Shared Treatment Decision Making in a Collectively-Funded Health Care System: Possible Conflicts and Some Potential Solutions

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1. Introduction

In recent years there has been a growth of interest in, and advocacy of, clinicians sharing treatment decisions with patients.[1-3] Both conceptually and practically, shared decision making (SDM) involves various steps, but the key characteristics are the provision of comprehensive and comprehensible information to patients regarding treatment options, and the willingness of clinicians to share deliberation and decisions regarding appropriate management. These characteristics are consistent with a developing movement towards more accountable public services, providing more information to actual and potential customers and showing greater responsiveness to their wishes. However, a movement towards greater SDM in collectively-funded health care systems runs the risk of accentuating conflicts between the demands of individual patients and the interests of other patients and of potential patients. It is, therefore, important to consider policy responses that can ameliorate these conflicts and help ensure a relationship of trust between clinician and patient which is a prerequisite to the successful implementation of SDM.

This paper describes the types of conflict that are likely increase in the wake of greater SDM in collectively-funded health care systems, and considers a range of possible policies to reduce the incidence of these conflicts. It is argued that SDM is most likely to be successful if a clear distinction is made between the 'clinical' information and guidelines given to clinicians about the effectiveness of alternative forms of management, and the 'system' guidelines which indicate which interventions the system will fund from collective resources. It is further argued that the risk of conflict with SDM will be reduced if the system guidelines – and the cost-effectiveness analysis which underpins them - are able to recognise and reflect the heterogeneity that exists

in individuals' preferences. Section 2 of this paper considers the characteristics of SDM; Section 3 describes the conflicts that are likely to emerge given its use in collectively-funded health care systems; Section 4 assesses some possible policy responses to these conflicts and Section 5 offers some conclusions.

2. Shared decision making

2.1 Alternative conceptual frameworks for treatment decision-making

It has long been recognised that there exists an asymmetry in the distribution of information and knowledge between clinicians and patient.[4] The traditional clinical response to this situation was a paternalistic approach to treatment decision-making. With this approach, the clinician would elicit information from the patient and decide which treatment (s)he should undergo accordingly, with little or no consideration of the patient's preferences.

In recent years, alternative frameworks have emerged in which treatment decision-making can be categorised. Whilst emphasising that treatment decisions making should not be seen as black and white and that doctor-patient interaction is likely to be characterised by combinations of approaches, Charles *et al* describe two alternative decision making frameworks to the paternalistic model: informed decision making and shared decision making (SDM).[1,5] The former involves a flow of information, mainly from the clinician to the patient, but all deliberation and decisions are the responsibility of the patient. In that the only relevant preferences are those of the patient, this informed decision making can be considered equivalent to the agency relationship described in the economics literature.[6] SDM involves a two-way flow of information – from doctor to patient regarding treatment options, positive and negative effects and the likelihood of such effects; and from the patient to the doctor regarding such factors as values and constraints. In addition, SDM is characterised by shared deliberation about the preferred treatment and an agreed decision.

The consideration of alternatives to the paternalistic model has been prompted by developments in recent decades. Firstly, there has been a recognition that treatment decisions invariably involve trading off positive and negative effects of interventions, and that this is an inherently value-laden process in which the doctor's greater medical knowledge and information gives him/her no special aptitude. Decisions involving trade-offs require the exercise of preferences, and the individual patient is uniquely placed to provide preference information. The second development has been a realisation that patients wish to participate more fully in decision making. This is consistent with individuals generally becoming more informed, keen to extend and exercise their legal rights as consumers and less deferential to professionals. For example, a survey of 210 patients with hypertension found that 53% wanted to participate in treatment decisions.[7] A number of studies have found that this willingness declines with age.[2]

2.2 The practice of shared decision-making

Of the alternative conceptual frameworks, SDM has received more attention at the level of applied research and in practice. This is likely to have been, in part, a response to the perception that neither patients nor clinicians would be keen for all decision-making

responsibility to be handed to the patient. In other words, SDM is probably seen as a 'sensible' middle way between paternalism and informed decision making.

At a practical level, Charles *et al* argue that there are four essential characteristics of SDM:[1]

i. both the patient and the doctor (and possibly others, such as relatives) take part in treatment decision-making;
ii. there is a two-way flow of information between the clinician and patient;
iii. both the clinician and patient express treatment preferences; and
iv. a treatment decision is made when both the clinician and patient agree on the most appropriate treatment.

These characteristics have proved attractive to the policy-making and research communities. In the UK, for example, there have been government initiatives such as the patient partnership strategy,[8] the launch of a standing group on consumers in NHS research,[9], a special issue of the *British Medical Journal* devoted to partnerships with patients[10] and the launch of a new international journal on patient and public participation in health care decision making.[11]

A major area of research activity has now opened up internationally. For example, in the USA a randomised controlled trial has been undertaken to estimate the costs and benefits of SDM in benign prostatic hyperplasia,[12] and trials are underway to assess SDM in menorrhagia and ulcerative colitis.[13] Considerable research has gone into the development and evaluation of decision aids to help patients form treatment preferences and hence facilitate the SDM process. These aids have included decision boards and interactive computer programmes. A recent systematic review of randomised controlled trials to evaluate decision aids in health care found 17 studies and showed that aids can improve patients' knowledge, reduce decisional conflict and encourage patients to participate more fully in SDM; but the review found little evidence of an effect on patient satisfaction or the outcomes of decisions.[14]

Beyond the levels of concept and research, there is some doubt whether SDM has yet been successfully implemented. For example, in a survey of 425 women with menorrhagia managed in general practice, only in 34% of women with a treatment preference was the general practitioner aware of that preference.[15] It may be that the limited diffusion of SDM is due to under-development of the concept or a lack of success in the development of practical information and decision-making tools. Alternatively, SDM may not become widespread until the environmental constraints that it faces are addressed, most notably the problems of its use in collectively-funded health care systems.

3. Shared decision making in collectively-funded health care systems: sources of conflict

If a clinician wishes to practice evidence-based medicine in a health care system which does not have resource constraints they will follow Sackett *et al's* description of the process:[16]

"Doctors practising evidence based medicine will identify and apply the most efficicious interventions to maximise the quality and quantity of life for individual patients; this may raise rather than lower the cost of their care." (p. 72)

This can be easily translated into SDM, because the clinician is able to disclose information on all treatment options and detail their risks, benefits and trade-offs. Together, the clinician and patient would be able to choose their preferred treatment regardless of its impact on resources.

When resource constraints exist, the implementation of SDM is unlikely to be so straightforward. Whether a collectively-funded health care system is based on public funding or private insurance, the resources available are finite. As a result, limits have to be set on the availability of interventions to individual patients; in other words, when finite resources are devoted to one individual's management, they cannot be used for the care of other patients or potential patients. Herein lies the source of the potential conflicts arising from SDM in such systems. When a patient shares deliberation about treatment options with their clinician, they will expect to be advised fully about the risks and benefits of each treatment option and helped to consider the full implications of those effects as a means to agreeing a preferred form of management. Within a collectively-funded health care system, however, the clinician may not be able to provide the treatment that the patient prefers as this would ultimately be unsustainable given finite resources.

This potential conflict creates a clear dilemma for the clinician: whether or not to provide information to the patient on all treatment options – as the patient may expect – or a more limited sub-set which are considered affordable. How should the clinician act if all treatment options are described and the SDM process indicates an agreed preference for a treatment which does not represent a cost-effective use of collective resources? In some health care systems, the clinician is given a budget to devote to the care of his/her patients, so they have some flexibility to provide the preferred treatment despite it not representing good value for money from a collective perspective – but the clinician will be aware that such decisions are unsustainable and will incur opportunity costs for other patients in the system. In other health care systems the clinician will be precluded from providing treatments which do not represent a cost-effective use of collective resources. In this situation the clinician is faced with telling the patient that their preferred treatment is not available from collective resources.

The conflict takes on another dimension in some health care systems when the remuneration of the clinician is linked to the number of patients on his/her books and when patients are free to switch between doctors. In this context, the dilemma regarding information provision may have direct financial implications for the clinician practicing SDM. If the patient forms a strong preference for a treatment option that the clinician is unwilling or unable to provide because it is not cost-effective, the clinician may lose the patient from their books and the remuneration they bring. The likelihood of this manifestation of the conflict will depend on the health care system. In the NHS, for example, it is possible that a patient will leave a primary care practice, which has refused to prescribe him/her a drug which is not cost-effective, in search of a practice that will satisfy their preferences; but this is unlikely, especially will the advent of primary care groups which will effectively remove a choice of practice for most patients.

In systems based more fully on private insurance, such as in the USA, however, some patients may be more willing and able to move between physicians until they obtain their preferred treatment. Again, the source of the conflict is the resource constraints in the system which prevent the clinician treating each patient as if they were the only individual covered by the health care system, coupled with the patient's wish to be treated in that manner.

Another potential source of conflict relates to the possible time burden of SDM. It is likely that, in order to achieve the characteristics of SDM regarding mutual information provision and deliberation and agreed decisions, the consultation will have to be longer than under a more paternalistic decision-making framework. This additional demand on clinicians' time will have different implications, depending on the health care system. In some systems, it is possible that the clinician simply will not be reimbursed for the extra time required to practice SDM – in effect, they will receive funding to practise only paternalistic medicine. In other systems reimbursement policies may not be a disincentive to provide SDM, but there may, nevertheless, be clear opportunity costs. For example, in a cash-limited health care system, patients are likely to have to weight longer to see their physician. However, one of the implications of the successful implementation of SDM may be that patients are more satisfied with their care and its outcomes, which results in fewer follow-up visits to the clinician. The overall effect of SDM on patients use of clinician time is an important research question.

A further dimension of the conflict relates to the objectives of the health care system. So far, it has been assumed that the conflict between the individual doctor-patient partnership and the collective relates to efficiency concerns within a system with finite resources. In other words, the focus has been on the conflicts that may arise when a patient expresses a preference for a treatment which is not considered cost-effective. However, SDM may also accentuate conflicts relating to the equity objectives of the system. A health system with an equity objective of equal utilisation for equal needs, for example, may seek to limit variation in treatment decisions within particular patient groups, one source of which would be variation in patient preferences as articulated through SDM.

SDM may accentuate conflict in respect to a combination of efficiency and equity objectives if the latter took the form of equal access for equal need. This may require each individual in a given patient group to have the same opportunity to undergo a given treatment. In other words, if a treatment option was made available for one patient, it may also have to be made available to all other similar patients. If a clinician was being responsive to the objectives of the health care system, therefore, he/she may only agree to provide preferred treatments that are funded from collective resources if each and every other patient that might present with the condition could undergo such treatment if they preferred it. This source of conflict sheds more light on the clinician's dilemma: should they accept a role as agent of the individual patient or of the health care system?

The extent to which SDM is inimical to the equity objectives of the system will, however, depend on the exact definition of that objective. In the case of equal utilisation or equal access for equal need, much depends on the definition of 'need'. If this is defined as capacity to benefit and, in turn, this is measured in terms of potential improvement in health outcomes, then SDM may conflict with the equity objective. This is because

preferences will thus be precluded from consideration if equal utilisation for equal need is the objective; and, if equal access for equal need is the objective, preferences will only be considered if all patients can be offered the same choice which may be precluded because of resource constraints. If, however, capacity to benefit is seen not only as potential outcomes but also individuals' preferences over those outcomes, then SDM need not conflict with the equity objective of the system because 'need' is itself partly a function of preferences.

4. Ameliorating the conflicts

The implementation of SDM may not be successful unless the risk of these conflicts is reduced. Although conflicts of this type may arise within any collectively-financed health care system, whatever the decision-making framework adopted, the use of SDM risks accentuating them and increasing the proportion of doctor-patient encounters which are characterised by conflict. If SDM is an important policy objective, a range of possible approaches to ameliorate conflicts needs to be considered.

4.1 Informing patients only about cost-effective treatment options

One possible way of addressing the potential heightening of conflict between the preferences of the individual patient and the interests of the health care system and the population it serves is for the clinician to restrict the information flow between him/herself and the patient. The assumption of this putative solution is that it is possible to reduce the risk of a patient expressing a strong preference for a treatment that the system deems not to be cost-effective by the clinician simply not informing the patient that the treatment exists. This would involve the guidelines which are issued to clinicians focusing on cost-effectiveness rather than effectiveness and, given that such literature is likely to be an important source of information to the clinician about treatment options, the method, in effect, seeks to constrain the information given to the clinician.

However, this proposed approach has some major limitations. Most importantly, it assumes that patients only receive information from clinicians, indeed from one clinician. In reality patients obtain information about ill-health and treatment options from a myriad of sources. In a recent study of women referred to hospital with menorrhagia, for example, 37% of women indicated that they had received information from friends, 22% from family and 22% from magazines.[17] With the advent of new information sources such as the internet, it will be even more unlikely that a patient will remain ignorant of effective treatment options, particularly those that the health care system considers not to be cost-effective as that in itself may increase media attention. Furthermore, in some contexts, patients will see a series of doctors and other clinical staff about their condition, with perhaps each one providing information about treatment options. Unless there is strict adherence to a system-wide line about which treatments can be mentioned, it would seem likely that patients will learn about treatment options that are not considered appropriate to fund from collective resources. It seems reasonable to predict that the longer a patient has suffered from a condition, the more informed they will be about treatment options.

If clinicians seek to limit the SDM exercise to a sub-set of cost-effective treatment options, while patients are acquiring information about *all* treatment options, the chances of reaching agreement about appropriate management may be reduced. More fundamentally, the trust that the patient needs to feel for their clinician if SDM is to successful will be threatened if the doctor constrains information provision and is perceived to be acting on behalf of the system rather than the individual patient. It would seem, therefore, that this putative approach to lessening the potential conflicts associated with SDM could in fact accentuate it, with the clinician being the potential focal point of the conflict.

4.2 Allowing the SDM process to determine whether treatments are cost-effective

A second possible approach to reducing the conflict between the preferences of the individual patient, given expression through SDM, and the interests of other patients and potential patients, is to include the costs of treatment options within the information presented to patients and the deliberation process. In effect, the objective would be for the SDM process to incorporate a cost-effectiveness analysis where the clinician and patient weigh-up the relative benefits of treatment options *from the perspective of the individual patient* against their relative opportunity costs in terms of the preferred treatments that other patients and potential patients will not be able to receive from collective resources. The approach to the problem would involve the guidelines provided to clinicians including information about both the effectiveness and cost attributes of treatments which would then be passed to the patient as part of the SDM process.[18]

The limitation of this approach is that is relies on the individual patient being able to reach agreed treatment decisions putting equal weight on their own preferences and the interests of others. There are examples of individuals acting altruistically in health care – for example, blood donation. Furthermore, the willingness of patients explicitly to consider the interests of unknown others is likely to vary within individuals, according the type and severity of disease, and between patients according to their age, personal circumstances and culture. However, it is surely unrealistic to assume that sick individuals will consistently be able to participate in SDM to achieve socially efficient and equitable treatment decisions.

4.3 Distinguishing 'clinical' from 'system' guidelines

A more successful approach to reducing the incidence of conflict arising from the use of SDM in collectively-funded health care systems is likely to be for there to be a clear distinction between what is effective and what is cost-effective. This would be reflected in the first stage of information flow – from the health care system to the doctor – in the provision of two separate types of guideline.[19] The first type of guideline would be 'clinical' and would describe the effectiveness attributes of treatment options for given patient groups; that is, survival probabilities, risks of adverse effects and overall implications for health-related quality of life. This form of guideline would reflect Sackett *et al's* conception of evidence-based medicine described above.[16] The 'system' guideline, on the other hand, would focus on the cost-effectiveness of treatment options from the perspective of the system and the population it serves. In the UK, clinical guidelines might be generated by professional organizations such as the royal colleges, rather than the NHS, and the production of system guidelines is one of the stated purposes of the National Institute for Clinical Excellence.

How would this distinction help the process of SDM? Both types of guideline would feed into the information flowing from clinician to patient. The patient would be informed about the effectiveness attributes of all treatment options that exist for their particular condition. This information would, however, be accompanied by a clear statement about which interventions can be funded from collective resources. Hence the clinician is not restricting the information flow to the patient and they are able to commit themselves to agreeing a treatment which satisfies the patient's preferences, but against an explicit backdrop of knowledge about what the system will fund.

In principle, the system guideline could provide either a *recommendation* about which treatments are not good value for money for particular patient groups and sub-groups, or actively preclude the use of particular forms of management because they are not a cost-effective use of collective resources. However, it is likely to be the case that the more proscriptive the system guideline, and hence the less flexibility offered to the clinician, the greater the reduction in the risk of conflict with SDM. This is because a proscriptive system guideline would operate as a *fait accompli,* and both the doctor and patient will be forced to accept the situation as a starting point for the SDM process. In other words, the less room for maneuver the clinician is given by the health care system, the less likely the patient will identify the clinician as the source of the problem and the more scope for successful SDM.

The realistic objective of this approach would be to reduce the number of patient-doctor encounters characterised by conflict, not to eliminate conflict. There will still be patients who have strong preferences for a treatment which is not available from collective resources. However, the use of clear system guidelines about which treatments it will fund should remove the focus of the conflict away from the doctor-patient encounter and towards the health care system where the source of accountability for resource allocation decision-making should lie. Clearly, the issue of whether patients should be permitted to pay for a preferred treatment which the system will not provide from collective funding would have to be considered. Although the complete preclusion of private funding is probably impossible – the patient cannot easily be prevented from going abroad for privately-funded treatment – the decision about whether this is permitted is clearly a political one reflecting, in part, the equity and ethical principles of the system.

4.4. Enhancing the methods of cost-effectiveness analysis for system guidelines

The success of separating clinical from system guidelines is likely to be greater if the cost-effectiveness analysis (CEA) upon which system guidelines are based were able to reflect the heterogeneity of individuals' preferences more fully than has hitherto been the case. Conventional CEA reflects the preferences of a sample of individuals through the values they attach to health states. Although various groups can and do provide these preference data, there are strong arguments for the use of a sample of the public as they are the ultimate source of resources and are potential patients.[20] Preference data can then be reflected in the measure of benefit – typically in CEA, the quality-adjusted life-year (QALY).

It is well known that there is marked variation between individuals in the values they attach to health states – for example, in a survey of 3395 community raters, the mean value of a health state characterized by severe pain but good levels of health on other domains (the EQ-5D health state 11131) was 0.20, but the standard deviation was 0.60 and the inter-quartile range was -0.33 to 0.72.[21] However, CEA effectively ignores this variation through the use of an 'all or nothing' approach.[22] According to this, the cost-effectiveness of an intervention is assessed on the basis of *mean* preferences from the sample. If the incremental cost-effectiveness ratio (ICER), based on mean preferences, falls below a threshold willingness to pay per unit of extra benefit, the intervention is considered cost-effective and can be made available. If, however, it is higher than the threshold, it is deemed not to be cost-effective and the system guidelines would preclude its provision, from collective resources, for all patients in the clinical group considered. However, this blanket refusal to fund a treatment because it is not cost-effective on the basis of *mean* preferences ignores the fact that, within the sample of the public who provide preference data, there may be sub-groups whose preferences are markedly different from the mean. Furthermore, if the preference data for the CEA were to be taken from one of these sub-groups, the ICER for the treatment may fall below the threshold willingness to pay whilst, on the basis of mean preference data from the whole sample, the intervention would not be considered cost-effective.

This possibility of reflecting heterogeneity of preferences has given rise to the concept of preference-based sub-group analysis. There has been some consideration of the methodological and practical implications of this when *patients'* preferences are used in CEA.[22-24] However, as noted above, there is a strong case for the use of public preferences in CEA, and this is reflected in methods guidelines[25] and the widespread use of multi-attribute utility instruments such as the EQ-5D and Health Utilities Index. The principles and practical implications of preference-based sub-group analysis using the public's preferences have recently been considered.[26] This would be analogous to clinical sub-group analysis where baseline and outcome data from clinical trials and observational studies are used to identify clinical and demographic characteristics of patients that *predict* better outcomes than the whole-group average. Indeed, *clinical* sub-group analysis is frequently used in CEA.

There are two key steps to the use of preference sub-group analysis with public preferences. The first mirrors the description above and that is to identify whether a treatment that is deemed not to be good value for money, on the basis of the whole-group mean from public preferences, may be considered cost-effective when the mean preferences of one or more sub-groups are considered separately. For example, assume that, in the comparison of hysterectomy and transcervical resection of the endometrium (TCRE) for the management of menorrhagia, hysterectomy is not considered cost-effective on the basis of overall mean public preferences. However, there maybe a sub-group of individuals whose preferences are sufficiently different to the average such that, if the mean preferences from that sub-group were used in the analysis instead of the whole-group mean, hysterectomy would be considered cost-effective.

The second crucial step would be the application of this sub-group analysis to decision making at the level of doctor-patient encounter. A prerequisite for this would be that

the preference sub-groups from the sample of the public would be identifiable in terms of their socio-demographic characteristics. For example, in the menorrhagia example, the sub-group might consist of women aged over 40. If sub-groups from amongst the public can be identified, this could be operationalised with patients. The system guideline could indicate, therefore, that women will be offered TCRE for menorrhagia, but women aged over 40 years could additionally consider hysterectomy.

In addition to the advantages that preference sub-group analysis may hold for reducing conflict from SDM, there is also a strong efficiency argument for its use.[26] Just as for clinical sub-group analysis in CEA, if the objective of the system is to maximize health gain from limited resources and if health gain is a function of individuals' preferences, then any reduction in the heterogeneity of patient benefit will further serve that objective.

5. Conclusions

In principle, SDM can contribute to a more patient-centered process of health care delivery. However, to achieve successful implementation of this framework of decision-making to replace the conventional paternalistic framework will require a number of hurdles to be overcome. Some of these hurdles concern how it can be made to work at the level of doctor and patient, including the willingness and ability of clinicians to participate in this form of decision making, the need for efficient ways to facilitate information flow, both ways, between the clinician and patient and the requirement for decision-making tools to help doctors and patients agree treatment decisions.

This paper has focused on a rather different hurdle associated with the environment within which SDM will typically operate – namely, that of collectively-funded health care systems. It has been argued that, given the constraints that collective funding places on a clinician's freedom to provide all treatment options, SDM may accentuate conflicts between individual patients and clinicians. It is further argued that the best means of reducing the proportion of doctor-patient encounters characterised by conflict is the clear separation of clinical and system guidelines, with the latter providing limited room for maneuver regarding which treatments clinicians are permitted to provide from collective funding. The value of system guidelines in this respect may be increased with the use of preference-sub-group analysis to reflect the heterogeneity of individual preferences in the methods and results of CEA.

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