

Annotated Bibliography: Beyond Informed Consent

Fred R. Murray MA

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Overview

Objectives:

- 1) To review key literature concerning shared-decision making
- 2) To provide insight into the scope of the literature to assist course planners define learning objectives for participants.
- 3) To identify key methodology resources to aid course designers

Data Sources:

Journal articles (primarily from MEDLINE database), books and edited books.

Study Selection:

Journal articles were mainly selected using the National Library of Medicine's online search service, [PubMed](#).

Three main methods were used to select articles:

- 1) Key search terms were determined by comparison of MESH headings of a group of articles listed by actuating PubMed's Related Articles function. These included: physician patient relations, physician patient communication, informed consent, decision making, physician role, patient participation.
- 2) PubMed search for key authors' names, MESH headings and some text words (e.g. shared decision-making) yielded a selection of articles. Once 'good' articles had been identified, PubMed's 'related articles' function was used to search for articles of a similar nature.
- 3) Hand search of bibliographies of selected articles
Searches were downloaded into ENDNOTE 3.0, a personal bibliographic database program. Duplicate entries were eliminated. This process yielded 650 articles. 76 of these were selected for inclusion in this bibliography by virtue of their fit to main topic areas defined by a brainstormed outline and accessibility online or through a medical library.

Data Extraction:

Data was extracted in accordance with the guidelines recommended by Haynes (1990) for review, research, and opinion articles. After each resource was abstracted, it was coded for its content.

A. Content of Message

- 1) What information
- 2) How much information
- 3) Timing of information
- 4) Tone
- 5) Interaction of message with, method, environment, physician and patient characteristics
- 6) Type of message
- 7) Descriptors used

B. Method/Model

- 1) How decisions are reached now
- 2) Pros/cons
- 3) Physician perspective of effectiveness
- 4) Patient perspective of effectiveness
- 5) Recommendations for how decisions should be shared
- 6) Situational choices of approaches (e.g. with surrogates)
- 7) Best/recommended practices, curricula, training methods

C. Physician Characteristics

- 1) Experience
- 2) Gender
- 3) Practice type
- 4) Knowledge of the disease
- 5) Perceptions of the patient's wishes
- 6) Knowledge of the patient
- 7) Past experience
- 8) Medical training impact on decision making
- 9) Medical training impact on communication skills/style
- 10) Style: authoritarian vs. partnership building
- 11) Busy practice
- 12) Attitudes, beliefs, values
- 13) Race

D. Patient Characteristics

- 1) Age: infant, child, teen, adult , senior
- 2) Mental status: e.g. dependant adult
- 3) Gender
- 4) Level of education
- 5) Socioeconomic status
- 6) Race/ethnic background
- 7) Attitude
- 8) Role – e.g. parent, child
- 9) Stressors – illness, money, family responsibilities
- 10) Preferences for shared decision making
- 11) Expectations
- 12) Experience

E. Effects of Shared Decision Making

- 1) Patient not taking advice/ accepting patient's decision or withdrawing from case
- 2) Changes (pro/con) in the physician/patient relationship
- 3) Education/comprehension
- 4) Health benefits

F. Blood and blood products

- 1) Krever Inquiry implications

G. Legal Implications

- 1) Responsibilities

Data Synthesis
Conclusions/Recommendations

A. Content of Message

Much of the literature in this area focuses on questions surrounding meeting the legal and ethical requirements of 'informed consent'. (e.g. Do patients want information? How much information? How is that information best shared (particularly related to descriptors associated with risks and benefits)?)

Legally, physicians must share information about the nature of the problem, the procedure or treatment alternatives available, the risks and benefits of each. Some authors suggest that the process should include additional steps of assessing patient's understanding and giving patients a clear opportunity to voice a preference.

Patients want information. They may not, however, want this information in order to make a final decision about their own medical care. Such decisions are often left to the physician. Also, although patients often want their family or close friends informed, they still tend to prefer that their physicians make decisions for them. Several reasons for these findings are postulated: 1) patients adopt a 'sick role' or an almost childlike dependency on caregivers (passive, wanting to be cared for), 2) patients take their cue from the manner and actions of physicians and other health professionals, 3) patients are not given the chance to make decisions, 4) passivity may be a cultural norm

The issue of whether patients are capable of understanding the medical information presented has been made moot by the legal requirement that disclosure must be in terms reasonable patients would understand.

When informing patients about the risk potential of various treatments, physicians are recommended to use both quantitative and qualitative/numerical descriptors. The literature points out the high variability of patients' perceptions of verbal (e.g. "minimal risk") and numerical (e.g. 1/100,000 or 80%) terms.

How much information and when should it be shared? The answer it seems is that *it depends*. North American studies tend to support the idea that patients expect and should be told everything they want to know. However, some of the literature addresses an ethical position that physicians should *not* disclose information the patient (and maybe the patient's family) might not want. Effectively, it is as much the patient's right to receive information as it is to *not* receive information. There may be cultural influences in this. In Spain and in Japan, physicians often do not disclose the nature of the serious illness to the patient either by unilateral decision or by one in concert with family members. Conversely in the U.S., physicians routinely tend toward full disclosure. Dealing with the questions in a practical sense, physicians need to communicate effectively with patients to determine their desired level of information.

B. Method/Model

The decision-making models discussed extend along a continuum of inversely related physician/patient control. At one end there is the traditional/paternalistic model where the physician makes the decision without much patient input. At the other end is the 'patient-as-consumer' model, where the patient exercises 100% of the decision making responsibility and the physician's role is to provide adequate information for the patient to make an informed decision. Between these two extremes is the 'partnership model' (physician and patient share decision making).

Concerns are levied about the models at either end of the

continuum. Are patients capable of making good medical decisions? Do they really want to? Ethically, should they be able to access treatments that may not be beneficial or appropriate. At the other end, concerns center on how physicians can make decisions for patients when: 1) they are often unaware of the patient's values and beliefs, 2) they are often poor judges of patient expectations for treatment (e.g. prescriptions), and 3) often there is considerable medical uncertainty between alternative courses of actions.

Shared decision-making represents a middle ground. It brings forward the strengths of each position. The physician provides information and provides medical expertise. Patients provide information about what they are experiencing, express their values and beliefs and decisions are made collaboratively.

Decision-making is also influenced by the contexts of care (e.g. the severity of the illness or injury, implications of proxy decision-makers, advance directives.). Decision-making styles preferred by physicians and patients and the interaction of each also factors into the equation.

The recommended or *best practice* regarding information sharing and decision making is one of *sustained partnership*. It can be considered to be part of the shared decision making model. It is grounded on a strong physician patient relationship, which in turn is based on strong communication skills and longevity of the relationship. From the first interview, physicians should make it clear that decisions are a shared responsibility. The physician's role is to provide the patient with information they need to understand the problem at hand, the treatment alternatives, the risks and benefits. The patient's responsibility is to disclose the information about their health that the physician requests as well as disclosing their own values and beliefs (not easily apparent to physicians otherwise). Together the physician and patient will negotiate a decision about treatment. Physicians should endeavour to get a comprehensive picture of the patient's values and beliefs and offer them assistance in preparation of advance directives. Decision-making level of control should be tailored to the express wants and needs of the individual patient.

Information is a key element described in the decision making process. Physicians are encouraged to provide patients with the information they need, to the depth they desire and in a form that they can understand. The literature recognizes the time intensive nature of this educative process. While it is considered to be part of the physician's legal responsibility and generally beneficial to the physician patient relationship, a number of alternatives are presented to the one-on-one process. (e.g. Email, web pages, health pamphlets, use of audio-taped interviews so the patient can go back over information discussed, and interactive videodisk programming...)

C. Physician Characteristics

Any number of variables can influence physician's style or approach to decision making. For example, it appears that strong socialization processes in medical training, the physician's gender, type of practice and whether he/she has participated in communication skills training all have an impact.

It is important for physicians to have strong communication skills and to recognize the filtering effect of their own attitudes, values and beliefs on communication with patients. Michael Balint suggested that the physician was the most frequently used 'drug' in medical practice and that learning about its properties was most appropriate.

It is also important for physicians to recognize the context of health care. They may be advocates but they are also gatekeepers. They possess more medical knowledge and understanding of the disease process. They are often of higher socioeconomic status than their patients are. They may also be under constraints of time enforced by health care management. These factors all conspire against partnership.

D. Patient Characteristics

The literature suggests many variables that can affect the physician patient relationship and the patient's role in shared decision making. While most patients want information, most also defer to their physicians in making decisions about their medical care. For example, older, less educated, non-white, married male patients and those with lower economic standing appear to be more likely to adopt a passive role. However, it must be pointed out that within each of these classifications there is tremendous variability. Some older patients, for example, want to have 100% control over medical decisions. Statistics, however, point simply to correlation not causation. The effects of multiple patient characteristics or of context (e.g. severity of illness) on adopted roles is not well understood.

Individual patients should be treated as individuals. Just as physicians should try to understand the impact of their own characteristics in this communication equation, so should they try to understand the patient's. Active encouragement must be given patients to ensure they ask the questions they want answered.

E. Effects of Shared Decision Making

Some evidence is provided suggesting benefits of shared decision-making processes to health outcomes, development of a strong physician patient relationship, the bi-directional flow of information and health care costs.

Shared decision making does not necessarily mean that the *best* medical decision is agreed upon. Nor does it suggest that there is equal partnership. It does suggest that decisions that are reached are mutually acceptable (though this might not be completely the case if the physician opts to withdraw from the case and refer the

patient).

F. Blood and blood products

Shared decision making issues around use of blood or blood products in treatment appear not to be much different than that required for other medical procedures or treatments. Patients have a right to full disclosure of the problems, alternatives to treatments, and the risks and benefits of each. They have a right for the information to be presented in such a manner that they can understand the associated implications. They also have a right to participate in the decision making process.

The Krever Commission of Inquiry of the Canadian Blood Supply has brought to the fore a pervasive problem in 'informed consent'. Physicians are aware of risks of treatments and procedures and often have made decisions on behalf of their patients, effectively not giving them an opportunity even for input in the decision. This is not acceptable. Krever's recommendations include:

1. explanation of risks and benefits of, and alternatives to, allogenic blood transfusion in language the patient will understand. The description is to be compared to other risks (e.g. risks of anaesthesia or of a surgical procedure),
2. opportunity for the patient to ask questions, repetitively if necessary, such that he/she will understand there is no such thing as zero risk,
3. that the patient's express consent is received sufficiently prior to the procedure that an alternative to blood transfusion, if necessary, is possible,
4. that all patients are informed of the blood product(s) used and the quantity administered.

Physicians should not presume to accept risk that is not theirs to assume. Steps taken to share decision-making should be documented in the patient's record. There may also be some expectation that reasonable efforts must be made to inform past patients about new knowledge concerning potential health risks derived from the use of blood products.

F. Legal Implications/Responsibilities

The literature traces decision making, informed consent and malpractice from the historical roots in the 1900's to present. It documents a shift in legal thought from physician-centered to patient-centered approaches. The most recent test is one that recognizes the level of information that a *reasonable patient* may want to have to be able to make an informed decision. Specifically, physicians must discuss the nature of the problem, the alternatives of treatments, and the risks and benefits of each. They must also be sure that the patient understands the implications associated with decisions.

The literature supports the underlying ethical principles of 'informed consent' as a patient right and further suggests that such consent needs to be considered for all treatments and procedures, no matter how insignificant (there is discussion about the practicality of this position however).

Brody (1980) recommends that 'informed consent' be seen as part of a larger process of *mutual participation* in decision-making, a clinical approach.

1. Establish a conducive atmosphere (open-ended questions, prompt response to patient's questions, encouragement of questions).
2. Ascertain patient's goals and expectations (persistent inquiry usually following description of the nature of the problem to the patient)
3. Educate the patient (informed consent: nature of problem, pros and cons of alternatives, evaluation and treatment approaches, and - when warranted - the physician's recommendations)
4. Elicit patient's informed suggestions and preferences and
5. Negotiate any disagreement between physician and patient.

The literature also addresses issues around advance directives and surrogate decision making. It describes the challenges of using advance directives (Proxy/Agent unavailable; advance directive not available, not in a useable form, not providing sufficient direction concerning vital issues, or not current – i.e. addressing issues of significance to the individual at the current stage of life or health condition). There is a general recommendation for physicians to assist patients to express their wants, needs, and values pertaining to medical care. Further it is suggested that physicians should help patients define their wishes in advance directives by explaining the ramifications of such decisions and the circumstances that might arise.

H. Training Issues

The complexity of the communication involved in shared decision-making makes it imperative that participants in this course be afforded skills training that is evidence and problem-based, experiential, recursive and builds on prior learning. A short course cannot be expected to describe or offer experiences in dealing with every eventuality. However, representative issues and tasks might include: 1) the interview with the new patient (setting the tone for future transactions), 2) shared decision-making concerning 'routine' procedures/treatments, 3) encouraging involvement in decision-making by patients who tend toward passivity, 4) building rapport in order to explore patient's values and beliefs, 5) involvement of family and surrogate decision makers, 6) opportunities for physicians to share their expectations for shared decision-making by supposing they were the patient, 7) brainstorming solutions for how physicians can involve patients more in decision-making and how physicians can provide patients with relevant information.

Annotated Bibliography

1. Annas, G. J. (1995). Women and children. *N Engl J Med*, 333(24), 1647-51.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=7477216&form=6&db=m&Dopt=b>

Description of Context:	This article discusses the impact of what the author calls 'market-driven managed-care medicine' on discharge of new mothers from hospital.
Topic/Scope:	The author describes the pressure exerted on physicians for early discharge of women and infants by health management organizations and the legislation that is now appearing to put this decision back into the realm of the physician and patient. He argues that currently obstetricians and pediatricians cannot exercise appropriate medical judgement when under intense pressure to contain costs. He notes that a proposed federal law will put the final decision about whether a woman will be allowed to stay for a full 48 hours in hospital post-delivery will be up to the woman. This extends beyond the collaborative decision-making model used by the American Academy of Pediatrics (AAP) and American College of Obstetricians and Gynecologists (ACOG.) The article draws a parallel between the legislative approaches on this issue to one taken for Emergency Medical Treatment and Active Labour. The author advocates for legislation that will put protection of patients before business profits. He considers that such legislation will do so defining a minimum standard of care and by supporting decisions made within the doctor-patient relationship.
Conclusions/Recommendations:	<p>The environment in which health care decisions are being made extend beyond the immediate physician patient relationship. This article points out the pressures that HMO's might bring to bear on physicians and other health care providers, who in turn may exert their own influence on patients. Decisions should be made in the patient's best interest. Patients should have considerable input to medical care decisions - if not the final decision.</p> <p>[FRM Note: This article is mainly a political commentary. It does, however, address a significant issue in the changing environment of health care. HMO's and other approaches that make health care businesses or compete like businesses can change the fundamental relationship of trust in the physician-patient relationship. They add another variable to the complex equation of physician patient communication. Patients are forced to look beyond the straight forward discussion with their physician (informed consent) to seek underlying reasons for physicians recommendations. They are being treated like consumers rather than patients.]</p>

2. Annas, G. J. (1998). A national bill of patients' rights. *N Engl J Med*, 338(10), 695-9.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=9487001&form=6&db=m&Dopt=b>

Description of Context:	In January of 1998 President Clinton called upon Congress to enact a national bill of rights in health care. The author describes the historical context leading to this initiative and discusses some of the features of proposed legislation.
Topic/Scope:	This article provides a brief description of the history of patient rights, the

rise of consumerism in health care in the U.S. and a discussion of elements needed for a national bill of patients' rights. It touches on the patients' right for decision making unfettered by financial conflicts of interest imposed by health management organizations. It lists 'Rights' the author believes are necessary: 1) right to treatment information, 2) right to privacy and dignity, 3) right to refuse treatment, 4) right to emergency care, 5) right to an Advocate.

Conclusions/Recommendations: The author believes the basic outline of a national bill of rights for patients, provided by the President's Commission, shows promise of returning the trust relationship between physicians and their patients.

[FRM Note: this article covers a lot of ground in legal and ethical considerations of the the physician patient relationship. It lauds the proposed Bill of Rights as a means to empower both the patient and the physician to make shared decisions in the patient's best interest.]

3. Barber, N. (1995). What constitutes good prescribing? *BMJ*, 310(6984), 923-5.

http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?db=m_d

Description of Context: A model of good prescribing is offered that takes into account risks and benefits, the need to reduce costs, and the right of the patient to make choices in treatment.

Topic/Scope: The prescriber of medication should have four aims: to minimize risk, to maximize effectiveness, to minimize costs and to respect the patient's choices. The latter might be considered of utmost importance since it is the patient who ultimately decides if he/she will fill the prescription, take the drugs or use them in the manner suggested. The author contends that listening to patients' choices for the medications (e.g. taste, route, effectiveness, side effects, frequency, cost...) and informing them so they can make or review these choices has a dual benefit: 1) it enhances the physician patient relationship, 2) may improve compliance. The author comments on the challenge of pressure on prescribers from agencies demanding cost control and from patients demanding unnecessary or ill advised treatments (e.g. a name brand rather than a generic drug or antibiotics for viral infections).

Conclusions/Recommendations: A case is made for involvement of the patient in the decision making process about pharmacologic treatments.

4. Beckman, H. B., & Frankel, R. M. (1994). The use of videotape in internal medicine training. *J Gen Intern Med*, 9(9), 517-21.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=8002688&form=6&db=m&Dopt=b>

Description of Context: This article explores the use of videotape as a teaching tool for communication skills

Topic/Scope: The article discusses the advantages and disadvantages of videotaping communication skills training sessions. It also provides a guide to

facilitating a successful videotaping program and potential barriers.

Conclusions/Recommendations:

Videotaping, when properly employed, can be a powerful tool for teaching communication skills. Learners or groups of learners can review their own behaviour and problem solve methods to improve their performance. The learning opportunity is enhanced with feedback from other group members and a trained facilitator. By maintaining an archive of videotapes physicians can see their progress over time. The process is not without pitfalls. Shared decision making requires effective communication between physicians and patients. Through analyzing communication behaviours on a videotape learners can become more skilled at recognizing verbal and non-verbal cues to patients desire for more information or more input into the decision making process.

[FRM note: This is a concise overview covering the use of videotape as a teaching tool.]

5. Beckman, H. B., Markakis, K. M., Suchman, A. L., & Frankel, R. M. (1994). The doctor-patient relationship and malpractice. Lessons from plaintiff depositions. *Arch Intern Med*, 154(12), 1365-70.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=8002688&form=6&db=m&Dopt=b>

Objective(s):	To gain insight into the issues that prompted individuals to file a malpractice claim
Design:	Descriptive review of randomly selected plaintiffs' depositions in settled malpractice suits. Information extracted included demographic information about the plaintiff, details about the case, information about the defendant, why the plaintiff was suing, and explicit description of any difficulty in the relationship between the health provider and the patient.
Setting:	N/A
Subjects:	45 plaintiffs having given discovery depositions in settled malpractice cases
Interventions:	None
Measures:	Retrospective analysis of frequency of various type of relationship difficulties. Consensual validation of categories of problem relationship issues.
Results:	Most of the plaintiffs were the patients themselves. 20% were the patient's spouse. Plaintiffs were generally young and well educated. Relationship issues were identified in 71% of the depositions. These were categorized into four categories of problematic relationship issues perceived by the patient: 1) not understanding the patient and/or family perspective (13.1%), dysfunctional delivery of information (26.4%), 3) devaluing patient and /or family views (28.9%), and 4) desertion (physician being unavailable or sending a surrogate, patient feeling abandoned)(31.6%).
Conclusion(s):	Patients filing malpractice suits often have issues with their physician's communication skills and style of relating to them. Encourage physicians to adopt a more patient-centered approach.

[FRM Note: The sample size of this study is relatively small but it is interesting because it deals with physician patient relationships that have ended very badly - the patient filed a malpractice suit. That communication skills were so strongly implicated in these cases is worthy of note. The message drives home that physicians are judged as much by their perceived attitudes as by their medical skill.]

6. Beisecker, A. E., & Beisecker, T. D. (1990). Patient information-seeking behaviors when communicating with doctors. *Med Care*, 28(1), 19-28.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=2296214&form=6&db=m&Dopt=b>

Objective(s):	To determine: 1) To what extent do patients desire information from physicians? 2) To what extent do patients feel they should make decisions? 3) To what extent do patients engage in information seeking communication behaviour during medical encounters? 4) What factors influence or explain patient information seeking behaviours?
Design:	Comparative study - sociodemographic survey prior to the patient's interaction with the physician, 2) tape recording of the entire interaction, 3) tape recorded interview with the physician immediately following the interaction, 4) opinion survey mailed to the patient 10 days after the appointment
Setting:	University based rehabilitation medicine outpatient clinic
Subjects:	Patients: Convenience sample of 106 patients (42 men and 64 women) ranging in age from 17 - 85 years and suffering from a wide range of physical ailments and disabilities one might expect at a rehabilitation clinic. Physicians: Psychiatrists
Interventions:	None
Measures:	Sociodemographic survey - age, gender, race, marital status, education, occupation, income and prior experience with the physician to be seen. Opinion survey - Beisecker: Desire for Information Scale and Locus of Authority in Medical Decision-making. Two coders counted patient communication information seeking behaviour. Hierarchic regression analysis performed to investigate whether or not patient information-seeking behaviour was related to antecedent variables (demographics, type of illness, reason for visit, first vs. repeat visit...).
Results:	Patients desired as much information as possible on a wide range of subjects (Mean score = 64.9 in a possible range from 14 - 70; Mode = 70). Patients on the whole preferred to defer to physicians for decisions ($p < 0.0001$). Patients exhibited on average 3.4 information seeking behaviours during their interviews (SD = 4.3, Range = 0 - 24). 30 patients made no attempts to seek information, even though many indicated a strong desire for information. Information seeking behaviour is not influenced strongly by sociodemographic characteristics. The length of the interview, the patient's diagnosis and the specific reason for the patient's visit had an important impact on the number of information seeking behaviours made by

the patient. Patients with interactions with physicians for more than 18 minutes, those patients who indicated that patients should be the locus of decision making authority, older patients and those not coming for a disability evaluation tended to seek more information. Interviews in this study lasted on average between 18 - 19 minutes.

Conclusion(s): Indicated desire for information often is not translated into information seeking behaviour by patients. Although patients in the rehabilitation clinic setting indicated a strong desire for information many did not actually seek information or made little attempt to solicit information from their physician. Information seeking behaviour by patients seems to be influenced by situational variables (e.g. length and purpose of the medical interaction) more so than the patient's sociodemographic characteristics. Despite expressing desire for information, patients also indicated that medical decision making was mainly the physician's role or responsibility.

7. Beisecker, A. E., Murden, R. A., Moore, W. P., Graham, D., & Nelmig, L. (1996). Attitudes of medical students and primary care physicians regarding input of older and younger patients in medical decisions. *Med Care*, 34(2), 126-37.
<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=8632687&form=6&db=m&Dopt=b>

Objective(s): To determine whether: 1) physicians, residents and medical students vary in their attitudes toward decision making input from patients, 2) they believe physicians should have greater input than patients, 3) physicians grant younger patients different decision-making authority than older patients, 4) physician gender affects their attitudes toward patient input to decision-making

Design: Systematic allocation of three sample groups (medical students, residents, physicians) into two study sub-groups. The sub-groups were asked to respond to a vignette about either a 25 or 75-year-old patient, indicating about the locus of control for making 13 medical decisions. Due to alternate assignment of subjects drawn from an alphabetized list approximately 50% of each sample group was represented in each sub-group.

Setting: Faculties of Medicine at two large mid-western US universities

Subjects: First year (n=311), third year (n=227), family medicine or internal medicine residents (n=120) and medical faculty (n=160). 69% were male.

Interventions: One group answered questions about vignette involving a 25-year-old patient. The other group responded to the same vignette but the age of the patient was described to be 75 years.

Measures: Descriptive statistics (mean, standard deviation, and standard error), t-test for comparisons to the scale midpoint. ANOVA differences in mean scale score by age of patient. Independent variables included gender, institution, and level of medical training. First year medical students' responses were deleted from the sample for secondary analysis of the influence of training level.

Results: Over half (51.5 - 90.6%) of the respondents indicated that both the

physician and patient should make decisions for 9/13 medical care issues. In 4/13 decisions, respondents indicated the locus of control should be with the doctor. These included: what information should be covered in the patient's medical history (58%), whether there is a need for more medication (64%), which drug to use (59%) and what dosage of a given drug to use (89%). (Note that 311 of total respondents were first year medical students)

As a large group, respondents were more apt to advocate greater decision making authority by the older patient than by the younger patient. Faculty (physicians) tended to advocate for greater decision making authority for the younger patient.

Attitudes favouring physician authority increased with increasing level of medical training. Students significantly favoured more patient involvement than did residents and physicians ($p < 0.05$). Faculty advocated significantly less patient input in decisions than did residents or students ($p < 0.05$). Women and those with less medical experience advocated greater patient input in decisions.

Conclusion(s):

There appears to be a socialization effect that happens with increasing exposure to medical training. Physicians and residents were significantly more apt to advocate for a physician locus of decision control over input from patients. The type of decision influenced the respondents advocated locus of control. Specifically, medical care issues concerning dosages, which drug, need for more medication and information to be covered in the medical history were claimed by over 50% of respondents to be the purview of the doctor.

[FRM Note: the results of this study have ramifications for marketing of this course. Physicians must be made aware of the discrepancy between patients expectations for some say in decisions and their position. It must be acknowledged that physicians are better able to make some decisions (e.g. dosages), but the position should be that patients should still be involved in some way even with these decisions.]

8. Blanchard, C. G., Labrecque, M. S., Ruckdeschel, J. C., & Blanchard, E. B. (1988). Information and decision-making preferences of hospitalized adult cancer patients. *Soc Sci Med*, 27(11), 1139-45.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=3206248&form=6&db=m&Dopt=b>

Objective(s):

To determine:

- 1) medical and demographic characteristics of those patients preferring to participate in their medical care versus those who prefer a more traditional physician patient relationship
- 2) possible impact on patient preference for participation in their medical care of specific physician behaviours.

Design:

439 physician patient interactions during morning rounds were observed. Physician behaviours related to role performance and technical competence were assessed using a checklist. Comments about patient diagnosis, prognosis and demographics were also recorded. Observers also assigned a subjective rating (0 - 100 scale) of the extent to which the physician met the patient's need during the visit, and the observer's perception of patient

involvement in the interaction. After morning rounds, observers returned to survey patient's perceptions about the physician's visit concerning such items as provision of information, allowing questions, consideration for the family and provision of emotional support. Patients were also asked to estimate the length of the interaction and to rate satisfaction with the day's visit, perception of level of involvement and the extent to which they felt their needs were met.

Setting:	University based hospital medical oncology ward
Subjects:	Hospitalized adult cancer patients being visited by five oncologists (mean age = 55, slightly more than half were male)
Interventions:	None
Measures:	Frequency data for specific physician behaviours, observer and patient rating scales of perceived value of the visit
Results:	<p>92% of the sample preferred that all information (good or bad) be given to them. 69% of patient indicated they would prefer to participate in decisions regarding medical care. The group of patients wanting all of the information was not different in sex, diagnosis and prognosis from the group of patients who did not. The group not wanting information was composed of older and sicker male patients.</p> <p>Younger patients ($p < 0.001$), those having been given a prognosis of less than 3 months or greater than one year ($p < 0.05$), and those who were not bedridden ($p < 0.001$) were more apt to want to participate in decision making. Lung cancer patients were more apt to want the physician to make decisions.</p> <p>The actual length of time of the visit or that perceived by the patient did not influence the patient's decision-making preferences.</p>
Conclusion(s):	<p>Cancer patients generally want to know all of the information - good or bad. Most want to participate in decisions about their care. However, since almost a third of cancer patients did not, some strategies need to be employed so as not to unwittingly overburden patients not wanting to participate.</p> <p>[FRM note: this article points out the complexity of the interaction between an array of variables that impact patient's desired level of participation in decision making. Noted are variables of age, sex, severity of illness, type of illness. Physicians need to deal with individual patients' needs, not base their style of interactions on group norms]</p>

9. Boisaubin, E. V., & Dresser, R. (1987). Informed consent in emergency care: illusion and reform. *Ann Emerg Med*, 16(1), 62-7.
http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?db=m_d

Formal review of this article was not undertaken because the description of the method and the results was rather sparse. Nonetheless it does offer some interesting commentary of the process of informed consent in a hospital emergency unit. Of particular note are comments about the process of having patients sign 'consent forms' prior to their being seen by physicians and not truly understanding the implications of such forms. This process does not meet the intent nor the spirit of *informed* consent and does little to enhance

the physician patient relationship or the patient's understanding of the medical decisions to be made.

10. Braddock, C. H., 3rd, Fihn, S. D., Levinson, W., Jonsen, A. R., & Pearlman, R. A. (1997). How doctors and patients discuss routine clinical decisions. Informed decision making in the outpatient setting [see comments]. *J Gen Intern Med*, 12(6), 339-45.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=9192250&form=6&db=m&Dopt=b>

Objective(s):	To describe the informed consent process used routinely in the offices of primary care physicians
Design:	Cross sectional, retrospective analysis of doctor patient encounters that were previously audiotape recorded for an educational program to improve patient communication. Tapes were randomly assigned to one of three coders who scored them according to six criteria (elements) for informed decision making: description of the nature of the decision, discussion of alternatives, discussions of risks and benefits, discussion of related uncertainties, assessment of the patient's understanding and elicitation of the patient's preferences.
Setting:	Primary care physicians' offices
Subjects:	44 primary care physicians from metropolitan Portland, Oregon. 54% were general internists, 46% were family physicians.
Interventions:	None.
Measures:	Coding of decisions, comparison of discussion leading to clinical decisions by Chi square or one-way ANOVA. Non-parametric approximations for Chi square and one-way ANOVA were used for nominal variables (e.g. decision type).
Results:	<p>Frequency and type of decisions: All clinical visits resulted in at least one decision (Mean =3.2 decisions/visit). Most common were decisions about medications (19%), diagnostic laboratory tests (15%), specific dietary or physical activity regimens (11%) and screening procedures (8%). Decisions requiring a signed consent form only occurred in 10% of the visits.</p> <p>Discussions leading to decisions tended not to meet the requirements of informed consent. 51% had only one element of the six required, 15% had none of the elements (Mean = 1.3 elements / discussion). No discussions contained all of the elements. The most frequently discussed element of informed consent involved the clinical issue and the decision to be made (83%). All of the remaining elements were discussed less than 20% of the time (Range: 2% - 19%). Decisions about management included significantly more elements of informed consent than those in the diagnostic category ($p < 0.05$). When written consent was required significantly more elements were addressed. The most frequently included element was 'the nature of the problem requiring a decision' (83%). Discussion of risks and benefits occurred in 9% of discussions. Least frequently (2%) were discussions about the patient's level of understanding.</p> <p>Management decisions more often included discussions about alternatives</p>

($p = 0.004$), risks and benefits ($p = 0.008$), than diagnostic decisions.

Conclusion(s):

Physicians rarely, if ever, engage patients in discussions involving all of the elements required for 'informed consent'. In some instances they discuss none of the elements. The author suggests three possible reasons why more complete discussion does not occur: 1) physicians fail to recognize some decisions as needing informed consent (e.g. routine blood and other diagnostic tests), 2) physicians consider that extensive discussion is more appropriate for some clinical decisions than for others, 3) physicians are busy and are not compensated for extra time spent with patients in lengthy discussions.

Identify practical suggestions to help physicians conduct brief, focused, yet comprehensive interviews with patients. Encourage physicians to practice these communication skills.

[FRM Note: this article points out that within the practice environment busy physicians will often take short cuts in 'informed consent'. Although it stresses the bioethical rationale for discussion of the elements in even routine clinical practice, it does recognize that in some situations discussion of all elements is impractical and perhaps not clinically necessary. Many patients want more information and to participate more completely in decisions to be made for their medical care. Others may prefer to let the physician make decisions and are content with limited information. The solution seems to rest with acquiring the skills necessary to strengthen the physician patient relationship - where physicians have a solid understanding of the patient's values and beliefs and patients are comfortable asking for more information. This requires prior explicit discussion with patients about their preferences and periodic affirmation of continued desire for whatever levels of information the patient has chosen.]

74. Brody, D. S. (1980). The patient's role in clinical decision-making. *Ann Intern Med*, 93(5), 718-22.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=7212484&form=6&db=m&Dopt=b>

Description of Context:

Traditionally physicians have taken a paternalistic approach, making decisions for patients. The patient's role was to be passive, dependent and compliant. This is no longer true. Ethical and moral justifications, malpractice claims and judgements, the stances taken by medical professional societies and demands of patients all exert pressure on physicians to change and for patients to assume greater levels of autonomy.

Topic/Scope:

This article describes the traditional approach to decision-making and various factors influencing the change in patient role and level of autonomy. Models of participation are presented (activity-passivity, guidance - co-operation, mutual participation) and a four step clinical approach for *mutual participation* is suggested.

- 1) Establish a conducive atmosphere (open-ended questions, prompt response to patient's questions, encouragement of questions).
- 2) Ascertain patient's goals and expectations (persistent inquiry usually following description of the nature of the problem to the patient)
- 3) Educate patient (informed consent: nature of problem, pros and cons of alternatives, evaluation and treatment approaches, and - when warranted - the physician's recommendations)
- 4) Elicit patient's informed suggestions and preferences, and

5) Negotiate any disagreement between physician and patient.

The article outlines potential advantages of mutual decision-making. It stresses the ethical position that in light of medical uncertainty, the inability for physicians to know everything (medical knowledge as well as patient's values/beliefs), the arbitrary nature of many medical decisions, and benefits that can be derived (enhanced physician patient relationship, patient outcome benefits, and potential cost benefits) there is just cause for physicians to adopt a different approach.

Conclusions/Recommendations:

The author states that the patient role in decision-making is a complex issue without universal solution. He recommends physician approach patients as individuals and tailor efforts to engage patients in decision-making to the needs and preferences of each.

[FRM Note: this article is useful for its description of general steps toward creating a climate conducive for patients to begin to participate in decision-making. It seems to be written for clinicians and it uses arguments that might tend to engage them and promote their trial of 'new ideas' about involving patients in decision-making.]

11. Capen, K. (1995). Informed consent and blood transfusions: what does Krever's interim report mean to doctors? *CMAJ*, 152(10), 1663-5.

<http://www.ncbi.nlm.nih.gov/cgi-bin/Entrez/REFERER?/htbin-post/Entrez/query%3fdb=m&form=6&uid=7743451&Dopt=1>

Description of Context:

This article reports on issues, pertaining to informed consent, 'the patient's right to decide' and medical record keeping, brought out in an interim report of the Krever Commission of Inquiry of the Canadian blood system.

Topic/Scope:

Although physicians have long known that the blood supply cannot ever be made totally safe, they have accepted that the risk on behalf of their patients. Rarely were these risks ever discussed with patients and few hospitals demanded a signed consent form prior to patients being given blood or blood products.

Krever 's recommendations include: 1) the explanation of risks and benefits of, and alternatives to allogenic blood transfusion in language the patient will understand. The description to be compared to other risks (e.g. the anaesthesia, the surgery procedure) 2) the opportunity for the patient to ask questions, repetitively if necessary, such that he/she will understand there is no such thing as zero risk. 3) the patient's express consent received sufficiently prior to the procedure that an alternative to blood transfusion, if necessary, is possible, 4) the informing of all patients of the blood product used and the quantity administered.

Physicians should take the following steps to ensure a paper trail of the consent: 1) document in the patient's chart the discussion of risks, benefits and alternatives, 2) document the blood products used in the patient's chart, discharge summary and in a letter to the referring physician.

Krever also called on licensing bodies to develop a 'standard of practice' concerning physicians getting informed consent before administering blood/blood products

The 'standard of disclosure' by the Supreme Court is no longer simply the actions of a reasonable physician. The standard is "that information which the physician ought to know a reasonable person, in the place of the specific patient, would want to have disclosed prior to making a decision to undergo a procedure or treatment." (p. 1665) Failure to do so provides grounds for liability in negligence. The author describes a CMA discussion paper that suggests that withholding information by reason of 'therapeutic privilege' (i.e. that receipt of the information might harm the patient) should rarely happen.

Conclusions/Recommendations:

Physicians need to take seriously their patients' legal rights to information about the risks and benefits of, and alternatives to transfusion by allogenic blood or blood products. Communication to the patient in terms they, as a reasonable person, can comprehend is most critical. Documentation of the communication is also important.

78. Capen, K. (1998). There's more to Krever's report than the blood issue--much more. *CMAJ*, 158(1), 92-4.

<http://www4.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=9475919&form=6&db=m&Dopt=b>

Description of Context:

The Krever Commission's report has implications for physician patient communication that extend beyond the issues of the tainted blood scandal.

Topic/Scope:

This article provides a concise summary of the implications of the Krever Commission for physician practice. It addresses issues of 1) informed consent, 2) standards of practice, 3) clinical practice guidelines, 4) duty to report, 5) physician-patient communication, therapeutic privilege, and 6) participation in advisory committees.

Conclusions/Recommendations:

Informed Consent: The requirement for informed consent applies specifically to administration of blood or blood products. Consent forms signed on hospital admission do not meet the requirements. Patients must be 'informed' well in advance of surgery of alternatives to blood products. All efforts to provide information must be documented.

Acceptable Standards of practice: It is important that physicians remain current with scientific and medical knowledge and be able to apply this knowledge in their clinical practice.

Clinical Practice Guidelines: Physicians should make a reasonable effort to be aware of relevant CPG's. These should be applied to clinical practice adapted as necessary to the needs of the individual patient. (issue was taken with poor dissemination and implementation of CPGs)

Duty to Report: Krever recommended that licensing bodies 'enforce the standard of practice that requires physicians to report notifiable diseases.' (e.g. adverse transfusion reactions should be reported to the national blood service. Patients are to be notified when such reports are made. Public health needs over-ride the need for physician-patient confidentiality.

Physician-patient communication: Krever points to the impact of lapses in physician-patient communication. (e.g. notification of groups about possible risks, contact tracing of sexual partners, notification of patients as part of a national 'look-back' program). On an individual level, Krever

identified where break down of communication led to death of the patient and of the patient's partner.

Therapeutic privilege: As a general rule physicians should disclose information concerning patients' health and treatment. The Krever recommendations and those arising from subsequent civil action support disclosure to the patient. Efforts to disclose should be recorded.

Participation in Advisory Committees: physicians are encouraged to become involved in the development of CPGs and act as strong advocates for patients and patient groups.

[FRM Note: this article addresses mainly legal issues arising from the Krever Commission. A strong thread throughout the article is the need for effective physician-patient communication. Most significant within this is the need to share information with the patient and others. Documentation is important for legal reasons. However, it could also be a practical application of the 'patient review' process recommended by Delbanco (1993, 1996). Again, this article stresses that the issues surrounding informed consent and shared decision-making regarding use of blood products is not different from such concerns about any medical procedure or treatment.]

76. Centeno-Cortes, C., & Nunez-Olarte, J. M. (1994). Questioning diagnosis disclosure in terminal cancer patients: a prospective study evaluating patients' responses. *Palliat Med*, 8(1), 39-44.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=8180739&form=6&db=m&Dopt=b>

Objective(s):	To assess: 1) the disclosure of diagnosis to patients with terminal cancer, 2) the level of suspicion the patient might have about their diagnosis, 3) the attitude of the patient toward being informed, 4) the possible influence of the truth over other psychosocial needs.
Design:	Survey - semi-structured personal interview to determine whether the patient was informed about his/her disease and his/her level of suspicion about the disease. Completion of a psychosocial wellbeing instrument.
Setting:	Spanish University Hospital-based oncology service and palliative care ward.
Subjects:	97 in-patients with advanced malignant disease, no cognitive impairment, hospitalized for more than 5 days. 64 patients in a standard hospital ward of a university hospital-based oncology service. 33 patients in the palliative care unit.
Interventions:	None
Measures:	Coding of verbally given responses. Comparison of psychosocial ratings collected on a closed response form between 'informed and not-informed' groups using the Mann Whitney U-test.
Results:	68% of patients in the sample stated they had not been informed of the nature of their disease. Only 42% of patients in the palliative care unit and

27% of patients in the oncology service ward had been informed.

54% of non-informed patients suspected their diagnosis. A further 6% of this group were certain of their diagnosis. 40% of non-informed patients did not contemplate their true diagnosis. One-third of non-informed patients indicated they would like to have more information (12% indicated they wanted full disclosure). 42% indicated either they didn't want more information or answered 'a little'. (The patients not wanting more information tended to be female, older and having a better prognosis)

Measured by the psychosocial wellbeing instrument, the informed group tended to have better communication with relatives ($p < 0.001$), friends, physicians ($p < 0.001$) and nurses ($p = 0.01$) than the non-informed group. They also comprehended the information given better and had a more positive attitude toward receiving further information. The relationship with physicians ($p = 0.01$) and trust in the care provided was also better in the informed group ($p = 0.01$).

Conclusion(s):

Patients within the Spanish culture do not uniformly desire disclosure of true diagnoses. More than 1/3 of patients who have not been informed stated they did not want any more information. Conversely, 12% of non-informed patients indicated they wanted full disclosure. There was evidence of a culturally motivated 'conspiracy of silence' and a phenomenon of withdrawal ("Spanish Death") that was perceived to give some level of warning to dying patients.

Since there is such variability in Spanish culture concerning the wishes of patients for truth disclosure the physician should explore patient's attitudes before proceeding. The author recommends that physicians attempt to change patient's negative attitudes toward disclosure in order for the patient to reap psychosocial benefits.

[FRM Note: this article addresses cultural variability in patient's desire for information (specifically truth disclosure about disease). It should not be assumed that a strategy that might be recommended for encouraging patient participation in decision making will necessary be transferable to other cultures.]

12. Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med*, 44(5), 681-92.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=9032835&form=6&db=m&Dopt=b>

Description of Context:

The concept of shared decision making has heretofore been rather poorly and loosely defined. The authors attempt to organize the issues (legal, moral/ethical, social, psychological) surrounding shared decision making, define some key characteristics that distinguish it from other models of decision making and outline some research problems yet to be resolved.

Topic/Scope:

This article begins with an overview of the current status of shared decision-making, the legal and ethical bases and the impact of the changes that have occurred over time on the physician-patient relationship. It discusses the implications of advances in methods and means to provide medical care and addresses issues of medical uncertainty. It also details the

importance of information in the process of decision making and its pivotal role in power issues between physician and patient.

The authors identify central elements of three models of decision making:

1) Paternalistic/professional-as-agent decision-making model

(physicians assumes primary role of decision maker, the patient adopts a passive role - i.e. the 'sick role'),

2) Informed decision-making model (physicians are providers of information to patients thereby enabling/empowering them to make decisions on their own behalf)

3) Shared decision-making model -

a) Requires a minimum of two participants, the physician and patient/proxy
(See interesting discussion about the dynamics when other people beyond the dyad are added to the scenario (p. 685))

b) Both parties (physicians and patients) take steps to participate in the process of treatment decision-making
(explores possible rationale for patients not accepting an active role in decision making (p.686))

c) Information is shared by both parties
(discussion of perspectives of physicians and patients about the uses of information (p. 687))

d) Treatment decisions are made and both parties agree to the decision
(Does not mean both parties agree that the treatment option chosen is necessarily the best one, just that they both endorse it as the treatment to implement. Mutual acceptance is a necessary prerequisite of shared decision making, but on its own it doesn't define the model. Mutual acceptance may or may not occur in Paternalistic and Informed models as well (p.688) (? coercive power issues))

Measurement Issues: the article discusses some of the problems inherent in researching medical decision making (e.g. the complexity of inter-related personal, cultural, contextual variables involved makes the use of quantitative instruments too simplistic and confining). The authors recommend more use qualitative research methods.

Conclusions/Recommendations:

Models of decision making carry with them implicit assumptions. These tend to colour or shape approaches that are taken to study or to improve decision making communication. The authors provide more definitive criteria for what is and isn't shared decision-making.
(For example, within the Informed Model is the assumption that providing the patient information will equalize the power differential between the physician and patient and will result in the patient accepting a greater role in decision making. We know, however, that many patients declare not to want that role. What is not known are the reasons that patients might want more information but still may prefer deferring to the physician.)

The issues/variables surrounding shared decision-making are complex and little is really known about their influence on making of decisions (correlation vs. causation). We don't know about the confounding effect(s) of these variables presenting simultaneously. The authors suggest that these areas of future research might be fleshed out by more qualitative methods.

[FRM Note: Excellent article (perhaps the 'Gold standard' for comparison

of models) providing clear and concise description of the issues and lots of hints for future directions. Good review and insights with implications for education]

13. Cichon, E. J., & Masterson, J. (1993). Physician-patient communication: Mutual role expectations. *Communication Quarterly*, 41(4), 477 - 489.

I couldn't get this article. Its description in the author's abstract sounded as though the article would be very useful.

14. Coulombe, L. (1995). Talking with patients. Is it different when they are dying? *Can Fam Physician*, 41, 423-37.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=7539652&form=6&db=m&Dopt=b>

Description of Context:

This article asks the question: Is talking with patients who have terminal illness really different? Her short answer is "no" ... and "yes". The author suggests that physicians might have difficulty talking with dying patients because the physician doesn't know what to expect..

Topic/Scope:

The author shares a qualitative (personal) impression of what she experiences as a palliative care physician, and offers explicit suggestions for physicians. Addressed are issues surrounding the delivery of 'bad news', recognition that patients have values that sometimes mitigate against accepting the 'best' treatment, and awareness of patients' needs for information (about their condition, what might happen and the length of 'time left'). Lesson's learned about dealing with the family of dying patients are also shared. The author discusses the patient and the physician's roles (including their respective roles in decision-making), illustrating each with descriptions of her past cases.

The author's recommendations are summarized in bulleted point form throughout the text under the headings:

- a) listen carefully to individual stories
- b) meet patients at their level
- c) be honest
- d) do not be afraid
- e) be humble
- f) do not assume that you know what patients want
- g) be practical
- h) commit only to what you can reasonably deliver
- i) advocate for patients in the medical system
- j) realize that the patient is simply living with a better defined limit

Conclusions/Recommendations:

Physicians can offer dying patients expertise and medical knowledge, practical information about resources, equipment and services to aid in daily living, and most importantly to can offer honest, compassionate care. Physicians should be aware that dying patients' need for physicians are highly individualized - to help explore what is important in their lives, to expose their vulnerability and fears, to gain knowledge that will enable them some level of control over their lives. They may choose to make their own decisions or to consult with their doctor and make them collaboratively.

The author stresses that her 'best work' is done when she approaches her patients without an agenda (i.e. when she is just 'present and sensitive to what (her) patient is telling her').

[FRM Note: this article provides a good qualitative description of the physician's approach to the dying patient. It provides concrete ideas, supported by descriptions of representative cases. One gets a sense of physician patient collaboration in decision-making in action. It is important, too, in that it addresses a difficult area of communication that physicians have identified.]

15. Deber, R. B. (1994a). Physicians in health care management: 7. The patient-physician partnership: changing roles and the desire for information. *CMAJ*, 151(2), 171-6.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=8039062&form=6&db=m&Dopt=b>

Description of Context:

Physician and patient roles are changing. Models of the physician patient relationship are evolving from one of physician paternalism to increasing respect for patient autonomy. There are barriers to be overcome if patients are to be expected to be able to make informed decisions.

Topic/Scope:

This article reviews models of the physician patient relationship and literature about the barriers to participation, the effect of participation on patient outcome and the extent to which patients want to be informed. The author promotes a model of shared decision making. She points out the need for the development of educational tools to differentially 'inform' patients and describes efforts to use interactive videodisc technology to meet this need.

Barriers presented include characteristics of the patient (e.g. adoption of the 'sick role', the situation/context of care (e.g. amount of time available to provide information to patients, emergencies where the patient are too sick or cannot respond), and the environment (physical and psychological).

Conclusions/Recommendations:

It is evident that providing patients information improves outcomes. It is also evident that realities of practice (time constraints due to work load, no compensation for increased time with patient...) and uncertainty of patient's wishes with regard to information/truth (particularly concerning sensitive topics such as sexuality etc.) makes the goal of 'informed consent' difficult to attain. The author recommends adoption of technological means to address this problem.

[FRM Note: the interactivity of videodisc technology has some educational appeal but it is an expensive alternative. Since this article was written the Internet has 'happened'. A lot of information (some of questionable value) is available on many topics. This is a less expensive but not an inexpensive option. Privacy is an issue with either solution. Also, I'm not sure either means is an effective substitute for information provided one-on-one from a trusted, knowledgeable health care provider at a 'teachable moment'.]

16. Deber, R. B. (1994b). Physicians in health care management: 8. The patient-physician partnership: decision making, problem solving and the desire to participate [see comments]. *CMAJ*, 151(4), 423-7.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=8055402&form=6&db=m&Dopt=b>

- Description of Context:** This article reviews literature on the extent to which patients wish to be involved in making decisions on their medical care.
- Topic/Scope:** The author provides a brief overview of articles representative of "sensitive paternalism" vs. 'shared' decision making models. Characteristics of patients who wish to participate are described. The author then differentiates between 'decision making' and 'problem solving' and suggests that the literature has not made this distinction - largely grouping both activities under the heading 'decision making'. She posits that physicians and patients are involved in an implicit contractual relationship, whereby the physician's responsibility includes problem solving and decisions are made jointly.
- Conclusions/Recommendations:** Decision-making requires bi-directional flow of information between physician and patient. Patients need to supply information to physicians about what they are feeling, their values, beliefs and concerns. Physicians need to supply patients with the elements of informed consent (perceived problem, prognosis, treatment alternatives, risks and benefits).
- [FRM Note: dividing the process of decision making into problem solving and decision making is interesting. Can the two really be separated? Problem solving is not necessarily just the physician's domain. The patient has a distinct role in problem solving in that he/she provides the physician with information needed to make the differential diagnosis.]
17. Deber, R. B., Kraetschmer, N., & Irvine, J. (1996). What role do patients wish to play in treatment decision making? *Arch Intern Med*, 156(13), 1414-20.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=8678709&form=6&db=m&Dopt=b>

- Objective(s):** To test the hypothesis that most patients do not wish to be involved in problem solving, but that many wish to act as decision makers.
- Design:** Questionnaire-based survey with four sections: Problem solving Decision-making Scale (PSDM), Autonomy Preference Index, Health Opinion Survey (HOS), Weinberger et al coping style-demographics and background questions.
- Setting:** Cardiovascular Investigation unit of a teaching hospital
- Subjects:** 300 (72%) cardiovascular patients scheduled for an angiogram, staying in either the Day Bed Unit or the Short Stay Unit, able to speak and read English, not experiencing complications while in the hospital, and agreeing to participate in the study. Subjects were predominantly male, with a mean age of 59.6 years recruited over a three month period from patients scheduled for angiograms.

Beyond Informed Consent Annotated Bibliography

- Interventions:** None.
- Measures:** Survey subsections included scales to measure the desire for information and participation in decision making. Demographics collected included: age, sex, marital status, education level, employment status, overall health and co-morbidity.
- Results:** Deber points to several previous studies that indicated patients level of interest in participation in decision making. She contends that these studies did not clearly define what was meant by 'making a decision'. Deber breaks down the decision process into two parts: 1) Problem solving (PS) and 2) shared decision making (DM).
- Preference for information - Results confirm the literature that many patients want information. Rarely do they wish to have information withheld. Older patients were more likely than younger patients to want less information.
- Preference for involvement - patients lean toward physician control in issues of PS, less so in issues of DM. This was significantly higher for circumstances involving mortality (higher stakes?) than morbidity.
- Conclusion(s):** Decision making requires a partnership of the physician and patient. The patient trusts the clinician to problem solve for them. They do prefer to have a say in decisions made - particularly those that affect quality of life or impinge on the patient's values.
- The physician's role then is to problem solve and communicate information to the patient structured such that the patient can make a decision if he/she so desires. This information should include: available alternatives, expected probabilities, risks and benefits of each. There is also a role of "providing the necessary emotional support to patients and their families in assisting them to make often difficult choices."
18. Deftos, L. J. (1998). The evolving duty to disclose the presence of genetic disease to relatives. *Acad Med*, 73(9), 962-8.
<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=9759098&form=6&db=m&Dopt=b>
- Description of Context:** As more becomes known about the human genome and the genetic bases of many human diseases there arises concern about legal issues surrounding the notification of relatives of patients diagnosed with genetic diseases.
- Topic/Scope:** This article describes pertinent cases and discusses the issue of notification of patients' relatives that they may be genetically susceptible to disease. The policies of disclosure and of ethical breach of confidentiality are presented. The article makes apparent that the legal requirement for this type of disclosure is not universal through the US. It also discusses the situation that may arise of relatives choosing not to know.
- Conclusions/Recommendations:** Physicians should discuss the need to inform relatives and if possible get their permission to do so. Disclosure to relatives, with or without consent of the patient, is recommended when the purpose is to prevent harm and should be limited to the extent needed to prevent harm. It is recommended that disclosure to relatives should be made in cases of diseases that are

'serious or fatal, treatable or curable, and transmitted dominantly with high penetrance'.

[FRM Note: This article deals on the fringe of communication and the physician patient relationship regarding decision-making. It addresses more the ethical and legal issues surrounding medical findings. However, in discussions surrounding the patient's diagnosis, prognosis, treatment alternatives there is latitude to open discussion about the patient's values, attitudes and beliefs toward disclosure to relatives ... particularly in situations like the one described in this article.]

19. Degner, L. F., & Sloan, J. A. (1992). Decision making during serious illness: what role do patients really want to play? *J Clin Epidemiol*, 45(9), 941-50.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=1432023&form=6&db=m&Dopt=b>

Objective(s):	To determine the roles people want to assume in selecting cancer treatments To compare the roles identified by cancer patients vs. those of the general population To identify key demographic and disease/treatment factors were most predictive of these preferences
Design:	Survey -chart review for disease and demographic data, questionnaire-type cards (symptom distress scale), two 5-card card sorts (Subjects - patients and householders were asked to sort two 5 card sets in order of preference. One card sort depicted physician patient decision making ranging from patient autonomy - collaboration - physician controlled. The second set of card depicted the patient's wishes 'family decision making on his/her behalf' again ranging from total family control - collaboration - total physician control.) Householders were also asked to project what their role preferences would be if they developed cancer. Both groups of subjects were interviewed in person.
Setting:	two tertiary referral cancer clinics in Manitoba
Subjects:	Patients - consecutive sample of 436 patients presenting at the clinic (over 18 years of age and within 6 months of initial diagnosis of cancer) Householders - systematic random sample of 482 householders over 18 years of age, with balance of males and females
Interventions:	None
Measures:	Results of card sorts coded for preference order, symptom distress scale (5 scale Likert scale) (Chi square, ANCOVA
Results:	Only 12% of newly diagnosed cancer patients preferred to take an active role in decision making (29% collaborative, 59% passive). They preferred for the physician to be involved in decision making if they became too ill. Only 10% wanted the family to dominate decision-making. This compared to 64% of householders who indicated a preference for the active role (27% collaborative, 9% passive) and who wanted to delegate decision-making to their family (40%). Younger people preferred an active role, both for

themselves and for their family, if they became too ill.

Among cancer patients and householders, older subjects preferred less control. Higher educated cancer patients preferred more control. This was also a trend in householders. There was a trend for more control among female cancer patients more so than in males. This trend was not found in the householder group. Female patients with reproductive cancers wanted more control than did male patients with reproductive cancers. No other gender effect was noted for other types of cancers.

Patients and householders indicating a preference for active control for themselves also preferred that their family assumed more control in their stead if they became too ill (p= 0.000)

There was a non-significant trend for rural patients to defer to physician control

Conclusion(s):

Newly diagnosed cancer patients prefer to leave treatment decisions to their physicians.

The approach of newly diagnosed cancer patients to decision making is markedly different from people who have not faced the cancer diagnosis. The best clinical approach is to assess preferences of each patient individually.

[FRM Note: This study is important in that it shows that a diagnosis of serious illness may change the way people approach decision making. Physicians should take this propensity into account. The question arises, however, does the physician encourage the person to take a more active role or make the decisions? This is likely to be an individualized solution best dealt with as the physician becomes better acquainted with the patient and has a deeper appreciation for the person's values and beliefs]

20. Degner, L. F., Kristjanson, L. J., Bowman, D., Sloan, J. A., Carriere, K. C., O'Neil, J., Bilodeau, B., Watson, P., & Mueller, B. (1997). Information needs and decisional preferences in women with breast cancer. *JAMA*, 277(18), 1485-92.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=9145723&form=6&db=m&Dopt=b>

Objective(s):

To determine: 1) the preferences of women with breast cancer for the level of participation in decision making, 2) the extent of involvement the women perceived they had achieved, 3) the women's priorities for information (correlated with sociodemographic, disease and treatment variables).

Design:

Survey, 3- part nurse administered questionnaire. 1) sociodemographic, disease, treatment data, 2) preferences for role in decision making (card sort), 3) priorities for information.

Setting:

Two tertiary clinics and 2 community hospital oncology clinics.

Subjects:

Consecutive sample of 1012 women diagnosed with breast cancer. Median age 58-61 years (tertiary clinic vs oncology clinic). 43% had less than high school education, 67% were married, 35% were retired, 42 % had a relative with breast cancer, 10% had a sister or mother with breast cancer., 54% in Stage II of the disease and had been treated with a mastectomy (61%), within 2 months of diagnosis (28%) or more than two years since diagnosis

(55%).

Interventions:

None

Measures:

Chi square for differences between subset groups

Results:

Preferred roles: women with breast cancer want a substantial amount of control over decision making (22% wanted to select own treatment, 44% wanted to select treatment in collaboration with the physician, 34% wanted the physician to make the decision). The group wishing to make the decision for themselves or collaboratively were typically women: 50 years and younger, having more than a high school education, married, having had a lumpectomy. Women over 70 years were 1/5th as likely to want to take an active role in decision making as women younger than 50.

Extent of involvement achieved: 42% of women considered they had achieved their desired level of participation in decision making. Women closer to the time of diagnosis were more apt to consider they had achieved desired participation (50%). 15% thought they'd been pushed to assume more control over the decision than they would have liked. Only 21% of those desiring full control over the decision had achieved this. 51% of women wanting a passive role achieved this.

Priority of information needs (highest to lowest): 1) chances of cure/ stage of disease, 2) treatment options/risk of a family member getting breast cancer, 3) sexuality. Information needs appear to change over time. Younger women were more concerned about issues of physical attractiveness and sexuality than older women. Older women were concerned more about caring for oneself at home than younger women. No differences in needs for information based on education level, stage of disease, or role played in decision making.

Conclusion(s):

Assume that women will want some control over decision making. The first priority for physicians to address with breast cancer patients should be with respect to chances of a cure and the spread of the disease (stage). Discuss issues of appearance and sexuality with women under 50 and issues of self care with women over 70.

[FRM Note: this article is important because it shows some of the variables that affect a breast cancer patient's desired role in decision-making. It also shows that patients have variable preferences for types of information. Group norms can only show possible trends. They don't predict or suggest approaches for individual cases.]

21. Delbanco, T. L. (1992). Enriching the doctor-patient relationship by inviting the patient's perspective. *Ann Intern Med*, 116(5), 414-8.

<http://www.ncbi.nlm.nih.gov/cgi-bin/Entrez/referer?/htbin-post/Entrez/query%3fdb=m&form=6&uid=1736775&Dopt=1>

Description of Context:

Proposes that physicians should incorporate systematic questioning of patients (Patient's Review) into their practices. This will enhance the physician patient relationship, improve understanding of patient's values and beliefs and can serve as a way to self-audit one's practice.

Topic/Scope:

Describes succinctly the concerns patients identified in focus groups in a

previous study. These concerns are classified into seven 'dimensions of care': 1) Respect for patient's values, preferences and expressed needs, 2) Coordination and integration of care, 3) Communication and education, 4) Physical comfort, 5) Emotional support and alleviation of fears and anxieties, 6) Involvement of family and friends, 7) continuity and transition. Provided is a table of questions that might be asked related to each of these areas of concern. Collection of the answers to these sorts of questions form the basis of a patient's review - a process the author describes as a necessary part of the clinical encounter. The data need not be collected all at once, instead a profile can be gathered by adding bits more each visit. Some of the information can be collected by survey, from patients is waiting to be seen.

The author suggests further that physicians should consult with their patients about their practice by requesting a random sample of 200 patients to complete a survey. The instrument should be designed to provide the physician feedback on his/her attention to the areas of concern summarized in the seven dimensions of care. This audit process can form the basis of a personalized quality improvement program. The process could also be beneficial to the patient - teaching them the framework for addressing concerns to physicians.

Conclusions/Recommendations:

Physicians are encouraged to systematically gather information about their patients, over time compiling a detailed portrait of them - a patient's review. They are further encouraged to ask patients for feedback on the physician's practice.

[FRM Note: the 'practice audit' approach may be an interesting pre-course assignment. It would focus participants attention on their own practice related to shared-decision making. It could also form the basis for Mainpro 'C' credits if the course is co-sponsored by the CFPC or a Canadian university.]

22. Delbanco, T. L. (1993). Promoting the Doctor's Involvement in Care. In M. Gerteis (Ed.), *Through the patient's eyes: Understanding and promoting patient centered care* (pp. 260 - 279). San Francisco: Jossey Bass Publishers.

Description of Context:

Doctors tend to feel left out of efforts to improve patients' hospital care, yet they of any health providers are in the best position to dramatically improve patient care.

Topic/Scope:

This chapter addresses what physicians think about their patients, hospitals and practices, and presents a wealth of suggestions concerning how they may be involved more actively in promoting patient-centered care. Suggestions are also provided concerning how physicians can make their own practices more patient-centered.

Conclusions/Recommendations:

Recognize that:

- 1) Physicians like data - and prefer specifics rather than generalizations
- 2) Physicians would rather listen to their patients than to others
- 3) Physicians believe they are already patient-centered

Encourage physicians to:

- 1) Help solve difficult/important problems.

- 2) Participate in focus groups with peers concerning issues of patient care
- 3) Analyze aggregate data about their own patients
- 4) Improve the way they communicate and to deal with patients as individuals
- 5) Teach house staff and other health care workers

Encourage communication between physicians and patients by recommending that:

- 1) physicians audiotape important conversations they have with patients and then give them the tape.
- 2) physicians write summaries of important information and interactions provide them to the patient
- 3) physicians provide pertinent educational materials to patients and their families
- 4) physicians adoption of computer technology (facilitate by providing workstations and computer training).

[FRM Note: this chapter provides a good overview of physicians' perspectives of the environment in which they work. It provides some interesting ideas for involving physicians in patient centered care and encouraging them to initiate similar micro-initiatives in their own offices]

23. Delbanco, T. L., Stokes, D. M., Cleary, P. D., Edgman-Levitan, S., Walker, J. D., Gerteis, M., & Daley, J. (1995). Medical patients' assessments of their care during hospitalization: insights for internists. *J Gen Intern Med*, 10(12), 679-85.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=8770720&form=6&db=m&Dopt=b>

Objective(s):	To summarize patients' experiences with hospitalization, their preferences for involvement in care and desire for information.
Design:	Survey - phone interviews.
Setting:	Stratified sample of nonprofit public and private hospitals.
Subjects:	Random sample of 2839 patients of a stratified (ownership, geographic region and teaching status) sample of public and private nonprofit US hospitals. Oversampled from some hospitals in order to obtain similar numbers of hospitals in each strata sample of public. Patients were included if they were adults, discharged and not readmitted to general medical or surgical services, indicated they were not too sick to answer questions, completed the phone interview and had not had surgery during their stay in hospital.
Interventions:	None
Measures:	Frequency distributions of sociodemographic and other patient characteristics, occurrence of a 'problem' reported by the patient and their stated preference for involvement in their care. (ANOVA)
Results:	1.8% of patients reported not being involved in medical decision making as much as he/she would have liked. 10.2% indicated they didn't have enough say in medical treatments. 10.5% indicated the physician had talked in front of them as if he/she were not there

23.5% indicated important side effects of medications they received were not explained in a way they could understand. 9.3% reported not being told the purposes of those medicines. 22.4% reported not being told about the pain or discomfort that might be experienced from tests performed. 12% indicated that test results were not explained so they could understand them or why the test were being done (9.7%). Family members were not given enough information (9.8%) and 16.8% reported that family members were not given complete information to be able to care for the patient upon discharge. A fifth of patients (21.4%) reported not being told what they could do to help their own recovery and 32.5% reported not being advised of danger signals about their illnesses that should prompt calls for help. 27.6% reported that their physician spent less than 5 minutes speaking with them prior to discharge. (Nurses spent even less time - 17.1%)

11.8% of patients indicated they were not involved in making decisions about their care as much as they would have preferred. 10.7% reported they didn't have enough say about their treatment. 94.4% thought that the patient and the family should be given 'news' even if it was 'bad'. 98.9% thought that the patient should be told about available choices of treatment. Males, older patients and less educated patients generally agreed with statements that 'hospitalized patients should not make decisions about his/her medical care' and that 'you should go along with your doctor's advice, even if you think it's wrong'. Women, younger and more educated patients did not agree with these statements ($p < 0.0001$)

Conclusion(s):

Patients want information. However, there is substantial variation in expectations of patients regarding their role in medical decision making. Physicians need to involve patients by providing information about risks, benefits, prognosis, alternative therapies... and incorporate patient's input into clinical decisions. They need to develop a standardized way of eliciting patient preferences. Many of the concerns reported indicate deficient communication between physician and patient.

[FRM Note: excellent article, cross sectional survey.]

24. Delbanco, T. L., & Daley, J. (1996). Through the patient's eyes: strategies toward more successful contraception. *Obstet Gynecol*, 88(3 Suppl), 41S-47S.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=8752227&form=6&db=m&Dopt=b>

Objective(s):

To review the literature on studies of patient satisfaction and effective involvement of patients in decisions about care

Data Sources:

Focus groups, anecdote, patient survey data and literature review

Study Selection:

English language search of Medline (1970 - 1996) using terms: patient satisfaction, consumer participation, patient participation, self-care, contraception and contraceptive behavior. Also reviewed previous studies conducted by the authors.

Data Synthesis:

Physicians need to assess the patients' priorities, their current level of knowledge, the extent to which they want to be involved in decision making and what kind of recommendations they might find most helpful. The author points out that patients often don't remember or understand the significance of probability statements. Physicians often make incorrect

assumptions of patients' needs or preferences (including preferences for gender and sexual orientation of the health care provider). The key issue identified is to open lines of communication so that the uncertainty is reduced and the foundation of a successful physician patient relationship is established.

Patients tend to want more information/education, more discussion of psychosocial issues and encouragement to bring forward questions they might have. Some issues or problems may be difficult for the patient to introduce. Physicians can pave the way for productive interviews by asking patients to complete questionnaires, read pamphlets, view videotapes or use a health-related interactive computer program prior to the interview. The author also discusses the benefits of 'health care contracting' and of peer support/education groups. Such devices 'activate' the patient to participate more in the decision process and their own health care.

Physicians need to understand that the patient is the best teacher - specifically about the patient's own needs and preferences but also about their ethnic or cultural group, health beliefs and practices. Communication is a two way street. The author encourages physicians to share details of the patients' record with them, write/dictate notes to reinforce information given, audiotape their interview and send a copy home with them, follow up office visits with a phone call to talk about specific questions/issues that arose, use email/voice mail. Physicians are encouraged to query individuals and groups of patients and to learn from them.

Conclusion(s):

Physicians need to open lines of communication to exchange ideas, information and perspectives with patients. Without communication physicians are forced to act on assumptions that may not be appropriate for individual patients. Dealt with creatively, opening communication links need not take more time, rather it holds the potential of focusing patients thoughts and activating their interest in their own health care.

[FRM Notes: Physicians' education is grounded in science. Much as they might discuss probabilities with their patients, they may tend to make assumptions of a patient's needs or preferences based upon the premise of a perceived probability - one perhaps internalized through experience they have had with countless other patients. They need to be reminded that a probability is only the likelihood that something will occur. It doesn't address a particular instance - this patient having this prior health and health care experience, having this ethnic/cultural and socioeconomic background, education, gender, with this problem, etc. Communication is the only way to be sure this patient is not one that falls outside the internalized probability analysis. This article seems to encourage physicians to extend their practice - to become creative in the ways they deal with patients, and to conduct their own research about patients and groups of patients in their practices. An approach from this 'scientific' perspective might be more appealing to physicians than encouraging them to simply to use a set of specific skills.]

25. Elwyn, T. S., Fetters, M. D., Gorenflo, W., & Tsuda, T. (1998). Cancer disclosure in Japan: historical comparisons, current practices. *Soc Sci Med*, 46(9), 1151-63.
<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=9572605&form=6&db=m&Dopt=b>

Objective(s):	1) To determine cancer diagnosis disclosure patterns among Japanese physicians compared to that of physicians in the United States 2) To determine the clinical factors Japanese physicians use when considering to disclose a cancer diagnosis. 3) To discover patterns of disclosure of the cancer diagnosis to family members of competent cancer patients in cases where the patient has not been told the diagnosis.
Design:	Survey of physicians, questionnaire (used instruments of Oken (1961) and Novack et al (1979) modified to evaluate culturally relevant factors for Japan). Demographic data collected included: age, sex, years in practice, number of cancer patients treated, number of cancer patients told the diagnosis, resident or faculty status, type of practice. The instrument also asked what factors the physician considered when deciding whether to tell the cancer diagnosis and which the physician deemed to be the most important factors (e.g. patient characteristics, family characteristics, disease characteristics, physician comfort level with respect to disclosure). If disclosure had been made to people other than the patient, the physician was asked to describe that person and to describe the patient's age. Physicians were also asked their 'usual policy' for disclosure to the patient, how often they make exceptions to this policy, whether this decision is affected by personal attitudes toward cancer and life-threatening illness, whether they would like to be told if they had cancer, and what the likelihood of changing this policy in the future.
Setting:	Private medical school hospital in rural Japan and affiliated satellite clinic.
Subjects:	77 physicians in wide range of practice, excluding pediatrics
Interventions:	None
Measures:	Likert scale rating of some questionnaire items, short response items. Basic descriptive statistics were used on all demographic variables comparing tell and no-tell groups.
Results:	<p>The mean estimated number of cancer patients who were told about their diagnosis doubled in the past decade (comparing current study (45%) to previous one (22%)). 56% of physician respondents indicated that they were more likely to 'tell' now than they were 10 years ago. 66% indicated they refer the patient to a specialist to be told the diagnosis. Japanese physicians reported a wider range of factors they might consider compared to those reported by a survey of American physicians. The three top factors were: 1) the patient's expressed desire to be told, 2) relative's wish about telling the patient, 3) ability to obtain family support. (American study results indicated the top three factors to be: 1) patient's expressed desire to be told, 2) patient's emotional stability, and 3) patient's age)</p> <p>Type of cancer, age of patient, stage of illness and prognosis were described as factors that influenced 'tell/no tell' decisions. Regarding 'policies for disclosure', Japanese respondents' were most apt to disclose if the patient wished it (73%). They were less likely to disclose if the family opposed this action (77%). A mixed/neutral response was likely if patients requested disclosure and family members opposed it. Who the physician told, when the patient was not told, varied according to the age of the patient (e.g. 20 - 40 year old patient, the physician told the Parent (94%) and the spouse (87%); patient aged 61 or more, the physician generally told the patient's</p>

child or spouse.) 68% of Japanese physicians indicated they thought that their 'disclosure policy' would change in the future.

86% of Japanese physicians indicated they would like to be told if they had cancer (compared to 100% of American physicians in another study).

Conclusion(s):

A great many factors impinge on a Japanese physician's decision to 'tell' or 'not-tell'. There is evidence of cultural variability in this decision process (between Japanese and American physicians). There is also evidence that suggests that the personal policy of disclosure that Japanese physicians employ is in a state of transition (similar to the changes of attitudes of American physicians over a 30 year period).

Physicians should ask patients if they would like to know or not to know - in order to respect patients' rights to choose either path.

[FRM Note: This article points out the cultural diversity of physicians thinking about informing patients about illness. It describes multiple factors that impinge on their decision without even addressing the effects of combinations of the factors, including whether physicians have accurately perceived the wishes of patients or their families and the cues they may have given that might have influenced those wishes. Involvement of the patient directly seems to be the only practical solution.]

26. Ende, J., Kazis, L., Ash, A., & Moskowitz, M. A. (1989). Measuring patients' desire for autonomy: decision making and information-seeking preferences among medical patients [see comments]. *J Gen Intern Med*, 4(1), 23-30.
<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=2644407&form=6&db=m&Dopt=b>

Objective(s):

1) To what extent do patients want to participate in medical decision making, 2) What patient characteristics influence these preferences? 3) How are these preferences affected by varying the severity of disease?

Design:

Survey. Created and tested the Autonomy Preference Index (API) which has 8 item scale on information seeking and a 15 item scale on decision making. Patients selected at random from physician lists of returning patients were asked to complete the survey - statements about decision making and information behaviour.

Setting:

University based primary care clinic (General Internal Medicine)

Subjects:

312 (39% of population) randomly selected patients from the lists of returning patients of each attending, fellow and resident at the clinic.

Interventions:

None

Measures:

Univariate (Pearsons) analysis to uncover insignificant associations and then multivariate analysis (two tailed t-test and ANOVA. Mean scores on the three vignettes were compared using t-tests.

Results:

Decision making: Patients preference for making decisions was found to be generally weak. Younger patients, and patients with more favourable health status tended to express stronger preferences for decision making. Patients less interested in making decisions were more satisfied with how decisions

were being made. 75% of patients wanted more input into decisions about the minor illness vignette than they expressed for the major illness vignette. 25% wanted increased input when the illness was more severe. The former group (75%) tended to be better educated than the latter group (25%). Sociodemographic influences only accounted for 19% of the results - individual patient characteristics were more important to decision making preferences.

Information seeking: Patients wanted information (79.5%). Patients' desire for information was not found to correlate with desire for decision making or patient satisfaction

Conclusion(s):

Patients tend to want information but are weakly predisposed to decision making. Younger patients want more input in decision making than older patients. When grave illness vignettes were posed patients wanted less decision making power, preferring their physician to assume greater responsibility ('paternalism with permission'). This suggests that patients want to understand and be involved in decisions but may not want to make the decisions themselves. The results were highly variable. Individual characteristics rather than sociodemographic tags were more important to decision making preferences (i.e. patients need to be treated as individuals).

[FRM Notes: This article suggests to me that physicians need to keep all patients informed about their illness, results and implications of tests etc. Patients are willing to let the physician assume a significant role in actual decision making, but want to be part of the process]

27. Ende, J., Kazis, L., & Moskowitz, M. A. (1990). Preferences for autonomy when patients are physicians. *J Gen Intern Med*, 5(6), 506-9.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=2266433&form=6&db=m&Dopt=b>

Objective(s):

To assess physicians' preferences for patient autonomy when they are the patients (i.e. to determine if reducing the gap in knowledge between patient and physician influences whether patients will assume a greater role in decision-making)

Design:

Survey. Physicians and patients were asked to complete a questionnaire (Autonomy Preference Index- API). The physician group did this as part of a Continuing Medical Education event offered in two consecutive years. The patient group completed the survey after a medical visit. The API administered to physicians was slightly modified. The results were compared.

Setting:

Physician group: CME event in Boston on two consecutive years.
Patient group: randomly selected patients of a University-based primary care outpatient clinic

Subjects:

Physician group: 151 internists and family physicians (90% general internists, remainder family physicians or sub-specialists) practicing primarily in eastern (58%) and mid-western(32%) US

Patient group: random sample of patients returning for appointments to the clinic but after the office visit

Beyond Informed Consent Annotated Bibliography

Interventions:	None - other than slight modification to the API completed by physicians. A statement reminding them to answer the questions from their perspective as a patient as opposed to as a physician (The author describes their responses as from 'patient-physicians'.)
Measures:	Used a correction factor to account for differences between the physician and the patient populations (no change to significance of any findings was made). Adjusted mean scores compared by two-tailed t-tests for the two groups, ANOVA F-tests for three groups (age, sex, education). Comparison of means between groups.
Results:	Both the physician and patient populations preferred shared decision making. Physicians indicated significantly ($p < 0.001$) stronger preference for making decisions than regular patients in each of the three illness vignettes described in the API. However, all scores indicated less somewhat less than 50:50 shared decision making was desired. Decision making preferences of a subgroup of physicians who were seeing a physician regularly themselves were not significantly different than 'regular' patients posed questions about the most severe illness (MI) vignette. Physician-patients differed from patients in that they did not seek as much information from 'their physician'.
Conclusion(s)	<p>Possessing medical knowledge and being of relatively the same socio-economic class as physicians doesn't radically change 'patients' apparent desire to share decision making responsibilities. This suggests that part of the 'role' of being ill is to have someone care for and assist in the making decisions.</p> <p>[FRM Notes: Data from physicians responding as patients moves a step toward equalizing some of the variables that have been found that effect patient's decision making preferences (education level and other socio-demographic influences). It might be argued that it would be difficult for physicians to respond as if they were patients without carrying forward biases gained through socialization processes of medical training and culture. This perhaps might have resulted in the level of significance achieved between real patients and physician patients in this study. However, the fact that even physicians would choose shared decision making (of no more than 50:50) when they could imagine themselves as ill is important.]</p>

28. Faden, R. R., Becker, C., Lewis, C., Freeman, J., & Faden, A. I. (1981). Disclosure of information to patients in medical care. *Med Care*, 19(7), 718-33.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=7266120&form=6&db=m&Dopt=b>

Objective(s):	To study the difference between what patients want to know and what physicians report actually disclosing
Design:	Survey, self administered questionnaires
Setting:	Subjects from Johns Hopkins Seizure Clinic (inner city black neighbourhood in Baltimore), Walter Reed Army Hospital outpatient clinic (provides care for active and retired military personnel and their dependants). Physicians were members of the American Academy of Neurology or the Child Neurology Society.

Beyond Informed Consent Annotated Bibliography

- Subjects:** Physicians: random sample of pediatric and adult neurologists. (Predominantly male (80%), aged 40 years or less (51%))
Patients: Convenience sample of parents of pediatric patients being treated at Johns Hopkins (Predominantly young (<40, 69%), female (87%), white (80%), Seizure Clinic and of adult patients selected from Walter reed Army Hospital outpatient clinics (aged <=40(79%), female (58%, white (85%), completed at least 1 year of college (53%) .
- Interventions:** None
- Measures:** Light-Margolin Chi Square test for difference between groups. Spearman Rank Order Test to describe which sorts of information are disclosed in relation to apparent risk. Patients were given a questionnaire to complete while waiting for their appointment with a physician. They were asked to imagine this was the first time their doctor had diagnosed their problem and had recommended therapy. Then they were asked to check off a list of risks and benefits they would like to be informed about if they were going to consent to therapy. Physicians were asked to complete a questionnaire indicating what information they routinely tell patient(or parents) about two therapies.
- Results:** 90% of parents and patients checked off that they wanted to know all of the benefits and 80% wanted disclosure of all but two of the risks. Physicians were more likely to disclose risks in cases where harm was more apt to happen than to disclose according to the severity of the possible risks. Physicians reported routinely offering less information than the patients in the study indicated they would want to know. Not a single patient indicated that they would want a physician to withhold information from both them and their family compared to 20% of physicians who indicated non-disclosure was their preferred practice. 70% of patients indicated they wanted information so that they could decide whether to take the drug and be aware of what to expect. More than 50% of patients and parents (Compared to 33% of pediatric neurologists and 7% of adult neurologists) felt the ultimate decision about the treatment rested with the patient or parent. Over 81% of patients/parents felt that disclosure would make them 'a lot more' likely to adhere to the medical treatment and feel 'a lot more' confident in the both the drug and their physician. Physicians tended not to indicate support for full disclosure - i.e. they did not believe that patients would be more apt to have more confidence in the medication and adhere correctly to the prescribed regimens (50%). 25% thought that detailed disclosure would upset patients.
- Conclusion(s):** Physicians and patients have widely divergent views on the amount and type of information they would like to disclose or have disclosed.
[FRM note - physicians queried were not the patient's physicians - they were reporting on what they might do 'routinely', self reporting by physicians may have implicit bias, patients were asked to report preferences on a hypothetical circumstance - would they really do this if they were truly challenged with the medical problem?]

29. Finkelstein, D., Smith, M. K., & Faden, R. (1993). Informed consent and medical ethics [see comments]. *Arch Ophthalmol*, 111(3), 324-6.

<http://www.ncbi.nlm.nih.gov/cgi-bin/Entrez/referer?htbin-post/Entrez/query%3fdb=m&form=6&uid=8447739&Dopt=l>

Beyond Informed Consent Annotated Bibliography

Description of Context:

Informed consent is a symbol of the physician patient relationship and is an important principle of medical ethics. The physician is advised to care for the patient's values as well as their health, and to engage the patient in ongoing discussion leading to a shared decision as to the best course of action.

Topic/Scope:

This article addresses the issue of informed consent from perspective of an ophthalmologist. It gives an overview of the history of informed consent legislation and describes the circumstances and the changes in patients' attitudes over time that have shaped the laws as we know them. (e.g. Increased specialization has meant that solitary physicians no longer are solely responsible for care of a patient, Technological advances may offer remedies or treatments that might not be in the best interest of the patient, Advertising of services changes the trust relationship between physician and patient, and changes in social factors such as increased consumerism, individualism and awareness of individual rights).

The authors admonish not to confuse 'informed consent' with completion by the patient of a simple signed consent form. Patients should be informed and consulted always. Consent forms are needed mainly for particular interventions (admittedly a controversial stand). In general written consents should be required for all procedures that can be classified as research.

Conclusions/Recommendations:

"To safeguard the autonomy and interests of both patients and physicians, decision making in medicine must become a joint undertaking, depending more on the nature and quality of the entire fluid process of information exchange than on whether a particular disclosure has been made." (p. 326)

FRM Note: This article points out the influence of the total environment within which medicine is practiced. It also addresses the issue from the perspective of a specialist (ophthalmologist).

30. Gold, J. A. (1993). Informed consent [see comments]. *Arch Ophthalmol*, 111(3), 321-3.

<http://www.ncbi.nlm.nih.gov/cgi-bin/Entrez/referer?/htbin-post/Entrez/query%3fdb=m&form=6&uid=8447738&Dopt=1>

Description of Context:

Describes the legal issues of informed consent and provides examples.

Topic/Scope:

Describes a move from a "reasonable professional" standard of informed consent to one of the 'reasonable patient' (i.e. all the information that a reasonable patient may want to know in order to make further decisions about his/her medical care. Discusses disclosure of : 1) risks, 2) diagnostic information, 3) limitations of expertise, 4) physician's health status (including HIV status). Informed consent is more than just a signature on a specialized form, or the provision of a health information brochure.

Conclusions/Recommendations:

To be protected from successful legal action the physician must inform patients of risks and potential adverse effects associated with medical procedures as well as the risks associated with non-treatment. Physicians must also disclose results of diagnostic tests, limitations of their expertise. While some aspects of disclosure of personal health are still controversial, physicians are admonished to err on the side of overdisclosure.

31. Guadagnoli, E., & Ward, P. (1998). Patient participation in decision-making. *Soc Sci Med*, 47(3), 329-39.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=9681902&form=6&db=m&Dopt=b>

Objective(s): To review the research both for and against patient participation in decision-making

Data Sources: Medical and nursing literature

Study Selection: The authors selected studies dealing with different populations (real patients, healthy subjects given hypothetical problems, patient proxies) concerned with desire for participation in decision-making and the effects of participation on patient outcomes.

Data Extraction: Extracted 'desire for participation' data: size of sample, type of respondent, measure, result.
Extracted 'effect of participation on outcomes data: size of sample, type of participant, comparison made, outcome measure, results.

Data Synthesis: **Research with patients:** tends to support the position that patients want to be involved in decision-making when they have sufficient information about the options available and the risks and benefits of each.

Benefit of participation in decision-making or medical care: suggests that small sample sizes and follow-up periods that are too short make it difficult to draw clear conclusions. Literature reviewed indicated such benefits as increased satisfaction, better blood pressure control and compliance with treatment programs, better weight loss, short term alleviation of anxiety and depression, higher satisfaction with quality of life issues after given a choice about surgery following breast cancer diagnosis. Some articles indicated that relinquishing choice was not detrimental and suggested that leaving the decision to the patient increased anxiety.

Facilitating patient participation: The authors suggest that there is always going to be imbalance in the patient-physician relationship because the patient is 'sick and vulnerable' and the physician has 'expert knowledge'. Citing the report from the President's Commission (1982) it is noted that patients might agree to a paternalistic model because they are not on 'equal footing' with physicians from the start, they have learned that role, or may be unaware that different options are available. The goal should be to create an environment that will engage patients in decision making. They profile two strategies: interactive videodisc and use of decision boards.

The authors cite literature on differentiating patients according to their 'style' of decision making. (e.g. *delayers, deferrers, and deliberators*; *Type I*- 'You decide for me doctor', *Type II* - " I demand you do procedure X", *Type III* - "I cannot decide", *Type IV* - "Given the options, your recommendations and my preferences I choose treatment X"). They then discuss the idea of tailoring interventions to match patient's 'readiness to engage in decision making'.

Conclusion(s): Research tends to support patient's involvement in decision-making

(although sample sizes are generally small and samples are quite select). The authors believe that patient participation in decision-making is 'justified on humane grounds alone and is in line with a patient's right to self-determination' (p. 337). Regardless of patient's stage or style of decision-making physicians should encourage them to become involved. The authors suggest future research should explore use of the 'transtheoretical model of behaviour change' of Prochaska and Diclemente.

[FRM Note: tables summarizing results of reviews of literature on 'desire for participation' and outcomes from participation' are very useful. The article cites research pointing to the varying desire of patients to participate and suggests that tailoring programs to the patient's stage and style of decision-making might be useful. (i.e. situational approach to engaging patients)]

32. Hall, J. A., Roter, D. L., & Katz, N. R. (1988). Meta-analysis of correlates of provider behavior in medical encounters. *Med Care*, 26(7), 657-75.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=3292851&form=6&db=m&Dopt=b>

- Objective(s):** To summarize the relations between provider behaviours in medical encounters and patient outcomes, satisfaction, compliance, recall, and other patient attributes (social class, gender and age).
- Data Sources:** Medline 1966 - 1985, references in published papers, unpublished bibliography provided by the Society for General Internal Medicine, and a manual search of 10 journals and personal reprint files
- Study Selection:** 41 studies were reviewed. Studies had to: 1) be published in an English-language journal or book, 2) involve professional health care providers, 3) record provider-patient interaction using objective means, and 4) contain results relating provider behaviour or total amount of communication to provider or patient variables.
- Data Extraction:** Medline searches using search terms like: physician-patient relations, medical interviews, consumer satisfaction, patient compliance, and patient recall.
- Independent development of coding system (JH and DR), final system set by consensus.
- Data Synthesis:**
- Patient satisfaction:** Satisfaction was correlated most strongly with the amount of information provided by the health care provider. It was also related to: 1) greater technical and interpersonal competence, 2) more partnership building, 3) more immediate and positive nonverbal behaviour, 4) more positive talk, 5) less negative talk, and 6) more communication overall. Only 'question asking' had no correlation to patient satisfaction.
- Patient compliance:** Compliance was associated with more information given, fewer questions (except those about compliance), more positive talk, and less negative talk. Providers tend to take a dominant role in discussions about compliance.
- Patient Recall:** Information giving, less question asking, more partnership

building and more positive talk best predict recall and understanding.

Influence of Patient Social Class: Patients of higher social class received more information as well as more communication overall. Often physicians will follow technical descriptions with more simple ones to ensure effective communication. This group also received higher quality of care (technical and interpersonal) and more positive talk.

Gender: Female patients received more information and more total communication than males. They also were engaged in more partnership building and more positive talk. Providers interrupted encounters less frequently with females than with males.

Age: Older patients received more information, more total communications and more questions (concerning drugs), more courtesy and less 'tension release' (laughter). (Supports findings in the literature that older patients are more satisfied with their health care than younger people).

Race: White patients received higher quality of care than Blacks or Hispanics and more positive talk. There is some tendency for whites to receive more information (NS).

Conclusion(s):

The authors propose a model of reciprocity between patients and physicians to predict outcomes based upon provider behaviour. Behaviours by physicians in the task (information giving, question asking, technical competence) and socioemotional (partnership building, social conversation, positive and negative talk, interpersonal competence) domains are reciprocated by complementary behaviours in the same domain by patients. They contend that physicians must be adept at functioning in both domains. Physicians adapt their approach to the situation (e.g. partnership building and positive talk (socioemotional domain) may be used to encourage a man to reduce weight and adopt better eating habits. If it becomes evident that the man is not maintaining his diet or has gained weight, the physician's approach may be more task oriented and directed).

[FRM Note: this article provides evidence that physician behaviour can be related to a number of patient demographic variables. It does not explain causation - it just indicates correlation. The 'task' and 'socioemotional' domains are somewhat artificial, but they serve to group classes of behaviour which might be useful. A problem I can see is one of classification... depending on the tone of information giving, the context that it is given in, the patient's state of mind and his/her past experience in talking with physicians (or other people with authority) the message can take on multiple meanings: 1) "I need to remember this; it is important information." 2) "My doctor values me and wants me to be well." 3) "Here he goes again. Always the same thing. Why doesn't he just get a tape recorder to nag at me?" A strength of this study lies in showing that physicians do vary their behaviour relative to the patient characteristics. I suspect the blending of task and socioemotional domain related behaviours by physicians is likely something best learned experientially.]

77. High, D. M. (1988). All in the family: extended autonomy and expectations in surrogate health care decision-making. *Gerontologist*, 28 Suppl, 46-51.
<http://www4.ncbi.nlm.nih.gov/cgi-bin/Entrez/referer?/htbin-post/Entrez/query%3fdb=m&form=6&uid=3139501&Dopt=l>

Objective(s):	To determine: 1) what elderly people know about advance directives, 2) what formal or informal planning for surrogate decision-making they've done, 3) what assumptions, expectations and preferences elderly people have with regard to surrogate decision-making.
Design:	Survey, personal in-depth interviews using semi-structured instrument allowing for open-ended conversation/explanations. Participants were asked what they knew of, had done and might want to do concerning advance directives and proxy appointments in case they became incapable of making decisions on their own.
Setting:	University based volunteer pool in Fayette County, Kentucky
Subjects:	40 non-institutionalized seniors drawn from a volunteer research pool at the Center on Aging at the University of Kentucky. Sample was stratified according to gender, race, marital status and living arrangements. (Ages = 67 - 91, 26 female/14 male, 19 married, 19 were widowed and 2 were divorced. 5 were black, 17 lived on their own, all but two were in good health. 20 had completed high school, 16 had completed a college degree (10 with advanced degrees).
Interventions:	None
Measures:	Qualitative, exploratory format to discover categories of concepts employed by these seniors regarding advance directives.
Results:	<p>60% of participants had talked to another person about what sort of medical care they might want should they become terminally ill. $\frac{3}{4}$ of these had talked to more than one person. Only 6 participants had written instructions.</p> <p>90% had heard about 'living wills' but understanding of what they entailed was poor. Only 18% had actually signed a living will, although 37% indicated that they wanted to. Fewer than 15% claimed they had appointed a proxy decision-maker for health care and only 18% thought they might want to. Half of the participants either saw no need to because they trusted their family to make decisions or they did not want to.</p> <p>Participants felt that decisions would be best made by family members (spouse, child/children, sibling, other family). Respondents with more than one child most often opted for the children to reach a group decision on their behalf. Doctors and lawyers were least often mentioned.</p>
Conclusion(s):	The elderly may think that advance directives are a good idea, but they tend not to use them. They have a preferred hierarchical order of family members and associated others that they entrust with decision-making power. Quite often they indicate a preference for sharing decision making among their family group.

[FRM Note: this article is interesting because it indicates that elderly people tend to select their physician as a proxy decision maker when they have no family that can assume that role. Other articles have indicated that physicians play a significant role in decision making for the elderly. This may be the case, but the elderly participants in this study clearly indicated that they depended on their family to advocate for them. The physician needs to be aware of the issue of group proxy decision-making. Some strategies need to be developed for sharing decision-making with groups]

33. Iris, M. A. (1988). Guardianship and the elderly: a multi-perspective view of the decisionmaking process. *Gerontologist*, 28 Suppl, 39-45.

<http://www.ncbi.nlm.nih.gov/cgi-bin/Entrez/referer?/htbin-post/Entrez/query%3fdb=m&form=6&uid=3169593&Dopt=1>

- Objective(s):** To explore what elderly people know about advance directives and proxy decision making, and their assumptions, expectations and preferences with regard to surrogate health care decision making.
- To generate a hypothesis for future research
- Design:** Descriptive (exploratory) survey. In depth, semi-structured interviews were conducted to elicit information about their assumptions, expectations and preferences related to surrogate decision making. Tape recordings were transcribed and analyzed for emergent themes and catalogued.
- Setting:** Subjects were part of a volunteer research pool of the Center on Aging at the University of Kentucky
- Subjects:** Stratified sample of 40 non-institutionalized seniors (mean age 74). Sample was stratified controlling for gender, race, marital status and living arrangements. Only 4 subjects had not completed high school, 20 had completed high school and 16 had completed a college degree.
- Interventions:** None
- Measures:** Subjects were asked if they had written any instructions about what they would want in medical care if they became terminally ill.
- Results:** Most study participants (60%) indicated they had at least one discussion with at least one person about surrogate medical decision making. Only 6 indicated they had written instructions. Only 5 had written any instructions concerning long term illness and care. Typically the subjects indicated a preference for informal arrangements made for family members to assume decision making responsibilities. Those who did not have family members tended to have made more formal arrangements. Most agreed that 'living wills' and directives might be a good idea but exhibited some aversion or procrastination toward writing one. The elderly expect the following hierarchical order of surrogate decision makers: 1) spouse, 2) children, 3) siblings, 4) other relatives, 5) friends, 6) doctors and lawyers.
- Conclusion(s):** The results of this study of well educated seniors indicates little support for the concept that the elderly become more dependent on their physicians for decision making. It also debunks the assumption that the elderly prefer their physicians to be their surrogate decision makers. The preferences seniors have for surrogates will often place their care in the hands of groups

of people as opposed to individuals. This impacts the physician because the group will need to be fully informed so they can make medical decisions in the best interests of the incompetent senior. Physicians need to be sensitive to the elderly person's views about advance directives and their reliance on family as a means to extend their decision making autonomy.

34. Kalet, A., Roberts, J. C., & Fletcher, R. (1994). How do physicians talk with their patients about risks? *J Gen Intern Med*, 9(7), 402-4.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=7931751&form=6&db=m&Dopt=b>

- Objective(s):** To describe how often primary care physicians discuss risk of future illness during daily practice, the context and characteristics of this discussion and how the discussion is perceived by patients.
- Design:** Descriptive, audiotaped interviews of physician patient encounters
- Setting:** Private practice clinics of internists and family physicians
- Subjects:** Physicians: 10 internists, 9 family physicians in group and solo practice (38% of 50 agreed to participate).
Patients: convenience sample of 160 patients presenting at a regularly schedule appointment (median age 48, predominantly white (86%), insured (96%)
- Interventions:** None
- Measures:** Audiotapes coded by single research assistant. Reliability determined by randomly selected subset of tapes coded for comparison by one of the authors (75%). Chi square test for statistical significance of categories of data.
- Results:** Discussion about risk of future illness occurred in 26% of visits. 6/19 physicians did not discuss risk at all with their patients in the audiotaped interviews. Physicians stated the risk with certainty 57% of the time, 40% used qualitative terms, 3.4% used numeric terms. Patients indicated that they had their questions answered (96%) and had enough information (94%); however, only 47% felt they had talked about risks or benefits with their physicians. Only 3(7%) of patients who had discussed risk could identify the risk they'd discussed. Another 3 (7%) identified a risk discussion not identified by the coder.
- Conclusion(s):** Risk is not discussed by physicians routinely. When it is, physicians tend to be somewhat vague (i.e. do not use quantitative descriptors of probability). The author suggests this limits patient's ability to fully participate in decision making - i.e. to understand benefits, risks, alternatives and anticipated outcomes (effectively informed consent).
- [FRM note: only 38 % of physicians approached agreed to participate, no description of length of physician patient relationship. Definition of 'risk discussion' is any discussion about behaviour change, compliance with screening tests, treatment specifically intended to prevent cardiovascular disease, cancer, stroke, or osteoporosis. Is it possible that a sizeable number of this convenience sample of patients were visiting the physician for reasons that might have not have included a rationale for addressing such

topics? Little is said in the description as to reasons why patients were attending.]

35. Kaplan, S. H., Greenfield, S., Gandek, B., Rogers, W. H., & Ware, J. E., Jr. (1996). Characteristics of physicians with participatory decision-making styles [see comments]. *Ann Intern Med*, 124(5), 497-504.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=8602709&form=6&db=m&Dopt=b>

Objective(s):	To identify personal and practice characteristics of physicians associated with participatory decision-making styles
Design:	Descriptive Survey - self-administered questionnaire. Patients were asked about physicians' level of control and disposition to involve them in decision making. This generated a single averaged 'style' score for each physician, which was compared against various physician characteristics.
Setting:	Wide assortment of practice environments (solo or single specialty group practices, multiple specialty group practices and health maintenance organizations), varied practice types (family physicians and general internists, cardiologists, endocrinologists).
Subjects:	7,730 randomly selected patients from lists of 300 physicians. Patients were: well educated (mean completed years of education = 13.7), predominantly female (61%), white (78.3%) with one or more chronic disease (53%), and ages ranging from 18 - 106 years (20% were 65 years or older).
Interventions:	None
Measures:	Descriptive statistics comparing the perceived decision making style of physicians as perceived by their patients to physician demographics and other characteristics. Regression analysis of patient demographic information.
Results:	<p>Although this study was published in 1996, the data had been collected in 1986. Patients of physicians with higher participatory decision making style scores tended not to change physicians ($p < 0.01$ over a 12-month study period). Physicians with high volume practices were rated as less participatory compared to those with low volume practices regardless of type of practice ($p < 0.005$). Physician characteristics including: low volume of practice, previous primary care or interviewing skills training ($p < 0.05$), physicians' reporting satisfaction with personal level of autonomy ($p < 0.01$), white race ($p < 0.01$), and specialty were all associated with higher participatory decision making styles. Cardiologists had the lowest rating for participatory style.</p> <p>Neither physician age nor sex was significantly related to participatory decision making style.</p>
Conclusion(s):	Patients tend to be more loyal to physicians with a participatory decision making style. Physicians in high volume (busy) practices and some specialties (cardiology) tend to adopt a less participatory style. Primary care or interviewing skills training can improve one's participatory style.

The authors noted that patients rated physicians in all types of high volume practices as having a lower participatory styles. Further they estimated that practice volumes in managed care settings have tripled in the decade since the data was collected. This likely has even more negative implications for participatory decision making in such settings presently. (as opposed to 1986 when the data was collected)

[FRM Note: This article points to variability in participatory style associated with different practice types - primary care physicians tend to involve patients more than do some specialties (e.g. cardiologists). It also provides some data of interest to HMO's about patient satisfaction (loyalty), the effect of physician satisfaction about personal autonomy, and the impact of high practice volume.]

36. Katz, J. (1984). *The Silent World of Doctor and Patient*. London: Collier Macmillan Publishers.

Core Argument:

Encourages physicians and their patients to communicate more effectively about decisions to be made that may/will impact patients' health or well being.

Primary Evidence:

The author traces historical roots of what he refers to as the 'silent world of the doctor and patient'... the assumption - by both the physician and the patient - that the physician, as a well-intentioned medically learned individual, should assume the role of decision maker on behalf of the patient. He makes a case that medical training has heretofore indoctrinated physicians in this premise. Similarly, patients have been socialized to accept - seek even - physicians who will make such decisions.

Katz suggests this process of socialization has influenced even how 'informed consent' legislation has evolved over the last 90 or so years - the focus of which has become primarily on disclosure of risks. He considers shared decision making more than simply a process of obtaining informed consent. ["Decision making in medicine, in order to safeguard the autonomy of both parties, must become a joint undertaking that depends more on the nature and quality of the entire give-and-take process than on whether a particular disclosure has or has not been made."(p. 84)]

Katz contends that physicians resist shared decision making because the socialization process during medical training teaches them to do so. Physicians believe that medical decisions are too complicated for lay people to understand and are too difficult to explain. They consider the uncertainty of medical decision making process will make patients anxious and this is counterproductive to the effective therapy. Further they believe that when people are ill they are less able to make the best choices and consequently they *want* physicians to make the choices for them. Katz advocates for a move away from these traditional paternalistic notions. He implores physicians to reflect on the foundations of their biases and value judgements, and to communicate more openly with patients. He believes that physician patient relations will benefit from creating an environment of mutual trust (The physician is a well trained, technically competent and experienced professional. The patient is aware of his/her own needs and has the right and the ability to share in the decision making process. They each have the verbal competence to arrive at a decision).

Physicians, Katz says, need to acknowledge uncertainties of medical practice. Sharing these with patients will: 1) *make them less prone to accusations of promising more than medicine can deliver*, 2) *give patients a greater voice in decisions*, 3) *put the emphasis back on care rather than control* and 4) *reduce the feelings of psychological abandonment* (ignored, dismissed, patronized, disregarded) that patients feel when physicians keep most of their thoughts to themselves, deprive patients of information and retreat behind a curtain of professionalism. He discusses at length the meaning of this abandonment to patients - particularly those facing impending death.

Conclusion/Recommendations:

Open communication channels with patients. The physician should acknowledge the uncertainties of medical practice and their own human frailties. They should respect the patient's desire and right to participate in decisions that affect their lives. Without communication and mutual trust the physician patient relationship is doomed to one of coercion and manipulation.

37. Kurtz, S., Silverman, J., & Draper, J. (1998). *Teaching and Learning communication Skills in Medicine*. Abington, Oxon,UK: Radcliffe Medical Press Ltd.

Description of Context:

Over 25 years of literature has accumulated pointing to the complexity and the deficiencies of physician patient communication. Some articles have described efforts to address this issue by incorporating communication skills teaching in medical education and later periods along the physician education continuum. This book synthesizes the literature and offers a model for skill development that is evidence-based.

Topic/Scope:

The target audience for this book includes facilitators, medical educators, programme directors and learners involved in teaching and learning medical communication skills. Fundamental premises of this book include: 'communication is a core clinical skill essential to clinical competence', 'communication is a learned skill that needs to be taught... (and) taught effectively', 'communication skills teaching and learning is different' from other cognitive and technical skills acquired throughout the medical education process. In brief, it thoroughly discusses the *why*, *what* and *how* of: 1) teaching medical communication skills, 2) developing programmes that address this issue and, 3) supporting the ongoing education of facilitators. The book promotes a process of communication skills training that is evidence and problem-based, experiential, recursive and helical. Further, it shares tools found to be useful in providing participants feedback and self-evaluation and sample curricula.

Conclusions/Recommendations:

Communication skills form the bedrock upon which is built the physician-patient relationship. It is a core competency essential for medical diagnosis, decision making, treatment, and education/prevention. These are skills that can be learned and taught. This book is a 'must-read' for anyone wanting to create a programme to teach these skills.

[FRM Note: This book is **essential reading**. There is a companion book for learners that is also extremely good.]

38. Laine, C., & Davidoff, F. (1996). Patient-centered medicine. A professional evolution [see comments]. *JAMA*, 275(2), 152-6.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=8531314&form=6&db=m&Dopt=b>

Description of Context:	This article discusses the trend toward patient-centered care (i.e. a model of health care responsive to patient’s wants, needs and preferences).
Topic/Scope:	The article provides a concise overview of the changes that have occurred over time toward providing care that is more patient centered. It addresses such issues as informed consent, medical decision-making, the physician-patient relationship, changes in medical law, medical education, research and quality assessment.
Conclusions/Recommendations:	Informed consent: The authors suggest that a change in patient’s attitudes has occurred whereby patients expect to be given information about their disease, pathophysiology, treatment options and prognosis. “Honesty is the best policy”.
	Medical Decision-Making: The authors cite Slack (1977) as urging physicians “to stop thinking in terms of <i>compliance</i> , recognize the right of patients to make their own medical decisions and to help them do so”. They recognize that the process of sharing decision-making is time intensive and must be tailored to the needs and wants of individual patients. They also discuss the variability of patient’s preferences.
	Physician-patient relationship: The authors discuss several models of physician patient interaction promoting patient involvement in their own care. They also profile the recommendations of Delbanco. Physicians are encouraged to engage in systematic patient review processes, eliciting patient’s perspectives, values and preferences. This interaction forms the basis for physician-patient contracting of responsibilities.
	Medical law: The law backs the moral and ethical position of patient centered practice. This includes expectations for disclosure and involvement in decision-making. It also addresses the issues surrounding living wills, advance directives and involvement of significant others (e.g. families).
	Medical Research and Quality Assessment: Research and quality assessment initiatives now tend to be concerned with patient-based outcomes rather than just health outcomes. What might be considered by health professionals to be the best health outcome, might not be considered as such by the patient. (i.e. such research now is factoring in patient’s values and preferences)
	Physicians must be strong advocates for individual patients, despite the pervasive climate of 3 rd party insurers that push physicians to provide standardized care for groups of patients. Quality of care must be paramount importance, rather than simply cost of care.
	[FRM Note: good summary article – a worthwhile read.]

39. Laine, C., Davidoff, F., Lewis, C. E., Nelson, E. C., Nelson, E., Kessler, R. C., & Delbanco, T. L. (1996). Important elements of outpatient care: a comparison of patients' and physicians' opinions. *Ann Intern Med*, 125(8), 640-5.
<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=8849148&form=6&db=m&Dopt=b>

Objective(s):	To compare patients' and physicians' opinions on the importance of specific aspects of health care to perceptions of the overall quality of outpatient care
Design:	Survey - descriptive study
Setting:	Solo or small group practice in general internal medicine.
Subjects:	74 physicians practicing at least 60% of their time in general internal medicine thought to be exemplary physicians by the Governors of their state's College of Physicians. Physicians were predominantly male (78%) and only 7% belonged to an ethnic minority. 11 patients randomly selected from each physicians' appointment logs - predominantly female (67%), high school graduate or greater level of education (87%), self-described to be in 'good to excellent health' (65%).
Interventions:	None
Measures:	Physicians and patients ranking of 125 elements of care covering 9 domains of proficiency: physician clinical skill, physician interpersonal skill, support staff, office environment, provision of information, patient involvement, non financial access, finances and coordination of care. Ranking was on a 4 point scale (not important, moderately important, high importance, essential). Median importance attributed by physicians and patients were analyzed for significance using the Mann Whitney U test.
Results:	Disagreement that was statistically significant was found in 58% of elements rated by physicians and by patients. Physicians and patients agreed that clinical skill of the physician was the most critical element of quality health care. Nine of the 15 largest differences concerned the 'provision of information to the patient'. Patients ranked this domain second most important while physicians ranked it 6th in importance. Patients placed greater value on effective communication of health-related information than did physicians. Patients also placed higher value on patient involvement than did physicians though this was not statistically significant (P=.09)
Conclusion(s):	Physicians and patients have substantially different views of the relative importance of various aspects of provision of health care. Most notably patient rank communication concerning provision of information to the patient and the patient's family considerably higher in importance to quality health care than do physicians (e.g. explanations and information from their physician). Physicians should be made aware of this difference. Training programs should be made available to upgrade physicians communication skills.

40. Lantos, J. (1993). Informed consent. The whole truth for patients? *Cancer*, 72(9 Suppl), 2811-5.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=8402509&form=6&db=m&Dopt=b>

Description of Context: To outline and compare the legal and moral rationales behind informed consent and some problems with the implementation of 'informed consent.'

Topic/Scope: Do patients want to know the whole truth? Legally it may be in the physician's best interest to divulge as much as he/she knows in order to avoid being sued. Morally it can be argued that physicians should respect patients' need for autonomy and to provide them with as complete a picture as they might need to make the best decision. Four reasons why physicians should not presume to 'shield' patients from the truth include: 1) Medical tests often provide evidence of illness before the patient actually feels ill, patients need to be advised of their condition so that early treatment can be agreed upon, 2) Some modern therapies often will make the patient worse off initially before they begin to feel better, so patients need to be forewarned of this process, 3) There are often numerous therapeutic approaches available, so patients can be given the opportunity to choose one that least conflicts with their values, beliefs, feelings... 4) Patients agreeing to participate in clinical research must be informed about the research, expected risks and benefits and be given the opportunity to withdraw at any time. The author admonishes that 'informed consent' should be considered more than a 'waiver of liability' (i.e. Legal model of informed consent). A moral model would consider informed consent to be the thing to do because it is good for the patient to be involved in his/her own treatment. Lantos suggests that previous research about patients' attitudes toward communication of information is flawed because the data is drawn either retrospectively (from lawsuits) or from survey of individuals who asked hypothetical questions about what they'd want. He contends that real patients facing real decisions will react differently than either case - they would not act as potential litigants or rational consumers.

Conclusions/Recommendations: All patients, whether being informed for research protocol reasons or for legal/moral reasons deserve to receive information about the proposed intervention, goals, risks, benefits and alternatives to treatment. This should be standard practice, whether the procedure or treatment is routine or is new, or of major or minor risk.

41. Lerman, C. E., Brody, D. S., Caputo, G. C., Smith, D. G., Lazaro, C. G., & Wolfson, H. G. (1990). Patients' Perceived Involvement in Care Scale: relationship to attitudes about illness and medical care. *J Gen Intern Med*, 5(1), 29-33.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=2299426&form=6&db=m&Dopt=b>

Objective(s): Validation of survey instrument (Patients' Involvement in Care Scale - PICS), to examine the influence of three factors: 1) doctor facilitation of patient involvement, 2) level of information exchange, 3) patient participation in decision making.

Design: Survey

Beyond Informed Consent
Annotated Bibliography

Setting:	University based primary care clinic
Subjects:	Questionnaire development: Convenience sample of 131 patients presenting with new symptoms or exacerbation of previous symptoms at a University-based primary care clinic. Second sample of 81 patients to cross-validate preliminary findings. (Mean age = 38.6, female = 62%, black=80%). 8 primary care physicians were also asked for their input to survey elements Relationship of PICS to Patient Satisfaction: convenience sample of 60 primary care patients. Relationship of PICS to Illness Attitudes: convenience sample of 83 primary care patients
Interventions:	None
Measures:	PICS final version was 13 questions (Cronbach's alpha measuring internal inconsistency yielded 0.72 and 0.60 for the two samples). Items were broken into three subscales: 1) Doctor facilitation (DF) - patient's perceptions of the physician's efforts to facilitate patient involvement, 2) Patient Information Exchange (PI) - patient perceptions of the their role in eliciting or providing information exchanged between physician and patient, and 3) Patient Decision Making (PDM) - patient's perceptions of their role in the decision(s) made
Results:	DF and PI were correlated to changes in illness attitudes (level of understanding, reassurance, perceived control, and expected improvement in functional capacity). Patient Decision Making (PDM) subscale did not correlate with any of these items.
Conclusion(s):	Patients need to perceive that their physician has listened to their problems, concerns and questions. They need to perceive that they've been informed about their health problems and had an opportunity to share their opinions. Patients perhaps don't need to perceive that they have participated in the decision making process.* [*FRM note: to me the elements of DF and PI described amount to what I would consider having had input in the decision making process. DF and PI represent the bidirectional flow of communication... a sharing of perspectives. The items of PDM appear to be focused entirely on what the patient has done to exert autonomy in the decision making process. The authors' approach comes appears to come from the view that either the doctor or the patient must make the decision. It would have been interesting to have asked explicitly if patients felt they had shared in the decision making process.]

42. Levinson, W., Roter, D. L., Mullooly, J. P., Dull, V. T., & Frankel, R. M. (1997). Physician-patient communication. The relationship with malpractice claims among primary care physicians and surgeons [see comments]. *JAMA*, 277(7), 553-9.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=9032162&form=6&db=m&Dopt=b>

Objective(s): To identify specific, routine communication behaviours associated with

malpractice history of primary care physicians and surgeons

Design:	Compared communication styles of physicians and surgeons having malpractice claims vs. those with no claims. Audiotapes of 10 routine office visits were coded using the Roter Interaction Analysis System (RIAS) for content, process and emotional affect elements.
Setting:	Offices of primary care physicians and surgeons in Colorado and Oregon
Subjects:	Stratified sample of 124 primary care physicians and surgeons having at least 13 years of medical experience having no malpractice claims or two or more claims since graduation. Patients: Adults, not in acute distress, having had at least two prior visits to the physician
Interventions:	None
Measures:	Analysis of the audiotapes using the Roter Interaction Analysis System
Results:	Compared routine communication styles of claim and no-claim physicians and surgeons. The length of visit of 'non-claim physicians' tended to be 3.3 minutes longer on average than for claim physicians ($p < 0.003$). They tended more often to provide process/orienting information (e.g. describe the order of things to be done in the visit) ($p < 0.02$) and also tended to use humour ($p < 0.05$) and facilitate patient input (NS). There was no correlation between the information shared and malpractice claims history. Communication styles of surgeons were not found to correlate with malpractice history. Skills of facilitation, laughter and empathy were associated, though not significantly, with decreased risk of claims for surgeons
Conclusion(s):	<p>Physicians who take more time, facilitate opportunities for patient input and develop rapport with their patients tend to be less apt to have claims of malpractice. Communication style is less important in this regard for surgeons than for primary care physicians.</p> <p>[FRM Note: This article does not address shared decision making specifically. It does provide evidence of some differences between the communication styles of surgeons and primary care physicians. This may mean that the practice environments and the relationship that patients have with surgeons are different than with primary care physicians. These differences may influence how each might approach 'informed consent' and shared decision-making.</p> <p>The study also describes that provision of information was not predictive of claim history for either physicians or surgeons. It would have been interesting to know if the malpractice claims attributed to these physicians and surgeons could be correlated to their routine information sharing behaviour.]</p>

43. Lidz, C. W., Appelbaum, P. S., & Meisel, A. (1988). Two models of implementing informed consent. *Arch Intern Med*, 148(6), 1385-9.

<http://www.ncbi.nlm.nih.gov/cgi-bin/Entrez/referer?/htbin-post/Entrez/query%3fdb=m&form=6&uid=3377623&Dopt=l>

Description of Context: Clinical observation and empirical research suggest (circa 1988) that

informed consent may be considered by some to be an empty ritual that provides little benefit to the patient in participating in making of decisions.

Topic/Scope:

The author describes two models for implementing informed consent - as a *discrete event* and as an *ongoing process*. The former tends to be viewed as a bureaucratic means to meeting legislative requirements. The latter, the author contends, integrates 'informed consent' into the physician patient relationship. The process model recognizes that medical decisions are not generally singular or discrete events, rather they tend to evolve from the time there is suspicion that something might be wrong to when the patient finally leaves follow-up care. The process model relies on: 1) patients assuming the role of a member of the team having special insights and expertise, 2) physicians being able to relate to patients in a meaningful way, 3) clarification of the values and beliefs of both, physicians and patients. The process model is characterized by 'mutual monitoring' - the ongoing meaningful dialogue between physician and patient that serves bolster the three issues noted. The author illustrates the process model through five phases in the treatment process: establishing responsibility, defining the problem, setting goals, selecting an appropriate treatment and extended treatment/follow-up. The model recognizes that each player has a significant role to play during each of the phases. It also recognizes that during each phase the amount of patient autonomy and physician input to decision making may change... the goal should ultimately be to re-establish personal autonomy that might be relinquished cooperatively by the patient at some point during the process.

The author admits that the process model does not fit well in some practices (e.g. Anaesthesia and Emergency Medicine where specialized services are provided for patients and the physicians may have almost no relationship with the patient.) It is also conceded that the process model is likely to take more time than the event model.

Conclusions/Recommendations:

The process model described respects patients' right to share in making decisions - **all decisions** - pertaining to their medical treatment. It recognizes that decisions often need to be re-visited and provides the framework for ongoing refinement of the physician and the patient's understanding of each other's values and beliefs. It further recognizes the therapeutic value of a strong physician patient relationship. Where possible, encourage physicians to move toward a *process model* of informed consent.

[FRM Note: this article recognizes the situational or practice-related variability in the physician patient relationship. Primary care physicians undoubtedly have different relationships with their patients than might surgeons, anaesthetists and specialists in emergency medicine. While all physicians need to be cognizant of the requirements of informed consent and encouraged to involve patients in decisions concerning their medical care, the method/model used by each might be substantially different.]

44. Lipkin, M., Jr. (1996). Physician-patient interaction in reproductive counseling. *Obstet Gynecol*, 88(3 Suppl), 31S-40S.

<http://www.ncbi.nlm.nih.gov/cgi-bin/Entrez/referer?/htbin-post/Entrez/query%3fdb=m&form=6&uid=8752226&Dopt=l>

Beyond Informed Consent Annotated Bibliography

Objective(s):	To review the empirical and clinical foundations for effective patient counseling in contraceptive care
Data Sources:	Articles and chapters reviewed in the Annotated Bibliography of Doctor Patient Communication of the Task Force on Doctor and Patient by the American Academy of Physician and Patient (primarily sources extracted from MEDLINE review from 1969 - 1994).
Study Selection:	Expert consensus from the Committee on Bibliography of the American Academy on Physician and Patient
Data Extraction:	As above
Data Synthesis:	This article provides a concise overview of the structural and functional elements of the medical interview, physical and psychological barriers to effective communication, steps to consider in informing/educating patients, encouraging patient participation, facilitating partnership (activation), models of change, and efforts to change physician behaviour related to development of effective communication skills.
Conclusion(s):	<p>Physicians do not communicate well with patients. They need to learn to actively involve patients in the process of making decisions. They need to learn how to negotiate and encourage patients to negotiate. Physicians need to be reminded of the importance of developing strong relationships with their patients, based on trust.</p> <p>[FRM Note: this is an excellent summary of key articles. The tables concisely describe behaviours recommended during the interview and provide trigger questions and 'stems' for eliciting patient involvement. This article emphasizes development of basic communication skills associated with the interview]</p>

45. Mazur, D. J. (1986). What should patients be told prior to a medical procedure? Ethical and legal perspectives on medical informed consent. *Am J Med*, 81(6), 1051-4.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=3541590&form=6&db=m&Dopt=b>

Description of Context:	This paper explores the legal and ethical viewpoints in medical informed consent in the U.S. (but the author advises that similar requirements are needed in Canada and New Zealand).
Topic/Scope:	<p>The article traces the historical roots of informed consent legislation from the 1900's. From the 1900's to 1950's physicians could be charged on the grounds of battery for failure to inform their patients or on negligence regarding disclosure. From 1950 to 1972 the negligence was based on the practice of disclosure of peer physicians. Lawyers argued that physicians may not be the best people to set standards (ie. Intimating physicians as a rule did not inform patients well). Since 1972 grounds of medical informed consent has rest on the test of 'what a reasonable man/woman would want to know.' (Canterbury v. Spence and Cobbs v. Grant)</p> <p>Pragmatic Issues: informed consent has been a key issue in physician patient relations. Some States have put forth the effort to define criteria about of what patients should be informed, most others have continued in</p>

use of the standards of 'community of physician's peers or the 'test of the reasonable man'. Ethically, three main issues have arisen: 1) Are patients presented with appropriate information, 2) Do patients understand the information conveyed to them?, 3) Can patients make their preferences known to their physicians (or can physicians elicit their preferences) regarding alternative outcomes? — all three of these elements must be considered if a true informed consent has been given.

The author identifies difficulty in involving patients who are acutely ill, hospitalized and awaiting therapy in the decision making process. He weighs the concern of overloading the patient with detailed information they may not want or understand, and forcing them to choose with their own well being hanging in the balance. He suggests that physicians should engage patients in discussions regarding (advance directives) decisions well before the need for a decision about medical care arises.

Conclusions/Recommendations:

Physicians are encouraged to engage patients in discussion of their expectations and wants regarding medical care. Such discussions are needed in case a situation arises where the patient might not be able to make or communicate such decisions. He considers it important for physicians to know what the **patient's short (6 month) to long term (5 years) goals** might be in order to be better prepared for the 'joint task of informing patients about treatment alternatives and complications.

46. Mazur, D. J., & Hickam, D. H. (1991). Patients' interpretations of probability terms [see comments]. *J Gen Intern Med*, 6(3), 237-40.
<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=2066829&form=6&db=m&Dopt=b>

Objective(s):

To study patient's understanding of probability terms and preference for qualitative or quantitative descriptors

Design:

Survey, structured interview about 1) the meaning of probability terms, 2) whether patients wanted physicians to provide information about probability, 3) whether they would prefer such information in quantitative or qualitative terms.

Setting

General medicine clinic at a university-based Veteran's Affairs medical center.

Subjects:

Convenience sample of 133 patients presenting sequentially at a general medicine clinic. Patients were predominantly male (88%), older (Mean age=62), well educated (72 % graduated from high school or better).

Interventions:

None

Measures:

"Principal components factor analysis" grouping terms, mean values compared using analysis of variance measures and paired t-tests.

Results:

Only one patient didn't want to receive probability information from a physician. 32% wanted information in numerical terms, 35% wanted it in qualitative terms (e.g. most likely, never), 22% wanted the information either way and 8% wanted the information in both qualitative and quantitative terms. Patients' interpretations of qualitative descriptors yielded remarkable variability in terms of ascribing numerical values to

qualitative probability statements (The standard deviation for all but the terms certain or never ranged from 20% to 31%)

Conclusion(s):

Physicians need to communicate information to patients using terms they understand if patients are going to be able to participate effectively in shared decision-making. Qualitative descriptors of risk or probability are familiar to patients. Three groups of words tend to yield the best correlation of quantitative and qualitative value: 1) Certain/Never, 2) Possible/not unreasonable/improbable/unlikely/almost never (60.2 – 86%), 3) Almost certain/very likely/likely/frequent/probable (49.7 – 15.5%). The author recommends physicians to be careful about which category of qualitative descriptors he/she chooses from when describing probabilities to patients. It is feared that using descriptors incorrectly might be confusing to patients.

[FRM note: this survey doesn't address stability of patient's perceptions of probability statements over time. (e.g. if the patient is in a more optimistic mood will they attribute the same values to the statements) 1/3 of the patients indicated a preference for quantitative terms only. This does not mean that other means of conveying the information are not useful. Even these patients may well get valuable information from a description using both qualitative/quantitative terms]

47. Mazur, D. J., & Hickam, D. H. (1993). Patient preferences: survival vs quality-of-life considerations. *J Gen Intern Med*, 8(7), 374-7.

<http://www.ncbi.nlm.nih.gov/cgi-bin/Entrez/referer?htbin-post/Entrez/query%3fdb=m&form=6&uid=8410398&Dopt=1>

NOTE: This article is listed on MEDLINE as Mazur and Hickman. The actual article lists the second author as DH Hickam (a co-author in a number of other papers with Mazur)

Objective(s):

To assess patients' willingness to accept risk of morbidity for a chance at longer survival.

Design:

Survey, descriptive

Setting:

University-based Department of Veterans Affairs Medical Center

Subjects:

Convenience sample of 230 male general internal medicine clinic patients presenting for continuity care. Age (mean=65), completed high school or greater education (67%)

Interventions:

None

Measures:

Patients were randomly assigned to receive one of two survival curve graphs, one that showed a better short term survival but worse thereafter or a graph depicting a better short term survival rate but considerably worse long term rate than the first graph. Assistance was provided in interpreting the key features of the graphs. Patients were advised that both treatments depicted in the graphs would result in similar quality of life, their level of function would be minimally compromised with either treatment, the only difference was in terms the depictions of the two graphs. They were then asked whether they preferred the treatment that would yield better short term (treatment A) or better long term (treatment B) survival. Patients selecting treatment A were then asked if they would accept treatment A if there varying (100%, 1%, 10%, 20%...) chances of developing urinary incontinence and then describing what that would mean. The choices

stopped when the patient accepted the risk of incurring urinary incontinence over that of the benefit of long term survival. Similarly patient were asked to consider their 'gamble' on a risk of total impotence. Data was collected about previous history of aspects of incontinence or impotence.

Results:

The influence of morbidity risk in decision making was less when patients were confronted with substantial mortality risk differences in the two graphs. Men were more apt to accept the risk of urinary incontinence than that of total impotence. Men having had experience with either incontinence or impotence were more apt to accept these morbidity risks than those who had not.

Conclusion(s):

Patients approach decision making based upon personal values. They are willing to trade off long term survival with issues of quality of life. These trade-offs appear quite variable and under influences not necessarily easily discerned. Physicians should attempt to understand how patients use survival and quality-of-life data in medical decision making.

[FRM Note: Physicians need to gain some insight into the values and beliefs of patients. This article provides further rationale for physicians not to assume the paternalistic role of sole decision-maker.]

48. Mazur, D. J., & Merz, J. F. (1994). How age, outcome severity, and scale influence general medicine clinic patients' interpretations of verbal probability terms [see comments]. *J Gen Intern Med*, 9(5), 268-71.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=8046529&form=6&db=m&Dopt=b>

Objective(s):

To study the effect of the scale used to elicit verbal probabilities from patients, 2) to see if the severity of the outcome influences patient's interpretations of verbal probability statements

Design:

Survey. Patients were randomly assigned to cells of a 2X2 design, varying the scale and the health outcome. Short (odds = 100/100 to less than 1/1000) and long (odds = 100/100 to less than 1/1 Million) scales were described orally, supplemented with visuals. Patients were also randomly assigned to one of two health outcome groups - death from anesthesia vs severe pneumonia. Patients were presented with a hypothetical case and asked, according to which group they were assigned, to ascribe a numerical description to qualitative descriptors of probability (e.g. that the outcome was 'rare')

Setting:

General medicine clinic at a university based Department of Veterans' Affairs Medical Center

Subjects:

Convenience sample of 210 consecutive patients presenting at a Veteran's Affairs Medical Clinic. Predominantly male(88%), limited description of age range - split into groups of less than or greater than 65 years.

Interventions:

None

Measures:

Patient responses were transformed by logarithm and analyzed with ANOVA and linear regression techniques.

Results:

Given a numerical scale affording lower probabilities patients tended to use

the lower range values, ascribing lower probability for the same qualitative expression than those presented with a smaller scale. The outcome described influenced the numerical probability patients assigned. Patients ascribed 'rare' chance of death due to anesthesia a lower numerical probability than was assigned to a 'rare' risk of severe pneumonia. Age appeared to be a contributing factor. Older patients tended to ascribe higher probabilities for medical risks than younger patients. Some patients couldn't describe what a probability less than the lower limit on a probability scale might be.

Conclusion(s):

Physicians should be aware that patients understanding of qualitative descriptions of medical risk are highly variable. Severity of risk can be interpreted differently depending on the age of the patient, the type of outcome (death, pneumonia) and even the scale used to describe the risk (internalized by the patient).

[FRM Note: Qualitative description interpretations are very subjective and subject to other influences (e.g. perceived severity of the outcome). Numeracy skills are needed if only numerical statements of probability are used to describe risks. A combination of the two seems like an appropriate means to 'inform' patients of risks.]

49. Mazur, D. J., & Hickam, D. H. (1997). Patients' preferences for risk disclosure and role in decision making for invasive medical procedures. *J Gen Intern Med, 12*(2), 114-7.

<http://www.ncbi.nlm.nih.gov/cgi-bin/Entrez/referer?htbin-post/Entrez/query%3fdb=m&form=6&uid=9051561&Dopt=1>

Objective:

To assess the level of involvement patients want in decision making pertaining to invasive medical interventions. To determine whether the chosen role is related to their preference for a particular format (qualitative or quantitative) of description of the probability of risk.

Design:

Structured interview, augmented with written text of the questions for subjects to follow during the interview.

Setting:

Outpatient continuity care general medicine clinic at a University based Department of Veterans Affairs Medical Center.

Subjects:

Convenience sample of 467 patients (?male veterans) presenting at an outpatient clinic. Excluded were patients who were in moderate or severe acute or chronic pain and patients with moderate or severe cognitive problems.

Interventions:

None.

Outcome Measures:

Comparison of subgroups were analyzed using Fisher's Exact Test, Chi Square analyses. The relation between patient demographics / characteristics and level of preference for involvement in decision making was determined by to "multiple logistic regressions analyses". Independent variables included: age, formal education, patient's general health status, whether patient reported having ever been hospitalized with pneumonia, heart attack, cancer or stroke, and patient preference for quantitative or qualitative or both types of descriptions of risk.

Results: Patients preferred shared decision making (68.1%). 301/467 indicated that they preferred 50:50 ratio of input into decisions by the patient and physician. 93.7% of the subjects indicated that they wanted their physician to disclose risk information to them. 42.7% preferred qualitative description of risks. 35.7% preferred quantitative description of risks. 9.8% indicated a preference for both formats and 8.4% indicated either format would be fine. 3.4 % indicated they would leave it up to the physician to decide which format he/she would use. Patients who were younger, those having had at least one stroke and patients who preferred discussing risk with their physician in terms of numbers tended to prefer patient-based or shared decision making with their physicians.

Conclusions: Patients (?male veterans) prefer sharing in making medical decisions. When describing levels of risk, physicians should use a combination of qualitative and quantitative formats or simply quantitative terms.

[FRM Note: author seems to hedge his conclusions about whether patients prefer quantitative or qualitative descriptors of risk. Taken at face value his results suggest a slight preference for qualitative descriptors of risk. It would have been useful if half of the respondents were asked if they preferred quantitative vs qualitative descriptors and the other half asked if they preferred the obverse - qualitative vs quantitative descriptors. Primacy might have played a part in patients' choice.]

50. Meisel, A. (1992). Informed consent [editorial; comment]. *Arthritis Rheum*, 35(11), 1264-6.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=1445440&form=6&db=m&Dopt=b>

Description of Context: This editorial comments on the legal and ethical issues of informed consent and discusses the need for longitudinal research studies dealing with provision of information to patients and the physician patient relationship..

Topic/Scope: Informed consent is more than a process item or simply a legal requirement. It should be considered the "fundamental ethical precept of the doctor patient relationship." It speaks to the collaborative manner that physicians must approach their patients to optimize medical decision making. The ensuing discussion is on options, rather than a single option, and the risks benefits and alternatives of each. Information should be offered freely, as a matter of course, not relying on the patient to ask questions. The author suggests that longitudinal studies are needed to evaluate physician patient communications over time. He indicates a suspicion that patients garner information about their health over a period of time rather than simply at a single physician visit. Further he postulates that they might make their questions, wants and values known to a physician over time as well during follow- up visits.

Conclusions/Recommendations: Informed consent must be considered by physicians as more than simply complying with a legal requirement. Information sharing should be a routine event between a physician and his/her patient. This builds *trust* in the physician patient relationship. It helps patients build the knowledge they need to make an informed decision and to convey their wants, values and beliefs.

[FRM Note: Longevity of the physician-patient relationship not only makes it possible for physicians to better understand the patient's values and beliefs, it also (as this article points out) helps patients gather information from the physician over time. (i.e. their understanding of their medical condition is shaped over a period of time).

51. Nease, R. F., Jr., & Brooks, W. B. (1995). Patient desire for information and decision making in health care decisions: the Autonomy Preference Index and the Health Opinion Survey [see comments]. *J Gen Intern Med*, 10(11), 593-600.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=8583261&form=6&db=m&Dopt=b>

Objective(s):	1) To compare the 'Autonomy Preference Index (API)' and 'Health Opinion Survey (HOS)' measurements of patient desire for information and involvement in decision making, 2) To determine if there is a difference between desire for information and desire for involvement in decision making, 3) To identify patient characteristics associated with desire for information and for involvement in decision making.
Design:	Survey, cross sectional
Setting:	University-based primary care outpatient longitudinal and acute care clinic
Subjects:	167 patients with benign prostatic hyperplasia, back pain or mild hypertension who completed both survey instruments. Patients were predominantly male (75%), had more education than just high school (53%), white (98%), married (75%), living with family or friends (86%).
Interventions:	None
Measures:	HOS: 16 item questionnaire measuring desire for information and behavioural involvement. Asks what the patient usually does to seek information. Assesses the patient's desire to participate in self-care. API: Vignettes and 23 item questionnaire measuring information seeking and decision making preference. Asks what the patient feels the physician should do. Asks what the patient feels he/she should do with regard to making decisions Compared 'information' scores with 'decision making' scores and checked for significant differences across the two instruments using Wilcoxon signed-rank test (non-parametric analog to the paired t-test). Used Spearman rank correlation coefficient to correlate the scores of the two instruments
Results:	There is significant correlation for decision making and information between the API and HOS instruments. Higher desires for information and decision making were associated with younger age, higher education, employment and female gender. As the seriousness of the scenarios increased in the API, the desire for involvement decreased
Conclusion(s):	Patients have a high desire for information. This desire exceeds the desire for participation in treatment decisions. Clinicians should assume that patients will want information regardless of how the physician perceives

them to feel about participation in decision making.

There is substantial variation in patient's desire for information and involvement. This can be correlated to age, gender, level of education... however, how these variables are related is not known.

API and HOS scores indicate that the two tests are measuring slightly different values/beliefs. HOS appears to focus on information seeking behaviour rather than on patient desire for information.

52. Northouse, P. G., & Northouse, L. L. (1992). *Health Communication Strategies for Health Professionals*. Norwalk, Conn.: Appleton & Lange.

See Chapter 8 - Ethics and Health Communication (p 249 - 272.).

Description of Context:

Patients, family members, physicians and other health care professionals need to communicate effectively with one another to promote the ethical delivery of health care.

Topic/Scope:

Ethics and Health Communication (Chapter 8) provides an overview of the major tenants of the Hippocratic Oath and dimensions of biomedical ethics (beneficence, paternalism, autonomy, justice). It addresses 'informed consent' as a communication issue. It looks beyond the formal legal requirements to the interpersonal relationships underlying the 'consent' process - those between physician and patient and those involving the family as gatekeepers and among members of hospital ethics committees. Noting that "effective interpersonal relationships depend on honesty and trustworthiness", a section deals with truth telling and describes four approaches.

Conclusions/Recommendations:

Patients, their proxies and health care professionals share the responsibility to communicate effectively. This is emphasized in the section dealing with truth telling. How can patients be expected to give informed consent if they cannot comprehend what they have been told? Similarly, how can consent be ethically considered to be given if the physician has withheld information, or tells only part of the prognosis? Physicians have a legal and ethical responsibility to inform patients. The authors describe a continuum of truth telling that ranges from strict paternalism, to benevolent deception, to contractual honesty, to unmitigated honesty. A pattern of communication in the realm of contractual honesty (tell the patient as much information as the patient wants to know) is promoted as an ethically preferred level of information for obtaining consent. Patients are not burdened with more information than they have indicated they wanted, yet they do get some information.

[FRM Note: the authors have indicated that the patient's role is to provide physicians with clues to the amount of information they would like to receive about their condition. The physician's role is to analyze that information, determine the appropriate amount, and then tailor the information shared to meet these needs. While both parties participate in this communication process it doesn't seem like they have actually shared the responsibility for making medical decisions. To me, this posture weakens the spirit of 'informed consent' legislation. It puts incredible pressure on the relationship between physician and patient. Can this level of trust be built in the very brief relationship some specialists might have

with patients? (Family physicians, having longer term relationships with patients may have a better chance of judging this 'desired level' more accurately). Other literature has indicated that physicians are often poor judges of patients wants and needs. Are they going to be any better at deciding the level of information the patient has inferred they desire?]

53. Novack, D. H., Suchman, A. L., Clark, W., Epstein, R. M., Najberg, E., & Kaplan, C. (1997). Calibrating the physician. Personal awareness and effective patient care. Working Group on Promoting Physician Personal Awareness, American Academy on Physician and Patient [see comments]. *JAMA*, 278(6), 502-9.
<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=9256226&form=6&db=m&Dopt=b>

Description of Context:

Physicians attitudes, values, beliefs and past experiences influence how they communicate with their patients. This article proposes that improving communication and physician-patient relationships begins first with the physician's examination of self.

Topic/Scope:

This article draws from an extensive literature base to support its recommendation that through achieving greater personal awareness physicians will be better able to communicate with patients and in turn provide more effective care. It addresses such topics as the influence of core beliefs and values, gender biases, sociocultural influences, and family of origin influences. It explores physicians' feelings and emotional responses in patient care (e.g. boundary setting, conflict), challenging clinical situations (e.g. difficult patients, caring for the dying patient, medical mistakes) and self care issues (e.g. balancing personal and professional life, coping with stress and prevention of burnout). The author suggests trigger questions for the physicians to ask him/herself and proposes that elements of such introspection should be considered throughout the continuum of medical learning.

Conclusions/Recommendations:

Core beliefs, values, past experience (including medical training) and attitudes shape how physicians interact with patients. Understanding these influences can help physicians provide more effective patient care and possibly make the practice of medicine more fulfilling. Michael Balint suggested that the physician was the 'drug' most frequently used in medical practice and that learning about its properties was most appropriate.

[FRM Note: excellent article. Although it does not expressly deal with medical decision-making it does address the issue a critical area of communication. Physicians' attitudes, values, beliefs and past experience shape their approach to patients. Understanding one's own prejudices and 'paradigms' can begin to eliminate barriers to effective communication.]

54. Ong, L. M., de Haes, J. C., Hoos, A. M., & Lammes, F. B. (1995). Doctor-patient communication: a review of the literature. *Soc Sci Med*, 40(7), 903-18.
<http://www.ncbi.nlm.nih.gov/cgi-bin/Entrez/referer?/htbin-post/Entrez/query%3fdb=m&form=6&uid=7792630&Dopt=l>

Description of Context:

Communication is central to the physician patient relationship and to efficient and effective provision of medical care. The complexity of communication and the effects on patient outcomes has been documented in over two decades of published research. This article attempts to consolidate some of this information.

Topic/Scope: This article reviews the literature dealing with physician patient communication as it relates to:

- 1) purposes of communication (creating a good interpersonal relationship, exchange of information, medical decision-making)
- 2) analysis of communication (profiles of various 'interactive analysis system' that have been used)
- 3) specific communicative behaviours (instrumental vs. affective , verbal vs. non-verbal, privacy, high vs. low controlling behaviours, use of medical vs. lay language)
- 4) influence of communicative behaviours on patient outcomes (patient satisfaction, compliance/adherence, recall and understanding of information, health/morbidity outcomes)

Conclusions/Recommendations: This article provides a concise overview of key research in the area of physician patient communication. The authors categorize the literature in terms of research into background variables, process variables and outcome variables.

[FRM Note: I've included this article because it captures the breadth of the issues involved in physician patient communication. Effectively it describes the importance of communication to the physician patient relationship and the implication of communication (good and poor) to medical care. Threads of information pertinent to the discussion of shared decision making run throughout the text.]

55. Paris, J. J., Schreiber, M. D., Statter, M., Arensman, R., & Siegler, M. (1993). Beyond autonomy--physicians' refusal to use life-prolonging extracorporeal membrane oxygenation [see comments]. *N Engl J Med*, 329(5), 354-7.
<http://www.ncbi.nlm.nih.gov/cgi-bin/Entrez/referer?/htbin-post/Entrez/query%3fdb=m&form=6&uid=8259183&Dopt=1>

Description of Context: This article explores the issues of patient/surrogate autonomy regarding refusal of treatment recommendations and the position of the physician in situations where the patient/surrogate decision-maker demands treatment the physician does not believe will benefit the patient.

Topic/Scope: The article describes a representative case of a 5 year old boy whose parents demanded, on his behalf, that extracorporeal membrane oxygenation was to be maintained even though physicians had concluded that the treatment was futile. The issues include: 1) In light of increasing emphasis on patient autonomy, are physicians obligated to delegate all decision-making to the patient, 2) Are physicians obligated to provide treatment requested by patients or their proxies?, 3) What course of action is it reasonable for physicians to take? The article discusses the ethical and legal considerations of this case and bases its conclusions on the premise that shared decision making does not bind either the physician or the patient/proxy to domination of either party... the decision making capability is shared.

Conclusions/Recommendations: Confronted with a situation where the physician is being asked to treat the patient differently than he/she would want to do, using best judgement , the physician should 1) listen to the concerns of the patient/family/proxy, 2) explore medical possibilities, 3) make recommendations based on their judgement, 4) base their approach on their Hippocratic Oath - to act for the

benefit of the patient according to their ability and judgement. Physicians are cautioned to make decisions on sound well-established medical criteria (e.g. practice guidelines) or widely accepted social warrants that justify and limit the use of medical interventions. Ultimately, if the physician cannot provide a requested treatment (due to violation of conscience or professional judgement) he/she is recommended to make a reasonable attempt to transfer the patient to another physician.

56. Pelias, M. Z. (1991). Duty to disclose in medical genetics: a legal perspective [see comments]. *Am J Med Genet*, 39(3), 347-54.

<http://www4.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=1867289&form=6&db=m&Dopt=b>

Description of Context:

Increased recognition of patient autonomy and the legal and ethical right of patients to participate in decisions made about medical care has ramifications for medical geneticists.

Topic/Scope:

This article provides an overview of historical approaches to medical decision making and the legal issues surrounding informed consent. It further addresses the implications for medical geneticists regarding testing and counseling patients about deleterious genes, presumption of decision making power, and treatment of 'mature minors'. It discusses in detail the need for full disclosure (i.e. to avoid legal liability) and suggests that geneticists may also have a *continuing obligation to contact former patients* to apprise them of new information that they might want to consider.

Conclusions/Recommendations:

The physician patient relationship is a long term obligation that binds physicians morally, ethically and legally. Physicians should regard patients as partners in this relationship, affording them all the information that is available so they can make an informed decision. The legal landscape is changing. Where once decisions for minor children might have once been made by the medical geneticist and/or parents, there is now evidence of the courts recognizing the rights of children - particularly mature minors - to make decisions concerning their medical care.

[FRM Note: this article continues to stress the legal requirements of full disclosure and the need to respect patient autonomy - even of minor children. It also points out that physicians in a wide range of practice specialties are impacted. Lastly, it describes the longevity of the physician patient relationship.]

57. Peters, R. M. (1994). Matching physician practice style to patient informational issues and decision-making preferences. An approach to patient autonomy and medical paternalism issues in clinical practice. *Arch Fam Med*, 3(9), 760-3; discussion 764.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=7987509&form=6&db=m&Dopt=b>

Purpose/Context:

Describes a model for the physician to customize his approach in medical decision making depending upon the 'style' of the patient.

Topic/Scope:

This article presents a reasonable overview of the literature in support of a model that matches **patient's 'style'** (*Medical facility* - "the desire and

ability of a patient to acquire, process and understand relevant medical information" (p. 761) vs. *Level of Control* (desire for more/less control over medical decision making) with the **Physician's Style**. The intent of this flexible approach is to meet the needs of the patient thereby improving the physician patient relationship and, in turn, the health outcome.

Conclusion/Recommendations: The author contends that the literature supports this model for customizing a physician's approach to a patient. He acknowledges the difficulty of acquiring the necessary flexibility and the facility to recognize the patients' styles. He also points out that the physician must constantly be monitoring his/her approach since patients' individual styles can change as they grow older and their health status changes. (i.e. severity of illness)

[FRM Note: This approach seems manipulative and difficult to implement. Will the physician come across as being 'genuine' (a la Carl Rogers)? What effect will this have ultimately on the physician patient relationship - over time?]

58. Pfeifer, M. P., Sidorov, J. E., Smith, A. C., Boero, J. F., Evans, A. T., & Settle, M. B. (1994). The discussion of end-of-life medical care by primary care patients and physicians: a multicenter study using structured qualitative interviews. The EOL Study Group. *J Gen Intern Med*, 9(2), 82-8.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=8164082&form=6&db=m&Dopt=b>

Objective(s): To identify physicians' and patients' attitudes, preferences and beliefs toward discussions about 'end-of-life' medical care.

Design: Descriptive study using audiotaped, structured, qualitative interviews

Setting: Primary care outpatient clinics and offices at eight medical centres in six states.

Subjects: Patients: stratified sample of regularly scheduled ambulatory patients (>18 years of age, competent, English speaking, 30% non-white, 30% prognosis of less than 18 months, 30% over age 60)
Physicians: Convenience sample of Internists, family physicians and general practitioners perceived to be good communicators.

Interventions: None

Measures: Audiotaped interviews were transcribed verbatim, analyzed for thematic content by individual investigators and discussed separately by the investigators organized into 3 'teams'

Results: Patients wanted: 1) physicians to be honest and forthright in their discussion of end-of-life issues, 2) such discussions to be held when the patient was competent and capable of making decisions (throughout the physician patient relationship), 3) more emphasis on outcome information as opposed to process issues (cost, duration of illness, specifics of planned treatments), 4) physicians to play a significant role in discussions of end-of-life issues (more so than family, nurses, pastoral care workers, attorneys), 5) to leave decisions to physicians early in the treatment process but ultimately wanted to reassert control over the final decisions as the medical course proceeded.

Physicians: 1) thought it was their responsibility to initiate end-of-life discussions, 2) welcomed 'living wills' as a means to enter into such discussions but distrusted them as being too simplistic, too legalistic and perhaps even too confining for the patient over time, 3) identified multiple roles played even at different times with a single patient (lifesaver, neutral scientist, guide/manipulator, counselor, confidante).

Conclusion(s):

Physicians walk a narrow line between offering superficial information and overloading the patient. This study recommends physicians present the information in a candid manner, focusing on outcome, not the process of end-of-life medical care. It describes the varied roles physicians assume and explores reasons for these approaches. It recommends working toward the intimate role of confidante as opposed to the 'safe' distance afforded by the 'neutral scientist'.

[FRM Note: This is an excellent article addressing decision making and caring from both the patient and physician perspective — a must-read.]

59. Prestifilippo, J., Antman, K., Berkman, B. J., Kaufman, D., Lantos, J., Lawrence, W., Jr., Levine, R. J., & McKenna, R. J., Sr. (1993). The ethical treatment of cancer. What is right for the patient? *Cancer*, 72(9 Suppl), 2816-9.

<http://www.ncbi.nlm.nih.gov/cgi-bin/Entrez/REFERER?/htbin-post/Entrez/query%3fdb=m&form=6&uid=8402510&Dopt=l>

Description of Context:

This article points out that the elements of informed consent (US regulations) are the same for clinical research as they are for clinical practice. Despite this, how informed consent is dealt with by each is markedly different.

Topic/Scope:

This article compares the apparent differences in application of informed consent measures in clinical practice with that in clinical research. The author suggests that a standard consent form is not possible for clinical practice because it would not be responsive to the needs of individuals. Research, on the other hand, is generally conducted on defined samples of the population sharing certain specific characteristics. The article further addresses, in reasonable detail, ethical issues surrounding clinical trials, randomization and enrollment of minors.

Conclusions/Recommendations:

Patients and their surrogate decision-makers need to be fully informed of risks, benefits, prognoses and alternatives. The values and concerns of the patient or of minor children (particularly older adolescents) should be considered.

[FRM Note: this article primarily deals with issues of ethics with respect to enrollment in clinical trials. It does make the point that legally whether the patient is part of a clinical study or being seen in clinical practice they must be fully informed. It also addresses the need to involve the patient in the decision making process, specifically because physicians are not privy generally to patients' values and beliefs]

60. Rost, K., Carter, W., & Inui, T. (1989). Introduction of information during the initial medical visit: consequences for patient follow-through with physician recommendations for medication. *Soc Sci Med*, 28(4), 315-21.
<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=2705004&form=6&db=m&Dopt=b>

Objectives:	To determine: 1) if patients are more likely to follow treatment recommendations if the recommendations arise out of discussion where the patient has contributed information either independently or in response to physician questions (bi-directional introduction of information) , 2) if such discussion is more apt to have a stronger effect on patients receiving new treatment recommendations or patients being advised to maintain the status quo. (i.e. will the patient's be more apt to follow through with the recommendation)
Design:	Descriptive - Audiotapes of patient initial interviews were reviewed to determine levels bi- directional introduction of relevant information and interaction dominance. The relationship of these variables with patient 'follow-through' with physician recommendation for medication was studied.
Setting:	Veteran's Administration hospital general medical 'continuous care' clinic for patients with chronic medical problems.
Subjects:	45 male patients - criteria for inclusion: 1) adequate physical health status 2) literacy and willingness to self-administer the questionnaire, 3) prescription refill for new or previously prescribed medicine, 5) sufficient audio tape quality throughout the visit.
Interventions:	None
Measures:	Coding of interactions in three sections of the patient visit (history, examination and closure) and analysis using an interactional process system (REA) to quantify degrees of bi-directional introduction of information and interactional dominance. This data was correlated with prescription refill data over a period of three months.
Results:	Physicians dominate the introduction of relevant information more during the history taking than the examination section of the visit. Though physician dominance related negatively to bi-directional introduction of information, it was not related to the decision of patient's to follow-through ($r=-0.21$, $P=0.15$). Patients who answered physician's questions and offered their own information were more apt to follow-through with physician recommendations for new medication.
Conclusion(s):	The exchange of information between physician and patient, particularly during the examination phase of the visit, seems to be important in a patients decision to follow-through with recommendations. During this time patients volunteer information about "former diagnoses, remind the physician about previous test results, and report on the efficacy of previous treatments." (p. 320) They also give unsolicited information about family history and additional symptoms and concerns. Further they attempt to engage the physician in social conversation, suggesting attempts to get to know (establish rapport with) the physician. Shutting down this sort of

discourse may have some negative impact on the patient's decision to support the treatment.

Physicians should perhaps be taught to engage the patient - inviting patient's input particularly during the examination phase of the visit. Communication beyond responses to physicians questions should be encouraged.

61. Sanchez-Menegay, C., & Stalder, H. (1994). Do physicians take into account patients' expectations? *J Gen Intern Med*, 9(7), 404-6.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=7931752&form=6&db=m&Dopt=b>

Objective(s):	To determine if patient's expectations of care are met during medical visits and to determine if apprising physicians of patient's expectations prior to their visit changed physician's behaviour
Design:	Prior to their visit with their physician, patients were asked to complete a survey of their expectations and assorted demographic variables. Using a randomized cluster design the patients were split into two groups. The information about patient's expectations were either shared or not shared with physicians (i.e. appended to the patient's chart). Investigators then compared physicians statements of medical care provided with the patients stated expectations of care. The two groups were then compared.
Setting:	Primary care setting at a University outpatient clinic providing walk-in service
Subjects:	Physicians: specialists in general internal medicine (no information about number of physicians) Patients: 360 patients presenting at the outpatient clinic meeting study criteria (fluent in French, no acute medical problems, not return visits, no eye problems, not participating in other ongoing studies), agreement to participate, and completion of the full survey.
Interventions:	Asked patients to reveal their expectations of medical care
Measures:	Difference and concordance relations were examined using chi-square tests, McNemar tests and the kappa coefficient of agreement
Results:	Patients' highest expected forms of medical care were: 1) diagnosis (94%), 2) prognosis (82%), continuing care (80%), and prevention (76%). Physicians greatest frequency of responses were: 1) diagnosis and 2) prescription. Physicians rarely documented prognosis (0%), continuing care (49%) or prevention (20%) elements of care. Whether physicians were privy to patients' expectations or not, their documented responses were not significantly different.
Conclusion(s):	The authors suggest that patients' expectations of medical care are rarely met, particularly with regard to receiving information about prognosis, continuing care, prevention, tests, or receiving a specialist referral. Their expectations are exceeded only in that physicians tend to prescribe more often than patients expect. The authors suggest that writing a prescription is the physician's perceived endpoint of a medical visit.

[FRM Note: It is interesting that even when physicians were aware of the design and protocols of this study their behaviour did not vary whether they knew of patient's expectations or not. The question is: was the behaviour they did not vary the *sharing of information* or *the recording of this information the patients' records*? It would have been better if the visits had been audiotaped and coded. It is possible that physicians did address these patients' expectations and just didn't record this data in their charts. It would also be interesting to see this same sort of study replicated at a different site to determine if this behaviour is not just part of the culture and/or process expectations of this one clinic. It would also have been nice to know how many physicians participated in this study. Is the behaviour widespread or just that of a few physicians? Physicians could have been asked which patients they feel they had addressed prognosis, continuing care, and prevention etc and then the charts could have been compared and queried. The authors have also suggested that patients may have felt impelled by the design of the survey to report expectation levels greater than they really felt when they first arrived. It would have been nice to have interviewed patients on exit to assess whether they felt that physicians met their declared expectations.]

62. Schulman, B. A. (1979). Active patient orientation and outcomes in hypertensive treatment: application of a socio-organizational perspective. *Med Care*, 17(3), 267-80.

<http://www.ncbi.nlm.nih.gov/cgi-bin/Entrez/referer?htbin-post/Entrez/query%3fdb=m&form=6&uid=763004&Dopt=1>

- Objective(s): That the level of "Active Patient Orientation" (APO) to treatment is related to positive treatment outcomes (including cognitive, behavioural and physical responses to illness management).
- Design: Largely randomized trial with four treatment regimens affording comparison of value of different levels of APO. Patients were interviewed about perceptions of APO and were ranked (low, medium, high) dependant on their ordered APO scores. Physical, behaviour and cognitive outcomes were compared among the three APO groups.
- Setting: Hypertension clinics at a University hospital and a Veterans Administration hospital.
- Subjects: 99 outpatients diagnosed with essential hypertension. 91 were randomly selected and assigned to three groups: education (n=26), behavioural contracting (n=29) and routine clinic care (n=36). The remainder (n=8) were assigned to care of a nurse clinician. The routine clinic care group, unlike the others, did not deliver any systematic APO - effectively a control group.
- Interventions: **Routine clinic care group:** intake measurement of blood pressure and weight by nursing staff and medical consultation with physician
- Education group:** received routine clinic care plus 5 booklets on hypertension and were assigned to a nurse for follow-up and counseling.
- Behavioural contracting group:** same as Education group plus entered into jointly negotiated and agreed upon written contracts specifying rewards for achieving certain health behaviour targets.
- Nurse clinician group:** same as Education group except were followed

and counseled by a nurse clinician instead of a physician

Measures:

All patients were interviewed individually (in person, by phone, some mail). Patients completed a questionnaire which included the APO scale (4 points - Strongly agree to Strongly disagree). Scores on APO were calculated by averaging the responses to the 11 survey items. Additional oral/written questions collected data on cognitive and physical treatment outcomes. Blood pressure measurements were abstracted from clinic records by averaging diastolic bp across visits. Controlled blood pressure was defined as diastolic pressure less than 95 mm Hg.

Results:

Behavioural Outcomes: Increasing levels of APO resulted in corresponding improvement in blood pressure control. The prediction of perceived medication side effects appears inversely related to the level of APO. Patients rating their care high on APO were significantly more likely to report adherence than medium and low groups. There was no significant difference on this variable between medium and low APO groups. Patients afforded more APO had a somewhat greater tendency to adopt health-enhancing behaviours.

Cognitive Outcomes: Patients rating their care "high on Active Patient Orientation" were significantly more confident of their understanding of the prescribed treatment activities. The higher the APO group, the more likely the patients were to: express faith in staff, feel assured after visits, feel they derived more benefit from the treatment, feel what they were doing was effective in reducing their blood pressure.

Conclusion(s):

Previous studies (<1979) indicated that poor outcomes in blood pressure control were issues of patient compliance/adherence. Studies were undertaken to match individual traits or characteristics with rates of adherence. This article describes the phenomenon in socio-organizational terms. The premises tested are that treatment outcomes will be affected in a positive manner. if:

- 1) attitudes of health care professionals are supportive of patients' motivations and ability to contribute to the treatment process,
- 2) illness management is treated like a collaborative process (2-way communication and joint decision-making, active solicitation of patients' questions and thoughts),
- 3) medical resources are provided in a way that promotes self-care (e.g. full explanations, skills training, and special tools/regimen as required...)

This study suggests that patients actively involved in their treatment program are likely to accept, believe in, understand and carry out treatment recommendations. APO means forming a collaborative partnership between patients and health care professionals. The author describes this as desirable but also suggests that it might be difficult to overcome traditional views of doctor and patient. He suggests that APO can result in patients assuming more control over their care, use health resources more effectively, and achieve better outcomes (better control of blood pressure).

63. Smith, R. C., Lyles, J. S., Mettler, J., Stoffelmayr, B. E., Van Egeren, L. F., Marshall, A. A., Gardiner, J. C., Maduschke, K. M., Stanley, J. M., Osborn, G. G., Shebroe, V., & Greenbaum, R. B. (1998). The effectiveness of intensive training for

residents in interviewing. A randomized, controlled study [see comments]. *Ann Intern Med*, 128(2), 118-26.

<http://www.ncbi.nlm.nih.gov/cgi-bin/Entrez/referer?/htbin-post/Entrez/query%3fdb=m&form=6&uid=9441572&Dopt=r>

Objective(s):	1) To compare the effect of skills training on resident's <i>attitudes toward</i> and <i>skills in</i> interviewing patients; 2) To compare the effects of resident skill training on their patient's physical and psychological well
Design:	Randomized control trial
Setting:	Two university-based primary care residencies.
Subjects:	63 primary care residents (PGY1), 36 males, and 27 females. Residents were paid \$100 for participating in the evaluation (2 declined). Patients presenting to clinic or on inpatient units agreeing to be audiotaped. Simulated patients for evaluation purposes.
Interventions:	1 month full time residency rotation in interviewing skills and psychosocial topics (patient-centered interviewing and physician patient relationships). Weekly 3-hour seminar sessions - discussion of technique, demonstration and repeated role-play practice. Daily 3-hour supervisory sessions of interviews with inpatients or outpatients - direct observation or by recorded on audiotape. Focus on efficient data gathering, emotion handling, patient education, and management of psychosocial and psychiatric problems.
Measures:	<p>Pre and post-intervention questionnaire about resident's attitudes and confidence. Cognitive knowledge assessed by multiple choice tests. Behavioural data collected by evaluation of the first 15 minutes of audiotaped interviews with real patients and videotaped interviews of simulated patients. Raters of audiotaped interviews were blinded to whether the tape was from a member of the control or experimental group.</p> <p>Patient data collection by 3 questionnaires (satisfaction, general health, functional health) prior to the beginning of a resident's rotation, satisfaction questionnaire after a visit and telephone interviews three months after the interview (not the same patients as had completed the initial surveys).</p>
Results:	Trained residents were more knowledgeable than untrained residents were. Trained residents had a more favourable attitude toward interviews and psychosocial medicine than did untrained residents, and expressed more confidence in their abilities. Ratings of interview quality were higher for trained residents as opposed to untrained residents. Patients seen by trained residents expressed slightly greater satisfaction with medical visits (not significant). Responding to emotions, eliciting psychosocial data and being patient-centered were the strongest effects noted of interviews by trained residents - all skills central to establishing strong physician patient relationships.
Conclusion(s):	<p>Intensive training in patient-centered interview skills enhances residents' confidence and attitude toward patient interviews. The skills can be taught and learned. Effects on patient's attitudes show a positive trend but are not statistically significant.</p> <p>The authors suggest that the patient-centered interviewing model they've used in this study is responsible for gains. They discourage training in other 'models' until learners have demonstrated mastery of basic patient-centered</p>

interviewing techniques.

[FRM Note: This study involves concentrated training of residents for a full month. This would not be possible for training physicians. Elements of the program are interesting however (e.g. small group seminars held weekly to share cognitive information, demonstrate and role play practice skills, analysis of audiotaped interviews [providing feedback to learner and encouraging self evaluation], use of simulated patients), pre/post test questionnaires and assessment). The current basis for CFPC Mainpro C credits requires this pre/post test structure. Since member physicians are encouraged to accumulate 25 Mainpro C credits by 2001 this may be added incentive for physicians to participate in such a program.]

64. Stewart, M., Belle Brown, J., Weston, W. W., McWhinney, I. R., McWilliam, C. L., & Freeman, T. R. (1995). *Patient centered medicine: Transforming the clinical method*. Thousand Oaks, California: Sage Publications.

Description of Context:

A new clinical method is needed because the old method is no longer meeting the needs of the late 20th century (p.1). Proposed is a patient-centered approach that adheres to a more complex, holistic and humanistic model for viewing the medical encounter than it does to the science-based medical model. This approach doesn't discard the medical model entirely. It adapts and incorporates its strengths, such as problem solving.

Topic/Scope:

This book provides a thorough examination of the patient centered approach to medicine. It discusses the history of the model, the shortcomings of the medical model and the need for a different approach. It describes six elements central to the patient centered process: 1) exploring both the disease and the illness experience, 2) understanding the whole person, 3) finding common ground regarding management, 4) incorporating prevention and health promotion, 5) enhancing the doctor patient relationship, and 6) being realistic (with regard to time constraints, resources and being the sole provider of health care). The book also provides insights into how the patient centered approach can be taught (c/w objectives for each of the above 6 elements) and an overview of qualitative methods that make 'the implicit explicit'.

An important concept discussed is the realization of the complexity of human's experience and attitude toward illness. Physicians, adhering to the doctrine of specific etiology, are taught to diagnose and treat a single entity (e.g. a disease or a broken bone). They are aware of and incorporate understanding of feedback loops and the interconnectedness of processes within the body, but tend not to look too far for such constructs in a larger frame. The reality is that humans and humans' experiences are wonderfully complex. Each is unique, despite patterns that might be discerned by quantitative methods. The patient centered approach provides a means to greater understanding of the patient and what they are experiencing. It is grounded in moral and ethical position that recognizes the value of the perspectives brought forward by the physician and the patient. It describes a partnership where the roles and the issues of control are constantly in a state of flux (p. 91). It also addresses the realistic needs of both parties. Lastly it offers no pat solution or sequence of steps to take with individual patients, because the model considers that as patients are unique so should be the physician's approach.

Conclusions/Recommendations: Physicians should be made aware of other 'paradigms'. They should be encouraged to explore the limitations 'paradigms' put on their view of their practice and their patients. They should be encouraged to experiment using patient centered approach - effectively to run their own clinical trials.

[FRM Note: This model does not lend itself well to descriptions distilled down to such titles as "The 7 Steps to Shared Decision Making'. It does capture the complexity of the physician patient relationship. It also provides a means to comprehend the extreme variability reported in the literature for such things as the patient's desire for more or less information, or for more or less autonomy. The only possible solution it provides is to encourage physicians to communicate more comprehensively with their patients.]

65. Stiggelbout, A. M., & Kiebert, G. M. (1997). A role for the sick role. Patient preferences regarding information and participation in clinical decision-making. *CMAJ*, 157(4), 383-9.

<http://www.cma.ca/CMAJ/vol-157/issue-4/0383.htm>

Objective(s): To determine if preferences for information and participation in decision-making are related to patient characteristics and the context of the decision.

Design: Survey - self-completed questionnaire

Setting: University based hospital in the Netherlands.

Subjects: Consecutive sample of patients and people accompanying them.
Four groups of subjects:
1) 55 patients receiving treatment in a radiotherapy clinic,
2) 53 people accompanying the patients in 1) above.
3) 53 patients attending an outpatient clinic for post-surgery (non-malignant condition) follow-up
4) 36 people accompanying the patients in 3) noted above.

Interventions: None

Measures: Indicated preferences for information and participation in decision-making generally and with regard to four vignettes describing diseases of varying severity, treatment options and side effects. Non-parametric ANOVA used treating decision role as an ordinal variable.

Results: **Preferences for information:** 82% of subjects stated they would always want to be informed about all benefits and side effects of a medical treatment. The remainder indicated they would want this information only in some cases. No differences were seen between any of the groups (i.e. Whether they had undergone surgery, had cancer, or were companions). There was a slight trend for older patients (>65 years) to not necessarily want all available information. Subjects with more education (university/professional) indicated greater preference to be informed than did subjects with lesser education.

Subject groups tended to want more information responding to the vignettes portraying more serious diseases (effect not significant). Younger (p =

0.002) and higher educated ($p = 0.001$) subjects were significantly more apt to rate the information provided as insufficient.

Preferred decision-making role: Patients tended to defer the decision-making role to the physician but most indicated they would like the physician to consider their opinion. Patients with cancer (42%), their companions (41%) and patients having undergone surgery (38%) were most likely to respond that physicians should make the decisions, but "strongly consider my opinion". Companions of patients who had undergone surgery (43%) preferred that decisions should be made jointly on an equal basis.

Companions tended to prefer a more active role in decision-making than patients do ($p = 0.03$). Older subjects ($p = 0.006$) and males ($p = 0.01$) preferred a more passive role. There appeared to be some trend toward married males adopting more passive role and their spouses adopting a more active role.

Conclusion(s):

Both patient groups indicated preference for a more passive role in decision making. The authors suggest this is indicative of a 'sick role' patients adopt. Companions of patients having undergone surgery indicated a stronger preference for sharing decision-making equally with physicians.

Physicians should be made aware that patients and significant others want to be informed about benefits and risks of medical treatment. They may prefer however to take more passive role in decision-making. Being cognizant of the 'sick role' influences, physicians should encourage patient involvement. They should also be aware of 'family' needs for information and an opportunity for providing input.

[FRM note: this article points out that patients (and family members?) want information. It also indicates that patients may adopt a 'sick role' (assume less responsibility for decisions about their care). I would have liked to know the relationship of the companions to the patient. Their opinions would carry more weight if I knew they were immediate family members or trusted friends as opposed to the companions simply being kindly neighbours who volunteered to drive the patient to the clinic.]

66. Strull, W. M., Lo, B., & Charles, G. (1984). Do patients want to participate in medical decision making? *JAMA*, 252(21), 2990-4.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=6502860&form=6&db=m&Dopt=b>

Objective(s):

- 1) To learn how much information and discussion patients report receiving and how much they would prefer to receive about their disease or therapy.
- 2) To learn if patients play a role in decision making and whether they would like to.
- 3) To determine if physicians accurately estimate their patients' preferences about their health care.
- 4) To determine if demographics or health care related factors influence patients' preferences and clinician's ability to estimate those preferences.

Design:

Survey of patients' perceptions about the amount of information they received and would have preferred to receive, compared with their physician's perceptions of these measures.

Setting:

Three practice settings: a community hospital clinic, a free-standing health

maintenance organization (HMO), and a Veterans Administration outpatient clinic.

Subjects: Patients: Consecutive sample of 210 hypertensive patients (82% of those eligible), enrolled during three weekly study days at the above clinics. Enrollment proceeded until each setting had approximately 70 patients. Physicians: All clinicians caring for the enrolled patients participated in the study.

Interventions: None

Measures: All subjects were asked to complete a questionnaire that queried their perception of the amount of information about hypertension and therapy they received, the amount of each type of information they would have preferred, the level of participation in actual decision making they had and the amount they would have preferred to have had. One-third of these were interviewed more extensively to ensure the questionnaire was valid. Similar questionnaires were given to physicians, asking them to estimate their patients' reports and preferences about discussion and decision making.

Results: While 52% of patients indicated that they received substantial information, their physicians reported giving these amounts in only 38% of cases. Clinicians were more apt to underestimate the amount of information the patients thought they'd been given. 41% of patients would have preferred more information. Patients in HMO setting were more likely to want additional information. More patients (66%) of nurse practitioners and clinical pharmacists reported they got *a lot or all the information there was to know* than did patients (46%) of physicians.

Discussion: 55% of patients preferred extensive discussion about their therapy. Physicians tended to underestimate their patients' preference for discussion. Clinicians were more accurate when estimating the preferences of white, younger, more highly educated patients and to be less accurate for those patients treated in the community hospital clinic.

Decisions: Clinicians overestimated patients perceived involvement in making decisions. 37% of patients reported they participated in decision making, compared the clinician's estimate that 80% of the patients participated. Asked who should decide about medications, 47% of patients preferred that clinicians made therapeutic decisions. One-third thought the physician should 'strongly consider' the patient's opinion. Only 19% stated they wanted to share equally in making the decision. (i.e. Almost half of the patients did not want to play any role in actual decision making. Physicians overestimated patient's desire to participate in decision making

Conclusion(s): Physicians do not have very accurate perceptions about the amount of information they are sharing with patients or the amount of information the patients want. They also tend to overestimate patient's involvement in decision making. This discrepancy points to failure in communication between the physician and patient. There is also evidence of subtle biases in patterns of communication - more information giving was evident for younger, white, more highly educated patients than those treated in the community hospital setting.

This article also emphasizes that patients tend to want to take a passive role in decision-making.

67. Teno, J. M., Hakim, R. B., Knaus, W. A., Wenger, N. S., Phillips, R. S., Wu, A. W., Layde, P., Connors, A. F., Jr., Dawson, N. V., & Lynn, J. (1995). Preferences for cardiopulmonary resuscitation: physician-patient agreement and hospital resource use. The SUPPORT Investigators. *J Gen Intern Med*, 10(4), 179-86.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=7790978&form=6&db=m&Dopt=b>

Objective(s):	To examine physicians knowledge of patients' preferences for CPR and the relationship of patients' preferences and physicians' perceptions of these preferences on hospital resource usage.
Design:	Survey, prospective cohort study. Interviews of severely ill hospitalized patients or their surrogate(s) and their physician were conducted to determine the patient's desire for CPR. Other sociodemographic data was also collected. Patients or their surrogates were asked their preference for resuscitation efforts (CPR). This information was compared with the corresponding physician perception of the patient's wishes. Hospital records were used to determine severity level of illness, probability of hospital survival and to disclose the hospital resource utilization associated with each case.
Setting:	Five US university based medical centres (Massachusetts, North Carolina, Ohio, Wisconsin and California)
Subjects:	A sample of 2636 of 4301 patients enrolled in Phase I of the Study to Understand Prognosis and Preferences for Outcomes and risks of Treatments (SUPPORT). All were adults with life- threatening illnesses or their surrogates (others entrusted to make decisions on the patients behalf).
Interventions:	None
Measures:	Patient, surrogate and physician reports of patient preference for CPR and resource utilization measured in 1990 US dollars.
Results:	<p>1513 patients indicated a preference for CPR. Physician's perceptions of this preference agreed in 57% of the cases. In 17% of these cases physicians wrongly stated that the patient had decided to forgo CPR. The physician answered that he/she didn't know the patient's preference in 26% of these cases. 31% of the sample preferred to forgo CPR. Their physicians either did not know or thought the patient wanted CPR in 56% of these cases. 12% of the sample indicated they were unsure of their CPR preference. Physicians in 36% of these cases indicated that they were unsure of the patient's preference.</p> <p>Hospital resource utilization was lowest in cases when the patient preferred no CPR and the physician agreed. Higher costs were associated with physicians beliefs about patients preferences and uncertainty.</p>
Conclusion(s):	Beyond the issue of incurring higher hospital resource utilization when physicians are not aware or incorrectly assume a patient's preferences for aggressive resuscitation efforts is an ethical issue. Poor communication between physicians and their patients can result in provision of treatment that the patient doesn't want and may not be consistent with their values and beliefs. Surrogate decision-makers sometimes are not truly aware of the

patient's preferences or perhaps may not agree with their preferences. It is recommended that physicians ask patients their resuscitation preferences early on.

[FRM Note: This sort of scenario can play out in many other areas of medical decision making. I'd hesitate to recommend that physicians automatically follow patient's wishes, simply to realize a bottom line cost saving. However, this article shows that there are times when straight communication about preferences — sharing decision making — could enable the physician to avoid feeling compelled to take action he/she and the patient don't want.

68. Toop, L. (1998). Primary care: core values. Patient centred primary care. *BMJ*, 316(7148), 1882-3.
<http://www.ncbi.nlm.nih.gov/cgi-bin/Entrez/referer?htbin-post/Entrez/query%3fdb=m&form=6&uid=9632410&Dopt=l>

Description of Context:

This article suggests that the clinician-patient relationship is evolving from a model of paternalistic consultation to one that is more patient-centered, based on 'sustained partnership'.

Topic/Scope:

This article, part of a series on primary care core values, discusses in brief the forces exerted on the physician-patient relationship to change (e.g. changing physician and patient beliefs and expectations, organizational context of the practice, societal pressures). It describes a movement toward a patient-centered approach based upon 'mutual participation', where the physician 'helps the patient to help themselves and the patient is a participant in the partnership.' It describes defining features of the partnership (e.g. focus on the whole person, knowledge of the patient, caring and empathy, patient's trust, appropriately adapted care, and patient participation and shared decision making). The author suggests that the partnership is not necessarily equal and should involve other health care providers (e.g. nurses).

Conclusions/Recommendations:

Successful collaboration involves the *sustained partnership* of the physician, nurse and patient.

[FRM Note: this article is useful for defining features of the sustained partnership, noting the role of other health professionals and suggesting the somewhat controversial view that the partnership is not necessarily equal.]

69. Tulskey, J. A., Fischer, G. S., Rose, M. R., & Arnold, R. M. (1998). Opening the black box: how do physicians communicate about advance directives? *Ann Intern Med*, 129(6), 441-9.
<http://www4.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=9735081&form=6&db=m&Dopt=b>

Objective(s):

- 1) To learn how attending physicians in outpatient practices discuss advance directives with their patients.
- 2) To determine if these discussions follow an acceptable pattern of 'informed consent'.

Design:

Descriptive study

Beyond Informed Consent Annotated Bibliography

Setting:	5 outpatient primary care medicine practices (2 university-based general medicine clinics, 2 Veterans' Affairs general medicine practices, 1 university-based geriatrics practice)
Subjects:	56 physicians and their patients. Criteria for patient selection: aged 65 year and older or hospitalized twice in the same year for a serious medical illness, speak English, judged competent, had not discussed advance directives with their physician previously. Physicians were given the opportunity to choose the clinic session used and had input whether a randomly selected patient from that session would be appropriate for a discussion of advance directives. If deemed inappropriate the physician was asked about succeeding eligible patients until one was chosen.
Interventions:	None
Measures:	One audiotaped encounter was collected from each of 56 physicians. Physicians completed a self-administered survey of their background and attitudes toward advance directives. Patient demographic and attitudinal data was collected in face-to-face interviews. All audiotapes were transcribed and coded. These were compared against criteria of 'established standards of informed consent'. Sections included: 1) introduction of the topic of advance directives, 2) discussion of scenarios and treatments, 3) providing information, 4) eliciting patient values, and 5) identifying surrogate decision makers. A code was also developed to evaluate the quality of the process. Two raters coded transcripts independently. Disagreements were resolved by consensus of the two raters or of the entire research team. Text segments were identified, frequencies of each code were determined and correlated with other codes using Chi square and t-tests.
Results:	<p>Conversations about advance directives lasted a median time of 5.6 minutes. Physicians talk time tended to be double that of patients (3.9 vs 1.7 minutes). Usually discussions were framed related to scenarios (dire, reversible, uncertain consequences). 91% used a dire-consequences scenario. Only 29% used a chronic disability as a result of treatment as a scenario. Physicians tended to use vague language in describing the scenario ("very, very sick" or "had something that was very serious"). Rarely did physicians try to evaluate what these terms meant to patients or tried to define the vague terms. Qualitative probability terms ("reasonable hope", "nearly hopeless"...) were used in 34% of cases. Quantitative probability terms were introduced in only 11% of cases. Patient's personal values, their goals and reasons for care decisions were elicited in 71% of cases. Most often physicians merely determined desire for specific interventions and did not explore reasons. Physicians tended not to attend to emotional content in the discussions.</p> <p>Patients found the physicians' intervention worthwhile (96%) and that it was a good idea that physicians discuss such things with patients (95%).</p>
Conclusion(s):	Physicians discussing advance directives with their patients tended to use the easiest scenarios. More common, less clear cut scenarios would provoke more thought and be more useful to the patient writing an advance directive, or useful for future guidance in decision making by a surrogate. The discussions did not meet the 'standards proposed in the literature'.

[FRM Note: This article continues to point out that physicians tend to avoid

discussion of personal issue. They tend to be task oriented (e.g. once the patient had iterated their decision, the physician did not explore reasons). This approach, while expedient in a busy practice, does little to ensure the patient has understood the issues associated with the decision. It also doesn't tend to flesh out the patient's values and beliefs -- the rationale behind the decision. In the context of a shared-decision, such an approach would not prove that the patient had made an informed choice.]

70. Ubel, P. A. (1996). Informed consent. From bodily invasion to the seemingly mundane [editorial; comment]. *Arch Intern Med*, 156(12), 1262-3.

<http://www.ncbi.nlm.nih.gov/cgi-bin/Entrez/referer?/htbin-post/Entrez/query%3fdb=m&form=6&uid=8651833&Dopt=1>

Description of Context:

Commentary and response to Wolf et al (1996)

Topic/Scope:

The author describes in brief the approaches researchers have undertaken to develop decision-making aids for patients. He points out that as fast as these aids are developed so are the tools developed to evaluate them. He identifies some shortcomings he sees in the Wolf et al study (e.g. the statement provided to the control group in itself provided them with some information about PSA and is quite different than not advising them of PSA at all. He considers the 3 minute intervention described fell short of proving that it lessened people's desire for the procedure, rather he suggests that the control group should have not received any information about the PSA or a before/after test of preferences should have been performed on the experimental group.)

Conclusions/Recommendations:

Despite the shortcomings of the Wolf et al (1996) design, Ubel concludes that he is gratified to see that 'informed consent' has moved from just being "concerned with invasive bodily procedures to affecting decisions to order routine diagnostic screening tests." Patients values come into play in clinical decision making - physicians should give patients balanced information about risks and benefits of PSA tests and let them make the decision.

71. Wetle, T., Levkoff, S., Cwikel, J., & Rosen, A. (1988). Nursing home resident participation in medical decisions: perceptions and preferences. *Gerontologist*, 28 Suppl, 32-8.

<http://www.ncbi.nlm.nih.gov/cgi-bin/Entrez/referer?/htbin-post/Entrez/query%3fdb=m&form=6&uid=3169592&Dopt=1>

Objective(s):

To describe the degree of participation in medical care decisions by residents of long term care facilities and their preferred level of involvement (especially related to DNR orders). (residents = people living at the long term care facility, not medical residents)
To describe level of concordance between the residents' preferred level of involvement and nurses' perceptions of the residents' preferred level.

Design:

Survey of 198 residents from a purposive sampling of for profit and not-for-profit nursing homes in the greater Boston area. Nursing home residents were asked about their relationship with their doctor and nurse, how much information they received about their medical conditions and their preferred level of involvement. They were also asked specifically about whether DNR orders had ever been discussed, how involved they felt they should be

in such a decision and what their preference was regarding resuscitation. Nurses were also interviewed to provide their perceptions about resident's preferences.

Setting:	Profit and not-for profit nursing homes in the greater Boston area.
Subjects:	198 residents selected by staff members, who were not hearing impaired or having serious communication problems, not more than moderately impaired cognitive function or severe psychiatric or emotional problems. In larger facilities residents were selected randomly from a list, provided by nursing home staff, of residents meeting this criteria.
Interventions:	None
Measures:	Bivariate chi-square analysis of patients' responses about desired level and actual level of participation. Concordance between actual and nurse perceptions of desired levels using Spearman rank correlation and Chi square (McNemar test)
Results:	<p>Resident perceptions and preferences: Wide variation of responses were noted concerning the amount of information shared with residents. 40% of respondents reported that their doctors told them 'everything there is to know'. 19% indicated a 'moderate amount' and 41% indicated 'very little or nothing'. Patients reported receiving more information from their doctor than from their nurse. 54% of residents reported they had 'very little involvement' or were 'not involved' in health care decisions. Only 21% reported being 'completely involved'. 79% of residents reported that their current level of involvement was the 'right amount'. 20% reported they did not have enough involvement. Only 1% indicated they had too much involvement. 93% indicated that they had not been asked about a DNR decision. 62% indicated they would prefer to be involved in decisions about DNR. Individuals preferring to have input in DNR decisions tended to be younger, born in the US, had a nurse and doctor that knew them well but didn't consider that they knew them well.</p> <p>Concordance between residents' and nurses' perceptions was low. Nurses greatly overestimated the resident's perceived amount of information received (63% vs. 28% for 'all there is to know'). Nurses (64%) also overestimated residents' (35%) desire for being very involved in DNR decisions.</p>
Conclusion(s):	<p>Efforts must be made to improve communication between nursing home residents and nursing home staff. Residents are largely comfortable with the level of involvement they have in their care despite 41% indicating they received very little or no information and 54% indicating very little or no involvement.</p> <p>[FRM note: 60% of nursing home residents indicated that their doctor gave them a moderate amount of information or less. While this study does not report on specific details of the type of information, this data should raise a warning flag that physicians caring for nursing home residents are not likely providing adequate levels of information to comply with the requirements of 'informed consent'.</p> <p>While residents generally seemed to find their level of involvement appropriate, it is interesting to note that younger residents who were born in</p>

the US were more apt to want input into DNR decisions. I suspect this will be a trend for the future. There is evidence of growing desire for patient autonomy. As the current population of baby boomers ages, seniors will likely demand more control or input into their medical care.]

72. Woloshin, K. K., Ruffin, M. T. t., & Gorenflo, D. W. (1994). Patients' interpretation of qualitative probability statements. *Arch Fam Med*, 3(11), 961-6.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=2705004&form=6&db=m&Dopt=b>

Objective(s):	To determine (1) the effect of context, experience, age, gender, race, occupation, and education on patients' numerical interpretation of probability terms and (2) patient preferences for information about side effects (qualitative or numerical).
Design:	Survey
Setting:	University-based family practice
Subjects:	Patients 18 years of age and older and parents of patients younger than 18 years of age seen during January and February 1993 for any reason except complete physical examination. Subjects were predominantly female (69.8%) and white (87.5%). Males were more apt to have attended graduate school (40.8%). Females were almost twice as likely to have a health care-related occupation (32.3% vs 17.8%).
Interventions:	None
Measures:	Participants were asked to complete a 10 minute survey with three sections. In the first they were asked to ascribe a percentage value to the term 'unlikely' in 8 scenarios describing major and minor complications to procedure or medications. In the second they were asked to tell how many people out of 100 would be described by 10 randomly ordered qualitative probability terms. In the third section they were asked for basic demographic information and their preference for qualitative or quantitative probability terms.
Results:	Of 345 questionnaires distributed, 307 patients (89%) completed them. The rates assigned to the minor complications were significantly higher than the rates assigned to the major complications ($p = .0001$). Participants who had experienced the described complication reported significantly higher rates for the minor complications of vaccination and surgery ($p = .0001$ and $p = .0235$, respectively). Education had a significant effect only on the rates assigned to vaccination complications ($p = .0069$). (Patients with less than 4 years of college assigned higher rates to the minor vaccination complications than people with 4 or more years of college) Occupation had a significant effect only on the rates assigned to antibiotic side effects ($p = .0090$). 44.1% wanted to receive probability information using numbers only, 29.5% wanted words only and 26.3% preferred a combination of the two.
Conclusion(s):	Experience with some of the risks makes a difference for patients when describing numerically what a qualitative probability descriptor means. They tend to give the terms higher ratings associated with minor risks than when the terms are applied to situations describing major risks. Even

supposedly absolute qualitative terms like 'certain' were not described to mean "100% of the time". Only 67.8% of people ascribed 0% to the term "zero chance". Ascribing numerical values to a list of qualitative terms, non-whites tended to rate positive terms lower than did whites. Those with higher education tended to rate positive terms higher than non-whites. 30% of the patients wanted information about the risk in words, while 44% wanted it in numbers.

It is recommended that both numbers and words should be used to describe probabilities of risk to patients. Physicians should be aware of patient's prior experience with the risk described and the effects of confounding variables - level of education, race and occupation (related to antibiotic side-effects).

73. Wu, W. C., & Pearlman, R. A. (1988). Consent in medical decision making: the role of communication. *J Gen Intern Med*, 3(1), 9-14.

<http://www.ncbi.nlm.nih.gov/htbin-post/Entrez/query?uid=3339491&form=6&db=m&Dopt=b>

Objective(s):	To determine if: 1) clinicians inform patients of rationales for procedures/treatment more than they inform them of benefits, risks, or alternatives, 2) nursing personnel provide these essential elements of informed consent more than other disciplines, 3) there is more congruence between physicians and patients about the elements of informed consent when procedures are perceived to be important, invasive or risky.
Design:	Recorded observation followed by survey (interview)
Setting:	Primary care clinic at a Veterans Administration Medical Center
Subjects:	20 inpatients randomly selected from male patients 50 years of age or older, competent, English speaking, hospitalized less than 24 hours and admitted to a general medicine service in a Seattle Veterans Administration Medical Center. 11 second year residents and all health care personnel.
Interventions:	None
Measures:	Recorded observation of all diagnostic or therapeutic procedures and communication about upcoming procedures involving the patient and the physician (e.g. communication about rationales, benefits, risks and alternatives). Structured individual interviews with the clinician and the patient within three hours of the observation. (Descriptive statistics, chi square)
Results:	172 procedures were observed. Rationale was communicated most frequently. Rationale and benefits were both communicated significantly more often than risks and alternatives ($p < .05$). Residents consistently communicated the elements of informed consent more frequently than staff physicians. Nurses communicated less than physicians all elements except benefits. There was no significant relationship between communication and the perceived risks of the procedures performed. The greatest concordance between physicians and patients was noted in rationales for the procedure, as opposed to risks, benefits or alternatives
Conclusion(s):	Care must be taken to ensure that patients are given enough information to

Beyond Informed Consent
Annotated Bibliography

make an informed decision. Each element of the essentials of informed consent must be covered. Physicians appear to have a tendency to emphasize the rationale for a procedure, focus somewhat on the benefits and gloss over discussions of risk and alternatives.

[FRM Note: I find the varying approaches of each health professional interesting. That nurses tend to emphasize the benefits of the procedure/treatment would be in keeping with their supportive role - reassuring the patient that the decision is the right one. Residents tended to offer the most comprehensive information, as one might expect of a trainee eager to become competent in the task. That physicians give less information than residents might be a function of their expectation that the resident had already provided the information OR that they were taking short cuts in the process.]

Appendices

Appendix A - Literature Concerning the Content of the Message

Key

- 1) What information
- 2) How much information
- 3) Timing of information
- 4) Tone
- 5) Interaction of message with, method, environment, physician and patient characteristics
- 6) Type of message
- 7) Descriptors used

Author, Year, Record #	A1	A2	A3	A4	A5	A6	A7
Annas (1995,1)	A1				A5		
Annas (1998,2)	A1	A2				A6	
Barber (1995,3)	A						
Beisecker, et al. (1996,7)	A1	A2				A6	
Blanchard, et al. (1988,8)	A1	A2	A3		A5	A6	
Braddock, et al. (1997,10)	A1	A2			A5	A6	
Centeno-Cortes and Nunez-Olarte (1994,76)		A2			A5	A6	
Charles, et al. (1997,12)					A5		
Coulombe (1995,14)	A1	A2	A3	A4	A5	A6	
Deber (1994,15)	A1	A2			A5		
Deber, et al. (1996,17)	A1						
Deftos (1998,18)	A1	A2				A6	
Degner and Sloan (1992,19)	A5						
Degner, et al. (1997,20)	A1					A6	
Delbanco, et al. (1995,23)	A1	A2	A3				
Delbanco and Daley (1996,24)	A1					A6	
Elwyn, et al. (1998,25)	A1	A2	A3		A5	A6	
Ende, et al. (1989,26)	A1	A2			A5		
Faden, et al. (1981,28)	A1	A2					A7
Finkelstein, et al. (1993,29)	A1			A4			
Gold (1993,30)	A1	A2				A6	
Hall, et al. (1988,32)				A4	A5		
Kalet, et al. (1994,34)	A1					A6	
Laine, et al. (1996,39)		A2					
Lantos (1993,40)	A1	A2					
Lerman, et al. (1990,41)	A1					A6	
Levinson, et al. (1997,42)				A4	A5	A6	
Lidz, et al. (1988,43)					A5		
Lipkin (1996,44)		A2	A3		A5		
Mazur (1986,45)	A1	A2	A3				
Mazur and Hickam (1991,46)	A1	A2					
Mazur and Hickam (1993,47)	A1	A2			A5	A6	
Mazur and Merz (1994,48)	A1				A5	A6	A7
Meisel (1992,50)			A3				
Nease and Brooks (1995,51)						A6	
Northouse and Northouse (1992,52)	A1	A2					

Beyond Informed Consent
 Appendices

Author, Year, Record #	A1	A2	A3	A4	A5	A6	A7
Novack, et al. (1997,53)						A5	
Ong, et al. (1995,54)	A1	A2	A3	A4	A5	A6	
Pelias (1991,56)	A1	A2	A3			A6	
Peters (1994,57)					A5		
Pfeifer, et al. (1994,58)	A1			A4	A5	A6	
Prestifilippo, et al. (1993,59)	A1	A2					
Rost, et al. (1989,60)	A1		A3				
Sanchez-Menegay and Stalder (1994,61)	A1	A2				A6	
Smith, et al. (1998,63)					A5		
Stewart, et al. (1995,64)					A5		
Stiggelbout and Kiebert (1997,65)		A2	A3		A5		
Strull, et al. (1984,66)					A5		
Tulsky, et al. (1998,69)	A1	A2		A4		A6	
Wetle, et al. (1988,71)		A2			A5		
Woloshin, et al. (1994,72)					A6		A7
Wu and Pearlman (1988,73)	A1	A2				A6	

Appendix B - Literature Concerning Method/Model

Key

- 1) How decisions are reached now
- 2) Pros/cons
- 3) Physician perspective of effectiveness
- 4) Patient perspective of effectiveness
- 5) Recommendations for how decisions should be shared
- 6) Situational choices of approaches (e.g. with surrogates)
- 7) Best/recommended practices, curricula, training methods

Author, Year, Record #	B1	B2	B3	B4	B5	B6	B7	B8
Annas (1998,2)	B1						B7	
Beckman and Frankel (1994,4)							B7	
Braddock, et al. (1997,10)	B1	B2			B5	B6	B7	
Brody (1980,74) B1		B2			B5	B6		B8
Capen (1995,11)							B7	
Capen (1998, 78)							B7	
Charles, et al. (1997,12)		B2	B3	B4		B6	B7	
Coulombe (1995,14)					B5		B7	
Deber (1994,16)	B1				B5			
Deber, et al. (1996,17)				B4	B5		B7	
Deftos (1998,18)							B7	
Degner, et al. (1997,20)					B5		B7	
Delbanco, et al. (1995,23)		B4						
Delbanco and Daley (1996,24)					B5		B7	
Elwyn, et al. (1998,25)						B6		
Ende, et al. (1989,26)					B5		B7	
Finkelstein, et al. (1993,29)					B5		B7	
Guadagnoli and Ward (1998,31)						B6	B7	
Hall, et al. (1988,32)						B6		
High (1988, 77)						B6		
Iris (1988,33)						B6		
Kurtz, et al. (1998,37)	B1	B2			B5		B7	
Laine and Davidoff (1996,38)							B7	
Laine, et al. (1996,39)				B4			B7	
Lerman, et al. (1990,41)	B1			B4			B7	
Lidz, et al. (1988,43)	B1		B3		B5		B7	
Lipkin (1996,44)	B1				B5		B7	
Mazur and Hickam (1991,46)				B4	B5			
Mazur and Hickam (1993,47)					B5			
Mazur and Hickam (1997,49)					B5		B7	
Meisel (1992,50)					B5		B7	
Nease and Brooks (1995,51)					B5			
Northouse and Northouse (1992,52)							B7	

Beyond Informed Consent
 Appendices

Author, Year, Record #	B1	B2	B3	B4	B5	B6	B7	B8
Ong, et al. (1995,54)	B1							
Paris, et al. (1993,55)					B5		B7	
Pelias (1991,56)							B7	
Peters (1994,57)						B6		
Pfeifer, et al. (1994,58)					B5	B6	B7	
Prestifilippo, et al. (1993,59)						B6		
Rost, et al. (1989,60)			B3		B5			
Schulman (1979,62)	B1				B5		B7	
Stewart, et al. (1995,64)	B1	B2				B6		
Strull, et al. (1984,66)			B3	B4				
Teno, et al. (1995,67)						B6		
Toop (1998,68)						B6		B8
Tulsky, et al. (1998,69)				B4				
Ubel (1996,70)							B7	
Wetle, et al. (1988,71)	B3	B4						

Appendix C - Literature Concerning Physician Characteristics

Key

- | | |
|--|--|
| 1) Experience | 8) Medical training impact on decision making |
| 2) Gender | 9) Medical training impact on communication skills/style |
| 3) Practice type | 10) Style: authoritarian vs. partnership building |
| 4) Knowledge of the disease | 11) Busy practice |
| 5) Perceptions of the patient's wishes | 12) Attitudes, beliefs, values |
| 6) Knowledge of the patient | 13) Race |
| 7) Past experience | |

Author, Date, Record #	C1	C2	C3	C4	C5	C6	C7	C8	C9	C10	C11	C12	C13
Annas (1998,2)										C10			
Beckman, et al. (1994,5)					C5	C6						C12	
Beisecker, et al. (1996,7)	C1	C2				C6		C8		C10			
Braddock, et al. (1997,10)			C3								C11	C12	
Brody (1980,74)				C4									
Centeno-Cortes and Nunez-Olarte (1994, 76)					C5							C12	
Coulombe (1995,14)				C4	C5					C10		C12	
Deber (1994,15)										C10	C11		
Delbanco (1993,22)					C5		C7					C12	
Delbanco and Daley (1996,24)					C5	C6				C10			
Elwyn, et al. (1998,25)			C3									C12	C13
Ende, et al. (1990,27)				C4		C6		C8					
Kaplan, et al. (1996,35)		C2	C3					C8	C9		C11		C13
Kurtz, et al. (1998,37)								C8	C9	C10			
Levinson, et al. (1997,42)										C10			
Lipkin (1996,44)									C9				
Meisel (1992,50)					C5					C10			
Novack, et al. (1997,53)							C7					C12	
Ong, et al. (1995,54)	C												
Paris, et al. (1993,55)										C10			
Pfeifer, et al. (1994,58)			C3		C5					C10			
Smith, et al. (1998,63)									C9				
Stewart, et al. (1995,64)							C7	C8					
Teno, et al. (1995,67)					C5			C8					
Toop (1998,68)						C6							
Tulsky, et al. (1998,69)	C												

Appendix D - Literature Concerning Patient Characteristics

Key

- | | |
|---|--|
| 1) Age: infant, child, teen, adult , senior | 8) Role – e.g. parent, child |
| 2) Mental status: e.g. dependant adult | 9) Stressors – illness, money, family responsibilities |
| 3) Gender | 10) Preferences for shared decision making |
| 4) Level of education | 11) Expectations |
| 5) Socioeconomic status | 12) Experience |
| 6) Race/ethnic background | |
| 7) Attitude | |

Author, Year, Record #	D1	D2	D3	D4	D5	D6	D7	D8	D9	D10	D11	D12
Beisecker and Beisecker (1990,6)	D1	D2	D3	D4	D5	D6	D7			D10		D12
Beisecker, et al. (1996,7)	D1											
Blanchard, et al. (1988,8)	D1		D3							D10		
Centeno-Cortes and Nunez-Olarte (1994, 76)	D1		D3			D6						
Coulombe (1995,14)												D12
Deber (1994,15)								D8		D10		
Deber (1994,16)										D10		
Degner and Sloan (1992,19)	D1		D3	D4						D10		D12
Degner, et al. (1997,20)	D1		D4							D10		
Delbanco (1992,21)	D											
Delbanco, et al. (1995,23)	D1		D3	D4							D11	D12
Delbanco and Daley (1996,24)							D7			D10	D11	
Elwyn, et al. (1998,25)	D1					D6		D8			D11	
Ende, et al. (1989,26)	D1			D4	D5					D10		
Ende, et al. (1990,27)										D10		D12
Faden, et al. (1981,28)	D1		D3					D8		D10		
Hall, et al. (1988,32)	D1		D3		D5	D6						
High (1988, 77)				D4			D7					
Iris (1988,33)							D7					
Kalet, et al. (1994,34)							D7					
Laine, et al. (1996,39)		D3	D4									
Lantos (1993,40)										D10		
Lipkin (1996,44)	D											
Mazur and Hickam (1993,47)	D1		D3				D7					
Mazur and Merz (1994,48)	D1											
Mazur and Hickam (1997,49)										D10		
Nease and Brooks (1995,51)	D1		D3	D4	D5		D7					
Ong, et al. (1995,54)	D											
Paris, et al. (1993,55)								D8				
Pfeifer, et al. (1994,58)										D10		
Rost, et al. (1989,60)			D3									
Stiggelbout and Kiebert (1997,65)	D1		D3	D4						D10		D12

Beyond Informed Consent
 Appendices

Author, Year, Record #	D1	D2	D3	D4	D5	D6	D7	D8	D9	D10	D11	D12
Strull, et al. (1984,66)	D1			D4		D6				D10		
Teno, et al. (1995,67)									D9			
Tulsky, et al. (1998,69)	D											
Wetle, et al. (1988,71)	D1									D10		
Woloshin, et al. (1994,72)			D3	D4		D6						

Appendix E –Literature Concerning Effects of Shared Decision-Making

Key

- 1) Patient not taking advice/ accepting patient’s decision or withdrawing from case
- 2) Changes (pro/con) in the physician/patient relationship
- 3) Education/comprehension
- 4) Health benefits

Author, Year, Record #	E1	E2	E3	E4
Annas (1995,1)		E2		
Annas (1998,2)		E2,		
Barber (1995,3)	E1	E2		
Brody (1980,74)		E2		E4
Coulombe (1995,14)		E2,		
Delbanco and Daley (1996,24)			E3	
Faden, et al. (1981,28)		E2		
Guadagnoli and Ward (1998,31)				E4
Kaplan, et al. (1996,35)		E2		
Lerman, et al. (1990,41)		?E2		E4
Lidz, et al. (1988,43)		E2		
Lipkin (1996,44)		E2		E4
Ong, et al. (1995,54)	E	E	E	E
Paris, et al. (1993,55)	E1			
Pelias (1991,56)		E2		
Pfeifer, et al. (1994,58)		E2		
Rost, et al. (1989,60)	E1	E2		
Sanchez-Menegay and Stalder (1994,61)	E1			
Toop (1998,68)		E2		
Wu and Pearlman (1988,73)			E3	

Appendix F – Literature Concerning Blood and Blood Products

AND

Appendix G - Legal Responsibilities Regarding Informed Consent

Author, Year, Record #	Blood – Krever Commission Implications	Legal Responsibilities Regarding Informed Consent
Annas (1995,1)		G1
Annas (1998,2)		G1
Brody (1980,74)		G1
Capen (1995,11)	F1	
Capen (1998, 78)	F1	
Deftos (1998,18)		G1
Finkelstein, et al. (1993,29)		G1
Gold (1993,30)		G1
Laine and Davidoff (1996, 38)		G1
Lantos (1993,40)		G1
Mazur (1986,45)		G1
Meisel (1992,50)		G1
Northouse and Northouse (1992,52)		G1
Paris, et al. (1993,55)		G1
Pelias (1991,56)		G1
Prestifilippo, et al. (1993,59)		G1
Ubel (1996,70)		G1

Index

A

age, 26, 28, 29, 35, 38, 42, 45, 46, 48, 53, 58, 59, 60, 61, 63, 85, 86
Annas, G. J. (1995), 9
Annas, G. J. (1998), 9
Appendix A - Literature Concerning the Content of the Message, 88
Appendix B - Literature Concerning Method/Model, 90
Appendix C - Literature Concerning Physician Characteristics, 92
Appendix D - Literature Concerning Patient Characteristics, 93
Appendix E - Literature Concerning Effects of Shared Decision-Making, 95
Appendix F - Literature Concerning Blood and Blood Products, 96
Appendix G - Legal Responsibilities Regarding Informed Consent, 96

B

Barber, N. (1995), 10
Barriers, 24
Beckman, H. B., & Frankel, R. M. (1994), 10
Beckman, H. B., Markakis, K. M., Suchman, A. L., & Frankel, R. M. (1994), 11
Beisecker, A. E., & Beisecker, T. D. (1990), 12
Beisecker, A. E., Murden, R. A., Moore, W. P., Graham, D., & Nelmig, L. (1996), 13
Blanchard, C. G., Labrecque, M. S., Ruckdeschel, J. C., & Blanchard, E. B. (1988), 14
Boisaubin, E. V., & Dresser, R. (1987), 16
Braddock, C. H., 3rd, Fihn, S. D., Levinson, W., Jonsen, A. R., & Pearlman, R. A. (1997), 16
Brody, D. S. (1980), 17

C

Capen, K. (1995), 18
Capen, K. (1998), 19
Centeno-Cortes, C., & Nunez-Olarte, J. M. (1994), 20
Charles, C., Gafni, A., & Whelan, T. (1997), 22
Cichon, E. J., & Masterson, J. (1993), 23
cultural, 3, 22, 34, 36

D

Deber, R. B. (1994a), 24
Deber, R. B. (1994b), 25
Deber, R. B., Kraetschmer, N., & Irvine, J. (1996), 26
Defetos, L. J. (1998), 27
Degner, L. F., & Sloan, J. A. (1992), 27
Degner, L. F., Kristjanson, L. J., Bowman, D., Sloan, J. A., Carriere, K. C., O'Neil, J., Bilodeau, B., Watson, P., & Mueller, B. (1997), 29

Delbanco, T. L. (1992), 30
Delbanco, T. L. (1993), 31
Delbanco, T. L., & Daley, J. (1996), 33
Delbanco, T. L., Stokes, D. M., Cleary, P. D., Edgman-Levitan, S., Walker, J. D., Gerteis, M., & Daley, J. (1995), 32
disclosure, 3, 19, 27, 34, 35, 36, 39, 40, 41, 48, 57, 61, 67
disease, 2, 3, 27, 29, 30, 35, 36, 47, 76, 78, 92

E

education, 2, 23, 26, 29, 30, 33, 34, 38, 47, 49, 50, 51, 59, 61, 63, 73, 75, 77, 85, 86, 93
Elwyn, T. S., Fetters, M. D., Gorenflo, W., & Tsuda, T. (1998), 34
Ende, J., Kazis, L., & Moskowitz, M. A. (1990), 37
Ende, J., Kazis, L., Ash, A., & Moskowitz, M. A. (1989), 36

F

Faden, R. R., Becker, C., Lewis, C., Freeman, J., & Faden, A. I. (1981), 38
family, 2, 3, 23, 27, 28, 30, 32, 34, 35, 37, 39, 45, 46, 47, 52, 63, 64, 65, 66, 71, 78, 85, 93
Family members, 32
Finkelstein, D., Smith, M. K., & Faden, R. (1993), 40

G

gender, 3, 34, 45, 63, 85
Gold, J. A. (1993), 40
Guadagnoli, E., & Ward, P. (1998), 41

H

Hall, J. A., Roter, D. L., & Katz, N. R. (1988), 42
High, D. M. (1988), 44

I

informed consent, 2, 3, 16, 18, 19, 25, 40, 47, 48, 52, 55, 56, 57, 62, 64, 67, 70, 82, 83, 85, 86, 87
Iris, M. A. (1988), 45

K

Kalet, A., Roberts, J. C., & Fletcher, R. (1994), 46
Kaplan, S. H., Greenfield, S., Gandek, B., Rogers, W. H., & Ware, J. E., Jr. (1996), 47
Katz, J. (1984), 48
Krever Commission, 3, 18
Kurtz, S., Silverman, J., & Draper, J. (1998), 49

L

- Laine, C., & Davidoff, F. (1996), 50
Laine, C., Davidoff, F., Lewis, C. E., Nelson, E. C.,
Nelson, E., Kessler, R. C., & Delbanco, T. L.
(1996), 51
Lantos, J. (1993), 52
Lerman, C. E., Brody, D. S., Caputo, G. C., Smith, D.
G., Lazaro, C. G., & Wolfson, H. G. (1990), 53
Levinson, W., Roter, D. L., Mullooly, J. P., Dull, V.
T., & Frankel, R. M. (1997), 54
Lidz, C. W., Appelbaum, P. S., & Meisel, A. (1988),
55
Lipkin, M., Jr. (1996), 56

M

- Mazur, D. J. (1986), 57
Mazur, D. J., & Hickam, D. H. (1991), 57
Mazur, D. J., & Hickam, D. H. (1993), 58
Mazur, D. J., & Hickam, D. H. (1997), 61
Mazur, D. J., & Merz, J. F. (1994), 59
Meisel, A. (1992), 62

N

- Nease, R. F., Jr., & Brooks, W. B. (1995), 62
Northouse, P. G., & Northouse, L. L. (1992), 64
Novack, D. H., Suchman, A. L., Clark, W., Epstein, R.
M., Najberg, E., & Kaplan, C. (1997), 65
numerical descriptors, 3

O

- Ong, L. M., de Haes, J. C., Hoos, A. M., & Lammes,
F. B. (1995), 65

P

- Paris, J. J., Schreiber, M. D., Statter, M., Arensman,
R., & Siegler, M. (1993), 66
paternalistic. See traditional. See traditional. See
traditional. See traditional. See traditional
patients' rights, 9, 36
Pelias, M. Z. (1991), 67
Peters, R. M. (1994), 67
Pfeifer, M. P., Sidorov, J. E., Smith, A. C., Boero, J.
F., Evans, A. T., & Settle, M. B. (1994), 69
Physician and patient roles, 24
physician patient relationship, 3, 16, 18, 24, 27, 30,
33, 40, 47, 49, 55, 56, 62, 65, 66, 67, 68, 76, 81

- physician's role, 3, 26, 64
Prestifilippo, J., Antman, K., Berkman, B. J.,
Kaufman, D., Lantos, J., Lawrence, W., Jr., Levine,
R. J., & McKenna, R. J., Sr. (1993), 70
prognosis, 25, 27, 33, 35, 64, 72
Proxy, 3
psychosocial issues, 33

R

- Rost, K., Carter, W., & Inui, T. (1989), 70

S

- Sanchez-Menegay, C., & Stalder, H. (1994), 71
Schulman, B. A. (1979), 73
Smith, R. C., Lyles, J. S., Mettler, J., Stoffelmayr, B.
E., Van Egeren, L. F., Marshall, A. A., Gardiner, J.
C., Maduschke, K. M., Stanley, J. M., Osborn, G.
G., Shebroe, V., & Greenbaum, R. B. (1998), 74
socialization, 3, 38, 48, 49
socioeconomic background, 34
stage of illness, 35
Stewart, M., Belle Brown, J., Weston, W. W.,
McWhinney, I. R., McWilliam, C. L., & Freeman,
T. R. (1995), 76
Stiggelbout, A. M., & Kiebert, G. M. (1997), 77
Strull, W. M., Lo, B., & Charles, G. (1984), 78

T

- Teno, J. M., Hakim, R. B., Knaus, W. A., Wenger, N.
S., Phillips, R. S., Wu, A. W., Layde, P., Connors,
A. F., Jr., Dawson, N. V., & Lynn, J. (1995), 80
Toop, L. (1998), 81
Tulsky, J. A., Fischer, G. S., Rose, M. R., & Arnold,
R. M. (1998), 81

U

- Ubel, P. A. (1996), 83

W

- Wetle, T., Levkoff, S., Cwikel, J., & Rosen, A.
(1988), 83
Woloshin, K. K., Ruffin, M. T. t., & Gorenflo, D. W.
(1994), 85
Wu, W. C., & Pearlman, R. A. (1988), 86