about childhood nutritional deficiencies showed that explanations varied with the level of education of the mothers, with more educated mothers incorporating more biomedical concepts [14,21]. However, the authors showed that the explanations of these concepts continued to be based on traditional theories learned through community consensus and personal knowledge, with biological concepts added superficially. The structure of the resulting combination was incoherent [19].

There is sufficient evidence in the research literature examining prior knowledge and its influence on behaviour to establish that patients have prior knowledge about health and illness, and that this prior knowledge influences how they interact with health care materials [22], including technology. We are interested in patients' understanding of: (1) the concepts of health and illness: (2) diabetes and its management (monitoring and treatment); and (3) the influence of prior understanding on interactions with telecommunication technology.

We have chosen diabetes as the patient problem. Diabetes affects almost every aspect of the diabetics' lives. In addition, telecommunication systems have been developed in the area of diabetes mellitus in an attempt to improve the efficiency and effectiveness of its management [23-25]. The two groups involved in its treatment, patients and physicians, are likely to have different expectations of how the new methods of communication will be used and what will be achieved, creating the possibility for misunderstanding and miscommunication of information, generating treatment difficulties. An example of this is the introduction of blood glucose monitoring devices to be used by diabetics, which may result in inaccurate readings by patients due to improper use of the technology. If such errors do arise, they can be corrected immediately during the face-to-face communication of a doctor's office visit. However, through asynchronous communication methods such as technology, this kind of feedback is not always possible and errors may go unnoticed.

The absence of immediate verification of the accuracy of the data being transmitted by this method of communication requires consideration of the effort required in learning to use it. Patients are frequently trained in the use of new techniques and are sent home to implement them. As anyone who has taken home a new stereo, VCR, or computer can attest, once home many questions arise. This puts patients in the position of learning a new process, the use of the new technology, at the same time that they are trying to cope with the content (e.g. blood glucose levels). This is not trivial and creates a cognitive load that can be disruptive to successful completion of task [26], leading to errors the in communication.

In this study, we examine the conceptual understanding of illness by insulin-dependent diabetic patients and its relationship to their decisions about their diabetes management. The patients' models are then compared with the framework of physicians and how they make decisions about their diabetic patients. We next follow patients and physicians as they interact with a home care telecommunications system [23]. The errors generated in the use of telephone technology in both groups are then characterized to examine the relation between prior understanding and the nature of errors generated in using the system.

3. Methods

3.1. Subjects

3.1.1. Patients

Subjects were patients with insulin-dependent diabetes mellitus recruited from the Metabolic Day Centre of the Royal Victoria Hospital, a large tertiary care hospital in Montreal, Canada. Each subject had interacted frequently with the health care team and had received instruction about diabetes. All had been diabetic for at least 10 years.

3.1.2. Physicians

Senior physicians affiliated with McGill University were recruited for participation in the study.

3.2. Interview

3.2.1. Patients

In reviewing the literature, a number of factors were identified that appear to be important in lay decision making about health and illness. A semi-structured interview was developed based on this literature. Questions or probes focused on: the model of illness of the subject, the meaning of illness, actions related to illness, the effect of diabetes on daily life and on relationships, and on factors contributing to decision making related to illness.

3.2.2. Physicians

A typical patient scenario was developed by a nurse with expertise in diabetes and knowledge of patient profiles, based on detailed study of diabetic clinics and management centres. Subjects were given the scenario and were asked to think aloud as they went through the process of evaluating the patient [27], generating verbal protocols. The interviews were audiorecorded, then transcribed and analyzed for concepts related to the explanations of health and illness, and for factors affecting decisions about diabetes.

3.3. Use of technology

3.3.1. The system

The communication technology used in this study is the Diabetes Home Monitoring Module [23]. It consists of a central database at the University of Western Ontario, into which subjects could enter data about their diabetes. This data consists of their glucose levels, changes in diet, activity, stress, hypoglycemic reactions, and insulin doses. The system is able to provide feedback in the form of averages and ranges of glucose levels entered. An expert system that would provide more in-depth information to patients is planned but is not yet in place. The input device is a Vista 350 telephone, a Northern Telecom Canada telephone that is generally available. A major advantage of this type of device is that it does not require expensive equipment (such as a computer) or connections (such as a server). A display screen allows more information to be transmitted in both directions than is possible with a basic telephone, and a variety of keys support

more flexible entry of data than phones with only a number keypad.

3.3.2. The scenarios

A scenario was developed to represent a typical day for a diabetic patient. It included glucose levels at various times, a change in insulin dose, a hypoglycemic reaction, working and week-end days, and changes in all aspects of daily life addressed by the system (i.e. diet, activity, stress).

3.3.3. The procedure

Each subject (patients and physicians) was given the scenario and was instructed to enter this data into the telephone system, thinking out loud as they did so [27]. The interactions were audiotaped and videotaped, including video recording of the telephone screen itself, showing the subjects' input and the system's responses. Subjects were given no training as to use of the system, providing a more sensitive evaluation of the learning process involved in the assimilation of new technology. Audio recordings were then transcribed for analysis.

3.4. Analysis

A coding scheme was developed based on the categories of concepts addressed in the patient interview. Verbally generated protocols were transcribed and analyzed using the coding scheme. Each of these categories was identified in the protocols and the data were recorded as frequency of occurrence. The relationships between the categories were determined using analysis of semantic relations [14]. An example of the analysis is illustrated with an excerpt from a patient's transcript.

Patient: "I was very depressed and I didn't want to follow my diet and I just went off keel (ate what I wanted)".

'Depressed', 'diet', and 'going off keel' are concepts, and the categories are 'AF-FECT', 'REGIMEN', and 'DECISION' ACTION'.

Coding: "I got very depressed 'AFFECT' and I didn't want to follow my diet 'REG-IMEN' and I just went off keel 'DECISION'".

The patient's frame of mind affects the way (s)he feels about the regimen (s)he has been told to follow, which leads to the action of non-compliance. This is represented diagramatically below, with concept categories identified and the directionality of reasoning indicated by the direction of the arrows. In this example, reasoning is conditional, i.e. one concept conditional on the previous concept in the chain of reasoning, with both positive and negative conditional influences shown.

	(Neg)	INTENTIONS TO	DECISION
AFFECT		FOLLOW REGIMEN	- ACTION
(depressed)	COND rads to	(not wanting to follow diet)	COND (went off keel)
			(1)

COND: Directional Conditionality: Neg: Negative Influence.

3.4.1. Videoanalysis

Videotapes were analyzed with the aid of transcripts made of the audio recordings. Key concepts and difficulties related to utilization of the technology were identified. These occurrences were noted on the transcripts using software (CVideo) that allowed precise localization of the events on the videotape. The time taken by subjects to complete data entry tasks was time stamped using CVideo. The method used is based on techniques modified and refined at the Centre

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for Medical Education by Kushniruk et al. [28].

4. Results and discussion

4.1. Factors in decision making

4.1.1. Lay reasoning

Fig. 1 gives the percent frequencies of the concepts used by patients in describing their illness. The description of the categories used in Fig. 1 is provided in Appendix A. A striking feature of Fig. 1 is the dearth of biomedical concepts in subjects' narrations. The major contributing factor to lay explanations of diabetes and diabetes-related decision making was that of the more loosely structured, associationistic/opportunistic type of lay knowledge (30%). The effects of diabetes on daily life were described 17% of the time, the regimen itself 16%, and fear 16%. Fear included fear of stigma (7%), and fear of



Fig. 1. Patient's use of concepts in explanations of their decisions about diabetes.

complications (5%) and impaired functioning (1%). This indicates that half of the factors (49%) comprising lay conceptualizations of illness are related to daily functioning and maintenance of role integrity and lifestyle. Direction and information from the health care team was mentioned, but not frequently (8%). Social support (6%) and affect (5%) were described, though less frequently.

These results suggest that patients use lav knowledge to generate an understanding of illness and its effects on their lives. They are less concerned with underlying pathophysiological changes than with how to return to normal functioning and get on with their lives, or at the very least compensate for any negative effects of the illness. Having some knowledge about the relationships between glucose levels, insulin, diet, exercise, and stress (physical and emotional) helps them decide what actions to take. When patients are asked to explain the relationship between factors, for example the relationship between exercise and diabetes given below, their explanations consist of simple associations, with exercise and diabetes revolving around insulin. There is no biomedical justification.

Patient: "Exercise helps you to secrete more insulin"

This is in sharp contrast to the results from the transcripts generated by the physician interviews in describing how they would make decisions about the patient in the scenario.

4.1.2. Medical reasoning

The data show that each physician walked through a process whereby patient data was highlighted and evaluated for relevance to the hypothesis that the patient was diabetic. Alternative diagnoses were considered as well, however the scenario made the diagnosis clear and other diagnoses were unlikely.

Physician: "First of all she's obviously diabetic".

Unlike patients, when physicians were challenged for explanations and justifications of their interpretations, they all turned to the underlying biomedical knowledge of diabetes. The explanation was given in terms of pathophysiology. Other factors were rarely mentioned (one or two per subject).

Physician: "The polyuria is produced because the sugar gets in the urine and it acts as an osmotic diuretic, prevents the body the kidney from reabsorbing water from the urine".

There is a clear difference in the nature of the information that physicians and patients consider important or relevant in making decisions about diabetes. Therefore when making decisions, patients and physicians use a different nature of information as 'evidence'.

4.2. Schematic relationships in decision making

4.2.1. Law reasoning

A schematic network of concepts reported by patients in the interview transcripts about decision making related to diabetes was developed. The resulting network is shown in Fig. 2. Factors identified by patients as important are shown and the relationships between them are indicated by arrows (representing directionality of influence).

The results reveal the relationship among the five major factors affecting decision making, both directly and indirectly. Fear was related to both daily living and the regimen. Lay knowledge also influenced the regimen, which in turn related to daily life. Decisions were made based on an interacting web of the major concepts identified in Fig. 1, with the



Fig. 2. Schematic representations of factors affecting decision making by diabetic patients.

exception of information from the health care team. Lav knowledge directly influenced decisions as well as affecting compliance with the regimen. Compliance in turn impacted on activities of daily living, influencing the decision made. Fear and the regimen interacted with each other. For example, fear led to compliance with the regimen, and the regimen itself generates fear. This interaction then influenced lay decisions to be made about diabetes management. Following the regimen appeared to be the central factor in decisions related to diabetes. and how the regimen changed functioning in daily life. It should be noted that information from the health care team was not a major determinant in decision making.

4.2.2. Medical reasoning

Turning now to physicians. doctors were presented with a diabetic case scenario and were asked to verbalize their thoughts as they assessed the patient. In clinical settings, physicians usually see patients presenting with complaints (signs and symptoms), and their task is to explain the findings. The resulting train of thought is illustrated in the transcript excerpt shown:

Physician: "A fasting blood sugar of 160 I think pretty much says that she's diabetic. The postprandial is 200 also tells us she's diabetic. So either one of those by themselves I think meets criteria for diabetes".

During the interviews, the sequence of their explanations begins with descriptions of the signs and symptoms, followed by a diagnosis.

This has implications for compliance of patients with medical advice. With such varying frameworks, using such differing types of information, with such different goals and priorities in dealing with their disease (for example normal blood glucose levels versus normal lifestyle), it is little wonder that they do not listen to each other and frequently seem to be speaking different languages. In reality, they are. Physicians tend to provide clinical and biomedical information to patients. 'the why', with the goal of returning the patient to physiological normality or as close to it as possible. Patients want to know what to do, 'the what', with the goal being to return their lives to their pre-disease state or as close to it as possible. They do not want their lives to be ruled by their illness, nor do they want to be identified as socially deviant.

4.3. Communication technology

The Diabetes Home Monitoring Module, described briefly above and in more depth in Edmonds et al. [23], is a communication system that allows diabetic patients to send information to their physicians, improving the level of monitoring and consequently diabetic control. The accuracy of the information that is transmitted is critical to successful communication. Through analysis of the videotaped interactions between the subjects and the system, the data entered by the subjects were compared against the data provided in the scenarios. Only 73% of the data entered were found to be accurate. It should be noted that this is not an indicator of the overall accuracy with which patients transmit data to their doctors using this system, as it includes entries made with no training or knowledge of the system. Nevertheless, this indicates that errors do occur, that learning is required, and that, under the stresses and pressures of everyday life, errors will occur.

Fig. 3 shows that both patients and physicians correctly entered the blood glucose values fairly well (86 and 92% correct



Fig. 3. Mean percent frequency of data entered into the telecommunications system accurately by patients and physicians.

respectively). However, none of the patients correctly entered changes in insulin doses and only 33% of the hypoglycemic reactions were entered. Comparison of the accuracy of the entries of patients and of physicians shows a higher frequency of correct entries by physicians than by patients. No relationship was found between accuracy rates, experience with technology (from little experience to an informatician), and education level achieved (high school to MD).

The most common error made during the process of data entry was that of entering information on the wrong date. Five of the six subjects entered values for one date initially, but did not change to the second date when required to. Closer examination of this error in light of the findings discussed thus far reveals a possible explanation.

The task involved entering four glucose levels, two on one date, and two on another. After entering each level, the system issued the following prompts:

Verbal instruction: If you would like to record another blood glucose level, press Yes. If not, press No. Would you like to record another blood sugar entry?

Screen instruction: Would you like to record another glucose level for this date?

Each subject, when given this information, focused on entering glucose level without considering that they had not changed the date. Replying 'no' as instructed would have returned them to the main menu. They would then be required to select 'glucose' again, enter the new date, and then enter the glucose level and any other information about diet, activity level, or stress level they intended to provide.

Exclusion of information in the transmission to physicians has major clinical implications for medical decision making in that these are critical indicators of patients' status. That physicians are more accurate in entering information into the system is not unexpected given the previous discussion of the differences in understandings of the two groups. The error related to entry of the date suggests that subjects focused on the glucose levels and not the date, and the prompts to change the date were inadequate to overcome the shift in focus away from date and toward glucose level. Patients are required to learn to use the technology, as its framework is not consistent with their own intuitive model of diabetes.

4.3.1. Learning to use technology

The analysis of the videotape data of patients and physicians learning to use the telephone technology revealed two components to the initial use of the system. Since no prior instructions or demonstrations were given, subjects were required to learn to use the system and to enter the required content simultaneously. This proved to be a difficult task.

The amount of time subjects took to enter the first blood glucose level was compared with the time taken to make the last entry to determine if experience with the system had a positive impact on accuracy. Fig. 4 shows that this is indeed the case. Entering the first glucose value took an average of 107 s while entering the last glucose value took only 33 s. It is of interest to note that patients accomplished the task more quickly initially. This can be attributed to the level of experience of the subjects with technology. Subjects, both patient and physician, who reported experience with computer technology required a mean of 49 s to enter the first blood glucose level. Subjects reporting little or no such ex-





perience required 164 s. This difference disappears on the last glucose entry.

These findings suggest that, while initial use of the system is based on procedural knowledge, such knowledge is quickly gained through practice with the system. It can therefore be concluded that learning did indeed take place, and that it facilitated the accurate entry of information into the system. Facilitation of the learning process by (1) the provision of aids to memory and (2) the development of input processes that are consistent with the processes used by the patients in thinking about their illness would reduce the effort and cognitive load required to enter data and manipulate the system simultaneously, reducing the risk of error and miscommunication.

4.4. Reasoning patterns

4.4.1. Lay reasoning

The errors that subjects made when en-

tering data into the system suggest that they were guided by something other than the system itself during the data entry procedure. The relationship between glucose and diabetic control is clear to all subjects. However, they do not organize the concepts related to daily life based solely on the effect of these factors on glucose levels. An example from Appendix A illustrates this point. This subject describes the relationship between blood glucose level and what she eats, describing it as a causal association.

Patient: "Well let's say if I'll eat a pound of candies my sugar will go sky high and it might even cause a stroke!"

In the diagrammatic representation below, it can be seen that the concepts considered, represented by boxes. are carbohydrate intake, blood glucose level, and complication. The links are positive, causal relationships (CAU), represented by arrows. This is a temporal sequence of events.

Patient's narrative, temporal sequence:



4.4.2. Medical reasoning

Physicians were found to organize their framework in terms of the patients and their illnesses. The most important indicator is the blood glucose level. The observation of changes in glucose levels is made and an explanation for the finding is sought. In the following example, the remedy for diabetes is weight loss, and this is the aspect of importance to the physician. Analysis of the previous excerpts of a physician's transcripts illustrate this organization:

Physician: "A fasting blood sugar of 160 I think pretty much says that she's diabetic. The postprandial is 200 also tells us she's diabetic. So either one of those by themselves I think meets criteria for diabetes". Physician: "So she's overweight.... so that's already got me thinking that if she is insulin resistant, then I might be able to improve that by having her lose weight at some point if we can if we can manage that".

The physician's sequence is represented as:

have influenced the glucose level, as shown below:

Telecommunication system's sequence:



In addition to blood glucose values, patients are given the options of entering information about the following categories:

 Unusual events that have occurred prior to the glucose level being entered; carbohydrate intake; activity level;

stress level:



COND: Directional Conditionality : Concept

The decision made by the physician is to address the problem of obesity, which is directly related to diabetes. This is not compatible with the goals of patients, who are more motivated to maintain their lifestyles even if doing so contributes to their illness.

4.4.3. Telecommunications system

Turning to identification of how the telecommunications system [23] used by subjects in this study processes information. it was found that the input sequence begins with the date, then the blood glucose level. followed by a selection of factors that might

- Changes in insulin dose:
- Insulin reactions

When being used by lay people, the system forces them to make predictive inferences, which they do not normally do. Patients structure their accounts of illness in a narrative form [5]. In order to enter the information into the system, they must reorganize its structure in a way that is not natural to them, creating increased cognitive load and increased risk of error.

The input structure also does not consider the issues of importance to the patient, such as
the relationship between glucose level and complications. Patients are required to address a number of factors and categorize them to fit the system interface. The structure of the system relates more to the thinking processes of physicians, focusing on problem indicators required by doctors to make their decisions. The question that arises is: How can categories be developed that meet the information needs of the physicians while assuring that patients understand them sufficiently well to provide accurate information? Such categories can be generated through detailed characterization of the nature of lav reasoning about diabetes (quantification from qualitative data).

Analysis of the way that patients and physicians use the system (Figs. 3 and 4) and an examination of the processes guiding this use are consistent with the arguments made earlier that lay actions are guided by lay conceptualizations. Incompatibility between the lay frameworks and the input structure of the technology resulted in inaccuracy and miscommunication. Subjects interacted with the system based on how they saw the world. Studies examining the nature and effects of the errors patients make in using the telecommunications systems will guide system design so that errors with the potential to seriously compromise the patient are identified and minimized. Conflict between the patients' and physicians' models increases the effort required to learn to use the technology, increasing the level of frustration involved in using it, which in turn increases the risk that it will be used improperly or not at all. Introducing technology for patients to implement in their homes requires that they learn the skills required to interact with the system, skills which improve with practice. It must be considered however, that skills that improve with practice will also deteriorate with disuse. A patient going away for a month long vacation might be 'rusty' on returning. Daily life, with its time pressures, stress, and illness, may also lead to reduced performance. Development of interfaces that allow the patient to tell their story in their way increase the probability that the story will be told and that it will be told as accurately as possible.

Research on lay conceputalizations discussed earlier suggests that these findings are not restricted to diabetic patients, nor are they restricted to only this system. Interactions between users of technology, with one conceptualization, and the designers, with another, are likely to experience the same phenomena demonstrated in this study. For example, designers of Internet World Wide Web pages may have similar difficulties in reaching and meeting the needs of their intended audience and obtaining required information from them.

5. Conclusions

This study examined the role of prior conceptualizations in lay decision making and in interactions of lay people with technology. The data show that the nature of information that patients use as evidence in making decisions is based on their personal knowledge, which is validated in everyday experiences. These understandings are different from those reported in investigations of medical decision making, in which use of biomedical and clinical knowledge as evidence predominates.

These discrepancies in the nature of evidence used by the two groups create mismatches in the use of communication technologies that oblige patients to categorize information into the evidence that doctors require to make medical decisions about disease management. This categorization is not consistent with that of lay people. Successful communication is based on congruence of the communicators and of the method of communication. Potential mismatches between the meaning of information for the patients and for the physicians do not disappear when the information is transmitted through technology. Data transmitted by patients to doctors must include the facts that the doctors need to make decisions about diagnosis and management of disease. Technology must be designed so that it is efficient, however if the information that is transmitted is not accurate, then technology becomes an ineffective tool. The system described in this study, the Diabetes Home Monitoring Module [23], is designed for physicians to have efficient and effective access to patient data. But the value of the data input will be questionable if consideration is not given to how the patients view the system and to what the input/data categories 'mean' to them.

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Appendix A. Categories of concepts related to diabetes

Lay knowledge about diabetes

Description of factual knowledge about relationships between concepts related to diabetes without expression of underlying pathophysiological mechanisms.

Patient: "Well let's say if I'll eat a pound of candies my sugar will go sky high and it might even cause a stroke!"

Biomedical knowledge

Description of underlying patholophysiological mechanisms identifying causal links.

Physician: "The polyuria is produced because the sugar gets in the urine and it acts as an osmotic diuretic, prevents the body the kidney from reabsorbing water from the urine".

Patient: "Exercise helps you to secrete more insulin". (Inaccurate)

Health care team input

Statement of information, instruction, or direction from a member or members of the health care team.

Patient: "They (nurses) know an awful lot about diabetes and they know their clientele very well".

Regimen, rigidity

Specific reference to the diabetic treatment regimen associated with reference to inflexibility.

Patient: "The constant testing, the constant watching what you eat and wanting to eat chocolate and wanting to eat this and that".

Functioning in daily life (daily activities) Reference to restrictive decisions made about daily activities due to limitations imposed by diabetes other than those related to the treatment regimen. Patient: "I'd (patient's husband) love to go on kilometre runs, biking all day but I don't think you can do it".

Social support

Statement of positive influence from individuals, family, and/or community. Patient: "I will ask my children to help me".

Affect

Reference to mood, sense of well-being (positive or negative).

Patient: "I have a very bad depression. Because you lost your eye, you lost your job. and we can't have a baby, you know. It was a very bad period".

Fear

Experience of or expectation of negative outcomes related to diabetes, such as social stigmatization, complications, or impaired functioning.

Patient: "He told me I'm not a good girl because I don't do anything". Patient: "It's because of that (unstable blood glucose levels) I have problem with my eyes and my kidney and like that".

Patient: "I don't want to be like my father when he died. Well he was eighty-one, practically an invalid".

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