

Chapter 1

Shared decision-making in health care: Achieving evidence-based patient choice

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Health care communication

The relationship between a patient and their health professional is viewed as one of the most complex interpersonal relationships. It involves the interaction between people in unequal positions, often non-voluntary, often addressing vitally important issues, emotionally laden, and requiring close co-operation (Ong *et al.*, 1995). It has also long been recognized as a vital influence on the course of illness: Hippocrates observed that ‘some patients, though conscious that their condition is perilous, recover their health simply through their contentment with the goodness of the physician’ (Heritage and Maynard, 2006). There is a long history of studying the doctor–patient relationship in social sciences with seminal work from several authors, identifying the importance of the ‘sick role’ for the patient (Parsons, 1951), but also how doctor-centred behaviours attenuate therapeutic possibilities (Byrne and Long, 1976), and how the extent to which patients adopt passive roles and accept medical expertise and authority vary with the character time scale and severity of their illness and its treatment or options for self-treatment (Szasz and Hollander, 1956).

More recently, Roter and Hall (1992) described four basic forms of the doctor–patient relationship: default, paternalistic, consumerist, and mutualistic. *Default* relationships are characterized by a lack of control on either side and are far from ideal. *Paternalism* is characterized by dominant doctors and passive patients, whereas *consumerism* is associated with the reverse and a focus on patients’ rights and doctors’ obligations. Consumerism in health care is an extension of the value of individual autonomy, independence, control, and rationality seen in western societies today (Bishop and Yardley, 2004). However, this is also problematic, and analysis suggests that this may be because it privileges the representation of patients as ‘rational actors’ in medical encounters, when a central feature of these encounters is their embodied and emotional nature (Bishop and Yardley, 2004). *Mutuality* is characterized by a sharing of decision-making and often advocated as the best type of relationship.

Shared decision-making

Emanuel E.J. and Emanuel L.L. (1992) suggest that a medical encounter can be judged by three main dimensions – the extent to which the agenda is set by the doctor, patient, or both in negotiation, the status of the patient’s values (assumed by doctor, jointly explored, or unexamined), and the doctor’s functional role as guardian, advisor, or consulting technician. The mutualistic relationship is characterized by a broad balance in power and symbolic resources for each participant; the agenda is negotiated; the patient’s values are explored, and the doctor takes an advisory role regarding the patient’s goals and decisions. There is a range of views about what

constitutes patient involvement and participation in health care (Thompson, 2007) and a range of interpretations of what constitutes shared decision-making (Makoul and Clayman, 2005). However, the most commonly cited and generally accepted conceptualization of shared decision-making is that of Charles *et al.*, who identified the key features of shared decision-making as ‘involvement of both the patient and the doctor, a sharing of information by both parties, both parties taking steps to build a consensus about the preferred treatment, and reaching an agreement about which treatment to implement’ (Charles *et al.*, 1997).

Shared decision-making (or mutuality, ‘active involvement’, ‘partnership’) has gained a high level of policy support (Coulter, 2001; Coulter and Ellins, 2006). Paternalistic health care has fallen out of favour, replaced by the ‘patient-centred model’ (Stewart and Brown, 2001) which emphasizes patient autonomy, informed consent, and empowerment (supported also, for example, in General Medical Council descriptions of ‘Good Medical Practice’ (Council, 1998)). However, there is recognition that mutuality or shared decision-making may not suit all types of patients (Brundage *et al.*, 2005; Deber *et al.*, 2007; Edwards *et al.*, 2005). Furthermore, it is often difficult to achieve in practice (Berry, 2007; Towle *et al.*, 2006), and it appears something of an ideal that is far from reality in the everyday practice of doctors and experiences of patients.

Increased patient involvement and shared decision-making do produce beneficial results. Crawford *et al.*’s (2002) systematic review showed that higher levels of involvement resulted in better quality of care, increased satisfaction (for both patients and medical staff), and improved self-esteem for patients. Other systematic reviews also show the benefits of patient-centred care (Lewin *et al.*, 2003), and specific interventions such as those before consultations for helping patients address their information needs (Kinnersley *et al.*, 2007) and decision aids (interventions such as interactive websites, videos, leaflets to promote deliberative treatment decisions) (Murray *et al.*, 2005; O’Connor *et al.*, 2003). They report a range of cognitive, affective, behavioural, and health-status benefits.

Despite some caution on the extent of the benefits of shared decision-making on patient-based and health outcomes (Joosten *et al.*, 2008), it seems reasonable to continue to promote shared decision-making or other mutualistic approaches to health care, even though they are not widely adopted or achieved in practice (Carlsen and Aakvik, 2006). But to achieve change in practice, we need to examine the process afresh, in more depth, and gain greater understanding of the issues and influences at work. Some barriers to implementation in practice, such as professionals’ attitudes, skills, and time available, have been studied widely (Gravel *et al.*, 2006). But experiences of decision-making are likely to be highly influenced by personal preferences, experiences, and relationships, and also structural constraints (class, education, ethnicity, and culture). They will also vary over time as people are more exposed or familiar with involvement in decision-making (Longo *et al.*, 2006) and to vary from one situation or context to another for an individual patient. There is also recognition that people exhibit potentially contradictory or ambivalent stands in relation to assuming responsibility for their health and health care at different times and in different situations.

Reflection and questions

People are becoming more autonomous and taking responsibility for their health and health care (Coulter, 2002). However, the relatively slow rate of progress towards the model of fully health literate consumers, exercising their own agency rather than requiring an agent (the clinician) to act for them, warrants reflection. We need a deeper understanding of how decision-making is occurring (whether shared or not). We need to examine what is happening in the shared decision process and in the unequal process. This examination can be both theoretical and empirical. If we

can gain this deeper understanding, particularly perhaps when efforts are being made to adopt the shared or mutualistic approach, we will be in a stronger position to identify strategies to overcome the difficulties and promote shared decision-making.

However, the difficulties also generate more fundamental questions on which to reflect. Are we clear what we want as stakeholders in the field of shared decision-making practice and research – whether as patients, researchers, or clinicians? What is our understanding of shared decision-making and is it really what we want to achieve? It may have ethical justifications. It may or may not be efficient health care when examined from health economic perspectives. A range of health and health care benefits may be of different importance to different stakeholder groups including also policy-makers and payers for health care. We need to identify ways of implementing shared decision-making, but there is a more fundamental question to be answered first – *Do patients really want it?* The authors in this volume examine debate and explore a number of issues around these questions. Here we will outline the contributions to the volume, but first will make a few comments about terminology.

Shared decision-making or 'evidence-based patient choice'?

The first edition of this volume was entitled *Evidence-based patient choice – inevitable or impossible?* in 2001, reflecting work through the late 90s; this appeared to be a term gaining favour. There are also a number of related terms in the literature. As well as those noted in the Introduction, these include informed (shared) decision-making (Towle and Godolphin, 1999), patient-centred care (Stewart *et al.*, 1995), concordance (Marinker, 1997), participation and partnership (Coulter, 1997), informed consent (Gigerenzer, 2002), autonomy (Schneider, 1998), consumer involvement and consumerism (Entwistle *et al.*, 1996), expert patient (Kennedy and Rogers, 2001), and evidence-informed patient choice (Entwistle *et al.*, 1998). These have different meanings, nuances, and may be for different purposes.

We believe, however, that the term which has endured, and arguably has the highest profile, is shared decision-making (Charles *et al.*, 1997; Elwyn *et al.*, 2000). It has deficiencies, not least because it might be assumed to promote shared decision-making as the ideal model for all circumstances, when clearly this is not the case. We believe it can be viewed as a short-hand term, but which perhaps has the greatest impact and recognition, clearly signalling to wider constituencies what is proposed as a change in the way health care is practiced. Being short hand, it requires clarification. We suggest that what really represents is 'involving the patient in decision making, to the extent that they desire' (Edwards and Elwyn, 2006). Health care practitioners need to be able to gauge the patient's preferred level of involvement, and then employ skills and competencies to achieve that preferred level of involvement, whether a clinician-led, shared, or patient-led decision. A key contribution to this process comes from health information, effectively presented, and the scope of decision aids to enhance decision-making (O'Connor *et al.*, 2007).

The other area of terminological debate is around the labels and terms for the provider and the person using health care services. We clearly recognize that the terms 'doctor' and 'patient' are now somewhat outdated, and terms such as clinician or health care professional, and patient, client, user, citizen, or consumer (among others) may be more inclusive or appropriate depending on the context. These were discussed in the first volume (Elwyn and Edwards, 2001) and arguably this is an area where little updating is required eight years later, the range of terms remains varied, and is appropriate given the range of health care circumstances and contexts, and the purposes for which the terms are used in debate. However, where in the first volume we to some extent standardized terminology around 'clinicians' and 'consumers', in this volume authors have used various from among these terms, suitable to their field of analysis.

Overview of the second edition

The shared decision-making field has developed and broadened considerably in recent years. It is now 12 years since the seminal paper by Charles *et al.* (1997) and 8 years since the first International Shared Decision Making Conference in Oxford, UK, and the first edition of this volume (Edwards and Elwyn, 2001). The second edition retains the same five sections as the first examining the nature of health care, theoretical perspectives, conceptual development, evidence of shared decision-making in practice, and debating potential future developments. However, as the field has broadened, so have the number of issues and aspects worth including and debating. More particularly, the number of authors able to contribute expertise and experience has also increased, and the range of countries from which they come. Thus, we have invited over a hundred authors from 10 countries to contribute to this volume.

Section 1: Shared decision-making and evidence-based patient choice

Some of the headline issues have been introduced above and these are explored in more depth in the first section. Holmes-Rovner relates how the field has developed and evolved, particularly focusing on the progress with the international conferences and their showcasing of research and development (Chapter 2). The body of the section is devoted to the developments both in the concept of patient involvement (Entwistle, Chapter 3), but also in terms of how shared decision-making can fit in with the way health care is increasingly provided by teams of professionals (Legare, Chapter 4) and how this affects the roles of those professionals and of patients (Stacey and Thornton, Chapters 5 and 6, respectively).

Section 2: Theoretical perspectives

Several disciplines can shed light on the nature and purposes of shared decision-making. Chapters in this section contribute a range of theoretical analyses and discussions, from psychological (Bekker, Chapter 7), sociological (Rapley, Chapter 8; Murtagh, Chapter 12), ethics (Holm, Chapter 9), and economics perspectives (Kristiansen and Gafni, Chapters 10 and 11). These chapters show how the analysis of shared decision-making has progressed in recent years, in particular how a stronger theoretical base is now seen as vital for interventions. However, we also see the introduction of a more sceptical note – it is not assumed that shared decision-making is automatically ‘where we want to go’ (Gafni, Chapter 12).

Section 3: Conceptual developments

We start this section with the discussion of exciting developments that are arguably more usually not associated automatically with the shared decision-making field. These concern informed choice (Marteau, Chapter 13) and initiatives around the Expert Patient (Rogers, Chapter 14) and Health Literacy (Edwards, Chapter 15). Clayman and Makoul review how the concept of shared decision-making itself has developed (Chapter 16) and subsequent chapters examine how shared decision-making competencies (Elwyn, Chapter 17), values clarification (Llewellyn-Thomas, Chapter 18), and risk communication (Edwards, Chapter 19) are seen as part of that.

Again though, more questions arise, including fundamental ones about ‘what is a good decision’? Perhaps the differing views of this, expounded by Elwyn (Chapter 20) and Sepucha (Chapter 21), and noted also by Marteau (Chapter 13), show how difficult the theoretical and conceptual issues are in shared decision-making. With these difficulties – the lack of a clear understanding of what shared decision-making is, what its purpose is, and how to

achieve it and measure it – it is unsurprising that the shared decision-making field has encountered implementation barriers (Edwards, Chapter 19).

Section 4: Shared decision-making in health care practice

Despite these theoretical and conceptual concerns, a huge volume of evidence has accrued now about shared decision-making in practice – the pragmatic end of the spectrum is thriving! Coulter describes the experience and extent of shared decision-making in different international health care systems (Chapter 22), and Mazur describes the medico-legal perspectives (Chapter 23). Kinnersley summarizes a Cochrane review on how consumers can be helped in quite simple ways with their information needs in consultations – question prompt sheets may be a simple and modestly effective way of enhancing consumer involvement (Chapter 24). Schwartz shows how drug information, summarizing the benefits and harms of treatments, could be made available to consumers (Chapter 25). The vested interests of pharmaceutical companies militate against this currently in the United States, but Bastian describes how information resources have been made available in Germany under its universal insurance-based health care system (Chapter 26).

The main theme of this section, however, is around decision aids. Chapters 27–34 provide an overview (O'Connor, Chapter 27), summarize their effectiveness with data from the well-cited Cochrane review (O'Connor *et al.*, 2003; Stacey, Chapter 28), and examine the role of psychological theory – often lacking – in their development (Durand, Chapter 29) and the use of 'narratives' or patient stories (Winterbottom, Chapter 30). Llewellyn-Thomas also examines further research needs concerning decision support and decision aids, in the context of the Dartmouth–Hitchcock 'Decision Lab' (Chapter 34). Perhaps related technologies concern internet-delivered interventions (Murray, Chapter 31) and decision analysis (Thomson, Chapter 32). However, an important issue around the proliferation of decision aids in recent years (see also <http://decisionaid.ohri.ca/AZinvent.php>) concerns quality assurance. The International Patient Decision Aids Standards Collaboration was formed in 2003 and had developed quality criteria for their development and assessment (Elwyn *et al.*, 2006) (Chapter 33).

The rest of this section is given to illustrating decision support and decision aids in 15 health care topics. This is far from an exhaustive list of the important clinical topics where shared decision could be or is important – indeed it is likely to be important in any topic and any decision. We apologize to stakeholders in topics that have not been included. Rather a selection is included to illustrate the nature of decisions, the range of decision aids available, the experience available to date, and the lessons and prospects for the future that we may be able to learn from these exemplars. They cover a variety of medical, surgical, and screening or prevention topics.

Section 5: The next and possible future developments

This section starts by returning to the sceptical refrain. Even the academics and policy proponents have been reflecting some doubts about the nature or purpose of shared decision-making, just beneath the surface in a number of chapters in this volume. An experienced clinician (Price, Chapter 50) examines whether patients really want it? Shared decision-making is increasingly advocated in health care but is not widely adopted in practice. There are a number of potential reasons for this, including professional resistance, lack of skills, lack of time, and other structural barriers (Gravel *et al.*, 2006). These are summarized by Legare (Chapter 51) and analysed from a theoretical perspective using the Normalization Process Model, examining how shared decision-making and decision aids need to fit in with the usual *work* of the consultation (May, Chapter 52). However, shared decision-making (as currently proposed) pre-supposes that the patient is willing and able to participate. Earlier chapters have visited the issue in terms of patient

autonomy, power asymmetry (Murtagh, Chapter 12), and also the ‘agency relationship’ in health care (Gafni, Chapter 11). But it remains pertinent to ask the ‘emperor’s new clothes question’ about shared decision-making, decision aids, and so on: *do patients really want it?* Assuming for the moment that patients are willing and able to participate in health care encounters, and decision-making in particular, the implementation issues are important, as are issues around training and education of professionals, discussed by Towle (Chapter 53). There are exciting possibilities ahead in terms of how ‘decision support technologies’ and ‘information therapy’ can make invaluable contributions to shared decision-making, enabling consumers to be actively engaged in their health and health care. Elwyn describes the potential future development of decision support technologies (Chapter 54), and Kemper describes the development of information therapy in the context of commercial providers of health care, as evident in the United States (Chapter 55). All such developments require further evaluation and analysis of how they affect the patient’s contribution to decision-making. If we can understand better what happens when shared decision-making occurs, and what the differences are when it does not, we will be better placed to know when it should be promoted, how to do this, and what this will achieve – and when it should not.

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