



SHARED DECISION-MAKING IN THE MEDICAL ENCOUNTER: WHAT DOES IT MEAN? (OR IT TAKES AT LEAST TWO TO TANGO)

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Abstract—Shared decision-making is increasingly advocated as an ideal model of treatment decision-making in the medical encounter. To date, the concept has been rather poorly and loosely defined. This paper attempts to provide greater conceptual clarity about shared treatment decision-making, identify some key characteristics of this model, and discuss measurement issues. The particular decision-making context that we focus on is potentially life threatening illnesses, where there are important decisions to be made at key points in the disease process, and several treatment options exist with different possible outcomes and substantial uncertainty. We suggest as key characteristics of shared decision-making (1) that at least two participants—physician and patient be involved; (2) that both parties share information; (3) that both parties take steps to build a consensus about the preferred treatment; and (4) that an agreement is reached on the treatment to implement. Some challenges to measuring shared decision-making are discussed as well as potential benefits of a shared decision-making model for both physicians and patients. Copyright © 1997 Elsevier Science Ltd

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INTRODUCTION

Shared decision-making is increasingly advocated as an ideal model of treatment decision-making in the medical encounter (Veatch, 1972; Brody, 1980; Quill, 1983; Brock and Wartman, 1990; Gray *et al.*, 1990; Emanuel and Emanuel, 1992; Levine *et al.*, 1992; Deber, 1994). Yet, it is by no means clear what shared decision-making really means or the criteria by which to judge what falls within or outside the boundaries of this model. In order to be able to evaluate the merits and limitations of a shared decision-making model it is first necessary to be clear about what the model is. To date, the concept of shared decision-making has been rather poorly and loosely defined. This leads to considerable confusion because the same conceptual label can be used to subsume different underlying philosophies and principles of physician–patient interaction. Our goal in this paper is to provide greater conceptual clarity in thinking about shared decision-making, to identify some basic characteristics of this model and to discuss measurement issues.

Improved conceptualization of shared decision-making would have several benefits. It would make more explicit what advocacy of shared decision-

making means, allow for easier recognition when it does occur, and perhaps facilitate its practice by physicians and patients who have a preference for this model of joint decision-making. In so far as shared decision-making has been linked with positive patient outcomes (e.g. satisfaction and improvements in functional status), clarification of this model is clinically relevant (Egbert *et al.*, 1964; Schulman, 1979; Greenfield *et al.*, 1985, 1988; Brody *et al.*, 1989; Wennberg, 1990; Mahler and Kulik, 1990; Lerman *et al.*, 1990). Greater conceptual clarity could also guide research in this area by providing clearer direction on the types of information to be collected as relevant examples of shared and non-shared decision-making.

The increased and fairly new interest in shared decision-making derives from a number of different factors. For example, informed consent, now ethically and legally ensconced as a patient right, seems to imply at least a minimum of shared decision-making in the form of patient consent to treatment prior to any intervention (Sutherland *et al.*, 1989). Moreover, the principle of “informed choice”, ie. disclosure of treatment alternatives rather than merely informed consent has been endorsed at several government levels in Canada and the United States (Evans, 1987; Greene, 1992; Ontario Ministry of Health, 1994; Nayfield *et al.*, 1994).

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Interest in shared decision-making also has its origins in the consumer rights movement. Here, concern with patient participation in treatment decision-making has moved well beyond informed consent to include broader principles of patient autonomy, control, and patient challenge to physician authority (Haug and Lavin, 1983; Ende *et al.*, 1989; Charles and DeMaio, 1993; Llewellyn-Thomas, 1992, 1995). Shared decision-making is seen as a mechanism to decrease the informational and power asymmetry between doctors and patients by increasing patients' information, sense of autonomy and/or control over treatment decisions that affect their well-being (Eddy, 1990; Ryan, 1992; Emanuel and Emanuel, 1992).

A final factor is the changing nature of medical practice. During the last 20 to 30 years, there has been a dramatic shift away from acute care to chronic care and caregivers often manage illnesses or combinations of illnesses rather than cure disease. For such patients, sickness is not just a temporary status; rather, long-term and chronic illness may become a permanent part of their identity and status. In such cases, the physician-patient relationship is potentially a long-term one. The plethora of new drugs available requires that physicians work closely with such patients to develop the optimum pharmacological solution, a process that takes time, continuous monitoring and adjustment of medication types and levels. This process is likely to work best if both patients and physicians have a role in managing the illness and medication regimens.

For certain diseases, such as cancer, which are both potentially life-threatening and widely prevalent, there are key treatment decision points which may occur only once and arise early on in the course of the disease which have major consequences for the patient. Women with early stage breast cancer, for example, may be faced with the decision to have a lumpectomy versus mastectomy, and, following surgery, whether to have adjuvant chemotherapy and/or radiation. These are decisions which cannot be delayed without potentially serious implications for the health of the patient. Here shared decision-making becomes particularly important to address in the medical encounter, first, because several treatment options exist with different possible outcomes, and substantial uncertainty. Second, there is often no clear-cut right or wrong answer. Third, treatments will vary in their impact on the patient's physical and psychological well-being (Pierce, 1993). It is this latter type of treatment decision-making context which is our focus in this paper and we use early stage breast cancer as an example of a potentially life threatening disease.

We recognize that there are different types of treatment decision-making contexts (e.g. emergency treatment, long-term monitoring of medications in the treatment of chronic disorders such as hyperten-

sion, palliative care) and that different models of treatment decision-making may be more or less appropriate or feasible in specific contexts. To discuss issues of shared decision-making in all these would be an enormous task; hence, we choose the specific decision-making context as described above as our focus for this paper.

This focus is at the micro as opposed to the macro level of analysis where, clinically, there are several treatment options available and the choice of the best treatment for a particular patient requires value judgements on the part of the patient and physician. Our paper does not address macro level economic constraints, i.e. where policy makers have decided that for certain medical conditions, there will be a limited number of treatment options available through public or third party insurers. Also, we limit the discussion of decision-making at the micro level to competent patients.

MODELS OF TREATMENT DECISION-MAKING

Shared decision-making is only one among several treatment decision-making models discussed in the literature (Veatch, 1972; Thomasma, 1983; Emanuel and Emanuel, 1992; Levine *et al.*, 1992; Roter and Hall, 1992; Mooney and Ryan, 1993; Deber, 1994). Prominent among these are the paternalistic model, the informed decision-making model and the professional-as-agent model. Analysis of the prototype depictions of each of these models reveals some overlap in specific characteristics of each. In addition, many of these characteristics, such as information sharing, involve gradations rather than absolutes. In this paper, we want to clarify the central elements of the latter 3 models as they are portrayed in the literature, and argue that each falls short of depicting a model of shared treatment decision-making. We then identify what we see as necessary components of a model of shared decision-making, in particular, the exchange of both information and treatment preferences by both physician and patient and agreement by both parties on the treatment to implement.

On first glance, it seems easiest to differentiate the paternalistic model from shared decision-making because the former explicitly assumes a passive role for the patient in the treatment decision-making process. An early formulation of this model was Parsons' conceptualization of the sick role. Parsons argued that the sick role carried with it certain rights and obligations for patients (Parsons, 1951). Persons granted (by physicians) the (temporary) sick role status, for example, were excused from other role-related activities such as those of family and work, but they also had an obligation to try to get well, to seek expert help, and to comply with the medical regimen (Parsons, 1951). This model clearly placed the patient in a passive, dependent role *vis-a-vis* the physician as expert.

In more recent depictions of the paternalistic model, the physician is seen as dominating the medical encounter and using his skills to diagnose and recommend tests and treatments for the patient. In the extreme case, "the physician authoritatively informs the patient when the intervention will be initiated" (Emanuel and Emanuel, 1992). In the less extreme, the physician will give the patient selected information and will encourage the patient to consent to what the physician considers best (Emanuel and Emanuel, 1992). The role of physician depicted in this model is guardian of the patient's best interest. The physician does what he thinks is best for the patient, without eliciting the latter's preferences. Patient involvement (if there is any) is limited to providing consent to the treatment advocated by the physician (Emanuel and Emanuel, 1992).

Most would agree that this is not a model of shared decision-making in any sense. Efforts to formulate alternative treatment decision-making models have arisen, in part, in reaction to the perceived prevalence of the paternalistic approach (Levine *et al.*, 1992; Deber, 1994) which is viewed by many as inappropriate for many current treatment decision-making contexts. The extent to which this approach is currently practised by physicians is an empirical question; in emergency situations, for example, it may still be widely accepted and might, in practice, be the only feasible model for the task.

Both the informed and the physician-as-agent decision-making models derive from a recognition of informational asymmetry between patient and physician (Levine *et al.*, 1992). As Hurley *et al.* (1992) note: "The crux of the information problem is that while the health care provider possesses better knowledge regarding the expected effectiveness of health care in improving health status, the individual knows best how improvements in health status affect his or her well-being" (p. 4). Technical knowledge resides in one party to the interaction—the physician, while preferences reside in the other—the patient. Yet both types of information need to be combined if effective care that leads to health status improvements valued by patients is to be provided (Hurley *et al.*, 1992; Levine *et al.*, 1992). In the informed model this is accomplished by increasing the patient's knowledge of the possible risks of alternative therapeutic options and their clinical effectiveness, so that patients can make decisions that reflect both their preferences and the best scientific knowledge available (Hurley *et al.*, 1992).

The informed decision-making model incorporates the idea of information sharing (primarily from physician to patient); but we would argue that information sharing does not necessarily lead to a sharing of the treatment decision-making process. In fact, since the informed patient has overcome the problem of information deficit, presumably she is now enabled to make the treatment decision on her

own. Theoretically, in this model, an informed patient no longer needs to share the treatment decision-making process because she now possesses both components (information and preferences) viewed as essential to the task (Levine *et al.*, 1992). In this model, treatment decision-making control is clearly seen to be vested in the patient (Eddy, 1990). The physician's role is limited to that of information exchange, communicating the needed technical or scientific knowledge to the patient (Williams, 1988; Mooney and Ryan, 1993). As noted by Emanuel and Emanuel (1992), the physician "is proscribed from giving a treatment recommendation for fear of imposing his or her will on the patient and thereby competing for the decision-making control that has been given to the patient" (p. 2225). In other words, the physician's treatment preferences for the patient do not enter into the decision-making process.

If the paternalistic model leaves the patient outside the decision-making process, the informed model leaves the physician outside by limiting the role of the physician to one of information transfer. In the extreme case, information transfer can be done without the presence of any health care worker, for example, by the patient viewing an interactive video. We argue that unless both patient and physician share treatment preferences, a shared treatment decision-making process did not occur, no matter how much information may have been exchanged by either party.

The informed model is premised on the assumption that information is an enabling strategy, "empowering" the patient to become a more autonomous decision maker. Research has shown, however, that while patients typically express high preferences for information about their illness and its treatment (Cassileth *et al.*, 1980; Strull *et al.*, 1984; Beisecker, 1988; Blanchard *et al.*, 1988; Ende *et al.*, 1989; Lerman *et al.*, 1990; Beisecker and Beisecker, 1990; Waterworth and Luker, 1990; Silverstein *et al.*, 1991; Biley, 1992; Deber, 1994), their preferences for participation in treatment decision-making are much more diversely distributed (Vertinsky *et al.*, 1974; Strull *et al.*, 1984; Pendleton and House, 1984; Ende *et al.*, 1989; Beisecker and Beisecker, 1990; Silverstein *et al.*, 1991; Degner and Sloan, 1992; Ryan, 1992; Hack *et al.*, 1994). In other words, patients want information about their medical condition and treatment options without necessarily being responsible for making treatment decisions (Ende *et al.*, 1989; Beisecker and Beisecker, 1990; Ryan, 1992).

An informed patient may prefer to make the decision herself (or be required to do so by the physician), to share the decision-making process, or to delegate this responsibility to the physician. In Scenario 1 in the Appendix, for example, the physician clearly wants the patient to make the treatment decision. The patient, while claiming to be

well informed, nonetheless prefers that the physician decide. Many patients faced with a serious illness, substantial uncertainty as to the outcome, and a time pressure to make a treatment decision among several competing alternatives, feel extreme psychological and/or physiological vulnerability, which may make it difficult for them to participate in treatment decision-making no matter how well informed they may feel (Gray *et al.*, 1990; Ryan, 1992). Also, as this scenario points out, before patients can decide whether or not to share in decision-making, they must be offered the choice of participation by their physician (a point also made in a recent article by Ong *et al.*). Other patients may wish to participate but lack a systematic way of structuring the decision-making process. In this case, efforts to promote shared decision-making may well require interventions that not only provide patients with information but also with a way of thinking about treatment decision-making that helps them focus on key issues and evaluate relevant options.

One such intervention is the treatment decision aid, ranging in type from high cost interactive videos to low cost decision boards. Several decision boards have recently been developed and tested with women with breast cancer (Levine *et al.*, 1992; Whelan *et al.*, 1995). They provide the patient with detailed information about her treatment choices, outcomes, the probability of these outcomes and quality of life associated with each outcome. Treatment decision aids are a form of educational intervention. But they are also aids to treatment decision-making in that they provide a way of structuring the decision-making process, and breaking it down into a number of specific and sequential steps. As Llewellyn-Thomas (1995) notes: "A distinguishing feature of a decision aid is the inclusion of exercises designed to promote clarification of the patient's values regarding what is at stake and what it is that he or she is trying to achieve as a result of treatment" (p. 104). Decision aids are intended to provide information and to promote "self help" in the treatment decision-making process which enables the patient to more actively participate in this process, if this is her preference.

It seems fair to say that physicians such as medical oncologists who develop, test and use treatment decision-making aids are those who are already motivated to share treatment decision-making, since a primary goal of the aids is to help elicit patients'

treatment preferences. Physicians adopting the paternalistic approach are unlikely to use such aids precisely because they can help overcome traditional professional dominance over interactions in the medical encounter (Freidson, 1970; West, 1984; Hill Beuf, 1989; Waitzkin, 1991). Whelan, for example, recently reported (1995) that 97% of women with breast cancer who were assigned to a group in which the physician used a treatment decision board with information about the risks and benefits of breast irradiation following lumpectomy felt that they were offered a treatment choice compared with 70% of women in the no decision board group. To return to our main point, however, an informed patient who perceives that she has choices may still prefer not to make the treatment decision.

The professional-as-agent model is the flip side of the informed patient model of treatment decision-making. Its goal is also to resolve the informational asymmetry between physician and patient. But here, "the professional-as-agent assumes responsibility for directing the health care utilization of the patient... as an agent trying to choose what the patient would have chosen, had she been as well-informed as the professional" (Evans, 1984, p. 75). In other words, in this model, the physician makes the treatment decision, either assuming that he knows, or having elicited the patient's preferences for future health states, lifestyle choices etc. Both components (information and preferences) then reside in the physician, rather than the patient, and the former becomes the sole decision-maker.* Legally physicians cannot implement a treatment without at least eliciting patient consent. In practice, there may still be some physicians who assume that they know the patient's treatment preference, and act on this without first explicitly testing this assumption. Such cases are not likely to attain public visibility unless the patient subsequently launches a legal suit, claiming violation of patient rights to informed consent.

While there have been critiques of the physician-as-agent model (Evans, 1984; Mooney and Ryan, 1993), our interest is not to take sides in this debate. Rather we argue that this model is also not necessarily one of shared decision-making. In the purest form of this model, the physician makes the treatment decision as if he had the same preferences as the patient; decision-making is again portrayed as a one-sided process. By definition, in this model the physician's treatment preferences do not count (are excluded). The only treatment preferences that matter are those of the patient.

In summary, several models of treatment decision-making have been developed, partially in reaction to the paternalistic model. A closer examination reveals that none of these explicitly describes a process in which both physicians and patients necessarily share in decision-making, no matter how much information they share. The notion that information sharing and treatment decision-making are

*In the agency model, the physician is usually depicted as acting as the patient's agent, but this is not always the case. Williams, for example, defines a perfect agency relationship as one in which the physician gives the patient all the information the patient needs and the patient then makes the decision (Williams, 1988). Hence, the agency and informed models are also confused in the literature.

two separate goals in the medical encounter is beginning to be recognized in the literature on doctor-patient communication (Ong *et al.*, 1995). In the next section we argue that for shared treatment decision-making to occur, there needs to be a two-way exchange not only of information but also of treatment preferences.

CHARACTERISTICS OF SHARED DECISION-MAKING

In order to specify what falls or does not fall within the boundaries of shared decision-making, it is necessary to try to identify some of its key characteristics. Characteristics are signals of identification. The characteristics we identify can be thought of as minimum or necessary criteria for classifying a physician-patient decision-making interaction as shared decision-making, i.e. necessary but not always sufficient. There may well be other characteristics that are important that we have not included. It is also important to recognize that many of these characteristics are continuous rather than dichotomous variables in recognition of the fact that shared decision-making involves gradations rather than absolutes.

Shared decision-making involves at least two participants—the physician and patient

The first characteristic of shared treatment decision-making is that it involves at least two participants—a clinician, who in many cases will be a physician, and a patient. This seems self-evident: as noted above, if only one person makes the decision, the process is not shared.

Frequently treatment decision-making involves more than one patient and one physician (or other health care professional) in a single or sequential medical encounter. For example, research on physician and elderly patient medical encounters increasingly focuses on triad rather than dyad relationships in recognitions that many elderly patients bring a relative or friend to the physician's office (Rosow, 1981; Coe and Prendergast, 1985; Adelman *et al.*, 1987; Haug and Ory, 1987; Beisecker, 1988; Haug, 1994). Both conceptual and research interest has focused on the types of coalitions that can occur in such encounters. What this literature highlights is that family members or friends can play a variety of different roles within (or outside) the medical encounter relating to the patient's illness, treatment selection and management.

Roles which relate specifically to the treatment decision-making process can include, for example: (1) information gatherer, recorder or interpreter; (2) coach, e.g. prompting the patient to ask the physician certain questions; (3) advisor, e.g. advising the patient which treatment option to select; (4) negotiator, e.g. advocating on the patient's behalf regarding the timing or place of treatment or the patient priority in receiving treatment; (5) caretaker,

e.g. supporting and or reinforcing the patient's treatment decision. The involvement of family members in treatment decision-making may be particularly important with serious illnesses because of the stress engendered by the diagnosis, the uncertain outcome, and the potentially major impact of the illness trajectory and treatment management on other family members. These issues have received little attention in the shared treatment decision-making literature which focuses almost exclusively on the dyad relationship of physician and patient in the medical encounter.

When patients bring a relative or friend to a physician visit, the range and complexity of the interactional dynamics is automatically increased. In addition, the introduction of a third person enables the formation of coalitions. Coalitions (e.g. between the physician versus the patient and family member) may occur over such things as how much and what type of information is given by the physician, what is the best treatment and how and when to implement it. Studies of triad interactions between elderly patients, a family member and the physician have revealed the formation of numerous (and different) coalitions over numerous (and different) issues in a single medical encounter. However, the frequency and pattern of coalition formation is likely to vary depending on the treatment decision-making context. The triad relationship of elderly patient, physician and family member discussing treatment options for the long-term management of a chronic illness is different from the situation of a post-surgery woman with breast cancer who needs to make an important treatment decision under tight time constraints. Here, we hypothesize that fewer coalitions will be likely to occur because all parties will be motivated to reach consensus quickly on the treatment to implement so as to afford the best chance of recovery.

Also not well recognized in the literature on shared treatment decision-making is the fact that several physicians often participate in this process with a single patient. A breast cancer patient, for example, may have a family physician, surgeon, radiation oncologist, and medical oncologist, all of whom may have specific treatment preferences for the patient. For example, the surgeon may suggest a post-surgery treatment to the patient which she then has in mind when subsequently visiting the medical or radiation oncologist. If the latter presents a different treatment option, the result may be increased uncertainty and confusion for the patient. One study of patients in a cardiology unit reported that, not infrequently, five or more physicians were "making treatment decisions" about the patient's care (Lidz *et al.*, 1985, p. 248).

These examples suggest that limiting the conceptualization of shared decision-making to a physician-patient dyad may not, in many cases, reflect the current realities of clinical practice, where other

participants may well be involved. It misses altogether the important role that the patient's friends or family may play and the case of incompetent or seriously ill patients who require third parties to act on their behalf. There is almost no discussion in the shared decision-making literature on the implications of these situations for conceptualization and measurement of shared decision-making. Hence, we emphasize that a shared decision-making process requires at least two participants (i.e. it takes two to tango) but may often involve more than two.

Both parties (physicians and patients) take steps to participate in the process of treatment decision-making

Much attention has been focused on exploring patient preferences for participation in treatment decision-making. Over the years, several scales have been developed, with preferences for participation often conceptualized as a single continuum of the amount of participation the patient prefers (e.g. from none, to shared participation, to complete patient control or autonomy (Strull *et al.*, 1984; Beisecker, 1988; Brody *et al.*, 1989; Ende *et al.*, 1989; Beisecker and Beisecker, 1990)). The terms control and autonomy are usually not defined; nor is the term participation. To some, (Strull *et al.*, 1984) participation seems to incorporate the idea of sharing on an equal basis, but the specifics of what this really means in terms of input by both physician and patient is left unclear. Presumably, the complete patient control end of the continuum corresponds to the pure type informed model where the patient is the sole decision-maker. An implicit assumption behind much of this research seems to be that if patients express preferences, they will act in accordance with these preferences. Preferences become a proxy for behavioural intent, predictive of future behaviour.

Empirical research suggests that the link between patient preferences for participation in treatment decision-making and actual participation is not that strong. Patient preferences for information do not necessarily translate into information seeking behaviour; nor do patients who express preferences for some form of shared decision-making necessarily act on these in the medical encounter (Haug and Lavin, 1983; Beisecker, 1988; Beisecker and Beisecker, 1990; Ryan, 1992). Patient preferences

for shared decision-making do not seem sufficient to make it happen in reality*.

If the majority of patients say that they have a preference for information about their illness and potential treatment options, while a much smaller number express preferences to participate in treatment decision-making, this raises some interesting questions. First, why do patients want information if it is not to be used by them instrumentally to help them make a treatment decision? We discuss this issue in the next section. Second, why do patients say that they do not want to participate in treatment decision-making and what does this preference really mean? We think that the latter is an under researched area and one that deserves much more attention because there are a variety of different possible explanations which have different implications for determining when a shared treatment decision-making process is appropriate.

First, a stated preference (e.g. a patient's stated preference not to participate in treatment decision-making) may reflect an underlying and salient personality characteristic. In this case, introducing a decision aid to help the patient structure the treatment decision-making process is unlikely to have the desired effect, because the patient simply is not motivated to take an active role in the process and prefers that the physician decide.

For other individuals, a stated preference not to participate in treatment decision-making may reflect a situationally specific response. For example, a woman faced with the diagnosis of early stage breast cancer may not want to take an active role in treatment decision-making because of perceived information or skill deficits. Here, an intervention such as a decision aid can provide information and help the patient structure the decision-making process. The intervention could, in fact, help to promote a more active treatment role preference by the patient.

In still other instances patients may express a preference for a passive role in treatment decision-making because they have learned through previous interactions that a more active stance is not well received by providers. For shared decision-making to occur, there needs to be complementary role expectations and behaviour between physician and patient around this issue. No matter how much the patient wants to participate, if the physician is not willing, then shared decision-making will not occur. Similarly, if the physician is willing but the patient is not, then the process will not be shared. It is in this sense that we emphasize that "it takes at least two to tango".

Finally, preferences for a passive role in treatment decision-making may reflect, in some instances, a cohort effect. For example, research suggests that elderly patients often prefer a more passive role in treatment decision-making than younger patients (Coe and Prendergast, 1985; Haug, 1994). This is

*Alternatively, it is possible that some patients preferring an autonomous decision-making role are constrained to share the process with their physician. In our culture, physicians have the authority to act as gatekeepers to health care. They control medical knowledge, technology, access to treatment and even norms of behaviour in the medical encounter (Ryan, 1992). At a minimum, the patient needs the physician's consent to her treatment choice in order to obtain most services.

likely to change over time as the generation of baby boomers with higher education levels and higher expectations encounter the health care system.

In summary, the patient preferences literature provides only a partial answer to the question of what role patients want to play in treatment decision-making because it fails to consider that preferences may be situationally determined, and hence, subject to change. Moreover, by limiting the conceptualization and measurement of preferences to only the patient side of the equation, it misses the important interactional dynamic with the physician which is crucial to making shared decision-making happen in reality*. By and large, physicians set the norms of interaction in the medical encounter. If the physician is not motivated to share decision-making, the patient cannot force this to happen. Her only option is to seek out another physician whose expectations about how the decision-making process should occur is similar to hers.

If preferences are not enough, then what steps do physicians and patients need to take in order to share in the treatment decision-making process? We suggest that for the physician it means first, establishing a conducive atmosphere so that the patient feels that her views about various treatment options are valued and needed (Brody, 1980). Second, it means eliciting patient preferences so that treatment options discussed are compatible with the patient's lifestyle and values. Third, it means transferring technical information to the patient on treatment options, risks and their probable benefits in as unbiased, clear and simple a way as is possible. Fourth, physician participation would also include helping the patient conceptualize the weighing process of risks versus benefits, and asking patients questions in order to ensure that the causal assumptions (information) underlying their treatment preferences are based on fact and not misconception.

Finally, shared decision-making would also involve the physician in sharing his treatment recommendation with the patient, and/or affirming the patient's treatment preference. The physician would need to be careful, however, not to impose his values about the best treatment onto the patient.

There may always be a danger in a shared decision-making process that the physician's values will influence the patient, even if this is not his intent. Many patients have been socialized to think that the physician knows best, that they lack the expertise to make the treatment decision, that a trusting relationship with the physician means trust-

ing his judgement about the most appropriate treatment, or that agreeing with the physician will result in better or more personal care.

For the patient, shared decision-making means that she must be willing to engage in the decision-making process, that is, to take responsibility for disclosing preferences, asking questions, weighing and evaluating treatment alternatives and formulating a treatment preference. This is a problem solving task that goes beyond information transfer. Scenario 2 in the Appendix depicts such a shared decision-making process. Both patient and physician discuss and evaluate treatment options and together they build a consensus. We suggest that the test of a shared decision-making process is if both parties adopt the complementary roles outlined above, and if both parties are satisfied with their level of involvement.

Information sharing is a prerequisite to shared decision-making

In the typical case, information sharing is a prerequisite for shared decision-making. At minimum, the physician needs to lay out treatment alternatives and their potential consequences for the patient in order to obtain informed consent. Without such information, there might be nothing for the patient to evaluate and deliberate about. As noted earlier, patients may also bring information obtained through other means to the encounter. Both patients and physicians bring both information and values; it is not simply a question of physicians bringing knowledge and patients bringing values.

As a practical problem, it is often not clear what type and amount of information patients want from physicians, or why they want it. Patients may want more information than physicians think is needed instrumentally to help distinguish the pros and cons of various treatment options. Similarly, the types of information physicians desire from patients is not always clear. Is it the patient's full illness narrative or only those elements of the patient's story that the physician thinks relevant to suggesting treatment options?

The physician's primary professional obligation is to apply expertise in the treatment of patients. Time constraints, the potentially rapid course of many diseases, and financial incentives all operate to encourage physicians to complete the decision-making process as quickly as possible. In this situation it is likely that patient information is sought by the physician primarily for its instrumental use in identifying treatment options that are compatible with patient values.

The value of information about treatment alternatives, and their risks and benefits for the patient, is less well understood (Haug and Lavin, 1981; Beisecker and Beisecker, 1990; Ryan, 1992). As noted earlier, studies indicate that many patients have high preferences for information about their

*This research does, however, demonstrate heterogeneity in patient preferences for participation in treatment decision-making. This in turn suggests that any attempt to define a single normative model of treatment decision-making which both physicians and patients "ought" to follow might not fit with empirical reality.

illness and its management but do not engage in information seeking behaviours or in treatment decision-making. The value of information, from the patient's perspective, does not appear to lie (or lie solely) in its potential use as an aid to decision-making. More important may be the psychological reassurance or reduced uncertainty which information is thought to provide at a time of great stress and vulnerability (Mooney and Ryan, 1993). More research is needed in order to more completely understand the value of information from the patient's perspective.

Research evidence also suggests that when physicians infer patient preferences for information and for participation in treatment decision-making, they often fail to get them right (Strull *et al.*, 1984; Waitzkin, 1984; Ryan, 1992). If the medical interaction is to reflect patient role preferences, these need to be made explicit by the patient either on her own initiative or elicited by the physician as part of the information exchange.

A treatment decision is made and both parties agree to the decision

Shared decision-making is usually depicted, either implicitly or explicitly as a type of decision-making process. But shared treatment decision-making can also refer to an outcome, i.e. a shared or agreed upon decision. The shared process relates to the roles that patients and physicians play and involves complementary role expectations and behaviour. Agreement between physician and patient about the treatment decision is one possible outcome of this process; others include no decision or disagreement as to the preferred treatment. In Scenario 3, for example, both the physician and the patient reveal their preferences about treatment but they cannot reach an agreement.

The test of a shared decision (as distinct from the decision-making process) is if both parties agree on the treatment option. This does not mean that both parties are necessarily convinced that this is the best possible treatment for this patient, but rather that both endorse it as the treatment to implement. The physician may feel, for example, that the patient would really be better off with another treatment but agrees to endorse the patient's choice as part of a negotiated agreement in which the patient's views count. Through mutual acceptance, both parties share responsibility for the final decision.

This is an important characteristic and helps to distinguish shared decision-making from other models of decision-making. In the extreme case of the paternalistic and informed models, decision-making and ultimate responsibility for the decision are clearly vested with the physician or the patient respectively, and whether the opposite party accepts the decision is not relevant. Mutual acceptance may or may not occur with other models of decision-

making (paternalistic and informed) but it remains a necessary prerequisite for shared decision-making.

However, mutual acceptance does not always indicate a shared decision-making process. A paternalistic process of decision-making, for example, can result in a shared decision. How do we know when mutual agreement on the decision to implement is reached? An explicit and verbal acknowledgement provides one potential indication and can be ascertained through observation. Sometimes, the agreement may be implicit, and signified by a behavioural intent by the patient to return for treatment or by the physician to book a future treatment appointment. A verbal agreement at one point in time may not hold over time. In Scenario 4 in the Appendix, it appears that an agreement has been reached at the end of the medical encounter but, subsequently, the patient changed her mind and did not return for treatment.

SOME MEASUREMENT ISSUES

If there is confusion about what shared treatment decision-making means conceptually, then there is bound to be difficulty in measuring it empirically because of disagreement over what one is looking for as defining characteristics. We have described our ideas about this above. Even so, major methodological issues remain. For example some of the defining characteristics of a shared decision-making model overlap with those of other models and some characteristics may be present in varying degrees. Both these conditions make it difficult to establish clear boundaries or thresholds of what is inside versus outside the shared treatment decision-making box. This is particularly true for the measurement of a patient's level of participation in treatment decision-making. For example, if a patient simply agrees to a treatment decision suggested by the physician, does this mean she participated in the treatment process? We do not think so, but the issue still remains, to what extent does the patient need to reveal and discuss treatment preferences in order for her interaction to be defined as one of shared decision-making? Also, a given medical encounter may start as one model of interaction, but evolve into something else as the encounter unfolds. This may make it difficult to precisely classify any given medical encounter as falling within one model or another.

Empirically measuring if and how patients deliberate over treatment choices and the process they use to arrive at a decision is no easy task. Observation techniques are frequently used to measure physician-patient communication more generally, using different interaction analysis systems. Many of these have been recently summarized in an article by Ong *et al.* (1995). These systems are

designed to identify and quantify salient features of physician-patient communication. Observation methods alone, however, have some limitations when it comes to measuring decision-making processes that occur "in the patient's head" and may not be made explicit either through verbal or non-verbal behaviour. From what we observe, we would need to make attributions about the patient's intentions and internal decision-making processes. For example, in Scenario 1, is the patient's question to the physician a form of information gathering so that she can better evaluate treatment options or is she trying to get the physician to make the decision for her? Does her ultimate agreement with the physician's recommendation reflect a thoughtful consideration of the alternatives, deference to physician authority, or reluctance to engage in the decision-making process? The same observation could yield several different stories or interpretations.

Similarly, structured questionnaires that have used a Likert type scale to measure patient preferences for or actual participation in treatment decision-making in previous studies also have limitations. They simplify and structure the measurement process to such a degree that little information is gleaned about the dynamics of shared decision-making or the interactional process involved. Moreover, as noted earlier, it is often not clear how to interpret different preferences.

We think that an important area for future research is a more in-depth exploration of why patients hold different treatment preferences, and what meanings patients ascribe to these preferences. Qualitative methods such as illness narratives or semi-structured interviews seem well suited to this task for several reasons. First, they allow for an in-depth exploration and, hopefully, increased understanding of a complex process: how patients think about decision-making in general and treatment decision-making in particular. Second, they allow more freedom for the patient to structure the discourse of the interview so that the information captured reflects patients' perspectives rather than researchers' preconceived measurement categories. Third, with qualitative interviews it is also possible to pay much more attention to social, cultural and illness contexts which may influence patients' views about appropriate roles in treatment decision-making. Such interviews may also be used to generate information about what patients perceive are barriers to shared decision-making and the kinds of interventions they suggest (if any) that would help them to adopt a more active treatment decision-making role.

In making the above recommendation we do not mean to suggest that qualitative methods are the only appropriate ones for studying issues related to shared decision-making. For many issues, a combination of qualitative and quantitative methods may well be appropriate. The particular methods

adopted should be those most useful in generating the best information about the specific question of interest.

CONCLUSION

Because shared decision-making is increasingly advocated as an ideal treatment decision-making process, one might be tempted to try to identify explicit behaviours prescribing how to engage in this process. The ability to define specific behaviours holds appeal because it would provide a form of instructional guide, but we think it is also problematic. There is no single route to shared decision-making; some of the characteristics we describe can be met by a variety of different behaviours. Also, the physician-patient relationship is a personal, and often trusting relationship. To develop a standardized checklist of concrete and invariant steps for shared decision-making would not fit this decision-making context where the preferences of both physicians and patients can vary widely and change over time. While a checklist approach may resonate with many physicians in terms of a clinical framework of decision-making (Sackett *et al.*, 1985), it may not resonate with patients' models of decision-making or constructions of their illness experience. Finally, shared decision-making is in some sense a matter of perception. Similar objective states of shared decision-making (if these could be defined) might well be both perceived and valued differently by different patients.

Perhaps more important than prescribing specific behaviours would be to agree on certain fundamental principles around treatment decision-making—for example, that patients' preferences for participation be elicited and acknowledged, that patients be given choices as to how the decision-making process will proceed, and that their choices be respected and adhered to in the physician's behaviour.

Herein lies one of the benefits of a shared decision-making approach. It offers a potential middle choice of treatment decision-making models between two polar extremes. On the one hand, the paternalistic model is characterized by physician dominance of the decision-making process. On the other hand, the informed decision-making model seems to limit the role of the physician to one of transferring information, enhancing the patient's ability to engage in autonomous decision-making with ultimate control but also responsibility for the treatment choice. Empirical research demonstrates that many patients, for whatever reasons, prefer not to assume full decision-making control. But many may also not like the idea of no say at all. Shared decision-making offers an intermediate alternative for both physician and patient. For the patient it offers some say without total responsibility, and for the physician, an opportunity to go beyond a role

of transferring information to also participate in, but not dominate, the decision-making process.

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APPENDIX

A patient with newly-diagnosed early breast cancer comes to see her oncologist. The physician reaffirms the diagnosis and discusses with the patient her concerns. The physician outlines the various treatment options, the pros and cons of each, and asks the patient about her preferences for treatment, given her lifestyle and values. The patient responds that she feels knowledgeable about the disease and the pros and cons of various treatment options but can't decide; she would prefer that the physician make the decision. The physician responds that the patient is in the best position to judge because this decision involves placing a value on various treatment outcomes and weighing the benefits versus the risks of each option. The physician tells the patient to think it over and come back in another week with the decision. The patient comes back but still has not made a decision. Finally, the patient says: what would you do, if it was your wife? The physician says: if it was my wife, I would choose option A, but my preferences may well be different from yours. The patient replies: I will go with option A. (**Scenario 1**)

A patient with newly diagnosed early breast cancer comes to see her oncologist. The physician reaffirms the diagnosis and discusses with the patient her concerns. The physician outlines the various treatment options, the pros and cons of each, and asks the patient about her preference for treatment, given her lifestyle and values. The patient responds that she feels knowledgeable about the disease and the pros and cons of various treatment options. After discussing these issues at length, the patient says that she prefers option A. The physician reminds her: do you understand that with option A, as I mentioned earlier, there are a number of side effects, e.g. you will feel sick for several months. The patient responds that she understands and still prefers option A, for reasons which she reiterates. The physician agrees and says: I think that is a good choice for you. (**Scenario 2**)

A patient with newly diagnosed early breast cancer comes to see her oncologist. The physician reaffirms the diagnosis and discusses with the patient her concerns. The physician outlines the various treatment options, the pros and cons of each and asks the patient about her preferences for treatment, given her lifestyle and values. The patient responds that she feels knowledgeable about the disease and the pros and cons of various treatment options. She indicates that she wants to try a new experimental treatment (A) that she has read about in a magazine. The physician responds that he does not think that this is an appropriate treatment option because its effectiveness has not been proven. The patient says that she still prefers treatment A. The physician again tries to dissuade the patient from this decision and says he cannot provide this treatment. The patient says then I will have to go elsewhere, and she leaves the physician's office. (**Scenario 3**)

A patient with newly diagnosed early breast cancer comes to see her oncologist. The physician reaffirms the diagnosis and discusses with the patient her concerns. The physician

outlines the various treatment options, the pros and cons of each, and asks the patient which one she prefers, given her lifestyle and values. The patient responds that she feels knowledgeable about the disease and the pros and cons of various treatment options but she wants the physician to decide. The physician responds that the patient is in the best position to judge because this decision involves pla-

cing a value on various treatment outcomes and weighing the benefits versus the risks of each. The patient says, in that case, I will go with treatment A. The physician sets up the follow-up treatment visit. The patient does not return for the treatment. The physician later discovers that the patient has instead gone to another physician. **(Scenario 4)**