

ANALYSIS

Stop the silent misdiagnosis: patients' preferences matter

Correct treatment recommendations require accurate diagnosis not only of the medical condition but of patients' treatment preferences. **Al Mulley**, **Chris Trimble**, and **Glyn Elwyn** outline how to ensure that preferences are not misdiagnosed

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In recent decades, rapid advances in the biosciences have delivered an explosion of treatment options. This is good news for patients, but it makes medical decision making more complicated. Most critically, an accurate medical diagnosis is no longer sufficient to identify the proper treatment. Just as important is an accurate preference diagnosis.¹ Every option for treatment (a term that we use broadly here, to include procedures, tests, and even watchful waiting) has a unique profile of risks, benefits, and side effects. Doctors, generalists as well as specialists, cannot recommend the right treatment without understanding how the patient values the trade-offs. Regrettably, patients' preferences are often misdiagnosed. We outline a method for making better preference diagnoses.

Historical perspective

"Listen to the patient: he is telling you the diagnosis," William Osler urged students he taught at Johns Hopkins and Oxford more than a century ago. Osler knew that the patient's story was often critical to an accurate diagnosis. Like many of his contemporaries, Osler saw diagnosis as the medical profession's foundational skill. The right treatment, after all, depended on the right diagnosis. Generations later, skill in diagnosis remains a source of professional pride for many physicians, while the spectre of a misdiagnosis or missed diagnosis can provoke sleepless nights.

Medicine has changed since Osler's day, in that there are now more diagnostic technologies and more treatment options. Although the rising accuracy of diagnostic tests has allowed doctors to rely less on listening when determining the cause of symptoms,² listening is growing in importance when deciding which of the many treatment options best fits each patient's priorities.

The task of diagnosing preferences challenges the culture of medicine at its core—in particular, the widespread assumption that the right treatment choice is a matter of science alone. This assumption remains convenient for patients and doctors alike. It allows doctors to believe that they are the experts who make

decisions, and it allows patients to believe, quite simply, that doctor knows best. Unfortunately, the assumption is flawed.

The silent misdiagnosis

Many doctors believe that they already incorporate patient preferences into their treatment recommendations. It is difficult for doctors to be sure, however, because a preference misdiagnosis generally goes unnoticed.

To see why, let's consider two women, Linda and Susan. Linda is 58 and healthy; Susan is 78 and has heart failure. Both women have breast cancer diagnosed. Both are shaken by the news, and both silently dread surgery. After some discussion of the options, however, both accept their doctor's counsel that surgery is best.

Linda's operation goes well. However, when the pathologist examines Linda's excised breast tissue, he can find no signs of cancer. There had been an administrative mix-up in handling the results of the needle biopsy of Linda's breast lump. When the error was discovered, the hospital administration immediately launched an inquiry. Meanwhile, Linda considered legal action.

Susan's surgery, a mastectomy, was also routine, and in her case, the pathologist confirmed the cancer. Nonetheless, postoperatively, Susan struggled with anxiety and sadness. The situation became more difficult for her after she spoke to a friend with breast cancer who had opted not to have surgery. The friend had opted for hormone therapy to slow the cancer's advance, thinking she would probably die of something else before the breast cancer had any adverse effect. After the conversation with her, Susan felt intense regret. Had she considered all of her options more carefully, she would not have proceeded with surgery. Not seeing any point in reliving the past, Susan tried stoically to just move on.

Linda and Susan were both victims of misdiagnoses. Linda's was a medical misdiagnosis, Susan's was a preference misdiagnosis. These are very different kinds of error, but the

consequences were the same. Both patients had unnecessary surgery.

The responses, however, could not have been more different. In Linda's case, the corrective actions by the medical establishment were numerous, immediate, and loud. For Susan, there were no corrective actions. The problem was not even recognised. A preference misdiagnosis is a silent misdiagnosis. Few doctors would want to deliver an unwanted treatment (or to fail to deliver a patient's preferred treatment) if they were aware that it was happening. Sadly, Susan's experience is not anomalous. Similar stories are plentiful in medicine, across a wide range of treatment decisions (box 1).

How to make a preference diagnosis

In the ideal, fully informed patients rationally and confidently choose their treatment. However, this ideal is difficult to attain. Even diligent patients who extensively study the benefits, risks, and side effects of each option may not always feel confident enough to simply announce their preference. Instead, they may ask for a recommendation.

When patients seek guidance, doctors need to ground their advice in not just a medical diagnosis but also a preference diagnosis—an inference of what a patient would choose if he or she were a fully informed decision maker. Doctors can follow three steps to make a preference diagnosis: adopt a mindset of scientific detachment; use data to formulate a provisional diagnosis; and engage the patient in conversation and deliberation (figure 1).

Adopt a mindset of scientific detachment

To diagnose preference accurately doctors have to eliminate bias, which requires resisting several natural instincts. For example, doctors may often ask themselves, "What would I do in this situation?" or, "What advice would I give my spouse, parent, or loved one?" These questions can mislead because the patient may value the risks, benefits, and side effects of the various treatment options differently. Similarly, doctors must be aware of the natural tendency to imagine that the right treatment for the patient happens to be the one that the doctor specialises in, or the one that the doctor's medical institution delivers in high volume.

Formulate a data based provisional diagnosis

Next, perhaps even before speaking to the patient, doctors ought to take advantage of any available data that suggest what the patient's preference is likely to be. This is analogous to the way doctors make medical diagnoses. They start with an informed guess—a provisional diagnosis—and then refine the estimate by gathering more information. Box 2 shows some possible sources of data.

Unfortunately, although such datasets could be powerful in helping doctors form provisional preference diagnoses, they are currently sparse to non-existent. Their development should be considered a priority since the information could close much of the gap between what patients want and what doctors think patients want.

That said, data based predictors of preference will never provide a definitive conclusion. Indeed, no doctor should ever blithely assume that the patient in front of them is the "average" patient.

Engage the patient in conversation and deliberation

Because data based predictors of preference have limitations, the process of diagnosing preferences must, whenever possible, continue with patient engagement. The process of engaging patients in their treatment decisions has been termed shared decision making and has recently been described as a sequence of three types of conversation: team talk, option talk, and decision talk (box 3).¹²

Team talk

When faced with a serious medical problem, many patients expect their doctors to tell them what the treatment should be. The first step is to break this expectation. The patient needs to understand that when there is more than one reasonable treatment option, the best choice depends on what matters most to them.

That said, patients should never be abandoned to decide alone. Indeed, when a patient asks for a recommendation, they ought to get one. Furthermore, no patient should ever feel judged as inferior because they desire an expert recommendation when facing a consequential medical decision.

Thus, the doctor and the patient, in many cases supported by relatives and carers, choose a treatment as a team. Generally speaking, the doctor is the expert on medicine, while the patient is the expert on his or her priorities. Combining the expertise of both the doctor and the patient has been the goal of shared decision making for over thirty years.¹³

Option talk

Once the patient understands why they are "on the team," doctors can present a list of options and explain the risks, benefits, and side effects of each. The verbal and non-verbal cues that doctors receive from patients as they present the facts will help determine the preference diagnosis.

This may sound simple, but it is where preference diagnosis becomes complex, challenging the communication skills of even the most proficient clinicians. When a patient reports a treatment preference, it is just an opinion based on what the patient knows at that moment. These opinions may be influenced by irrational hopes or fears, or by the accurate or inaccurate imaginings of what the future holds. Interpreting the patient's reactions as they react to new information requires judgment and skill.

A wide range of patient decision support tools (often called decision aids), are now available to help engage and inform patients, including brief tools that can easily be used in clinic visits.¹⁴ For example, one page comparisons of the risks, benefits, and side effects of the relevant treatment options can help patients consider and articulate their fears and desires. The use of option grids (www.optiongrid.co.uk), which are organised according to the questions most frequently asked by patients, is one possibility that is being evaluated.¹⁵

If patients desire more information, doctors can also suggest sophisticated decision support tools.¹⁶ Although this sounds time consuming, most tools are designed for use by the patient alone, or possibly with their family or with a health coach, so the demand on the doctor's time is limited. To ensure continuity of care, the use of and output from such tools should be documented in a patient's health record.

Not all patients will exhaustively study relevant information. That said, the more the patient learns, deliberates, reflects and reacts, the less likely a preference misdiagnosis becomes.

Box 1: How bad is the problem of preference misdiagnosis?

Three categories of evidence suggest it is high:

Gaps between what patients want and what doctors think they want

- Doctors believe that 71% of patients with breast cancer rate keeping their breast as a top priority, but the figure reported by patients is just 7%.³
- Doctors believe that 96% of breast cancer patients considering chemotherapy rate living as long as possible a top priority, while the figure reported by patients is 59%.³
- In a study of dementia, patients placed substantially less value than doctors believed on the continuation of life with severely declining cognitive function⁴

Patients choose different treatments after they become better informed

Unfortunately many patients are poorly informed about the risk and benefits of treatment. For example, in a recent American study of elective percutaneous intervention (PCI) for stable coronary artery disease, nearly 90% of patients believed that PCI would reduce their risk of a heart attack despite definitive evidence to the contrary.^{5,6}

Once patients become well informed, however, they frequently change their decisions:

- Once patients are informed about the risks of sexual dysfunction after surgery for benign prostate disease, 40% fewer prefer surgery⁷
- A British randomised trial showed a relative reduction in the rate of surgery to treat abnormal menstrual bleeding of more than 20% (absolute reduction from 48% to 38%) when women were informed with a decision aid and interviewed to clarify their treatment preferences⁸
- A randomised trial of a decision aid for coronary heart disease in Toronto showed a relative reduction in preference for surgical treatment of more than 20% (an absolute reduction from 75% to 58%) for patients with stable angina⁹

Geographical variations in care

- The Dartmouth Atlas of Health Care (US data)¹⁰ and the NHS Atlas of Variation (UK data)¹¹ show differences so dramatic that they are typically reported as multiples not percentages. For example, Medicare recipients in Miami consume roughly three times as much healthcare per capita as Medicare recipients in Minneapolis.¹⁰
- In the UK, per capita expenditures for care of patients with cancer or musculoskeletal, circulatory, or respiratory problems vary twofold to threefold among NHS primary care trusts.
- The provision of percutaneous coronary intervention (PCI) to patients with stable angina varied nearly 10-fold across 152 primary care trusts in England in 2010, from just more than 10 to just fewer than 100 per 100 000 people a year.¹¹

Analysis shows that uncertainty about what patients want is one of only two major contributors to these variations, the other being scientific uncertainty about what treatments do. When doctors face either type of uncertainty, the local availability of resources seems to have tremendous influence on treatment decisions.

Box 2: Data sets for provisional diagnosis of preference

Aggregate priorities—Although patients may not always be able to express which treatment they prefer, almost all can express their priorities (which could also be called outcome preferences). Data sets can be compiled that report such facts as “only 7% of breast cancer patients rate keeping their breast as a top priority.” Critically, such data must be gathered from patients who are actually sick. Hypothetical preference data would be of dubious value

Treatment choices—The treatment choices made by patients who are particularly well informed, such as those doctors make for themselves, could be aggregated and reported

High level priorities—Patients have priorities related to health issues even when not confronted with a specific medical choice. For example, some may be particularly averse to experimental treatments. Others may be unusually concerned about how their body looks. Such desires and fears could be recorded in their medical records, with recognition that a major event such as the diagnosis of a serious illness would be likely to alter a patient's priorities

Decision talk

Patients will often say to their doctors, “You’re the expert. What should I do?” If doctors are confident in their preference diagnosis, they should confirm their understanding of the patient’s priorities for different health outcomes and then offer a recommendation. Otherwise, they can say something like, “It’s a tough decision, and I am not ready to make a recommendation. I’d like to learn more about what is important to you.”

Other patients will be able to make a confident choice on their own. When a well informed patient announces a treatment decision that is consistent with their stated priorities, there is no need for doctors to make a preference diagnosis. The patient has self diagnosed. However, sometimes the decision may seem inconsistent with the patient’s stated priorities, in which case doctors should point out the inconsistency and encourage further deliberation.

Because doctors are the healthcare providers most responsible for treatment decisions, we have focused on their role. However, other health professionals often have more in-depth conversations with patients, and their insights can be important in diagnosing preferences.

Preference diagnosis is also important in chronic conditions such as diabetes or asthma. In this situation, decision making and patient preferences are more dynamic and evolve over time as therapies are tried and the patient’s health and priorities change. Crucially, some studies have shown that patients who are engaged in decision making are more motivated and that their clinical outcomes are better.¹⁷

From patients to policy

Policy makers can make two important contributions to stopping the silent misdiagnosis. Firstly, resources should be allocated to compiling the data (box 2) that doctors need to make provisional preference diagnoses—for example, by recording, at scale and in aggregate, how patient preferences change as they become better informed about treatment options and their related outcomes. Secondly, estimates of the incidence of preference misdiagnoses could be developed, by furthering the ongoing research into measures of decision quality. Ideally, doctors who make preference errors would get rapid feedback. Policy makers in the UK have already made strong commitments to making care more preference sensitive. Indeed, shared decision making leads the policy agenda.¹⁸

Box 3: Team, option, and decision talk—the gist of shared decision making*Team talk*

- Inform the patient that choice exists—that there are multiple reasonable treatment options and that the right choice depends on the patient's priorities
- Convey that, while the doctor is the medical expert, only the patient can be the expert on the patient's fears and desires
- Invite the patient to form a team with the doctor to explore the treatment options and what matters most to the patient

Option talk

- List the treatment options and then discuss the risks, benefits, and side effects of each. When feasible, include a non-treatment option such as watchful waiting or active surveillance
- Observe how the patient reacts
- Continue to engage in option talk for as long as the patient wishes to learn more about options or the doctor wishes to learn more about what is important to the patient

Decision talk

- Inquire: "Do you feel ready to make a decision or receive a recommendation?" (If not, propose additional option talk)
- If a well informed patient announces a sensible treatment choice that seems consistent with the patient's stated priorities, offer enthusiastic support. (Otherwise, propose additional option talk)
- If the patient asks for a recommendation, confirm that you understand what matters most to the patient, offer a recommendation, and ask the patient if the recommendation feels right

Better diagnosis of patients' preferences may reduce the cost of healthcare

Better diagnosis of patients' preferences would repair a fundamental flaw in market based health systems around the world, including the UK's managed internal market and the wide open US market. For either market to work effectively, there must be an accurate signal of demand. But every preference diagnosis error is also an error in the demand signal. These errors subsequently lead to inaccurate assessments of wants and needs. Decisions on investment or disinvestment cannot be solely based on historical demand, because these figures are distorted by widespread preference misdiagnoses and do not reflect the demands of well informed patients.

Evidence from trials shows that engaged patients consume less healthcare.¹⁶⁻¹⁹ More work is needed to understand the magnitude of this potential benefit, but it is tantalising to consider that budget challenged health systems around the world could simultaneously give patients what they want and cut costs.²⁰

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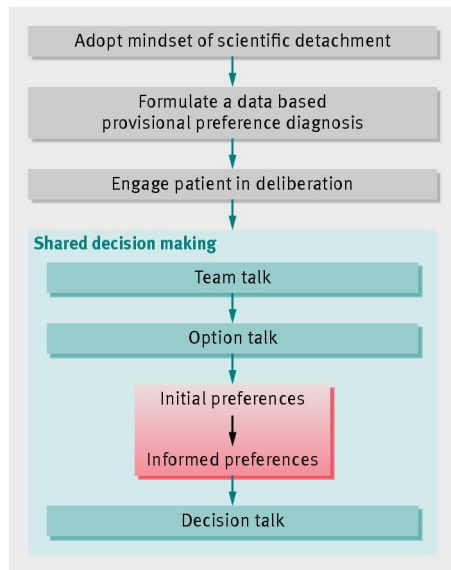
Key messages

The ideal of a well informed patient making a confident medical decision is worth striving for, but it is a difficult aspiration to achieve in daily practice, especially for patients who are seriously ill, worried, or vulnerable

When a patient asks for a recommendation, doctors ought to give one that is grounded not just in a medical diagnosis but also a preference diagnosis—an inference of what the patient would choose were they sufficiently confident and well informed to decide on their own

Doctors can gather information relevant to a preference diagnosis through patient interaction—by presenting the risks, benefits, and side effects of each possible course of action and observing how patients react

Figure



Steps for diagnosing preference ³