

Shared decision-making in primary care: the neglected second half of the consultation

GLYN ELWYN

ADRIAN EDWARDS

PAUL KINNERSLEY

SUMMARY

The second half of the consultation is where decisions are made and future management agreed. We argue that this part of the clinical interaction has been 'neglected' during a time when communication skill development has been focused on uncovering and matching agendas. There are many factors, such as the increasing access to information and the emphasis on patient autonomy, which have led to the need to give more attention to both the skills and the information required to appropriately involve patients in the decision-making process. This analysis, based on a literature review, considers the concept of 'shared decision-making' and asks whether this approach is practical in the primary care setting. This study, and our ongoing research programme, indicates that future developments in this area depend on increasing the time available within consultations, require improved ways of communicating risk to patients, and an acquisition of new communication skills.

Keywords: patient involvement in decision-making; shared decision-making; risk communication; patient-centred communication.

Introduction

THE doctor-patient relationship is changing rapidly towards a more active partnership, fostered by the increasing access to information about treatments and the consumerist trends in modern society. This shift towards involvement is also evident in policy statements. 'Collaboration' and 'partnership' are the key political words of the late 1990s. But it was earlier, as if to counter-balance the 'internal market' reforms, that the policy of involving patients in their healthcare decisions (both at individual and community levels) was published. In 1991, *The Patients' Charter*¹ included the statement that 'you (the patient) have a right to have any proposed treatment, including any risks involved in that treatment and any alternatives, clearly explained to you before you decide whether to agree to it'. In 1996, *Patient Partnership: Building a Collaborative Strategy*² emphasized the intention to 'promote user involvement in their own care, as active partners with professionals'.

While it may be necessary to change the way the second half of the consultation is conducted in order to achieve these goals, how to do this within primary care encounters is less clear. The aims of this paper, which is based on a literature review,³ are to describe the difficulties posed by the ways that general practi-

tioners (GPs) currently discuss treatments with their patients, and to propose alternative methods by which they could share information and achieve shared decision-making. We have not attempted to consider patient involvement in decision-making at the macro level of policy-making and prioritizing resources.

The second half of the consultation

Byrne and Long⁴ analysed over 2000 consultations and identified a general structure that consisted of six phases:

1. Establish relationship
2. Determine reason for attendance
3. Conduct a verbal/physical examination (solve problem)
4. Consider the condition
5. Detail further management
6. Terminate consultation.

Phases one to three cover the first half of the consultation up to the point when the clinician considers that he or she has reached a full understanding of the patient's problem. Much emphasis has been placed on the importance of this task,⁵ and if it is not achieved it is unlikely that the consultation will have beneficial outcomes. However, our focus with regard to information sharing and shared decision-making is on phases four and five of the consultation.

Byrne and Long reported that a discussion of the patient's condition occurred in less than 25% of consultations, and patients have been found to be dissatisfied with the explanations of their condition and the information they receive.⁶ Our own research⁷ confirms the findings of others^{4,8,9} that, in many consultations, there is little meaningful dialogue between GPs and patients about the nature of the problem and the possible therapeutic actions.¹⁰

We believe that skills necessary to enhance this 'second half of the consultation' have been neglected to date and, thus, involvement and empowerment are at present distant fantasies. We will now describe conceptually and practically how these goals might be achieved, starting from a discussion of the different models of decision-making in a medical context.

Models of decision-making in a medical context

Models of clinical decision-making in the consultation can be represented as a spectrum from a paternalistic model at one end, to the informed choice model at the other end.^{4,11} In between these is the model of shared decision-making (Figure 1).

The paternalistic model is supported by Parsons'¹² conceptualization of the sick role. Specifically, this obliges the patient to seek 'expert' help and comply with the medical regimen. It is a consulting style where the physician does what is thought best for the patient without necessarily eliciting the latter's preferences. Byrne and Long⁴ found this style of consultation to be used most frequently. By keeping the patient as passive recipient of the doctor's 'expert' advice, it clearly has the superficial attraction of maintaining the professional's status.

It is possible to argue that the logical opposite to the 'paternalistic' model is consumerism, where patients (well informed or otherwise) have predetermined views about preferred options.

G J Elwyn, senior lecturer, BA, MRCP, Department of Postgraduate Education for General Practice and Department of General Practice, University of Wales College of Medicine. A Edwards, lecturer, MRCP, and P Kinnersley, senior lecturer, MRCP, Department of General Practice, University of Wales College of Medicine.
Submitted: 13 July 1998; final acceptance: 14 December 1998.

© British Journal of General Practice, 1999, 49, 477-482.

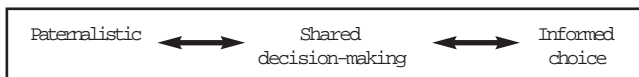


Figure 1. Spectrum of patient clinician interaction.

One extreme form is the patient who discharges him or herself from care, despite advice to the contrary. However, the 'informed choice' decision-making model is usually placed at the opposite end of the spectrum and describes a process whereby patients receive information from their physicians about treatment choices, which they are then left to make. The information imbalance between patient and doctor is recognized — 'technical knowledge resides in one party (the physician) while preferences reside in the other (the patient)'¹¹ — and a concerted effort is made to fully inform the patient about the choices available. The patient now has both the information required and the personal preferences necessary for decision-making. Indeed, the physician may feel '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'.¹³ There is concern that the 'informed choice' model, where control over decision-making is vested entirely with the patient, may lead to increased anxiety and, if taken to its extreme form, may lead to patients feeling that they have been abandoned.¹⁴ An illustration is the dilemma many feel when a clinician fully explains the risks and benefits of antenatal screening for Down's syndrome, but steadfastly declines to guide the decision.

Sharing information and sharing decisions are not synonymous;¹⁵ they are separate goals within the consultation and require different skills. While it is possible for the sharing of information to occur alone (after which either the patient or the doctor makes the decision), shared decision-making cannot occur unless preceded by the sharing of information. It also requires specific attention to be paid to how decisions are made in the consultation and the reaching of agreement over the treatment decision. It may even be the case that the agreement will be that one or other of the participants will make the decisions alone. Charles¹¹ points out that none of the models explicitly describe 'a process in which both physicians and patients share in decision-making, no matter how much information they share'.

It may well be that different types of health problems need different decision-making models, and this requires further exploration. But if we were to share decision-making with patients, what would be the characteristics of the process? In summary, the characteristics are reported as follows:¹¹

- Shared decision-making involves at least two participants — the doctor and the patient — and often many more (their respective networks of family or professional colleagues).
- Both parties (doctors and patients) take steps to participate in the process of treatment decision-making.
- Information sharing is a prerequisite to shared decision-making.
- A treatment decision (which may be to do nothing) is made, and both parties agree to the decision.

Contained within each step are areas that can be expanded and discussed. For the purpose of this paper, the information sharing stage, which, if it contains probabilistic data, is often known as 'risk communication', requires an 'open two-way exchange of information and opinion' (i.e. preferences) about risk¹⁶ so that management decisions can be based on a better understanding of the options and outcomes. This process cannot, by definition, occur within a doctor-centred consultation, and the process of shared decision-making is integral to the wider concept of patient-centred consulting.¹⁷

Why should we share decisions?

'Sharing decisions' may be a desirable end in itself on humanistic grounds.¹⁸ In addition, there is a growing body of evidence confirming the problems that occur owing to poor communication between doctors and patients and that contribute to non-adherence with therapy, advice, or other management plans.¹⁹ Because 'shared decision-making' has previously been loosely and poorly defined, there is no specific evidence to support shared decision-making in practice. However, the benefits of effective communication on patient satisfaction have been clearly identified.⁹ Studies of 'participatory consulting styles' and 'patient-centred consulting styles' have provided confirmation of benefit.⁷ Stewart²⁰ reports that where patients 'perceive' that they have achieved 'common ground' with physicians, there are fewer demands on laboratory and referral services. Her review²¹ concluded that four key dimensions of communication were related to positive outcomes:

- the provision of clear information,
- questions from the patient,
- willingness to share (discuss) decisions, and
- agreement between patient and doctor about the problem and the plan

It has also been found that if people take an active part in making decisions about their care, they have better health outcomes, as exemplified in the achievement of improved diabetic control in studies by Greenfield and Kaplan.²²⁻²⁴ Recent work also reveals the complexity that underlies these apparent relationships between patient involvement and improved health outcomes. Street²⁵ found that the patient's perception of decision control is a key issue with both stable and dynamic characteristics, depending on the patient personality, their involvement within the consultation, and the eventual health outcome. Huygen *et al*.²⁶ showed that certain types of consulting styles could improve the health of patients across a practice list. Work confirming this is beginning to be published from the secondary care sector, illustrating the benefits on patient satisfaction and long-term outcomes of 'participatory physician' styles.²⁷ There will also be times when patient preferences will be in direct conflict with clinical guidelines: the wish to receive antibiotics for viral illnesses is a classic example that can threaten both the doctor-patient relationship²⁸ and health outcomes.²⁹ Shared decision-making will need to accommodate many such modifiers.

'Effect modifiers'

Despite this and the breadth of evidence accumulating about the benefits of 'effective' communication on patient satisfaction^{9,21} and on patient adherence to treatment,^{19,30} there are some discordant notes from other studies.³¹ These give an indication of the important 'effect modifiers' on benefit from patient involvement in their management — it is not always the most appropriate model for a consultation, depending on patient characteristics or the context of the consultation.

Savage and Armstrong³² randomized 359 patients to receive 'directive' and 'sharing' consulting styles, verified by assessing a subsample of 40 recordings. The 'directing' style had a better effect on satisfaction levels but only in those with self-limiting illness or chronic conditions, echoing similar work by Thomas.³³ These results appear to indicate that if the 'sharing strategies' are followed mechanically or ritualistically then they are insensitive to the situational context and will not produce improved health outcomes.

Other patient characteristics that are likely to be effect modifiers are lower educational status, severity of illness, and advanc-

An elderly lady (aged 82) has been suffering from right upper quadrant pain for some two years and eventually consults her family doctor. He refers her to a surgeon who, with the aid of ultrasound findings, confirms a diagnosis of cholecystitis. The surgeon then suggests that cholecystectomy is an option, and that he would be happy to do this if the patient is agreeable. This situation of contributing to the treatment decision is completely novel to this lady — she has been used to being told 'what treatment she should have' — and she now feels highly uncertain and anxious. She chooses to discuss the situation with her family doctor again who has more of an understanding about her expectations for involvement in decision-making, and is more positive about opting for cholecystectomy. She then informs the surgeon that she will have surgery.

This scenario illustrates how a long-term context of involvement in decision-making is important, and that it cannot be imposed out-of-the-blue. Once introduced to the concept of involvement in decision making (whether suddenly or in the longer term), patients may still find it hard to participate in the decision-making to the level expected by the physician. (A footnote to this scenario records that the patient's gallbladder histology subsequently returned showing early stage carcinoma, thus showing that if the patient's participation in the decision had been to defer treatment this would have had major consequences. Truly sharing decisions means that doctors must still retain responsibility to advise where necessary, and cannot opt out or 'abandon' the patient simply to an 'informed choice' without expecting negative consequences.)

Box 1. Case history.

ing age (Box 1). But no one variable, illness condition or sociodemographic, could be regarded as predictive.³⁴ It is also important that the imperative to 'share decisions' must not come out of the blue — if it is unexpected then it may cause anxiety rather than alleviate it, and fail to achieve the desired improvements in health outcomes.

Do patients want to share decisions?

Most of the work evaluating patient preferences for participation has been done in North America, and has been critically analysed by Deber^{35,36} and reviewed more recently by Guadagnoli.¹⁸ It is not known whether these findings can be applied directly to other patients with different medical problems and contexts. Much of the research is based on surveys using different instruments, thus making comparisons difficult. It would appear that patients' desire for information is stronger than their desire to be involved in decision-making.^{34,37-39} However, research carried out using hypothetical questions or scenarios may not truly reflect patients' views when they are actually taking part in a consultation. The link between 'patient preferences for participation' and actual participation is not that strong.¹¹ For example, a majority of healthy subjects stated that they would want to select their own treatment if they were to have cancer; however, only a minority of patients with cancer shared this view.⁴⁰ Again it should be questioned whether such findings can be transferred to primary care where patients are most often likely to be involved in smaller decisions about less serious problems.

Although patients may dislike the 'doctor uncertainty' that may be conveyed by shared decision-making,⁴¹ doctors tend to underestimate both how much information patients wish to receive and the level of involvement they prefer to have in decision-making.⁴² GPs are often unaware of patients' views on treatment,¹⁰ and may also lack the skills to elicit patients' preferred choices. Recent work has showed that prescribing decisions about antibiotics are guided by GPs' perceptions of patient expectations rather than actual expectations.⁴³

Although many doctors now subscribe to the view that patient preferences should be considered when treatment decisions are

taken, the ability to elicit preferred choices is often lacking. A study⁴⁴ that followed up 425 women who consulted their GP with menorrhagia found that half the doctors were unaware of their patients' views. Other work in different settings^{10,39,45} has demonstrated that patients, perhaps because they feel their doctors are not interested, rarely make demands for information or for increased involvement. This tendency can be modified, and previous work demonstrates that patients can be 'trained' to increase their participation,⁴⁶ although this approach is unlikely to be practical on a widespread basis.

Assumptions and generalizations clearly cannot be made, and the literature points to the need to ascertain involvement preferences within consultations and for the need to develop ways of accurately assessing preferred levels of participation. Methods to categorize the role patients wish to take in decision-making have also been developed, and can be used in research to indicate which option patients favour.⁴⁷

The fact that the majority of patients indicate a desire for more information about their illness and potential treatment options, but a much smaller number express preferences to participate in treatment decisions, gives rise to interesting speculations such as, how are preferences affected by situational factors or learnt behaviours? Recent developments in psychology indicate the existence in screening programmes of 'blunters' (avoidance behaviour) or 'monitors' (attenders), and points to the effect that personality has on levels of involvement.⁴⁸ The 'preference' studies consistently show that sociodemographic variables are not useful in predicting who wants more or less active roles in medical decision-making, and there is a concern that hypothetical studies (the majority) do not accurately reflect 'actual' views. The principles of 'patient involvement' however, should not override preferences for participation assessed within the consultation. Doctors largely determine the communication styles: patients do not insist on shared decision-making, however open they are about their preferences. Perhaps it is also illogical to ask about a patient's preferred role in decision-making until they have realised the possible harms and benefits of the choices they face, and the associated probabilities. Then, and only then, can it be legitimate to ask an individual whether or not they wish to take an active part in deciding what is best for them. The effects of well-defined and skillfully implemented shared decision-making processes in real clinical contexts clearly require assessment.

Ethical and medicolegal perspectives

These variations between patients also raise ethical and medicolegal issues. The law, as far as it concerns the doctor-patient relationship, has been static in the United Kingdom for a number of years,⁴⁹ but there is increasing pressure on doctors to address the issue of 'informed consent'.⁵⁰ In the United States, consumer and patients' rights have been, and are still, evolving to change the way in which patients and health care professional arrive at decisions. Many would argue that the move towards adopting the 'informed choice' model is a direct consequence of doctors consulting defensively.

The ethical position itself is not clear-cut because the principle of autonomy is not necessarily beneficial⁵¹ and may conflict with the equally valid principle of beneficence. In many ways, the recent developments in palliative care communication made explicit the duty of the clinician to respect patient choice.⁵² Lupton⁵³ has described the ambivalence patients feel between wanting to behave 'in a consumerist manner' and their equally strong desire 'at other times to take on the passive role' and invest their trust in professionals. Shared decision-making offers a balance to these opposing positions by actively involving

patients in decision-making but also by requiring the professional to use his or her expertise and experience to guide the patient and make decisions if required. Consequently, shared decision-making would appear to be consistent with the new ethical principle of 'relationality' proposed by Bottorff *et al.*⁵⁴ This principle promotes the provision of accurate honest information in the context of the individual situation, examining the ethics of care in terms of such factors as response, interpretation, accountability, and social solidarity, often counterbalanced against other values such as truth and confidentiality.

What problems prevent shared decision-making in the primary care context?

Studies of consultations^{4,8-10,20} in general practice have consistently revealed that sharing information about the identified problems, identifying treatment options, and sharing the decision about the preferred future management rarely occurs, and there do not seem to have been any significant changes since the mid-1970s.¹⁰ There are many proposed explanations for this, drawn from practitioners themselves⁵⁵ and from social science analysis, such as:

- it takes time,
- it is threatening to the 'power' relationship between doctor and patient,
- continuity of care means that treatment decisions are often coloured by prior experiences of both patient and clinician in that particular setting,
- there is a lack of training/experience/modelling,
- a lack of skill in 'sharing' and 'involving' patients in decision-making,
- a lack of information about risks and benefits,
- a lack of skills and tools to convey information about risks and benefits,⁵⁶ and
- patients are perceived not to like the 'doctor uncertainty' it may convey.⁵⁵

Lack of time may be used as a reason for not giving patients information or involving them in decisions. However, Howie has demonstrated the benefits of providing patients with more time and has developed the concept of 'patient enablement' as an outcome in its own right. He has shown that time spent within consultations appears to be directly related to the quality of care: more time producing greater benefit and increasing the ability of patients to understand and cope with their health problems.^{57,58} Beisecker³⁹ found that the degree to which patients sought information from their doctors depended, among other things, on how long the consultation lasted and whether they were invited to make inquiries. Street⁵⁹ confirms that participation in decision-making is increased when physicians exhibit patient-centred behaviours. Although having enough time within consultations is important for 'shared decision-making', perhaps time should be regarded as necessary but not sufficient.

The lack of time will not be contested, but GPs may not be as ready to admit that a lack of skills in sharing decisions and information are also significant obstacles.^{60,61} Pilot work we have undertaken with GP registrars using simulated patients indicates that these doctors are not familiar with the skills required to 'share decisions', and that patients are equally tentative about the process of involving themselves in decisions. This may occasionally backfire, deterring the doctor from continuing efforts to share decisions.

Our traditional skills enable us to achieve working diagnoses, to suggest treatment strategies, and to plan future management, but we are not usually well equipped to share detailed informa-

tion about the probabilities of the available treatment outcomes. It is very difficult to obtain and present data about risks and benefits to patients in a meaningful non-technical way. Only 10%–30% of clinical decisions are backed up by evidence.⁶² Furthermore, the information that is available is often not in a form that actually assists us.⁶³ Information about diagnoses, drug therapy, and operative interventions are inevitably pooled data, and are therefore difficult to 'particularize'.

The 'average' patient is a rarity.⁴¹ The patient in the consulting room may have heart failure, osteoarthritis, live alone, take warfarin, and be at risk of falling down the stairs. Arriving at a shared decision in this context involves more than obtaining information about the best way to treat heart failure in an elderly man. Developing risk communication tools for a course on shared decision-making⁵⁵ has illustrated how difficult it is to portray the risks and benefits of commonly met problems. Our pilot work indicates that how information is presented (verbal, tabular, graphical versions) has a major influence on the depth of patient involvement in decision-making.⁵⁵ The development of decision aids (leaflets,⁶⁴ videos,⁶⁵ boards,⁶⁶ and web pages⁶⁷) needs to be undertaken in the light of this type of research, and our findings also indicate that communication skills in shared decision-making will need to be developed if professionals are to make appropriate use of these tools.

How might we achieve shared decision-making within consultations?

Shared decision-making clearly rests in the paradigm of patient-centred medicine.¹⁷ Stewart²¹ has described the concept of finding common ground, and it is this component of the consultation that is being considered in detail. The conceptual clarification that has occurred recently^{11,68} allows a set of 'competencies' to be described:⁶⁹ skills that facilitate the shared decision-making process within consultations. Box 2 illustrates the steps that need to be taken in order for patients to share in the decision-making process; it is assumed that the agenda-matching and problem-solving phases of the consultation have been successfully completed, and that patient role preferences are respected.

Pilot work in clinical contexts suggests that this model will need to be modified.^{55,70} We suggest a further competency to be included after the 'transfer of technical information', which concerns checking patient understanding of this information (personal communication: W Rosenberg, 1998). The understanding of apparently simple information still varies enormously between individual patients, and requires careful and sensitive clarification.⁷¹

Steps:

- Establishing a context in which patients' views about treatment options are valued and necessary
- Eliciting patients' preferences so that appropriate treatment options are discussed
- Transferring technical information to the patient on treatment options, risks, and their probable benefits in an unbiased, clear, and simple way
- Physician participation includes helping the patient conceptualize the weighing process of risks versus benefits, and ensuring that their preferences are based on fact and not misconception
- Shared decision-making involves the physician in sharing the treatment recommendation with the patient, and/or affirming the patient's treatment preference.

Box 2. Steps for patients to share in the decision-making process.⁶⁹

Conclusion

Shared decision-making offers a model for the management stage of the consultation, with the underlying aim of achieving an active partnership between patient and doctor. There is no specific evidence for the shared decision-making model, but the patient-centred approach — in which it is embedded — has demonstrated improvements in short-term outcomes (patient understanding and satisfaction), patient adherence, and a reduction in the use of resources (laboratory services and referral).²⁰

As we have stated, shared decision-making does not happen regularly. Some of the 'competencies' required for shared decision-making are being formulated, but a checklist of behaviours or steps taken during a consultation may never 'resonate with patient's models of decision-making or constructions of their illness experience'.¹¹ It should be possible to obtain observable evidence of shared decision-making, but we may need to go beyond the analysis techniques currently used to assess the physician-patient interaction. Observation alone will not capture the process that takes place 'in the patient's head', where, ultimately, decision-making occurs. Neither will observation of interaction enable the longitudinal aspect of decision-making to be determined: the effects of patients discussing options with family and others.

Having learnt to explore both the biomedical and personal agendas, GPs are now faced with the challenge of providing patients with information and learning how to share decisions with them. How these skills are best developed and what tools should be deployed to share information about risks are areas that need further work. There will always be a concern that the doctor's view (mediated via the way the doctor frames the information¹⁶) will sway the patient.

A mood of questioning consumerism and the unprecedented electronic access to information is re-defining the role of the generalist. The clinician should be prepared to adapt to the patient's preferred role, to hand over, share, or take overall responsibility for decision-making. For the patient, involvement will bring new responsibilities: a requirement to evaluate risks and benefits. Primary care practitioners are uniquely placed to share decisions with patients. It is an important task, best done before patients enter the potential bias of secondary care perspectives. For too long we have neglected the second half of the consultation.

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Acknowledgements

Thanks are due to Professor Nigel CH Stott, Professor Richard Grol, Professor Ian Russel, Professor Roisin Pill, Professor Richard Edwards, Dr Jane Moore, Dr Richard Gwyn, Dr Simon A Smail, Dr Michel Wensing, Dr S Koppel, and Professor Clare Wilkinson. Funding was provided by the Welsh Office of Research and Development.

Address for correspondence

Dr G J Elwyn, Department of Postgraduate Education for General Practice and Department of General Practice, University of Wales College of Medicine, Cardiff CF4 4XN. Email: elwynG@cf.ac.uk