

# How do patients' treatment preferences compare with those of clinicians?

A A Montgomery, T Fahey

## Abstract

**The shared model of medical decision making has been proposed as the preferred method of determining patients' treatment. However, agreement may be more difficult to achieve if patients' and clinicians' preferences are polarised. The aim of this paper is to explore how closely patients and clinicians agree in their preferences for different treatment options. Only studies that made quantifiable estimates of preferences were included. There is some evidence that patients and health professionals often do not agree on treatment preference in the areas of cardiovascular disease, cancer, obstetrics and gynaecology, and acute respiratory illness. However, the magnitude and direction of these differences vary and may depend on the condition of interest. Most of the research to date is cross sectional; longitudinal research is required to investigate whether preferences change over time and are related to treatment choice, adherence to medication if taken, and health outcomes.**

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The shared model of clinical decision making is advocated as the preferred approach of determining patients' treatment. Definitions of shared decision making, the processes involved, and how it can be achieved in everyday clinical practice have been published in several recent papers.<sup>1–3</sup> In this model the decision making process is broken down into different analytical stages, although in practice these may occur together. Firstly, there is a two way exchange between doctor and patient of any medical and personal information that may be relevant for decision making. A period of deliberation for both doctor and patient, potentially with others, then follows. Finally, both should declare their treatment preference and there should be agreement on the appropriate treatment to be implemented.<sup>1</sup> The goal of shared decision making is clear—namely, consensus on which treatment to implement. However, patients and clinicians must go through several stages before achieving this end result, and agreement may be more difficult to achieve if patients' and doctors' initial preferences are polarised. The purpose of this paper is to explore agreement between patients and clinicians in their treatment preferences.

## Key messages

- Differences in treatment preferences between patients and health professionals exist in cardiovascular disease, cancer, obstetrics and gynaecology, and acute respiratory illness.
- The magnitude and direction of these differences are not consistent according to clinical condition of interest.
- Prospective research is required to investigate whether preferences change over time and are related to treatment choice and health outcomes.

The methodology employed to compare patient and clinician treatment preferences varies. We have structured the paper according to study type, using the following hierarchy:

- (1) Direct comparison of patient and clinician treatment preferences using the same method of preference elicitation and, if possible, using the patients' own clinician.
- (2) Comparison of patient preferences with consensus and/or evidence based guidelines.
- (3) Comparison of patients and clinicians using different methods of preference elicitation.
- (4) Single group studies: these have only been included if the evidence base for treatment options is equivocal and individual preferences are likely to play a large part in determining treatment.

Within each level of this hierarchy we have further identified: (a) studies of patients suffering from the relevant condition and stating a preference for a real treatment choice; (b) studies of patients suffering from the relevant condition making a hypothetical choice; and (c) studies of members of the general public making a hypothetical choice.

Preferences in all these types of studies have been measured using a variety of methods. Participants have simply been asked to state the option they would choose; thresholds for treatment have been assessed using a "minimum important clinical difference"; strength of preference for various options has been assessed using Likert scales; and utilities have been measured using rating scale, time trade off, and standard gamble methodologies.

This paper is not intended to be an exhaustive overview of the literature on patient and physician preferences. Instead, we have provided examples from cardiovascular disease, cancer, obstetrics and gynaecology, and acute minor respiratory illness. These are clinical areas where individual preferences can play a

Division of Primary Health Care, University of Bristol, Bristol BS8 2PR, UK  
A A Montgomery, MRC health services research training fellow  
T Fahey, senior lecturer

Correspondence to:  
Dr A Montgomery  
alan.a.montgomery@bristol.ac.uk

large part in determining treatment and, as much of the published evidence is in these areas, they should serve to illustrate the research base to date. We searched Medline (1966–2001) and Embase (1950–2001) for papers using the MeSH terms “attitude of health personnel”, “physician attitude”, “nurse attitude”, “patient attitude”, “decision making”, “patient acceptance of health care”, and “patient participation”. Only primary studies that made quantifiable estimates of preferences were included; discussion papers were not included.

#### **Direct comparisons of patients’ and clinicians’ treatment preferences**

We found only one study that directly compared preferences of patients and health professionals facing a real clinical decision.<sup>4</sup> Increasing emphasis on patient choice in obstetrics in the UK prompted this study of caesarean section rate between doctors and non-medical women. Of 1212 low risk pregnant women participating in a study of fetal growth, 52 were medical doctors. Each doctor was matched with the next non-medical woman recruited to the study for age, parity, smoking status, and socioeconomic group. Of the doctors, 16 (31%) had a caesarean section, of which 10 were elective compared with a total of 14 (27%) in non-medical women, of which seven were elective. This study is particularly interesting in that it investigated clinicians’ decisions regarding their own health care rather than what they would choose for their patients. However, the sample size in this study was small and, although there was a possible trend towards an increased rate of elective caesarean section among doctors, the difference was not statistically significant.

More commonly, studies have compared patients or the general public with clinicians in their preferences for hypothetical treatment choices. Cardiovascular conditions provide an interesting setting to study differences in patients’ and clinicians’ treatment preferences. Absolute risks of cardiovascular events in patients with, for example, hypertension, hypercholesterolaemia, atrial fibrillation, and chronic stable angina can be quantified. This risk information, together with expected benefits and side effects of treatment, can be used in the decision making process. However, this information may also be a source of difficulty in agreeing treatment decisions. “Acceptable” levels of risks and benefit vary between individuals and, according to the shared decision making model, such preferences should be taken into account when considering treatment options.

Hypertension treatment guidelines from different countries specify different risk thresholds for treatment without explicitly stating how these thresholds were chosen. A Canadian study sought to determine the treatment thresholds of a random sample of family physicians (94 invited, 77% participated) and a consecutive sample of patients with mild essential hypertension attending their physician over a 3 month period (146 invited, 51% participated).<sup>5</sup>

It is not reported whether these were newly diagnosed or treated hypertensive patients. Treatment thresholds for six hypothetical scenarios were determined by eliciting the minimum reduction in cardiovascular risk that would outweigh the inconvenience, costs, and side effects of antihypertensive therapy (the minimum clinically important difference (MCID)). Data were collected using face to face and telephone interviews for patients and physicians, respectively. The study found that patients were significantly less likely to want antihypertensive treatment than physicians, particularly when the baseline risk was low: 49% *v* 64%, 68% *v* 92%, and 86% *v* 100% for 5 year cardiovascular risks of 2%, 5%, and 10%, respectively. Patients also expressed greater MCIDs—that is, they wanted greater benefits before accepting treatment.

A similar study has been conducted in the UK in adult members of the public selected from health authority lists rather than in hypertensive patients.<sup>6</sup> A total of 100 members of the public and 39 each of consultant physicians, general practitioners, and practice nurses were invited to participate in the study. A postal questionnaire was sent to each individual asking whether or not they would take blood pressure lowering drugs if one life would be saved for every 12, 33, 50, 100, or 250 people treated for 5 years (number needed to treat (NNT)). A higher NNT indicates a greater willingness to accept treatment. The overall response rate was 69%, ranging from 58% of members of the public to 82% of practice nurses. The threshold NNT for consultant physicians (100) was twice that for general practitioners (50) and three times that for practice nurses and the public (33). The treatment threshold recommended by the British Hypertension Society is an absolute cardiovascular risk of 10% over 5 years.<sup>7</sup> Assuming a relative risk reduction of 30% with treatment,<sup>8</sup> this corresponds to a 5 year NNT of 33, the same as that chosen by practice nurses and members of the general public. Although this study posed a hypothetical question about an individual’s own threshold for drug treatment, the willingness of doctors to accept treatment at lower absolute risk levels than lay people could lead to conflict when attempting to reach joint decisions on initiating antihypertensive therapy.

Attitudes towards chemotherapy among cancer patients have been examined in a questionnaire study of two hypothetical treatments.<sup>9</sup> One scenario presented a typical intensive chemotherapy regimen with associated side effects, the other a much milder treatment regimen. Participants were asked to rate the level of benefit in terms of chance of cure, prolongation of life, and relief of symptoms that would make the treatment worthwhile. Consecutive patients (n=100) about to receive chemotherapy participated in the study. It was made clear to participants by a research nurse that the scenarios were hypothetical and would not have a bearing on actual treatment decision or outcomes. Controls (n=100) matched for age,

sex, ethnic origin, and occupation were obtained from the community. Radiotherapists (n=88), medical oncologists (n=60), cancer nurses (n=303), and general practitioners (n=790) also participated. Patients were willing to accept intensive treatment with severe side effects for a much smaller chance of benefit in terms of cure compared with all other groups (1% chance of cure *v* 10–50%), prolonging life (12 months *v* 12–60 months), and symptom relief (10% chance of relief of symptoms *v* 50–70%). When asked whether they would accept intensive and mild treatments for a minimum chance of benefit (1% chance of cure or symptom relief and 3 month prolongation of life), patients were most likely (43–67%) and radiotherapists least likely (0–27%) to find treatment acceptable. Studying cancer patients about to receive chemotherapy but framing the treatments and benefits as hypothetical makes interpretation of these findings more difficult. Patients may be likely to say that they would accept any treatment that offers some possible benefit and hope, however small. Nevertheless, this study illustrates that it cannot be assumed that clinicians are in a position to advise patients about treatment options based on what they would theoretically accept for themselves.

Boyd and colleagues investigated utilities for colostomy in patients with rectal cancer, all of whom had already undergone treatment.<sup>10</sup> Patients with colostomy (n=40) and patients treated by radiotherapy without colostomy (n=11) were compared with surgeons and oncologists (n=40), and healthy student (n=30) and elderly (n=29) volunteers. Utilities for a scenario describing aspects of life with a colostomy were measured using the standard gamble, rating scale, and a treatment choice questionnaire. Regardless of the method used to assess utility, the highest mean values were given by patients who had already undergone colostomy (0.92 using standard gamble), and the lowest by patients treated solely with radiotherapy (0.80). The mean utility for physicians (0.91) was almost as high as that for patients with colostomy. Differences between the groups remained after controlling for age and sex. When used in a decision analysis, the differences in observed utility values had a major effect on the selection of treatment. Similar to other examples already given, this study highlights a disparity between physicians, patients, and the general public who probably have less knowledge of the health state in question. The finding that physicians and patients who are actually in the health state agree quite closely in their rating is interesting. The authors suggest that, although both patients with colostomies and physicians agreed that the description in the scenario was accurate, their closer knowledge of the health state may have caused them to assign higher utilities than the other groups. This could have implications for the way that information about treatments and likely subsequent outcomes is presented to patients.

### Comparisons of patients' preferences with consensus or evidence based guidelines

In a study of 97 patients with atrial fibrillation we found substantial discrepancies between published recommendations for warfarin therapy and the outcome of individual patient based decision analysis.<sup>11</sup> Decision analysis takes account of patient preferences by combining the probability of events with utilities assigned by the patient. Utilities for health states resulting from having atrial fibrillation and its treatment were assessed using the time trade off method. The outcome of the decision analysis was compared with treatment guidelines based on age and co-morbidity. Of 38 participants whose decision analysis indicated a preference for non-treatment with warfarin, 87% and 58% would have been treated according to age based and absolute risk based guidelines, respectively. Of 59 participants whose decision analysis indicated a preference for treatment, 5% and 19% would not have been treated according to the respective guidelines. Most of the discrepancies were “false positives”—that is, patients who would prefer not to be treated with warfarin but who would be recommended for treatment according to published guidelines. We are not suggesting that all patients would follow the treatment option recommended by decision analysis, rather that explicitly incorporating patient preferences into the decision making process may result in discordance with expert opinion about who should be treated.

### Comparisons of patients' and clinicians' preferences using different elicitation methods

It is now recognised that, for most acute respiratory illnesses, treatment with antibiotics is likely to be of only marginal benefit to individual patients, yet prescribing rates remain high.<sup>12</sup> This may be due in part to patient expectation or doctors' perception of patient expectation. We found two studies that compared patients' views and expectations of antibiotics with their general practitioners' prescribing behaviour. In these studies we have used prescribing as a proxy measure of doctor “preferences” although we acknowledge the limitations of this assumption.

A UK survey was carried out of previously well adults who completed a questionnaire at home after a consultation for acute lower respiratory tract illness.<sup>13</sup> Of 1014 eligible patients, questionnaires were returned by 787. General practitioners completed a data form during the consultation that included their certainty as to whether antibiotics were indicated and details of non-clinical factors influencing their decision. Most patients (87%) felt that antibiotics would help their symptoms and had both wanted (72%) and expected (72%) such a prescription. Of the 581 patients prescribed an antibiotic, GPs thought they were definitely indicated in 20%, probably indicated in 58%, probably not indicated in 21%, and definitely not indicated in 1%. GPs reported that patient expectation or “pressure” (further explanations

of these terms are not given in the paper) most commonly influenced the decision to prescribe even when they thought that antibiotics were not indicated. Patients who did not receive an antibiotic when they wanted one were more likely to express dissatisfaction and consult again with the same symptoms.

Similar results have been reported from the USA in patients consulting their family physician with respiratory infection.<sup>14</sup> Unlike the UK study, patients were not directly asked if they wanted an antibiotic but instead they were asked whether they thought that antibiotics were appropriate for treating their problem. Like the UK study, physician “preferences” are inferred from prescribing behaviour. Of 113 patients, 65% felt that antibiotics were appropriate for them and 63% were given an antibiotic prescription. Unfortunately the published data do not allow calculation of the cross-tabulation of patient expectation and actual prescribing. Physicians were able to accurately perceive patients’ expectations for antibiotic prescription in 50% of patients, and prescribing was related to what the physician thought the patient wanted. Patient satisfaction was not related to receiving a prescription, but was related to patients reporting that they understood the illness and that the physician had spent enough time with them.

#### Single group studies

Utilities for chronic stable angina were measured in a US study of 220 patients referred by cardiologists.<sup>15</sup> Patients with similar functional limitation according to a clinical scoring system were found to vary considerably in their tolerance of their symptoms. For example, there was a 33% chance that a patient with class II angina had a lower utility—that is, was more bothered by their symptoms—than a patient with clinically more severe angina (class III or IV). This study does not directly compare patients’ and clinicians’ preferences. However, the findings suggest that functional limitation as defined by a clinical scoring system devised by experts is not an adequate surrogate for patients’ own utilities. Furthermore, if treatment decisions are made by clinicians on the basis of such a scoring system, there is potential for substantial disagreement with patients’ own desires for various treatments.

#### Discussion

It seems from this summary of evidence that patients, the general public, and health professionals often have different preferences for treatment. The direction and magnitude of these differences do not appear to be consistent and may vary with the clinical condition of interest. For example, in cardiovascular conditions studies that compare patient preferences with both physician preferences and published guidelines suggest that patients are more averse to drug treatment than health professionals. However, two studies of acute respiratory illness indicate that patients request antibiotics for reasons that health professionals view as inappropriate.

These studies also highlight several limitations of the research conducted in this area to date. Most of the studies asked participants to state preferences about hypothetical treatment choices rather than real decisions that they face at the time. In addition, it seems that studies of treatment preferences appear to be almost exclusively cross sectional. Both these criticisms could be addressed by conducting prospective studies which would allow researchers to obtain preferences from patients before and after receiving information about the risks and benefits of various courses of action but before any treatment decision is actually made. Prospective designs would allow investigation of whether patients’ and health professionals’ preferences change over time, or are related to actual choice of treatment, compliance with treatment regimens where appropriate, and subsequent health outcomes. The studies included here comprised a wide range of sample sizes and only one<sup>6</sup> contained a sample size calculation. If studies aim to compare statistically quantifiable estimates of preference, they must be adequately powered to do so. The methods that researchers use to assess preferences vary from self-complete questionnaires<sup>14</sup> to formal utility assessment using computers.<sup>15</sup> Other methods are discussed elsewhere in this supplement.<sup>16, 17</sup> Researchers may need to devise an assessment instrument that is appropriate for their study, but piloting and testing are required to ensure its validity and reliability, and these should also be reported. Finally, though not necessarily a limitation, researchers should recognise that preferences may vary depending on the context in which they are sought. Patients with a given clinical condition stating preferences for real choices that they face at the time may give different responses from either patients or the general public stating preferences for hypothetical treatment choices.

Health professionals and patients ought to be aware that differences in treatment preferences will inevitably exist and recognition of this is an important first step to consensus of appropriate treatment choice. It has been recommended that guidelines explicitly acknowledge that patient preferences should be sought and that they may have a substantial influence on treatment recommendations.<sup>18</sup> An example is the guidelines of the Royal College of Obstetrics and Gynaecologists for the management of menorrhagia<sup>19</sup> which recommend that women’s preferences for watchful waiting, medical treatment, or surgery should be taken into account when deciding on appropriate treatment.

It should be noted that the extent of patient participation in decision making will depend on both their individual preferences for being involved and the clinical decision they face. Studies in patients with breast cancer<sup>20</sup> or undergoing joint replacement<sup>21</sup> found a desire for clinicians to have the dominant role in decision making and this topic is discussed in fuller detail elsewhere in this supplement.<sup>22</sup> However, the patient should be given the opportunity to participate if he/she chooses to.

Different treatment preferences exist between patients and health professionals in a range of clinical conditions. Research is needed to describe how final treatment decisions are currently reached when patients' and clinicians' preferences are not the same. Further research is also needed to find the optimum quantity, type, and format of information given to patients regarding benefits and risks of various treatment options. This may allow patients to state preferences from a more informed perspective and may facilitate shared decision making in real practice.

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