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# Importance of clarifying patients' desired role in shared decision making to match their level of engagement with their preferences

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ANALYSIS

# Importance of clarifying patients' desired role in shared decision making to match their level of engagement with their preferences

We should not assume that certain groups of patients don't want to or can't participate in decisions about their healthcare, say **Mary Politi and colleagues**, and they offer advice on how to determine how much patients want to be involved

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Many clinicians now recognise that shared decision making can have an important role in patient care. However, in some circumstances, clinicians may assume that patients such as those with limited health literacy or low education, and older adults do not want to participate in treatment decisions and prefer physician led models of care.[1-5] Evidence has shown that these patient characteristics are not consistent predictors of how involved patients want to be in making decisions.[1 6-8] We discuss factors that can contribute to this misconception and the importance of clarifying how involved a patient chooses to be during decision making. We also provide recommendations about how to assess patients' desired role in shared decision making.

## From theory to practice

Shared decision making is a process during which clinicians and patients collaborate to make health decisions, considering both the best available evidence and patients' preferences.[9] It is particularly appropriate for preference sensitive decisions in which there are several options available and evidence does not point to a clear best choice, such as when choosing surgery for early stage breast cancer. It is also appropriate when patients must make difficult trade-offs between benefits and harms, such as when choosing whether to have adjuvant chemotherapy. Patients are encouraged to take an active role in their healthcare by communicating their preferences to clinicians and sharing information that influences their decision.[10 11] Clinicians support patients through this process by communicating evidence and its uncertainty in understandable terms, helping patients clarify and construct preferences, and providing opportunities for patients to ask questions, state concerns, and share information.[11 12]

Shared decision making can improve patients' knowledge, lower decisional conflict, increase patients' involvement in discussions, help patients develop realistic expectations about options, and help them clarify their preferences.[13] It may reduce overuse of interventions with minimal or no expected benefits and underuse of beneficial interventions.[13 14] However, despite these advantages, shared decision making is not widely implemented in practice.[15 16] For example, a nationally representative study of US adults showed that primary care clinicians did not engage in shared decision making about common preference sensitive decisions such as choosing drugs to reduce risk of cardiovascular disease or deciding about cancer screening.[16]

One of the primary barriers to shared decision making may be clinicians' belief that some patients are either not capable of or do not want to feel burdened with making complex medical decisions under uncertainty.[17-20] Despite common misconceptions, evidence suggests that patient characteristics such as age, education, and health literacy skills are not consistent predictors of how involved they want to be in making decisions.[1 6-8] For instance, data show that many older patients want to be informed about their care decisions,[21 22] and many groups of patients want more involvement in decisions than they receive.[6 7] Even if clinicians are experienced and have a positive relationship with their patients, their inferences about patients' preferences are often inaccurate.[8] These inferences

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may negatively affect the doctor-patient relationship. Patients can feel vulnerable and reluctant to express their concerns to clinicians in these situations because they fear being labelled "difficult" and receiving suboptimal care.[23]

## Difference between deliberation and determination

It is important to distinguish between deliberation (considering factors that can influence a choice such as knowledge, preferences) and determination (making a choice).[24] Many studies have grouped patients who want their physician to make the final treatment decision (after considering patients' opinions) as those desiring passive or physician led decision making.[25-27] However, shared decision making does not imply that doctors and patients must have equal responsibility for the final decision. Shared decision making is a process and involves communication about options, engaging patients in discussion, and understanding patients' preferences, including what role they would like to play in the final decision.[10]

In a national study of almost 3000 participants, nearly all respondents (96%), regardless of their demographic characteristics, preferred to be offered choices about their care and asked their preferences.[28] About half (52%) of patients wanted to defer final decisions to their clinicians,[28] but they still wanted to engage in deliberation about the choice. In another study about patients' preferred role in decision making for invasive medical procedures,[29] about 80% wanted shared decision making or patient led decision making, and 93% of patients wanted their clinicians to share risk information with them. In a review of surveys about patients' preferences for participation in decisions, only 3-8% of patients stated they wanted no role in decision making.[8] A patient could still say to a clinician, "My preferences are to cure the disease as quickly as possible, but I would like to be able to continue working throughout treatment if possible. I am torn between option A and option B. What do you think I should do?" The clinician could then make a recommendation and still be engaging in shared decision making.

## Evidence about patients' desired involvement

Clinicians and researchers often ask patients how involved they would like to be in making a decision without providing context about why it is important that patients become engaged.[30] Patients who are informed about their options often have a greater desire to be involved in health decisions than patients who are left uninformed.[13] In addition, some of the evidence used to support beliefs regarding patient preferences and deference to clinicians is anecdotal or framed misleadingly. For example, the title and abstract of a recent study, "Breast cancer treatment decision making: are we asking too much of patients?" suggested that many patients thought they had too much responsibility for treatment decisions and subsequently regretted their choices.[31] A close review of the patient sample in this study showed that only 21% perceived that they had too much involvement in the decision, and many of those had limited knowledge about options.[31] Furthermore, regret levels were similarly high in patients who indicated too little involvement. It seems more likely that patients' limited knowledge in this study led them to feel ill prepared to participate in the decision, as found in past studies.[32] Nevertheless, it is easy to see how this study might be used to support a previously held belief that some patients do not want to engage in shared decision making.

## Importance of preparing patients

Many patients do not expect to be involved in decisions; nor are they aware that their preferences are essential to decisions because evidence fails to identify a clear superior option.[14] These patients often believe that there is one best treatment option and the clinician knows which it is. Acknowledging to patients the multiple options and the importance of their preferences in choosing one is thus a crucial first step in engaging patients in shared decision making. A clinician could say, "The best data we have suggest that there is more than one option for you, and the options work equally well. Your preferences are important to help us choose the right option for you. Let's talk about what is most important to you regarding your treatment."

Clinicians can improve patient participation by modest changes in how they communicate with patients.[33] By explaining options and their risks and benefits clinicians can answer the questions that patients need to ask to improve decision making,[33] taking the burden off patients. In patients with a propensity to defer health decisions to others, clinicians should provide information in a way that makes it understandable before determining the extent to which patients want to be involved in the decision. Preferences cannot be articulated or formed if the patient has inaccurate or missing information.[10] Many clinicians believe they are already considering patient preferences and priorities in their treatment recommendations.[34] Without engaging patients in a discussion of their values, clinicians often incorrectly assume patient values and preferences, resulting in a "misdiagnosis" of preferences.[34 35]

Values and preferences may be informed by experiences outside the clinical encounter. For example, a patient facing a choice of surgeries for early stage breast cancer may come to her physician with a strong preference for a mastectomy because she wants to control her health.[36] Shared decision making provides a framework to discuss her preferences in the context of the available evidence, ensuring that the decision is both in the patient's best interest and consistent with her informed values. Similarly, in the increasingly common situation in which a patient requests treatment that in the clinician's view is not evidence based, shared decision making can uncover the beliefs and values underlying this request and support both the patient and the clinician in conveying their viewpoints.

## Conclusion

The assumption that some patients are not able or do not want to participate in decision making is inconsistent with both the evidence and contemporary models of care. We suggest clinicians start by acknowledging equipoise, recognising underlying trade-offs between options, and offering treatment choices. They should discuss evidence based information without assuming some patients will not want to engage in shared decision making. Once patients are informed, they can decide whether they would like more (or less) responsibility for their health decision. This approach can improve patients' satisfaction, understanding, and confidence in their choices, whether or not they defer final decision making to their clinicians.[37]

Shared decision making requires more clinician training,[11 17 38] and might add time to the consultation.[13] However, its challenges are not insurmountable.[17 38] Supporting this patient centred approach is a necessary first step towards making systems level changes that can help overcome the other structural barriers to offering shared decision making.

**Key messages**

- Clinicians should not make assumptions about patients' desired role in shared decision making based on patient characteristics
- Clinicians should assess patients' desired role after acknowledging the decision and clinical equipoise
- Most patients want to engage in decision making to some degree, whether or not they choose to defer final decision making to their clinicians
- Patients' preferences about decision making cannot be assessed if they are unaware of the available options or how their values could affect their decision

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