Improving the Use of Information in Medical Effectiveness Research

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There is increased emphasis on improving the quality of health care by obtaining and disseminating information about the effectiveness and outcomes of care and by facilitating more consumer input participation in decision-making. We examine barriers to information use and the challenges that these barriers pose for effectiveness research. We divide our discussion into four goals of effectiveness research. These are: (1) to provide more information so that consumers, providers and policymakers can make "rational" decisions; (2) to incorporate patient preferences into health care decisions; (3) to develop guidelines that incorporate both individual perspectives and societal perspectives; (4) to use information to improve the practice of health care. We discuss four recommendations for improving the use of information: (1) the evidence on how people actually make decisions should be used to inform the design and implementation of effectiveness research; (2) decision-making should be structured through guidelines and policies; (3) criteria should be developed for determining which guidelines should fully incorporate patient preferences; (4) safeguards should be established to guard against misuse of information.

Key words: Effectiveness research, quality-of-care, consumer participation, patient preferences, guidelines, health policies, decision-making.

We are drowning in information but starved for knowledge.

John Naisbitt [1]

Where is the wisdom we have lost in knowledge?
Where is the knowledge we have lost in information?

T. S. Eliot [2]

INTRODUCTION

There is increased emphasis in the US, the UK and other countries on improving the quality of health care by obtaining and disseminating information about the effectiveness and outcomes of care [3–5] and by facilitating more consumer input and participation in decision-making [6–8]. Determining what is effective and measuring and incorporating patient preferences are key components of the move towards measuring quality and using quality information to guide patients and providers. Effectiveness research focuses on studying the relationship between health care and its clinical and quality-of-life outcomes in typical patients. More specifically, the Medical Treatment Effectiveness Program (MEDTEP) in the US consists of data development, outcomes research, practice...
guideline development and dissemination [9]. The assumptions behind these trends are that information about effectiveness and patient preferences for care will facilitate “rational” choice of the most effective and least costly alternatives and therefore a better functioning health care market [10-14].

In this paper we examine barriers to information use and the challenges that these barriers pose for effectiveness research. We focus on how information is used by patients, providers and policymakers in health care decision-making, rather than approaches to managing and disseminating information [15] or the debate over whether information should be obtained through experimental or observational data [16,17]. We discuss approaches to improving the use of information, not only during the dissemination stage, but throughout the design and implementation of effectiveness research. We do not argue that effectiveness research and consumer participation are misguided; rather, we argue that the optimal use of information requires adaptation to limitations of information use and recognition of the role of policies in structuring information use.

Effectiveness research has focused more on the benefits and less on the limitations of information use because of its emergence from a “rational choice” paradigm [4,18]. This paradigm, based heavily on economic theory and information science, relies on the assumption that individuals make “rational” choices based on a complete assessment of alternatives, using a consistent and logical decision-making process that maximizes their utilities, and that more and better information will facilitate this process [19]. (We enclose the terms “rational” and “non-rational” in quotes to indicate that we are referring to this paradigm. See [20] for more description of “rational choice” in health care.) In this paper, we examine theories and literature from multiple perspectives and disciplines that challenge the “rational choice” paradigm, particularly work emanating from alternative models of choice (e.g. prospect theory [21]).

We divide our discussion of how to improve information use into four goals which are identified as being key goals in the medical effectiveness literature. We begin by examining the challenges that barriers to information use pose for achieving these goals and then discuss four recommendations for improving information use.

GOALS OF EFFECTIVENESS RESEARCH AND BARRIERS TO INFORMATION USE

Goal No. 1: to provide more information so that consumers, providers and policymakers can make “rational” decisions

Generating more information and fostering “rational” decision-making in order to improve the effectiveness and quality of care is a major goal of effectiveness research [22,23]. Evidence suggests, however, that individuals are often not “rational” decision-makers, but that “non-rational” use of information may provide important benefits.

It is widely accepted that individuals often do not use available information to make decisions, such as information on physician fees [24,28] and quality indicators such as hospital mortality data [10] and health plan “report cards” [26]. There are several benefits, however, to consumers from what appears to be non-use of information, such as “ignorance is bliss”; that is, some ignorance may be optimal since obtaining and using information and comprehensively evaluating all alternatives for every decision entails “costs” in time and energy [27-30]. Additional information may produce information overload and people have a strong tendency to remain with the status quo [31] and to seek information that confirms rather than contradicts their prior decisions [32].

Furthermore, not making decisions can serve useful purposes. Even though patients may want more information from providers concerning their care, this may not translate into a desire for more participation in actual decisions [33]. One explanation is that letting providers make decisions, “choosing not to choose”, relieves anxiety over fears of making poor choices [34]. The traditional role of the provider as the authoritative decision-maker may reduce the threatening nature of highly personal situations that occur in health care [35].

Psychological costs and benefits, such as a sense of well-being and relief from anxiety, play a large role in health care decision-making [36]. Since psychological benefits are often more
difficult to measure than clinical benefits, decisions which provide little clinical benefit appear "non-rational" [36], even when they are "rational" from the patient's perspective.

Providers also make decisions that appear "non-rational"; for example, when they provide care that is judged to be inappropriate based on clinical criteria. The apparent subjectivity of providers' decisions may reflect, however, a gestalt type of decision-making rather than a lack of knowledge and, therefore, effectiveness research will not necessarily improve decision-making or outcomes [37]. Providers may also receive psychological benefits from apparently "non-rational" care, such as satisfaction from increasing a patient's sense of well-being.

We illustrate our points throughout the paper using the example of immunization. Policies to increase childhood immunizations often assume that providing more information about immunization benefits and greater access will increase use [38]. However, despite parents' knowledge of immunization benefits and free immunizations [39], many children are not immunized as recommended [38,40]. One reason that is often ignored is that parents' decisions to have their children immunized entails cognitive and psychological "costs" in addition to financial costs. Parents must choose to have their children get potentially painful shots that may produce side-effects [41] and which may provide more benefits to society than the individual child. Parents may fail to have their children vaccinated because they would feel more responsible for harm caused by a decision to vaccinate than by harm caused by a decision to not vaccinate ("omission bias" [42] and "outcome bias" [43]). Parents must often explicitly decide to make a separate visit where they may be asked to read information pamphlets that provide an "encyclopedic" picture of risks and benefits [40,44]. Therefore, given the psychological and cognitive "costs" in addition to the time and monetary costs, parents' inertia regarding their children's immunization may not be "non-rational" from their perspective and simply providing more information or increasing access may not increase immunization use.

Another example comes from consumers' choices between health insurance options. Many people have only limited understanding of their health care coverage [45], and choices between plans do not conform to a "rational" model of decision-making [46]. Some of the reasons include that the information "costs" involved in understanding coverage and comparing plans are not perceived as worth the benefits and the choice of a health plan is often not salient to individuals' immediate concerns. Apparently "non-rational" decisions may provide important psychological benefits; e.g. one reason that many people are attracted to plans with no deductibles, despite their higher price, is because they do not want to worry about out-of-pocket costs [46].

Goal No. 2: To incorporate patient preferences into health care decisions

Another goal of effectiveness research is to incorporate patient preferences into decision-making and guidelines to improve the quality of care [11,47]. For example, interactive videos designed to involve patients in treatment decisions are being developed in the US and the UK [8,48]. This goal goes beyond having providers ask patients about their feelings; rather, it has been suggested that patients explicitly make trade-offs between benefits and costs (often by eliciting "utilities") and that treatment decisions be made based on these preferences [6,49]. There are, however, numerous difficulties in eliciting and incorporating preferences into health care decisions [50-53], including "cognitive biases" in how people form preferences and use them in making decisions [54-56]. These biases are common to everyone, even those with special training such as physicians [56]. Some examples of cognitive biases are given below (for other reviews see [20,36,55]).

One type of bias occurs when preferences shift radically as a result of technically inconsequential changes in presentation or "framing" of information [21,57]. For example, several studies have shown that preferences for surgery depend on whether the outcomes are framed in terms of mortality or survival (e.g. [58,59]).

Another example of a cognitive bias is that people often do not have accurate risk perceptions and overvalue complete elimination of risk [60] and therefore have an unrealistic preference for eliminating the risk of medical care rather than merely reducing the probability
of harm [36]. Individuals are also more likely to believe that an event will occur when they can readily recall instances of the event occurring [55]. For example, people are willing to pay more for insurance when it is described as covering hospitalization for “any accident” than when it is described as covering hospitalization for “any reason”, partly because people can more readily recall accidents [61].

We return to our example of immunization. Parents develop perceptions of the risks and benefits of immunization that are not accurate [62], such as the belief that their children are less susceptible to disease than other children [63]. Parents’ preferences for immunization are likely to be unduly influenced by personal knowledge of cases where immunization did not prevent disease [41,62], media reports of side-effects [67], their desires to completely eliminate any risk of side-effects [64] and the “framing” of the vaccination decision [42]. These factors make it more difficult to incorporate parents’ preferences for immunization into health care decisions.

**Goal No. 3: To develop guidelines that incorporate both individual perspectives and societal perspectives**

Products of effectiveness research are practice guidelines, which are being developed in many countries, including the US, UK and Canada, to assist patients’ and providers’ decisions concerning appropriate health care [47,65,66]. Expectations for the guidelines are high; it is hoped that they will improve the quality of care and reduce costs by simultaneously increasing patient choice and guiding providers on the most appropriate care [67]. The evidence suggests that, although guidelines may be useful, decisions made by groups often suffer the same limitations as individual decisions, and it will be a challenge to incorporate consumer, provider and societal perspectives into guidelines.

Guidelines are often developed using a group consensus process which can add to the complexities involved in transforming evidence into guidelines [68]. Group decisions may suffer from the same cognitive biases as individuals’ decisions, such as misperception of risk [69], and are also subject to other biases such as premature concurrence or “groupthink” [70]. For example, NIH consensus conferences to develop guidelines have been criticized for producing bland recommendations with foregone conclusions [71], which result partly from the need to reach group consensus on complex issues in a short timeframe [68,72].

Including “stakeholders” such as consumers and providers in guideline development may improve acceptance of guidelines [7,15,65]; however, the perspectives of “stakeholders” often differ, making it difficult to incorporate all of these perspectives. Consumers want guidelines that allow them to receive the care that meets their perceived needs. These preferences, however, may not be “rational” and they may conflict with provider or societal perspectives; e.g. if patients demand care that is not indicated [20]. Providers want guidelines that will inform decision-making but not be used to enforce medical decisions [73]. However, there is often tension between meeting patients’ and society’s needs; e.g. providers give more weight to patients’ personal concerns if patients are viewed as individuals, but they give more weight to general criteria of effectiveness if patients are viewed as part of a group [54,74]. Policymakers want guidelines that will reduce costs without sacrificing quality, the promise of which was a major factor in the creation of the medical effectiveness agenda in the US [75]. In short, improving patient outcomes and maintaining provider decision-making autonomy may be difficult to accomplish while simultaneously reducing costs.

The creation of vaccine information pamphlets provides an illustration of the difficulties in incorporating both individual and societal perspectives. The development of these pamphlets was mandated in order to better inform parents of immunization risks and benefits [40,44]. The pamphlets, however, are viewed by many providers as a barrier to immunization participation because of their length, complexity and emphasis on risks rather than benefits. The ponderous nature of the pamphlets is partly the result of a group development process that attempted to incorporate diverse individual viewpoints into a societal perspective. As one physician stated when asked whether he would use the pamphlets, “Risk/benefit is more meaningful as a public health concept than as an individual choice concept” [44].
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**Goal No. 4: To use information to improve the practice of health care**

Although effectiveness information may improve the practice of health care [76], information is also used for political "ammunition" and to gain support for goals other than improving health care [77]. Providers fear that effectiveness information is really political "ammunition" in a fight over who will have control over the science of medicine [22]; i.e. they fear that guidelines, cloaked in a mantle of scientific rigor and objectivity, are thinly veiled attempts to reduce physician autonomy and authority. The effectiveness agenda can also be used to divert attention from controversial issues; the promise of reducing expenditure may appease those who call for stringent cost-containment efforts [3,78].

Effectiveness information may be used to protect the self-interests of involved groups, since information reflects the values and preferences of the groups that produce it [10,27,79]. Historically some guidelines issued by professional societies have served their self-interests [80]. Although many guidelines are now being developed by impartial groups, there is still concern over their potential misuse, e.g. there is concern that the pain guidelines issued by the Agency for Health Care Policy and Research (AHCPR) in the US are being quoted by malpractice attorneys out of context [81]. There is also concern that guidelines will be influenced by political agendas. For example, the AHCPR depression guidelines do not address which specialty should conduct specific procedures, an omission which avoids "turf battles" and gains acceptance for the guidelines [82]. This omission, however, may reduce their impact.

**RECOMMENDATIONS TO IMPROVE THE USE OF INFORMATION**

1. **The evidence on how people actually make decisions should be used to influence the design and implementation of effectiveness research**

   Effectiveness research must go beyond the "rational choice" paradigm and the optimistic view of information that underlies much of health research. This will require incorporating how individuals actually make decisions into the design and implementation of research and policies, not just the dissemination of information. For example, since one barrier to immunization is parents' perceptions that shots are painful [41], research should focus not only on the clinical effectiveness but also the psychological benefits of decreasing the number of injections, rather than just focusing on how to disseminate information about the need for multiple injections. Another example is the well-documented beneficial effect of placebos. One of the reasons why there have been limited efforts to understand placebo effects and to explicitly use this knowledge to improve outcomes is because placebo effects appear "non-rational" from a clinical perspective [83]. The development of research agendas is a step towards understanding and using placebo effects [84].

   Similarly, an understanding of how individuals choose between health plans can be used in structuring insurance benefits and health reform proposals. For example, health plans might be structured to address the psychological "costs" of cost-sharing while also reducing the potential for over-use of care.

   Conducting effectiveness research from a multidisciplinary perspective will help in moving it beyond the rational choice paradigm (see Phillips and Rosenblatt [85] for a review). Because guidelines are primarily developed for physicians, non-physicians have traditionally played a peripheral role [86]. Although individuals with multiple perspectives and areas of expertise, such as psychology and decision-making, are increasingly participating in effectiveness research, they may not be fully integrated; e.g. AHCPR's early descriptions of its program called for expertise in the areas of "clinical . . . epidemiology . . . research design . . . economics"; psychology or decision-making was not mentioned [9].

2. **Decision-making should be structured through guidelines and policies**

   Rather than trying to overcome limitations of information use by providing more information, a more productive approach may be to help individuals make decisions by structuring their decision-making through guidelines and
policies. The “rational choice” paradigm assumes that the limitations of information use can be overcome by providing more and better information, such as using videos to present standardized information to patients [8,48].

However, although great efforts are often made to teach people to overcome cognitive biases and avoid framing errors, it can be very difficult to correct these biases [36,87]. Another proposed solution to the problem of information use in the individual patient–provider encounter is to elicit preferences from groups of patients which are then incorporated into health care guidelines [49]. There are, however, numerous conceptual and methodological problems in aggregating individual preferences to form social preferences, such as choosing a representative group of patients and elicitting accurate preferences for conditions they do not currently experience [52].

The evidence we have discussed on how people actually make decisions could be used judiciously in a number of contexts to help individuals make decisions that will maximize societal outcomes while incorporating individual choice and decision-making. A simple example of how decisions can be structured and guidelines can be made more effective is provided by a study on physician compliance with cancer screening guidelines. This study found that compliance improved if physicians were required to justify their non-compliance, as opposed to simply receiving information or reminders [88]. One explanation of these results from choice theories is that the need to justify non-compliance “framed” the decision [21]. Non-compliance became a potential loss rather than a gain (i.e. physicians lose time in justifying non-compliance and forego a possible benefit for the patient), and non-compliance induced “cognitive dissonance” (i.e. physicians face a conflict in having to justify behavior that is at odds with guidelines with which they have expressed agreement).

Although structuring of decision-making is not a new concept [89], we are suggesting that it can be used much more widely and creatively. We return to our example of immunization to provide an illustration. A new vaccine becomes available that is more effective and less expensive than a currently available vaccine. The new vaccine, however, frequently causes inconvenient but short-term and self-limiting side-effects such as rashes, although it rarely causes significant side-effects such as neurological impairment. A guidelines committee has concluded, based on an analysis of the costs and benefits, that the new vaccine should be used; however, because of extensive media reports of side-effects, parents and providers are not using the new vaccine. To increase use of the new vaccine, guidelines could be developed which incorporate evidence on how parents and providers make vaccination decisions (as previously discussed in our examples). For example, the decision to use the new vaccine could be “framed” so that the new vaccine is the default choice and the old vaccine has to be specifically requested by parents and its use explicitly justified, and the benefits of the vaccine could be “framed” for parents in terms of the loss associated with not being vaccinated. Also, reimbursement policies could offer a rebate for use of the new vaccine, while benefit plans could offer the new vaccine as the default choice.

3. Criteria should be developed for determining which guidelines should fully incorporate patient preferences

Criteria should continue to be developed for which guidelines should fully incorporate patient preferences. Building on previous work [90,91], the conditions most conducive to patient preferences include those in which there are major differences and uncertainties in the possible costs, outcomes and treatments; where there are trade-offs between near-term and long-term outcomes and a possibility of a grave outcome; where individuals’ quality-of-life is differentially affected by different alternatives; where preferences for treatments and outcomes can be reliably measured; where patient, provider and societal preferences and objectives do not have irreconcilable conflicts; and where incorporating preferences is cost-effective. For example, effectiveness research on prostate cancer suggests that patients may prefer watchful waiting rather than surgery or radiation since there is uncertainty about the benefits of treatment and patients have different views of the benefits. Furthermore, society may benefit if unnecessary surgery is avoided [92]. Therefore,
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It is useful for guidelines on prostate cancer to emphasize patient preferences.

On the other hand, there are situations where the incorporation of patient preferences may not result in favorable health outcomes. These situations include those in which patients prefer alternatives that providers believe are not in their best interests or when patients or providers prefer treatments that are more costly than equally effective alternatives. In these situations, guidelines and implementation strategies should address how people's decisions can be structured to promote the alternative that is the most beneficial overall.

4. Safeguards must be established to guard against misuse of information

Effectiveness research may be used for purposes other than to improve the practice of health care, which may be appropriate or inappropriate. One safeguard against the misuse of information is full disclosure of interest group participation in effectiveness research, similar to recommendations for industry-sponsored research [93,94]. Disclosure would allow the users of guidelines to be aware of possible conflicts-of-interest and may increase acceptance of the guidelines if disclosure indicates that different perspectives have been represented. In particular, consumers can be more involved throughout the research process, which can not only guard against misuse of information, but can also promote more relevant research [7,95].

Another safeguard is for those involved in effectiveness research to be aware of the political implications of their work. The effectiveness agenda in the US was created in a particularly political environment [75]. Therefore, researchers need to be especially aware of how effectiveness research may be used for political "ammunition" and how their own work may be drawn into the debate.

Lastly, it is important to recognize the legitimate multiple uses of information. Effectiveness research should be credited not only with its obvious uses but also with its more subtle, but still legitimate, uses. For example, some people believe that one of the most important legacies of the effectiveness movement may prove to be the setting of the agenda for broader and longer-term advances that will strengthen the scientific basis for health care decision-making [96]. Therefore, the apparent non-use of effectiveness research, or the lack of "rational" decision-making, should not be the sole criterion on which the success of the effectiveness agenda is judged.

CONCLUSION

We have reviewed potential barriers to the use of effectiveness and quality information and recommendations for adapting to those barriers. We recognize that, in many instances, more information is truly beneficial. The danger is in over-reliance on the benefits of information, without understanding the limitations, and in misunderstanding the purposes for which information is used.

Acknowledgement: We gratefully acknowledge the contributions of our colleagues at the Institute for Health Policy Studies and the Center for AIDS Prevention Studies, Prevention Sciences Group, at the University of California – San Francisco. This work was partially supported by NIH FIRST Award R29 AI34864 (KAP), NIMH Center Grant MH19105 (KAP), and funds provided by the Cigarette and Tobacco Surtax Fund of the State of California through the Tobacco-Related Research Program of the University of California under Award 2KT0072 (LAB).

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