2004

Do patients want to participate in medical decision-making? : a critical review of the literature

Elin Elizabeth Lisska
Yale University

Follow this and additional works at: http://elischolar.library.yale.edu/ymtdl

Recommended Citation
http://elischolar.library.yale.edu/ymtdl/2870

This Open Access Thesis is brought to you for free and open access by the School of Medicine at EliScholar – A Digital Platform for Scholarly Publishing at Yale. It has been accepted for inclusion in Yale Medicine Thesis Digital Library by an authorized administrator of EliScholar – A Digital Platform for Scholarly Publishing at Yale. For more information, please contact elischolar@yale.edu.
Do Patients Want to Participate in Medical Decision-Making?
A Critical Review of the Literature.

Elín Elizabeth Lisska

YALE UNIVERSITY

2004
Permission to photocopy or microfilm processing of this thesis for the purpose of individual scholarly consultation or reference is hereby granted by the author. This permission is not to be interpreted as affecting publication of this work or otherwise placing it in the public domain, and the author reserves all rights of ownership guaranteed under common law protection of unpublished manuscripts.

Signature of Author

Date 5/7/04
Do Patients Want to Participate in Medical Decision-Making?
A Critical Review of the Literature.

A Thesis Submitted to the
Yale University School of Medicine
in Partial Fulfillment of the Requirements for the
Degree of Doctor of Medicine

By
Elin Elizabeth Lisska
2004
T113
+ Y12
7126
Abstract

DO PATIENTS WANT TO PARTICIPATE IN MEDICAL DECISION-MAKING? A CRITICAL REVIEW OF THE LITERATURE.
Elin E. Lisska and Liana Fraenkel. Section of Rheumatology, Department of Internal Medicine, Yale University, School of Medicine, New Haven, CT.

Previous studies have shown that patients’ desire to participate in medical decision-making varies enormously and that many patients do not want to participate. Most studies have defined desire to participate in decision-making without differentiating between problem solving tasks requiring medical knowledge and decision-making tasks. The objective of this study was to compile and summarize all data on this topic over the last 25 years and to determine whether patients want to participate. We hypothesized that: 1) the percentage of patients wanting to participate is increased in studies which differentiate between problem-solving and decision-making tasks and 2) most patients are unable to achieve their desired level of participation in clinical encounters.

We compiled the results of 75 studies examining patients’ desire to participate, chosen by a systematic approach. We calculated median desire to participate and summarized patients’ and physicians’ views on patient participation. We independently analyzed studies that separated problem-solving tasks requiring medical knowledge from patient decision-making. We compared congruence between patients’ preferred level of participation and patients’ actual level of participation in a clinical decision.

The largest proportion (median: 41%) of patients preferred to share decision-making responsibility with their physicians. Twenty-three percent of patients preferred to make their own decisions, while 32% preferred their doctors to make decisions. Twenty-one percent preferred a passive role when problem-solving tasks were eliminated from decisions, as compared to 32% of patients in studies not separating problem-solving tasks (p< 0.001). Less than 50% of patients achieve their desired level of participation in a clinical decision-making encounter; reasons for this discrepancy have not been well studied.

The majority of patients wish to be involved in decision-making, especially when they are adequately informed, but desired level of participation varies. Our findings indicate that further work is needed to develop processes to promote shared decision-making in clinical practice.
Acknowledgments:

Heartfelt thanks to my faculty advisor, Liana Fraenkel, M.D., for her invaluable support and continued guidance throughout the production of this thesis.

And to Sean, for everything else.
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>5</td>
</tr>
<tr>
<td>Specific Aims</td>
<td>16</td>
</tr>
<tr>
<td>Methods</td>
<td>18</td>
</tr>
<tr>
<td>Results</td>
<td>27</td>
</tr>
<tr>
<td>Discussion</td>
<td>45</td>
</tr>
<tr>
<td>Bibliography</td>
<td>56</td>
</tr>
</tbody>
</table>
Introduction

History of Decision-Making and the Doctor-Patient Relationship

Throughout history, society has often likened the profession of medicine to shamanism, with healers' possessing a very secret and esoteric fund of knowledge and wielding "magical powers" which permitted them prescribe miraculous cures. No layperson could ever hope to learn, understand, or perform the art of healing, and therefore remained at the mercy of the practitioner. This ancient superstition contributed to the evolution of medical paternalism, which flourished for centuries (1). The dogma of paternalism focused on the physician's superior knowledge and the patient's illness-derived helplessness. Physicians problem-solved and dispensed treatment without engaging in intellectual discourse with a patient unable to understand the intricacies of medicine. Paternalism demanded respect for physician authority, unquestioned compliance, and perpetuated ignorance from patients (2, 3, 4).

In the 1950s, sociologist Talcott Parsons heralded absolute physician authority and patient deferment as ethically just and fundamentally necessary for maintaining the framework of society. According to the Parsonian model, illness was, by nature, a "deviance" from normalcy, and patients were morally obliged to seek out and comply with professional advice (4). The extreme power imbalance was justified by the infirmity of a sick patient and by a "competence gap" in medical knowledge between physicians and patients (5). In 1956, Szasz and Hollender described the components of the doctor-patient relationship as physician-guidance and patient cooperation, wherein the patient seeks the expertise of a physician and is incapable of disputing the procured advice. The
idea of mutual participation in a clinical decision-making process was considered
“foreign” and impractical in most medical scenarios (2).

In 1957, an important judicial decision established a legal precedent that
served as a prominent strike against the fortress of paternalism. In Salgo v. Leland
Stanford Junior University, a 55 year-old patient with vascular disease sued his physician
after a diagnostic procedure left him a paraplegic. The defense argued that paralysis was
a known possible risk of aortography, and that therefore no negligence had occurred.
However, the plaintiff side argued that the patient had not been informed of the nature of
the procedure, nor the possible risks, and might not have agreed to the procedure had full
disclosure occurred. The term “informed consent” was coined, and a legal precedent was
established that justified charging physicians with negligence if they failed to obtain
informed consent for procedures (6).

In the 1960s and 1970s a shift towards patient autonomy occurred parallel to the
rise of consumerism. Patients no longer considered themselves to be subordinates in the
medical consultation, but rather “buyer[s] of information, consulting and decision
services” (7). Society recognized that a patient and a physician might disagree not only
in the desired outcome, but also in what constituted an acceptable and feasible treatment.
The consumerist movement abandoned the adage of “doctor knows best,” in favor of
patient rights, specifically the right to receive comprehensive, unbiased information, the
right to be privy to treatment alternatives, and the right to choose the most acceptable
course of action based on his/her own values (1, 7, 8). In a true consumerist model of
patient autonomy, the physician provides the patient with complete, unbiased information
about treatment options, and the responsibility lies upon the patient either to select an
option, or to reject advice and seek a second opinion (3, 7). The “competence gap” of Parsonian dogma was minimized as patients began to seek out information to control their own health care (9).

In 1979, more than three-quarters of a surveyed population possessed attitudes towards physician authority that challenged traditional paternalistic roles, believing that patients had the right to question their doctors’ advice, to seek second opinions, to be fully informed, and to rely on their own judgment in matters of health. Almost half of the surveyed population had actively disputed a physician’s recommendation on at least one occasion by confronting their doctors directly, by seeking a second opinion, or by changing physicians to achieve a more desirable recommendation (10). In 1980, Cassileth et al., examined the preferences of 256 cancer patients regarding information disclosure and participation in decision-making. To measure patients’ desire to participate, they developed a two answer forced-choice instrument, from which subjects selected one of two statements:

A. I prefer to leave decisions about my medical care and treatment up to my doctor

B. I prefer to participate in decisions about my medical care and treatment.

The investigators also asked subjects to attest whether they wanted their doctors to give them as much information as possible or only the minimal amount necessary. The investigators found that greater than 80% of patients wanted their doctors to disclose all available information regarding diagnosis and treatment and that 63% wanted to participate in decisions regarding their treatment (11).
**Shared Decision-Making**

The concept of shared decision-making arose as a balance point between the extremes of pure patient autonomy and physician omnipotence. Given that true paternalism was no longer a viable approach in an empowered population and given that most patients did not want to be solely responsible for decisions involving their health care, theorists began to formulate additional models of decision-making.

Emanuel and Emanuel proposed two moderate models in addition to paternalism and patient autonomy: the interpretative model and the deliberative model. In the interpretive model, the physician helps the patient to realize his or her own values in the context of a medical decision and selects for the patient the option that best fits. In the deliberative model, the physician suggests reordering of patient values to place health foremost and persuades the patient towards one particular course of action, although the decision is ultimately up to the patient (3). Both of these models illustrate a more balanced distribution of power. However, both inflexibly cast one player as the principal decision-maker: the doctor in the interpretative model or the patient in the deliberative model.

The model of shared decision-making (SDM) is a combination of both the interpretive and deliberative models, where power is distributed equally between physician and patient. The doctor provides the patient with information about treatment options, and the patient provides the doctor with information on his/her own values, or utilities, which would affect the treatment choice. Both physician and patient impart vital information to aid the decision-making process, both consider the treatment options, and
both come to agree on a final course of action as being sufficiently and mutually satisfactory (12).

**The Evolution of Instruments Measuring Patient Desire to Participate**

In 1984, Strull, et al., developed a new instrument devised to measure patient desire to participate (Figure 1). The instrument listed five statements describing increasing levels of patient participation and instructed patients to choose the one statement that best described their preferred role in decision-making. The instrument was developed to measure patients' general desire to participate in any and all medical decisions, without the context of a specific medical scenario. Testing this instrument on 210 hypertensive outpatients, the investigators found that over 75% of subjects picked roles describing minimal amounts of patient participation. The authors concluded that the majority of patients did not want to participate actively in medical decisions (13).

<table>
<thead>
<tr>
<th>Strull Questionnaire Roles</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>#1.</strong> Physician decides, “using all that’s known about the medicines.”</td>
</tr>
<tr>
<td><strong>#2.</strong> Physician decides, but should “strongly consider [the patient’s] opinion.”</td>
</tr>
<tr>
<td><strong>#3.</strong> Physician and patient “make the decision together, on an equal basis.”</td>
</tr>
<tr>
<td><strong>#4.</strong> Patient decides, but should “strongly consider the clinician’s opinion.”</td>
</tr>
<tr>
<td><strong>#5.</strong> Patient decides based on all he/she “knows or learns about the medicines.”</td>
</tr>
</tbody>
</table>

*Figure 1: Decision-Making Roles Described by Strull, et al.*

Subjects chose one role that best described their preferred level of participation in medical decision-making. Higher numbered choices represent higher level of patient participation in decision-making. Adapted from Strull, et al, 1984 (13).
In 1989, Ende et al. developed the Autonomy Preference Index. The scale provided 6 general statements about doctor-patient roles in decision-making to which subjects agreed or disagreed on a 5 point Likert scale. The instrument then described 3 scenarios-- an upper respiratory infection, high blood pressure, and an acute myocardial infarction-- and asked subjects who should make specific medical decisions within the context of these scenarios (Figure 2). Each response had a corresponding point value,

<table>
<thead>
<tr>
<th>Autonomy Preference Index: Scenarios</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Who should decide...</strong></td>
</tr>
<tr>
<td><strong>Upper Respiratory Infection</strong></td>
</tr>
<tr>
<td>• If a doctor’s visit is needed</td>
</tr>
<tr>
<td>• If a chest X-ray is needed</td>
</tr>
<tr>
<td>• What medication should be prescribed</td>
</tr>
<tr>
<td><strong>Hypertension</strong></td>
</tr>
<tr>
<td>• When the next check-up should be</td>
</tr>
<tr>
<td>• Whether medical leave from work is indicated</td>
</tr>
<tr>
<td>• Whether diet changes or medication are necessary</td>
</tr>
<tr>
<td><strong>Myocardial Infarction</strong></td>
</tr>
<tr>
<td>• How often the nurses should check vital signs</td>
</tr>
<tr>
<td>• Whether visitors should be allowed</td>
</tr>
<tr>
<td>• Whether a cardiologist should be called</td>
</tr>
</tbody>
</table>

Figure 2: The Autonomy Preference Index: Scenarios
Subjects responded on a 5-point Likert scale whether the doctor or the patient should decide each matter, with high scores indicating active patient participation. Full descriptions of scenarios preceded detailed questions in the original instrument. Adapted from Ende et al, 1989 (14).

awarding more points to answers describing active roles in decision-making. Scores were tallied from all sections, with 100 being the highest possible score indicating a
desire to actively participate. The investigators found that the mean desire to participate on a scale of 0-100 was 33 ± 13, indicating a low desire to participate. The study also showed that desire to participate decreased with increasing age and severity of hypothetical medical problem (14).

Degner and Sloan developed the Control Preferences Scale in 1992. Similar to the Strull Questionnaire, the instrument required subjects to rank the five roles describing varying levels of patient participation in order of their preference (Figure 3). The roles did not refer to doctor or patient knowledge about medicines, but otherwise resembled the Strull roles. Degner and Sloan designated responses A and B as active, C as collaborative, and D and E as passive. The investigators examined participation preferences of 436 newly diagnosed cancer patients and 482 members of the general public. Fifty-nine percent of cancer patients wished to play a passive role, while only 9% of the public wanted a passive role. This discrepancy between participation preferences of ill individuals and healthy non-patients was attributed to the “sick role,” where ailing patients suddenly feel less capable of shouldering decision-making responsibility. Older age and lower education level were associated with a preference for passive roles (15).

Strull et al., Ende et al. and Degner and Sloan all found that more patients preferred a passive role in decision-making. Later studies produced inconsistent results (16), and the belief that patients did not want to participate in medical decision-making persisted.
### The Control Preferences Scale Roles

<table>
<thead>
<tr>
<th>Role</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>A:</td>
<td>The patient should “make decisions about health care”</td>
</tr>
<tr>
<td>B:</td>
<td>The patient decides, “after strongly considering [the] doctor’s opinion”</td>
</tr>
<tr>
<td>C:</td>
<td>The physician and the patient should “share decision-making responsibility equally”</td>
</tr>
<tr>
<td>D:</td>
<td>The physician decides, “after strongly considering [the patient’s] opinion”</td>
</tr>
<tr>
<td>E:</td>
<td>The patient should “leave all health care decisions to [the] doctor”</td>
</tr>
</tbody>
</table>

Roles A & B are designated as active roles, Role C is classified as collaborative, and Roles D & E are labeled as passive.

**Figure 4: The Roles Offered in the Control Preferences Scale**

Adapted from Degner & Sloan, 1992 (15).

In 1996, Deber et al. suggested that the studies conducted by Strull et al. (13), Ende et al. (14) and Degner and Russel (17) found a low patient desire to participate because they did not specifically exclude problem-solving elements that required expert medical knowledge from medical decisions. In response, Deber and Kraetschmer created the Problem-Solving and Decision-Making (PSDM) scale, which described four problem solving (PS) tasks: 1) determining diagnosis, 2) determining appropriate treatment options, 3) determining risks and benefits of treatment options, and 4) determining likelihood of all risks and benefits (Figure 4). The scale also included two decision-making (DM) tasks not requiring medical knowledge: 1) determining how acceptable...
risks and benefits were to the patient and 2) selecting one treatment option. The investigators tested this instrument on 300 angiography patients and found that while 78% of patients wanted a passive role in problem-solving tasks, only 22% of patients wanted a passive role in decision-making tasks (18).

**Problem Solving Tasks requiring medical knowledge**

Determining the diagnoses  
Determine which treatment options are appropriate for patient  
Determining possible side effects and risk/benefits of treatment  
Determining likelihood of side effects and relative chances of risks and benefits

**Decision-Making Tasks**

Determining how acceptable side effects and risks/benefits are to the patient (patient utilities)  
Choosing best-matched treatment option, given patient utilities

**Figure 4: Problem-Solving Tasks versus Decision-Making Tasks**

Problem-solving tasks denote tasks requiring medical knowledge to complete. Decision-making tasks denote tasks *not* requiring any special medical knowledge.  
Adapted from Deber & Kraetschmer, 1996 (18)

**Previous Critical Literature Reviews**

Two previous literature reviews in which original study data were reported were identified. Benbassat *et al.* performed a limited review summarizing the results of 22 studies focusing on patients’ desire for information and desire to participate in decision-making. The authors concluded that previous studies showed enormous variability in patients’ desire to participate which could not be fully explained by socio-demographic characteristics. The authors re-emphasized the disconnect between patient desire for
information and desire to participate and concluded that more research was needed to explain this variance (16).

Gaudagnoli and Ward offered a second, also limited, review in which they examined the results of 14 studies measuring patient desire to participate and 15 studies measuring outcomes related to active patient participation. The authors focused on the variability of the design of previous studies and the conflicting results produced by outcome studies. The authors concluded that while the literature lacked consistent convincing data linking improved outcomes to patient participation, shard decision-making was ethically mandated for humane patient care (19).

**Justifications for Shared Decision-Making**

Legislative changes emphasize the shift towards patient autonomy. Legal basis for patient autonomy exists mostly in case law and legal precedent, and specific legislation varies from state to state. Case law now suggests that doctors should disclose the amount of information that a “reasonable person” would want to hear; this amount is decided by juries in individual malpractice cases (6). The U.S. Patient Bill of Rights now necessitates informed consent for all non-emergent medical procedures, and similar rulings exist in Canada and the United Kingdom (20, 21). The British National Health Services recommends “active partnerships” with patients (22, 23), and the World Medical Assembly endorsed patient autonomy in the Declaration of Helsinki in 1996 (20). Health policy experts have advocated patient involvement in decision-making in an effort to lessen malpractice legislature (24).
Shared decision-making may also correlate with improved health status. Studies demonstrate that actively involved patients experience a reduction in hypertension (25), lowered blood sugars (26) and shorter post-operative hospital stays (27). Active participation also leads to improved patient compliance (28) and higher self-rated health status (26, 29, 30).

However, despite ethical, legal and clinical justifications for shared decision making, if patients do not want to participate, pushing them to do so would infringe on their autonomy. Paternalism is not the answer, but it is unclear what model of decision-making patients would endorse. Therefore, continued study and continued review of studies exploring ways physicians can involve patients to their desired level need to be pursued.

The objective of this thesis is to review all available studies examining patients’ desire to participate from the last 25 years and to perform a best-evidence synthesis of the existing data. By compiling all available data, we hope to summarize patient preferences for decision-making in the clinical encounter, to identify the limitations of the instruments utilized in the current literature and to suggest goals for future research. We also will introduce a new theoretical model for shared decision-making between patient and doctor.
Specific Aims and Hypothesis

Study Aims

• Study Aim 1: To determine the level at which patients want to participate in medical decision-making, the reasons why patients prefer a given level of participation, and the clinical or socio-demographic factors associated with an increased desire to participate.

• Study Aim 2: To compare and contrast the distribution of preferred decision-making roles in studies which differentiate between problem-solving tasks versus decision making tasks and to explore the effect of Deber’s 1996 study on later studies measuring patient desire to participate.

• Study Aim 3: To summarize the available literature comparing patients’ preferred roles in decision-making and patients’ actual roles in clinical decision-making encounters.

• Study Aim 4: To examine physicians’ attitudes towards patient participation in medical decision-making.

• Study Aim 5: To identify limitations of current instruments commonly used to measure patient desire to participate

• Study Aim 6: To propose a new theoretical model for shared decision-making for further study.
*Hypotheses:*

• Hypothesis 1A: The majority of studies will report that more patients prefer that their doctors make medical decisions, although most will want the doctor to consider the patient’s opinion.

• Hypothesis 1B: Younger and better-educated patients will be more likely to want to participate in medical decision-making.

• Hypothesis 2: Only a minority of studies will have differentiated between problem-solving and decision-making tasks. Studies that examine preference for participation in decision-making—distinct from problem solving—tasks will be more likely to find that patients want to actively participate in decision-making.

• Hypothesis 3: Among the subgroup of patients who do want to participate in medical decision-making, most do not attain their preferred level of participation in clinical decision-making encounters.
**Methods**

**Literature Search:**

We conducted a search of the Medline and CINAHL databases, identifying articles from 1978-2003 which listed “patient participation” as a focus subject heading and “decision” as a subject heading or title word. We eliminated articles focused on end-of-life decisions, articles focused on decision-making competency and articles using pregnant subjects using the search parameters delineated in Figure 5.

<table>
<thead>
<tr>
<th>General</th>
<th>Eliminating End-of-Life Decisions</th>
</tr>
</thead>
<tbody>
<tr>
<td>*Patient Participation.sh</td>
<td>Advance directives.sh</td>
</tr>
<tr>
<td>Decision Making.sh</td>
<td>Resuscitation.sh</td>
</tr>
<tr>
<td>Decision$.mp</td>
<td>Resuscitation orders.sh</td>
</tr>
<tr>
<td></td>
<td>Cardiopulmonary resuscitation.sh</td>
</tr>
<tr>
<td>Eliminating Competency Decisions</td>
<td>Euthanasia.sh</td>
</tr>
<tr>
<td>Competen$.mp</td>
<td>Euthanasia, passive.sh</td>
</tr>
<tr>
<td>Capacit$.mp</td>
<td>Euthanasia, active.sh</td>
</tr>
<tr>
<td>Incapacit$.mp</td>
<td>Life support care.sh</td>
</tr>
<tr>
<td>Eliminating Pregnant Subjects</td>
<td>Hospice care.sh</td>
</tr>
<tr>
<td>Pregnancy.sh</td>
<td>End-of-life.mp</td>
</tr>
</tbody>
</table>

**Figure 5: Search Parameters**

List of search parameters entered into Medline and CINAHL databases for the literature search.

- (*): Focus subject heading
- (sh): subject heading
- (mp): mapped term to any article using word or phrase as subject heading, key word, title, author, or abstract.
- ($): Includes any possible grammatical ending to a word in the search.
  
  *(e.g. “competen$” would search for competent, competence, competency, etc.)*
We read abstracts of the articles generated by the database search and eliminated all articles focused on end-of-life or competency decisions. We also eliminated articles generated by the database search that did not focus specifically on patient participation in medical decision-making.

We scanned the Methods and Results sections of the remaining articles and subjected them to the inclusion and exclusion criteria listed in Figure 6. We cross-referenced bibliographies to gain additional articles, subjecting these to the same review criteria. The final list comprised of experimental studies addressing adult patients’ desire to participate in decision-making or doctors’ views on patient participation in medical decision-making.

**Inclusion Criteria**
1. Focused on patient participation in treatment decision-making
2. From the years 1978-2003
3. Experimental study design with patients OR doctors as subjects
4. Quantitatively or qualitatively examining patients’ desire to participate in treatment decision-making or doctors’ opinions on the matter
5. Published in a journal listed on MEDLINE or CINAHL databases

**Exclusion Criteria**
1. Not centered on end-of-life decisions
2. Not focused on competency of individuals to make decisions
3. Not using minors for subjects
4. Not using subjects whose competency is in question, including the mentally retarded, those with psychiatric illness, and those with debilitating neurologic illness or any form of dementia.
5. Not focused on parents making health care decisions for children, or pregnant women making health care decisions which could impact the unborn child

*Figure 6: Inclusion and Exclusion Criteria*
These criteria were utilized to develop final selection of articles for the literature review
We classified articles into three main categories:

- **Group 1:** Studies that quantitatively measured patients’ desire to participate in medical decision-making
- **Group 2:** Studies that qualitatively addressed patients’ desire to participate in medical decision-making
- **Group 3:** Studies that quantitatively or qualitatively addressed physicians’ views on patient participation in medical decision-making

If articles addressed both patient and physician views, we listed the articles separately in two categories. To facilitate data collection and analysis, we further subdivided Group 1 articles based on data collection and presentation (Figure 7):

- **Group 1A:** Studies utilizing a validated questionnaire to measure patients’ desire to participate where results were reported as proportions of subject population preferring active, passive or collaborative roles.
- **Group 1B:** Studies utilizing a validated questionnaire to measure patients’ desire to participate where results were reported as a mean desire to participate on a scale from passive to active.
- **Group 1C:** Studies utilizing newly designed questionnaires to measure patients’ desire to participate and/or where results were presented in a format that could not be compared with Group 1A or 1B studies.

**Data Collection:**

**Group 1: Patients: Quantitative**

**Group 1A: Data presented as proportions of subjects choosing each role**

For each of the studies in Group 1A we recorded the site, total number of subjects, gender, clinical setting and diagnosis, and we noted the instrument utilized to measure patients’ desire to participate. We identified which studies measured desire to
participate in a real medical decision imminently faced by the patient, versus studies measuring desire to participate in hypothetical scenarios. As the Control Preferences Scale and the Strull Questionnaire describe the same five roles, we converted all data measured by the Strull Questionnaire to the Control Preferences Scale Roles (Figure 3),
by changing Strull role #1 to CPS role E, Strull role #2 to CPS role D, Strull #3 to role C, #4 to B, and #5 to CPS role A, so that all data were in the same format. We recorded the proportions of the total study population that chose passive, active or collaborative roles. If a study measured desire to participate in more than one subject population, we listed each population’s data separately. We also recorded the actual roles that patients reported playing in a clinical encounter. We described the correlations between patient characteristics and preferred role in decision-making.

We documented whether studies separated problem-solving tasks (Figure 4) from decision-making tasks. We considered studies to have separated problem-solving elements if investigators utilized the Deber-Kraetschmer PSDM scale or if subjects were given detailed information completing the four problem-solving tasks before being asked to select their preferred role.

*Group 1B: Data presented as mean response on numerical scale*

For each of the studies in Group 1B we recorded the site, total number of subjects, gender, clinical setting and diagnosis. We also noted the instrument used to measure patients’ desire to participate, and we identified which studies were measuring patient desire to participate in an imminent medical decision versus a hypothetical medical decision. We recorded the mean level of desired participation reported by the study with standard deviation and described the correlations between patient characteristics and preferred role in decision-making. If a study measured desire to participate in more than one subject population, we listed each population’s data separately. We also documented
whether studies separated problem-solving tasks from decision-making tasks as described for Group 1A.

*Group 1C: Data presented in other formats*

We recorded the information regarding the site, total number of subjects, gender, clinical setting and diagnoses. We identified which studies measured patient desire to participate in an imminent medical decision versus a hypothetical medical decision. We described the correlations between patient characteristics and preferred role in decision-making. Other data could not be reliably compared to Group 1A or 1B studies and therefore were not recorded.

*Group 2: Patients: Qualitative*

We recorded the information regarding the site, total number of subjects, gender, clinical setting and diagnoses, and we compiled the data with Group 1. We then reviewed the papers and identified the major themes consistently raised by patients regarding participation in medical decision-making.

*Group 3: Physicians*

We reviewed the studies and identified common themes raised by physicians regarding patient participation in medical decision-making.
Data Analysis:

Patient Desire to Participate

Group 1A: We compiled data from each study and reported the proportion of subjects desiring to play active, collaborative or passive roles. We calculated the median and range for each role using Microsoft® Excel X. We reported frequencies of roles most commonly selected in studies.

Group 1B: These studies reported patient desire to participate as a mean response on a numerical scale from passive to active. We normalized all results by converting all original data to a 1 - 5 scale, with 1 - 2.5 indicating a mean desire of subjects to play passive roles, 2.5 – 3.5 indicating a mean desire to play a collaborative role, and 3.5 – 5 representing desire to take an active role. We compiled normalized data and calculated the range of values.

Group 1C: Results were not compiled due to the wide range of formats and instruments.

Patient Desire to be Passive

Group 1A: We recorded original data from studies which reported role preference as proportions of subjects choosing each of 5 roles-- 2 possible active roles, one collaborative role and 2 possible passive roles. We compared the proportion of passive subjects preferring “that my doctor make the decisions, after considering my opinion,” with the proportion preferring to “leave all health care decisions to my doctor.” We also
calculated the percentage of subjects preferring *not* to “leave all health care decisions to [their doctors].”

**Factors Associated with Decision-Making Role Preference**

We computed the number of studies determining the associations of younger age, high school education or higher, gender, race, health status or time from diagnosis with role preferences, pooling Groups 1A, 1B and 1C data together. We calculated the percentage of studies that showed each characteristic to be a significant predictor (p < 0.05), using each individual study as a unit of analysis.

**Problem-Solving versus Decision-Making**

Group 1A: We compiled all data from studies separating problem-solving tasks from decision-making tasks. We calculated the total number of subjects choosing active or collaborative roles and the total number of subjects selecting passive roles for all studies separating problem-solving tasks and for all studies that did not separate problem-solving tasks. We compared total numbers of subjects choosing active/collaborative versus passive roles for both groups of studies using the chi-square statistic (StatView 4.5).

Group 1B: We compiled all normalized data from studies separating problem-solving elements from decision-making tasks.
Group 1C: Data could not be compiled due to the wide range of formats and instruments.

**Actual Role**

Group 1A: We compiled data reporting the proportion of subjects playing passive, active and collaborative roles in a real medical decision-making encounter and calculated the median using Microsoft® Excel X for all three roles. We compared frequencies of actual roles with subjects’ preferred roles and reported the percentage of subjects who achieved their preferred role in a clinical encounter. We summarized studies that compared level of patient satisfaction with achieving preferred role in a clinical encounter.

*The medical student and faculty advisor jointly conceived the project topic, study aims and hypotheses. The medical student performed database searches, literature reviews, data collection and data analysis. The student and faculty advisor worked together to formulate conclusions and produce the written thesis.*


Results

Literature Search

The original search parameters, “patient participation” and “decision making,” generated over 1000 articles. Using the additional search parameters listed in Figure 5 to eliminate articles centered on end-of-life or competency decisions, we reduced the total number to 738. After reading abstracts and ruling out articles that did not meet stated parameters listed in Figure 6, 623 articles remained. We reviewed the Methods and Results sections of the 623 articles and executed our inclusion and exclusion criteria, eliminating all but 73 studies. When the same data was duplicated in more than one publication, we kept only the original study. We reviewed two additional papers (9, 31) found by cross-referencing bibliographies, bringing the final total to 75 studies.

Grouping Articles (Figure 8)

Fifty-nine articles quantitatively measured patients’ desire to participate (Group 1). Thirty-three presented data as the proportion of subjects selecting active, collaborative or passive roles (13, 15, 18-17, 20-22, 24, 32-56), 10 presented data as mean desire to participate (14, 57-65), and 16 presented data in other formats (9, 11, 26, 30-31, 66-76).

Nine articles qualitatively measured patients’ desire to participate in focus groups or open-ended interviews (Group 2) (23, 77-84). Seven articles focused exclusively on doctors’ views (Group 3) (85-91), and an additional 5 studies from Groups 1 or 2 also examined both doctors’ views and patients’ views (9, 13, 41, 51, 64).
Articles Generated by Literature Search

Figure 8: Literature Search Outcomes
Enumerates articles assigned to each of 3 main categories and 3 sub-categories. Studies that examined more than one group of subjects were treated as separate subject populations with separate data sets.

Setting of Studies and Study Populations:

The majority of studies (62%) examining patients' preferred role in decision-making (Groups 1 and 2) took place in The United States or Canada. Seventeen percent took place in The United Kingdom. Seventy-one percent of studies employed outpatients as subjects. Most (68%) used both men and women as subjects; 23% studied women
only and 9% studied men only. Seventy percent of studies recruited subjects with a common disease or medical problem; 37% recruited subjects with cancer (Table 1).

Table 1: Site, Setting, and Subject Populations

<table>
<thead>
<tr>
<th>Setting of Study</th>
<th>Number of studies</th>
<th>Gender</th>
<th>Number of studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient</td>
<td>5</td>
<td>Male</td>
<td>6</td>
</tr>
<tr>
<td>Outpatient</td>
<td>58</td>
<td>Female</td>
<td>16</td>
</tr>
<tr>
<td>Non-patient</td>
<td>5</td>
<td>Both</td>
<td>47</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Country of Study</th>
<th>Number of studies</th>
<th>Country</th>
<th>Number of studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>5</td>
<td>Hong Kong</td>
<td>1</td>
</tr>
<tr>
<td>Canada</td>
<td>16</td>
<td>The Netherlands</td>
<td>1</td>
</tr>
<tr>
<td>Finland</td>
<td>2</td>
<td>Sweden</td>
<td>3</td>
</tr>
<tr>
<td>France</td>
<td>1</td>
<td>The United Kingdom</td>
<td>12</td>
</tr>
<tr>
<td>Germany</td>
<td>1</td>
<td>The United States</td>
<td>27</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Diagnoses of SubjectsA</th>
<th>Number of studies</th>
<th>Diagnosis</th>
<th>Number of studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td>2</td>
<td>HIV</td>
<td>2</td>
</tr>
<tr>
<td>Back Pain</td>
<td>1</td>
<td>Hypertension</td>
<td>3</td>
</tr>
<tr>
<td>BPH</td>
<td>1</td>
<td>Hodgkin’s</td>
<td>1</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>10</td>
<td>Infertility</td>
<td>1</td>
</tr>
<tr>
<td>Breast Disease, Benign</td>
<td>1</td>
<td>Lung Cancer</td>
<td>1</td>
</tr>
<tr>
<td>Cancer, NOSb</td>
<td>11</td>
<td>Lupus</td>
<td>1</td>
</tr>
<tr>
<td>Cardiac Disease</td>
<td>4</td>
<td>Peptic Ulcer Disease</td>
<td>1</td>
</tr>
<tr>
<td>Chronic Disease, NOS</td>
<td>1</td>
<td>Prostate Cancer</td>
<td>3</td>
</tr>
<tr>
<td>Colon Cancer</td>
<td>3</td>
<td>Renal Disease</td>
<td>1</td>
</tr>
<tr>
<td>Diabetes Mellitus</td>
<td>3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

A Common Diagnoses Shared by Study Populations

b Not otherwise specified; Subjects had many subtypes of diagnosis
Instruments Utilized

Group 1: Patients: Quantitative

Forty percent of studies utilized The Control Preferences Scale (CPS), 14% of studies utilized the Strull questionnaire, and 16% of studies utilized the Autonomy Preference Index (API). Only 5% of studies employed the Deber-Kraetschmer PSDM scale. The remainder of studies utilized scales not widely used in the field (Table 2). Forty-seven percent of the studies asked only about patients’ general desire to participate in any medical decision. Thirty percent of studies used scenarios to describe hypothetical medical decisions, and 20% referred to actual medical decisions imminently faced by patients.

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Number of studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strull Questionnaire</td>
<td>8</td>
</tr>
<tr>
<td>Control Preferences Scale</td>
<td>23</td>
</tr>
<tr>
<td>Deber-Kraetschmer PSDM Scale</td>
<td>3</td>
</tr>
<tr>
<td>Autonomy Preference Index</td>
<td>9</td>
</tr>
<tr>
<td>Other</td>
<td>15</td>
</tr>
</tbody>
</table>

*A Absolute number of studies utilizing each questionnaire

B Any other instrument utilized by a study
Patient Desire to Participate in Medical Decision-Making

Group 1A (Table 3)

The median proportion of subjects classified as active was 23% (range: 3-78%), collaborative 41% (range: 19–80%), and passive 32% (range: 2–78%). Only 24% of the studies reviewed found that the majority of patients (>50%) selected roles classified as passive. Thirty-one percent of the studies demonstrated that the majority of subjects desired a collaborative role, and 6% of the studies found that the majority of subjects preferred an active role.

Group 1B (Table 4)

Table 4 presents the data from the 11 studies in Group 1B, displayed as mean desire to participate of each study population on a normalized scale from 1 – 5. Pooling all 11 studies together yielded a range of 2.1 – 3.3.

“Passive” role:

Twenty Group 1A studies presented original data of proportions of subject populations choosing one of 5 roles, as well as proportions choosing active, passive or collaborative roles (Table 5). Nearly two-thirds of the subjects in the “passive” category picked the less passive of the two choices: “I prefer that my doctor make decisions, after strongly considering my opinion.” On average, 85% of patients preferred a role other than “I prefer to leave all health care decisions up to my doctor.”
Table 3: Group 1A Studies: Proportion of subject population choosing each role: Part 1

<table>
<thead>
<tr>
<th>Study</th>
<th>Active</th>
<th>Collab.</th>
<th>Passive</th>
<th>Study</th>
<th>Active</th>
<th>Collab.</th>
<th>Passive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Degner and Russel, 1988</td>
<td>12</td>
<td>80</td>
<td>8</td>
<td>Deber, et al., 1996: P-S</td>
<td>78</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>Sutherland, et al., 1989</td>
<td>10</td>
<td>27</td>
<td>63</td>
<td>Caress, 1997</td>
<td>18</td>
<td>31</td>
<td>46</td>
</tr>
<tr>
<td>Degner and Sloan, 1992: Public</td>
<td>64</td>
<td>27</td>
<td>9</td>
<td>Degner, et al., 1997</td>
<td>22</td>
<td>44</td>
<td>34</td>
</tr>
<tr>
<td>Davison, et al., 1995</td>
<td>19</td>
<td>23</td>
<td>58</td>
<td>Rothenbacher, et al., 1997: Cancer</td>
<td>9</td>
<td>73</td>
<td>18</td>
</tr>
<tr>
<td>Llewellyn-Thomas, et al., 1995</td>
<td>31</td>
<td>31</td>
<td>38</td>
<td>Rothenbacher, et al., 1997: Chronic</td>
<td>17</td>
<td>49</td>
<td>34</td>
</tr>
</tbody>
</table>

*Values are percent of total subject population choosing each role
*Subjects who chose the two most active decision-making roles
*Subjects who chose collaborative roles
*Subjects who chose the two most passive decision-making roles
<table>
<thead>
<tr>
<th>Study</th>
<th>Active</th>
<th>Collab.</th>
<th>Passive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stiggelbout and Kiebert, 1997: Gen: Non-patient</td>
<td>26</td>
<td>32</td>
<td>42</td>
</tr>
<tr>
<td>Stiggelbout and Kiebert, 1997: Cancer</td>
<td>16</td>
<td>34</td>
<td>50</td>
</tr>
<tr>
<td>Stiggelbout and Kiebeter, 1997: Surgical</td>
<td>21</td>
<td>38</td>
<td>41</td>
</tr>
<tr>
<td>Stiggelbout and Kiebert, 1997: Non-patients</td>
<td>31</td>
<td>35</td>
<td>34</td>
</tr>
<tr>
<td>Davidson, et al., 1999: Past</td>
<td>19</td>
<td>24</td>
<td>57</td>
</tr>
<tr>
<td>Davidson, et al., 1999: Present</td>
<td>19</td>
<td>39</td>
<td>43</td>
</tr>
<tr>
<td>O’Dell, et al., 1999</td>
<td>36</td>
<td>32</td>
<td>32</td>
</tr>
<tr>
<td>Protiere, et al., 2000</td>
<td>22</td>
<td>52</td>
<td>26</td>
</tr>
<tr>
<td>Ramfelt, et al., 2000</td>
<td>6</td>
<td>64</td>
<td>30</td>
</tr>
<tr>
<td>Wallberg, et al., 2000</td>
<td>13</td>
<td>21</td>
<td>66</td>
</tr>
<tr>
<td>Brundage, et al., 2001</td>
<td>40</td>
<td>32</td>
<td>28</td>
</tr>
<tr>
<td>Fraenkel, et al., 2001</td>
<td>37</td>
<td>54</td>
<td>9</td>
</tr>
<tr>
<td>Gattellari, et al., 2001</td>
<td>20</td>
<td>45</td>
<td>37</td>
</tr>
<tr>
<td>Golin, et al., 2001</td>
<td>12</td>
<td>72</td>
<td>16</td>
</tr>
<tr>
<td>Stewart, et al., 2001: D-M</td>
<td>53</td>
<td>39</td>
<td>8</td>
</tr>
<tr>
<td>Stewart, et al., 2001: P-S</td>
<td>4</td>
<td>45</td>
<td>51</td>
</tr>
<tr>
<td>Bruera, et al., 2002</td>
<td>23</td>
<td>67</td>
<td>11</td>
</tr>
<tr>
<td>Caress, et al., 2002</td>
<td>22</td>
<td>34</td>
<td>44</td>
</tr>
<tr>
<td>Davey, et al., 2002: Test</td>
<td>38</td>
<td>54</td>
<td>8</td>
</tr>
<tr>
<td>Davey, et al., 2002: Treatment</td>
<td>40</td>
<td>55</td>
<td>5</td>
</tr>
<tr>
<td>Keating, et al., 2002</td>
<td>12</td>
<td>64</td>
<td>24</td>
</tr>
<tr>
<td>Davison, et al., 2003</td>
<td>51</td>
<td>42</td>
<td>7</td>
</tr>
<tr>
<td>Ford, et al., 2003</td>
<td>26</td>
<td>56</td>
<td>18</td>
</tr>
<tr>
<td>Whelan, et al., 2003</td>
<td>26</td>
<td>56</td>
<td>18</td>
</tr>
</tbody>
</table>

Median:\n\n\nActive: 22%\nCollaborative: 41%\nPassive: 32%

*Median of compiled data for each role*
### Table 4: Group 1B Studies: Mean Desire to Participate

<table>
<thead>
<tr>
<th>Study</th>
<th>Mean</th>
<th>Scale</th>
<th>Normalized Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ende, et al., 1989</td>
<td>33.2</td>
<td>0-100</td>
<td>2.3</td>
<td>0.5</td>
</tr>
<tr>
<td>Thompson, et al., 1993: API</td>
<td>2.1</td>
<td>1-5</td>
<td>2.1</td>
<td>0.67</td>
</tr>
<tr>
<td>Thompson, et al., 1993: DIQ</td>
<td>3.3</td>
<td>1-5</td>
<td>3.3</td>
<td>0.71</td>
</tr>
<tr>
<td>Catalan and Brener, 1994</td>
<td>53.9</td>
<td>15-75</td>
<td>3.1</td>
<td>0.4</td>
</tr>
<tr>
<td>Nease and Brooks, 1995</td>
<td>0.42</td>
<td>0-1</td>
<td>2.7</td>
<td></td>
</tr>
<tr>
<td>Holmes-Rovner, et al., 1996</td>
<td>3.6</td>
<td>5-1</td>
<td>2.4</td>
<td>0.86</td>
</tr>
<tr>
<td>Davis, et al., 1999</td>
<td>4.1</td>
<td>0-10</td>
<td>2.6</td>
<td></td>
</tr>
<tr>
<td>Mansell, et al., 2000</td>
<td>2.7</td>
<td>1-5</td>
<td>2.7</td>
<td></td>
</tr>
<tr>
<td>Adams, et al., 2001</td>
<td>3.4</td>
<td>5-1</td>
<td>2.6</td>
<td>0.8</td>
</tr>
<tr>
<td>McKeown, et al., 2002</td>
<td>56.2</td>
<td>0-100</td>
<td>3.2</td>
<td></td>
</tr>
<tr>
<td>Henderson and Shum, 2003</td>
<td>3.31</td>
<td>5-1</td>
<td>2.7</td>
<td></td>
</tr>
</tbody>
</table>

**Range**: 2.1 – 3.3

---

*a* Mean subject population desire to participate, as reported in study  
*b* Scale utilized by study, from passive to active  
*c* Data were normalized to a 1 - 5 scale; 1 - 2.4 represents a passive role, 2.5 - 3.5 represents a collaborative role, and 3.6 - 5 represents an active role.  
*d* When available, normalized to 1 – 5 scale  
*e* Range of all compiled Group 1B studies

---

**Factors Associated with Passive Participation in Decision-Making:**

Twenty-eight of 34 studies (82%) found age to be a significant predictor of desired role, with older patients preferring more passive roles. Less educated individuals preferred more passive roles in 21 of 27 studies (78%). Studies did not consistently find gender,
marital status, prognosis, functional health status, or time from diagnosis to be significant predictors of desired role in decision-making (Table 6).

### Table 5: Breakdown of “Passive” roles selected by Group 1A subjects

<table>
<thead>
<tr>
<th>Study</th>
<th>D&lt;sup&gt;b&lt;/sup&gt;</th>
<th>E&lt;sup&gt;c&lt;/sup&gt;</th>
<th>ABCD&lt;sup&gt;d&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strull, et al., 1984</td>
<td>31</td>
<td>47</td>
<td>53</td>
</tr>
<tr>
<td>Sutherland, et al., 1989</td>
<td>31</td>
<td>32</td>
<td>68</td>
</tr>
<tr>
<td>Hack, et al., 1994</td>
<td>14</td>
<td>6</td>
<td>94</td>
</tr>
<tr>
<td>Davison, et al., 1995</td>
<td>37</td>
<td>21</td>
<td>79</td>
</tr>
<tr>
<td>Llewellyn-Thomas, et al., 1995</td>
<td>16</td>
<td>22</td>
<td>78</td>
</tr>
<tr>
<td>Beaver, et al., 1996</td>
<td>35</td>
<td>17</td>
<td>83</td>
</tr>
<tr>
<td>Caress, 1997</td>
<td>31</td>
<td>15</td>
<td>85</td>
</tr>
<tr>
<td>Degner, et al., 1997</td>
<td>16</td>
<td>18</td>
<td>82</td>
</tr>
<tr>
<td>Davidson, et al., 1999 I</td>
<td>38</td>
<td>19</td>
<td>81</td>
</tr>
<tr>
<td>Davidson, et al., 1999 II</td>
<td>38</td>
<td>5</td>
<td>95</td>
</tr>
<tr>
<td>Protiere, et al., 2000</td>
<td>13</td>
<td>13</td>
<td>83</td>
</tr>
<tr>
<td>Ramfelt, et al., 2000</td>
<td>1</td>
<td>29</td>
<td>71</td>
</tr>
<tr>
<td>Wallberg, et al., 2000</td>
<td>56</td>
<td>10</td>
<td>90</td>
</tr>
<tr>
<td>Brundage, et al., 2001</td>
<td>17</td>
<td>11</td>
<td>89</td>
</tr>
<tr>
<td>Gattellari, 2001</td>
<td>25</td>
<td>12</td>
<td>82</td>
</tr>
<tr>
<td>Golin, et al., 2001</td>
<td>13</td>
<td>3</td>
<td>97</td>
</tr>
<tr>
<td>Bruera, et al., 2002</td>
<td>9</td>
<td>2</td>
<td>98</td>
</tr>
<tr>
<td>Caress, et al., 2002</td>
<td>41</td>
<td>3</td>
<td>97</td>
</tr>
<tr>
<td>Davey, et al., 2002 I</td>
<td>4</td>
<td>4</td>
<td>94</td>
</tr>
<tr>
<td>Davey, et al., 2002 II</td>
<td>3</td>
<td>2</td>
<td>98</td>
</tr>
<tr>
<td><strong>Median&lt;sup&gt;f&lt;/sup&gt;</strong></td>
<td><strong>31.0</strong></td>
<td><strong>13.0</strong></td>
<td><strong>85</strong></td>
</tr>
</tbody>
</table>

<sup>a</sup> Values are percent of Group 1A subject populations choosing each decision-making role

<sup>b</sup> “Passive” Role D: “I prefer that my doctor make decisions, after considering my opinion”

<sup>c</sup> “Passive” Role E: “I prefer to leave all health care decisions to my doctor” (15)

<sup>d</sup> Sum of proportions of subjects choosing roles other than E

<sup>e</sup> Studies examining 2 populations are designated with Roman numerals

<sup>f</sup> Median proportion of compiled studies choosing each role
Table 6: Predictors: Characteristics of Subjects Associated with Decision-Making Role Preference

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Examined / Reported in studies&lt;sup&gt;A&lt;/sup&gt;</th>
<th>Significant&lt;sup&gt;B&lt;/sup&gt; in studies&lt;sup&gt;C&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>34</td>
<td>28 (82%)</td>
</tr>
<tr>
<td>Education</td>
<td>26</td>
<td>21 (78%)</td>
</tr>
<tr>
<td>Gender</td>
<td>14</td>
<td>4 (29%)</td>
</tr>
<tr>
<td>Marital Status</td>
<td>9</td>
<td>4 (44%)</td>
</tr>
<tr>
<td>Health Status/ Prognosis</td>
<td>12</td>
<td>4 (33%)</td>
</tr>
<tr>
<td>Time from Diagnoses</td>
<td>4</td>
<td>2 (50%)</td>
</tr>
</tbody>
</table>

<sup>A</sup> Absolute number of studies that examined and reported associations between characteristics and role preferences

<sup>B</sup> p < 0.05, as reported in studies

<sup>C</sup> Absolute number (normal text) and percent (italics) of studies that found characteristics to be significant predictors of role preference

---

**Separating Problem-Solving Elements from Decision-Making:**

**Group 1A: Proportion of subjects choosing each role**

Deber, *et al,* in the landmark study, found that 78% of patients wanted a passive role for problem-solving elements of a treatment decision, but that only 22% of patients wanted a passive role for non-problem-solving elements (18). Stewart, *et al,* looking at women seeking treatment for infertility, found similarly that 51% of patients wanted a passive role for problem-solving components of the decision, but that only 8% wanted a passive role for non-problem solving elements (24). Whelan, *et al,* asked patients to
select their preferred role in an oncologic treatment decision, then gave patients full information about the two treatment options including risk/benefits, likelihood of side effects, likelihood of cure and alternative options. Initially, 17% of patients wished for a passive role, but, after receiving the information, only 7% of patients remained passive (56).

<table>
<thead>
<tr>
<th>Study</th>
<th>Active or Collaborative</th>
<th>Passive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Llewellyn-Thomas et al., 1991</td>
<td>32</td>
<td>28</td>
</tr>
<tr>
<td>Llewellyn-Thomas, et al., 1995</td>
<td>56</td>
<td>34</td>
</tr>
<tr>
<td>Deber, et al., 1996</td>
<td>225</td>
<td>75</td>
</tr>
<tr>
<td>Mazur and Hickman, 1997</td>
<td>369</td>
<td>98</td>
</tr>
<tr>
<td>O'Dell, et al., 1999</td>
<td>109</td>
<td>51</td>
</tr>
<tr>
<td>Protiere, et al., 2000</td>
<td>49</td>
<td>15</td>
</tr>
<tr>
<td>Stewart, et al., 2001</td>
<td>145</td>
<td>30</td>
</tr>
<tr>
<td><strong>Total</strong>:</td>
<td><strong>1356</strong></td>
<td><strong>364</strong></td>
</tr>
</tbody>
</table>

A Values are total numbers of subjects picking active/collaborative (roles A, B, or C on the Control Preferences Scale) or passive roles (roles D or E on the Control Preferences Scale)

b Sum of compiled values and percent of total (in italics)

Eight Group 1A studies separated out Problem-Solving (PS) tasks from Decision-Making (DM) tasks (Table 7). Three studies utilized the Deber-Kraetschmer PSDM scale (18, 24, 44), while the remainder provided patients with complete information that addressed all PS elements. Seventy-nine percent (1356 out of 1720 subjects) of the total number of subjects selected an active or collaborative role when problem-solving elements were eliminated from the decision, as compared with 68% (5456 out of 8085...
subjects) in studies that did not separate problem-solving elements. Chi-squared analysis showed a significant difference between the two groups ($\chi^2 = 82.216, p < 0.001$) (Figure 9).

![Figure 9: Role Breakdown in Studies Separating versus Studies Not Separating Problem Solving Tasks from Decision-Making Tasks](image)

Pie graphs depict percentages of total number of subjects classified as active or collaborative versus percent classified as passive. Rightmost pie graph refers to studies separating problem-solving tasks from decision-making tasks. Leftmost pie graph refers to studies not separating problem-solving tasks from decision-making tasks. Percentages of subjects choosing passive roles were significantly different for the two groups of studies by Chi-Squared Analysis.
Group 1B: Mean desire to participate in a subject population

Only one Group 1B study separated problem solving from decision-making. Thompson, et al, developed a version of the Autonomy Preference Index that separated out problem solving elements. Subjects taking the original API scored on average a 2.1 ± 0.6, on a scale of 1-5, 1 being passive, and 5 being active. On the new version, the average score increased to 3.3 ± 0.7, bringing scores into the collaborative range (57).

Comparison of Patients' Preferred Role with Their Actual Role in a Clinical Encounter:

Sixteen studies examined patients’ actual role in real medical decisions, retrospectively. Eight studies reported the percent of patients that were able to achieve their desired role (20, 32, 36, 39, 46-47, 53, 55). The majority of these found that less than half of the patients achieved their desired role in a real decision-making process (20, 36, 39, 46, 53). Only one study reported greater than 75% congruence (32). Patients reporting that they did not achieve their desired role in decision-making more often acquiesced to a more passive role than desired (20, 32, 37, 43, 46). No study explored the reasons why patients failed to participate at their desired level.

No study examined associations between role preference and likelihood of achieving preferred role in a clinical encounter. Degner, et al. noted that “women who... had the best chance of achieving their preferred role were those who wanted the most passive role in decision-making” (39). Another study found that only 50% of patients wanting an active or collaborative role actually achieved this role, while the rest acquiesced to a more passive role (55). Yet another study found that over half of the patients preferring the passive but less paternalistic role “I prefer that my doctor make
decisions, but consider my opinion” reported their doctor made the decision for them without asking for their opinion (39).

### Table 8: Actual Roles vs. Ideal Roles in Decision-Making

<table>
<thead>
<tr>
<th>Study</th>
<th>Active Role Actual (ideal)</th>
<th>Collaborative Role Actual (ideal)</th>
<th>Passive Role Actual (ideal)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strull, et al., 1984</td>
<td>3 (3)</td>
<td>11 (19)</td>
<td>86 (78)</td>
</tr>
<tr>
<td>Bilodeau and Degner, 1996</td>
<td>24 (20)</td>
<td>19 (37)</td>
<td>57 (43)</td>
</tr>
<tr>
<td>Caress, 1997</td>
<td>5 (18)</td>
<td>17 (36)</td>
<td>78 (46)</td>
</tr>
<tr>
<td>Davison and Degner, 1997</td>
<td>17 (25)</td>
<td>50 (44)</td>
<td>33 (31)</td>
</tr>
<tr>
<td>Degner, et al., 1997</td>
<td>23 (22)</td>
<td>18 (44)</td>
<td>59 (34)</td>
</tr>
<tr>
<td>Davidson, et al., 1999</td>
<td>14 (19)</td>
<td>10 (24)</td>
<td>76 (57)</td>
</tr>
<tr>
<td>Ramfelt, et al., 2000</td>
<td>6 (6)</td>
<td>14 (62)</td>
<td>80 (32)</td>
</tr>
<tr>
<td>Gattellari, et al., 2001</td>
<td>26 (19)</td>
<td>24 (46)</td>
<td>50 (35)</td>
</tr>
<tr>
<td>Davey, et al., 2002</td>
<td>12 (38)</td>
<td>41 (54)</td>
<td>47 (8)</td>
</tr>
<tr>
<td>Ford, et al., 2003</td>
<td>14 (18)</td>
<td>39 (47)</td>
<td>47 (35)</td>
</tr>
<tr>
<td><strong>Median</strong></td>
<td><strong>14 (19)</strong></td>
<td><strong>19 (44)</strong></td>
<td><strong>58 (35)</strong></td>
</tr>
</tbody>
</table>

\(^{A}\) Values are percent of study population describing their role in a clinical encounter as active, collaborative, or passive (normal text) and the percent of study populations preferring to be active, collaborative, or passive in medical decisions (italic text) as measured by the Strull Questionnaire or the Control Preferences Scale.

\(^{B}\) Median values of compiled proportions of subject populations having each actual and preferred role.
Figure 10: Comparison of patients’ actual roles with preferred roles.
Patients were asked to choose their preferred decision-making role and to choose the role that they had actually played in a recent decision during a clinical encounter. Columns represent median percentages of compiled subject populations with each role. Most studies reported less than 50% congruence between preferred and actual role.

Ten studies reported proportions of patients accepting each role as compared to their preferred roles. These data are shown in Table 8. Median proportions of subjects were as follows: 14% (range: 3-26%) of subjects categorized their actual role as active, 19% (range: 10-50%) as collaborative and 58% (range: 33-86) as passive. However, on average, 44% desired a collaborative role and 35% desired a passive role (Figure 10).

Five studies examined the association between patient satisfaction and congruence of actual and preferred roles. All five studies found that patient satisfaction was positively related to congruence between actual and preferred roles (20, 30, 53, 68, 74).
Group 2: Patients: Qualitative Studies: Identified Themes

Figure 11 lists the themes identified in Group 2 studies. Patients cited a lack of medical knowledge as the most common reason why they preferred passive participation (23, 78-80, 82-84). Patients also claimed they felt too sick to take responsibility for the decision (79-80, 82-83). Some patients cited that they wanted to be a “good patient” (77, 79), and that they feared being labeled as “difficult” and consequently jeopardizing their relationship with their doctor (83).

### Elements Serving as Barriers to Patient Participation
- Being a “good patient”
- Lacking necessary medical knowledge
- Feeling “too sick”
- Inadequate time with Clinician
- Relationship with Clinician that does not encourage participation

### Elements Promoting Patient Participation in Decision-Making
- Self-reliance
- Personal experience with illness
- Adequate information in comprehensible format
- Adequate time with Clinician
- Relationship with Clinician that encourages participation

**Figure 11: Themes uncovered in qualitative studies**

Reasons why patients chose to participate or to not participate in treatment decisions, as identified in Group 2 studies.

Patients frequently cited brevity of consultations as another barrier to participation (23, 82). Some patients also felt that their doctor discouraged participation, either by discounting their personal experience with treatment or their medical knowledge gained from outside sources (81), or by being unwilling to explore patient values that might affect the feasibility of a treatment (23, 81). Some patients felt that they lacked the courage to assert their desire to participate when their doctor was controlling a decision.
(82). Other patients felt that participating was too difficult, as their doctors used too much jargon in explanations (84), or could not place risk/benefit statistics in an understandable context (80).

Several subjects still felt that insisting on participation was important, citing reasons of self-reliance (83), and looking out for one's own body (78). These subjects stated that encouragement from the doctor to participate was the most important factor facilitating participation (23, 82).

Group 3: Physicians: Views on Patient Participation

Several studies asked doctors what they thought would be the ideal decision-making model for a treatment decision. In four studies, most doctors preferred the deliberative model, attempting to convince a patient to choose a particular course of action (23, 87-89). One study found that one-third of doctors felt that true patient autonomy over decisions could threaten the patient's health (89). Two studies found that over 90% of surveyed physicians felt that doctors should have more authority over decision-making than patients (9, 85). Some doctors felt that shared decision-making was not practical in an inpatient setting and should be reserved for the primary care consultation (90). Female physicians were found to be more likely to favor patient autonomy than male physicians (85), and younger physicians and medical students were also more willing to consider shared decision-making (89).

In two studies, a majority of doctors felt that shared decision-making was ideal, but reported that it rarely happens in practice (86, 91). Doctors cited lack of time in the clinical encounter (87, 90) and disbelief that patients possess enough knowledge to make
an informed decision (87) as reasons to avoid shared decision-making. Some doctors also felt that they themselves did not always know the actual risk/benefit statistics to communicate them accurately to the patients (87).

In one study, the majority of surveyed doctors felt that they could accurately predict which patients wished to be involved in decision-making (87). However, other studies have refuted this, showing that doctors could only accurately predict patients’ preferred roles less than half of the time, frequently overestimating or underestimating patients’ desired level of involvement (41, 51). The number of years spent treating the patient did not predict accuracy in estimating patients’ preferred roles (41). Doctors also tended to overestimate how involved patients perceived themselves to be, frequently considering a decision to be shared when patients actually felt they had less input than the physician (13, 64).
Discussion

Level of Participation Desired by Patients

The compilation of data in this literature review suggests that patients’ desire to participate approaches a bell-shaped curve. Some patients want to be highly active participants in treatment decisions. Other patients would prefer to leave the responsibility entirely up to their doctors. But the largest proportion of patients desire an intermediate level of participation. The majority of patients classified as “passive” want their doctor to “strongly consider [their] opinion,” indicating that even they expect a certain level of participation. These data do not support our initial hypothesis that most patients do not want to participate in medical decision-making.

Demographic Characteristics Associated with Increased Level of Participation

Younger age and higher level of education were consistently associated with increased desire to participate in medical decision-making in the studies reviewed, supporting hypothesis 1B. This may represent a cohort effect, as patients currently over the age of 65 may be comfortable with a more paternalistic doctor-patient relationship because they are accustomed to a minimal level of participation. Alternatively, it may be an effect of increasing frailty with age, independent of generational cohort; as younger populations age and acquire more complicated medical problems, they may begin to acquiesce to physician authority.
Education level has been shown to be associated with decision-making preference, even when controlled for age (11). In qualitative studies, the most frequently stated reason for not participating in medical decision-making was a lack of medical knowledge. Consequently, patients with less than a high school education may feel the knowledge gap more acutely and be unconfident of their ability to make informed decisions.

**Effect of Separating Problem-Solving Tasks on Patient Desired Level of Participation**

Studies separating problem-solving tasks from decision-making tasks classify a significantly smaller proportion of patients as passive, supporting our second hypothesis. However, the small number of studies attempting to disentangle these elements limits the number of conclusions that can be drawn from this result. Deber’s original study in 1996 showed a clear, reproducible difference between patient desire to participate in problem-solving tasks and decision-making tasks. We reviewed 30 studies published after 1996, and although Deber’s study was frequently cited, only five studies attempted to separate these elements and only two studies published after 1996 utilized the Problem-Solving Decision-Making Scale (24, 44), one of which Deber co-authored. The paucity of follow-up studies utilizing the PSDM Scale highlights a potential gap in our current understanding of the subtleties of patients’ desire to participate. The widespread belief that most patients do not want to participate in decision-making may no longer hold true if investigators differentiated between desire to participate and desire to problem solve. Furthermore, it has not yet been determined if the associations between passive role
selection and older age or lower education level will persist if problem-solving tasks are clearly separated from decisions.

**Patient Roles in Actual Clinical Encounters**

This review showed consistently low congruence between patients' preferred role and the actual decision-making role they played in a clinical encounter, supporting our third hypothesis. The biggest discrepancy was within the group of patients wishing to play collaborative roles, as less than 50% on average attained that level of participation. This is a clinically significant discrepancy, as patients desire a collaborative role most frequently and congruence between desired role and actual role is associated with increased patient satisfaction. Studies have not determined conclusively why this disparity exists. It is unclear whether something inherent in the clinical encounter, such as doctors' attitudes or time constraints, prevents patients from reaching their desired role, or if, when faced with an actual decision, patients change their minds regarding preferred role and want to relinquish more responsibility.

Further research needs to be done to explore ways that doctors can facilitate patient participation. Elwyn, *et al.*, surveyed the available literature on interventions encouraging patient participation and concluded that there was a lack of instruments designed to methodically evaluate whether physicians are able to effectively involve patients in decisions (92). Development of such instruments could also help physicians to cultivate behaviors that encourage patient participation.
Validity of Measurements in Reviewed Studies

The question must be raised whether the reviewed studies have successfully measured patients’ desire to participate in medical decision-making. One could argue that the Strull and CPS questionnaires measure patients’ desire to be decisive, not their desire to participate in the process. The exchange of information from patient to doctor—what benefits the patient hopes to gain from treatment, and at what cost, literally and figuratively—is a vitally important part of the decision-making process, and it is entirely separate from deciding which treatment is best. Subsequently, the weighing of options, the trade-off of risks and benefits with patient utilities, is a dynamic, engaging process requiring patient involvement. Yet the current instruments focus almost exclusively on who takes responsibility for ultimately selecting a particular intervention or treatment.

Entwistle, et al, examined actual roles played by 20 women deciding whether to have a hysterectomy. The study compared free response narratives by patients describing the decision-making process with a forced-choice selection using Degner’s and Sloan’s Control Preferences Scale. The investigators found that over half of the women’s narratives described levels of involvement inconsistent with the CPS role they reported playing. Study participants often focused on their participation during one specific moment of the decision-making process, whether or not this moment was representative of their involvement throughout the process. The authors argue that current instruments focus too much on who ultimately makes the final decision. Entwistle concluded that, because making treatment decisions was often a multi-step process, the CPS could not provide an accurate picture of patient involvement (93).
The validity of classifying a patient as active, passive or collaborative based on their selection of decision-making roles must also be examined. For instance, patients stating that they wanted their doctor make the decision but “strongly consider [the patient’s] opinion,” are labeled as passive. However to play this role, a patient must weigh the available options, formulate an opinion and voice that opinion. These patients would veritably be active participants throughout the entire decision-making process, yet they are labeled as “passive” and lumped in with patients who prefer to have no input in decision-making at all. This is a disservice to patients, because it perpetuates the misperception that a large proportion of patients prefer a paternalistic style.

The Desire for a Recommendation

The desire for a doctor recommendation is another issue that may cloud interpretations drawn from measuring the desire to participate. Psychologists have shown that individuals approaching a decision often fear that they will feel personally responsible if their choice results in unfortunate consequences. This belief may make patients reluctant to select an option on their own, without a doctor recommendation, because they do not wish to feel responsible for the occurrence of associated risks or side effects (94). Perhaps, in addition to separating out problem-solving elements from decision-making tasks, studies need to separate out desire for a recommendation from the desire to participate in medical decision-making. It is possible that current instruments are likely to classify otherwise active patients as collaborative or passive based solely on their desire for a recommendation. It is logical that patients, seeking an expert opinion
from a doctor, might not want to choose an option without a doctor first validating that choice with a concordant recommendation.

Johnson, et al., surveyed 76 breast cancer patients and found that 80% wanted to participate in decision-making, but that 74% of patients wanting to participate also wanted a doctor recommendation (73). Bradley, et al., studied the preferences of 52 clinic outpatients, using a newly developed questionnaire offering seven role choices to patients. Three roles portrayed the doctor making the decision, giving differing amounts of information and rationale. One intermediate role stated simply that the patient and the doctor share the decision-making responsibility. Three roles portrayed the patient making the decision, while receiving information and a recommendation from the doctor, receiving information only, or receiving neither information nor a recommendation. The most commonly picked role was “I make the decision with the doctor giving me both information and a recommendation,” illustrating that desires for both decision-making autonomy and a doctor recommendation are not mutually exclusive, and rather, are frequently concomitant (72).

**The Reciprocal Model of Decision-Making**

Shared decision-making, in its many forms, best embodies a compromise between paternalism and patient autonomy. The paucity of patients preferring to make decisions by themselves suggests that patients would not be in favor of pure patient autonomy, where decisions are left solely to the patient. Any model giving more authority to the physician than the patient cannot reliably provide optimal care, because only the patient
can decide whether the expected benefits outweigh the consequences of a treatment option.

Paternalism flourished in a time when treatment options were limited, and courses of action were fairly straightforward. With the advances of pharmacologic and interventional therapies, a single diagnosis often presents a myriad of medically acceptable treatment options. Evidence-based medicine frequently contradicts itself, and interpretations are often ambiguous (12). It is unclear whether patients understand the concept of medical uncertainty, or comprehend that a discussion of their values is often vitally important to navigate between the choices. Physicians have an obligation to explain this uncertainty to ensure informed decision-making.

We suggest a new model of shared decision-making, the Reciprocal Model (Figure 12). This model, like other models of SDM, emphasizes the give and take of information from both parties, but also emphasizes a system of checkpoints wherein the doctor ensures that the patient has understood the risks/benefits of the treatment options, and the patient ensures that the doctor has understood the patient’s values. The model allows the patient to request a recommendation without sacrificing involvement and gives the power to the patient to accept or reject a recommendation.

In this model, the doctor, after having completed problem-solving tasks, explains the treatment options, with risk/benefit profiles, to the patient and stresses that different patients might choose different options for different reasons. The patient, prompted by the physician, discusses his/her expectations of treatment benefits and debates the acceptability of risks, side effects, costs, and inconveniences of treatment options.
Figure 12: Reciprocal Model of Shared Decision-Making
A narrowing of the list of treatment options is undertaken together by both doctor and patient, whereby clearly unfeasible options per patient values are excluded.

The patient can then either choose one option from the narrowed list, or ask for a recommendation from the doctor. If the doctor offers a recommendation, he/she must also explain the reasons why the option best fits with the patient values, allowing the patient to double-check that the personal values have been correctly interpreted and honored. The patient can then either accept or reject the recommendation. In the end, a mutually agreed upon treatment option which encompasses a patient’s utilities will be selected, and both parties will have participated, irrespective of who suggests the final option. Our findings in the review suggest that this would be a beneficial model for shared decision-making, and we recommend further study of the application of the Reciprocal Model.

**Implications for Clinical Practice**

Studies indicate that patients have a limited desire to participate in problem-solving tasks because they feel they lack necessary medical knowledge. Physicians need to clearly communicate to patients that the problem-solving tasks of the decision-making process have been completed, and they need to emphasize to patients that choosing between the treatment options often becomes a personal, rather than medical, decision. Patients’ reluctance to participate due to lack of knowledge can also be minimized by physician efforts to provide information and promote patient education. Physicians should offer patients resources such as pamphlets, reading lists and validated decision-aids, when available. Physicians can encourage patient education by providing addresses
to Internet sites endorsed and validated by medical professionals, as well as contact information for organizations such as the American Heart or Cancer Associations, when appropriate.

Many patients may want to hear their doctors’ opinions on advisable courses of action. Physicians should offer to provide a recommendation if directly asked, or if the patient seems overwhelmed by the responsibility. However, a recommendation should only be offered after the patient’s utilities have been thoroughly explored so that the option reflects the patient’s wishes, not the doctor’s inherent biases. It is clear that patients’ preferences for involvement in decision-making is highly variable and difficult for a physician to predict. Therefore it is necessary for physicians to be flexible in approaching decision-making with a new patient.

It would be overly simplistic to suggest one model for every occasion. Shared decision-making is often impossible in an emergent situation and often impractical in others. Moreover, decisions between patients and physicians are not made in a vacuum; multiple third parties must be acknowledged. Limitations imposed by hospital policy, insurance companies and governmental fund allocation affect the feasibility of treatment options (1). Needs of family members and caregivers of patients are often equally important to consider. But these limitations can be considered without sacrificing the power balance of shared decision-making.

**Conclusion**

Our results concur with previous reviews regarding the enormous variability of patients’ desired levels of participation. However, in our review, an overwhelming
majority of patients wished to have some level of involvement in the decision-making process. This finding provides support for the continued practice of shared decision-making in clinical practice and stresses the flexibility physicians must exhibit in approaching a treatment decision.

Our critique also emphasizes several limitations regarding the interpretations and conclusions that can be drawn from the results of these studies. Further work is indicated to develop more inclusive instruments to measure patient desire to participate, more methods to measure patient involvement in clinical encounters, and more ways to examine physicians’ abilities to involve patients in decisions. Further work is also warranted to develop effective methods of teaching shared decision-making to professionals to facilitate its application in clinical practice.
Bibliography


Unpublished theses submitted for the Master’s and Doctor’s degrees and deposited in the Medical Library are to be used only with due regard to the rights of the authors. Bibliographical references may be noted, but passages must not be copied without permission of the authors, and without proper credit being given in subsequent written or published work.

This thesis by has been used by the following person, whose signatures attest their acceptance of the above restrictions.

NAME AND ADDRESS

DATE