PERSPECTIVE

Navigating the Unknown: Shared Decision-Making in the Face of Uncertainty

Zackary Berger, MD, PhD[1,2]

[1]Division of General Internal Medicine, Johns Hopkins School of Medicine, Baltimore, MD, USA; [2]Johns Hopkins Berman Institute of Bioethics, Baltimore, MD, USA.

In shared decision-making (SDM), patient and physician deliberate together on the basis of shared evidence, supporting the patient's choice among multiple options, informed by her values and preferences. One factor complicating the implementation of SDM is uncertainty, which has long been recognized in medicine but perhaps not sufficiently addressed in the context of SDM. In order to ensure that SDM can be realistically applied to real-world clinical encounters, the issue of uncertainty should be recognized and explicitly incorporated into SDM strategies. Here we propose practical approaches, based in doctor–patient communication science and bioethics, that may be of help for incorporating the uncertainty factor into SDM in the context of the doctor-patient encounter. We also discuss how decision aids might be more widely applicable through routinely acknowledging the preference sensitivity of decisions and supplementing these tools with a discussion of uncertainty.

KEY WORDS: Uncertainty; Shared decision-making; Decision aids; Decision; Patient-provider communication.
J Gen Intern Med 30(5):675–8
DOI: 10.1007/s11606-014-3074-8

In shared decision-making (SDM), patient and physician deliberate on the basis of shared evidence, supporting the patient's choice among multiple options, informed by her values and preferences.[1] Discussing practical complications in exercising SDM is an important element in enabling its widespread use.

The benefits of SDM include increased patient knowledge and confidence in decision-making, as well as the effect on treatment options that patients ultimately choose.[2] SDM enables patient autonomy, the exercise of which can be aided by the sharing of best evidence and clarification of options.[3] This philosophical underpinning assumes that, despite cultural differences and barriers of health literacy, every patient should be allowed to participate in decision-making.

Received March 19, 2014
Revised September 8, 2014
Accepted October 16, 2014
Published online December 24, 2014

The implementation of SDM can be complicated by several factors, including lack of knowledge and a power differential between patient and provider.[4] One such factor is uncertainty, which has long been recognized in medicine but perhaps not sufficiently addressed in the context of SDM.[5,6]

Han et al. define uncertainty as a "subjective perception of ignorance"[7]. Another definition might encompass multiple domains of uncertainty, such as epistemological uncertainty (arising out of the incompleteness or inapplicability of knowledge) and situational uncertainty (arising out of the physician–patient encounter).[8] A more pragmatic approach might acknowledge that uncertainty comes in many different forms that may overlap—e.g., a patient's feeling that the available evidence is not applicable to her might be exacerbated in the moment of decision.

SDM and associated tools can serve as a response to such uncertainty, enabling patients to orient themselves in the available evidence and decision options with the help of their values and preferences and deliberation with their provider. For that to be the case, however, uncertainty should be recognized and explicitly incorporated into SDM.

Here we propose practical approaches, based in doctor-patient communication science and bioethics, that may be of help for incorporating the uncertainty factor into SDM as it applies to the doctor–patient encounter, and the use of decision aids (DAs) to facilitate SDM in the context of that uncertainty. Ours is not the first work to consider communicative approaches to uncertainty in the context of SDM. The suggestions here differ from previous work (e.g., the "shared mind" concept formulated by Politi and Street) in that they acknowledge that residual uncertainty may exist even when good SDM practices are pursued,[9] and thus uncertainty is not to be eliminated but to be coped with and addressed.

UNCERTAINTY IN THE CONTEXT OF THE CLINICAL ENCOUNTER

As a practical approach, we suggest a "toolbox" of bioethical, clinical, and communicative principles that have been outlined in the literature in other contexts, summarized in Table 1, and further discussed below. We echo the suggestion made by Han et al.[5]: addressing uncertainty in SDM is more than addressing knowledge gaps, and "requires helping patients—and health

Table 1. Uncertainty Toolbox: Principles in the Approach to Uncertainty in the Clinical Encounter

Principle	Definition or Clarification	Example	Reference
Honesty	Intersects with other concepts such as integrity, truth-telling; empowers patients to decide on the course of therapy	"Whether statins should be used to prevent heart disease is a matter of dispute."	10
Recognition of emotion	Explicit mention of the non-cognitive element of the decision that may be felt by patient or provider	"It seems like you are very nervous about the possibility of cancer. I understand that might play into your desire to have a mammogram at your age."	11
Hope	The ability to envisage a positive outlook	"There is every reason to believe that regular activity and a healthy diet can favorably affect the progression of knee osteoarthritis."	12
Support/coordination of care	Presenting possible options and following up on their execution	"While I do not think that the evidence for prostate biopsy is unequivocal, many people would see a urologist in this instance, and I could discuss with him the goals for a referral."	13
Willingness to readdress	Actively presenting the possibility of future discussions in which other options might be chosen	"We can come back to this decision later. If things get worse you might want to make another choice."	14
Respecting personal decisions	Explicitly stating that the decision can rely on the patient's personal preference and that the provider will respect that	"While we are sharing the process of making this decision, you should feel free to make a decision which is right for you."	3
A lack of decision is possible	Offering the status quo as an option	"You don't have to make a decision right now."	15,16

professionals—cope with the consciousness of ignorance that cannot be remediated," accepting the existence of uncertainty in life.

1. *Honesty*. Honesty involves several overlapping principles that have been touched upon repeatedly in the literature on professionalism and shared decision-making—for example, unbiased information, presenting options, and partnership.[17,18] Understood more broadly, honestly involves not just the avoidance of explicit bias, but limiting the use of terms that might border on undue influence while not crossing the line into overt coercion. Thus, honesty would seem to argue against such locutions as "The guidelines state…" without recognizing that such recommendations apply differently to different groups of patients, and might not be applicable to a given individual. As recognized in the ABIM professionalism charter, honesty is part of recognizing a patient's autonomy, and as such, is a natural complement to SDM.[19] While the ABIM Physician Charter links honesty to concerns about medical error and adverse events, honesty could apply to the risk–benefit balance of any medical decision.
2. *Openness to Emotions and Non-Logical Thinking*. Both providers and patients make use of emotion, bias, and other non-logical, non-cognitive modalities in finding their way to a decision, and a provider comfortable with uncertainty should be able to identify and acknowledge those modalities. In fact, recognizing a patient's emotions can enable them to feel more satisfied with their decision-making.[20]

   Further, recognizing that providers, too, rely on realms outside the reach of medical evidence can help level the patient–provider hierarchy, helping each understand that the realm of uncertainty can put them on equal footing.
3. *Hope*. Both provider and patient need to allow space for positive outcomes in the face of uncertainty. This is recognized as a necessity in end-of-life circumstances,[12] but should apply to routine chronic care as well. For example, it might be impossible to predict for a given patient whether their osteoarthritis will improve, continue with stable symptomatology, or worsen. One can, however, discuss the best available options for treatment, and in that context maintain hope that the patient will manage to maintain her activity, even given the chronic and unpredictable nature of the disease.

   Operational definitions of hope outside the end-of-life setting are lacking. Although we are not concerned here with the spiritual variety of hope—for example, religious faith—we do suggest that the hope to be cultivated in situations of uncertainty shares something important with faith, and that is an attitude of trust in a potential positive outcome. Just as hope in the palliative care setting should be truthful (not deceptive), functional (useful to patients), and narrative (providing meaning), hope in the context of uncertainty can help provide a means for patients to navigate uneven terrain.[12] If hope involves such trust, this element of the toolbox can serve as a useful counterweight to honesty: if honesty is enabling the patient's autonomous participation in SDM, hope might depend on an advice-giver—the provider—who can outline a potential positive future.
4. *Support and Coordination of Care*. If the course and outcomes of a condition are unpredictable, one might expect that the primary provider would have recourse to specialists. However, specialist referral is not always

accompanied by explicit discussion about who is now primarily responsible for care—and thus risks giving the patient/family the impression, however mistaken, that they have been abandoned as they face an uncertain future.[21]

When the uncertain course of illness requires specialist referral, the primary provider and patient might explicitly consider "decision rules" for continuing involvement of the specialist, return to the primary provider, or, in some cases, management of the entire condition by the specialist, with occasional visits to the generalist.

While the primary provider might not think that referral to a surgeon or a specialist (e.g., to an orthopedic surgeon for osteoarthritis) is indicated at the particular stage of the patient's condition, part of the approach to uncertainty, as is widely accepted in SDM, is the presentation of all options. If, for some reason, the provider considers some of the possible options to be unworkable or inappropriate, she should communicate those rationales in detail.

5. *Willingness to Readdress*. Uncertainty is not necessarily permanent. New information may make the future course clearer or change the range of options. (For example, a cancer may progress; a fracture may affect mobility; a new diagnosis may affect the presentation of preexisting conditions; symptoms may recede, making further testing or diagnosis unnecessary.) This, too, is a principle that has been enumerated in models of SDM.

   Nevertheless, in the context of this uncertainty toolbox, we might see such revisiting in a different light. Patients may take different approaches to decision options based not on changed goals, new information, or worsening symptoms, but on different emotional states.[18]
6. *Respecting Personal Decisions*. Individuals may come to different conclusions on the basis of the same information, and these conclusions may not be the same as the provider himself would reach. However, as in every patient–provider relationship, those decisions should be respected if the patient presents them as hers.[22] Thus, while the term "shared decision-making" clearly connotes a process of deliberation and option selection carried out by two parties, since the personal preferences and values of the patients themselves are important to the outcome, the decision will be personal and should be respected as such by the clinician.
7. *Clarification of Goals over Time*. As patients cope with the presence of uncertainty, perhaps with the help of discussion with a nurse or physician, consultation with trusted advisors, or talking with family or friends, their goals may change or become clearer to them. Just as the patient and provider should be prepared to revisit options in light of new information and circumstances, they should also be ready to discuss modification of goals over time.
8. *A Lack of Decision is Possible*. In a landscape of uncertainty, refraining from making a decision is always a possibility. Many health care visits, from the patient's perspective, do not focus on decision-making.[23] The phrase "no decision is also a decision," despite its grain of truth, can be misleading, implying that the choice of no intervention is passive, in contrast to a choice to intervene. In an atmosphere of uncertainty, choosing not to make a decision can be an active route to coping with a situation.

   The "veil of experience,"—i.e., the patient's experience with lack of participating in shared decision-making—may influence patients to express a preference for the status quo.[24] Common sense would indicate, however, that even if patients are engaged to participate in shared decision-making, some might still prefer to "make no decision."

DECISION AIDS AND UNCERTAINTY

Because decision aids help patients to recognize options, understand that values affect the decision, discuss their values, and become involved in the decision in the manner that they prefer, these tools can reduce the impact of uncertainty. A Cochrane Collaboration systematic review from 2012, updated in 2014, showed that DAs compared to usual care resulted in lower decisional conflict related to feeling uninformed and unclear about personal values.[2]

In real-world settings, there are gaps remaining with regard to implementation of DAs. For example, the review by Stacey et al.[25] showed a lack of evidence regarding the effectiveness of DAs in identifying situations in which a decision could be made, as well as inconsistent evidence regarding the types of decisions for which DAs actually resulted in a change in patient choice: such change was found in 3 of 46 different decisions. For most types of decisions, the evidence regarding the effect of DAs is mixed, of low quality, or shows no effect at all. The effects of DAs were limited with respect to the ultimate choice that the patient made and on their satisfaction with the decision-making process.

Such limited impact on patients' decisions and their satisfaction with the process, despite the favorable impact on uncertainty, may have several implications. One is that existing DAs are not optimally designed, e.g., according to the IPDAS guidelines.[25] Another possibility is that uncertainty is not a particularly important consideration in decision-making. Equally possible, however, is that there is still a lack of clarity as to which decisions are most appropriate for the use of DAs. Some clinicians contend that "preference-sensitive" decisions, in which the risks and benefits of the alternatives are closely balanced, may be best suited to their use. In these situations, the goal may not be to reduce uncertainty, but to incorporate it into the decision-making process, as the patient's decision will highly depend on their own values and

preferences. Given the inherent uncertainty of medical evidence, preference-sensitive decisions may be more common than was previously thought.[26]

Decision aids already in existence might be supplemented, keeping in mind the toolbox elements described above. Such "supplemented" decision aids would provide opportunities to candidly discuss the uncertain nature of prognosis, as well as the inability of doctors in many cases to predict the natural history of disease, together with the significant prevalence of diagnostic error[27] and the imperfect nature of guidelines.[28] These tools would emphasize the hope and support that should be forthcoming, the willingness to readdress the situation as more information becomes available, and the respect that must be afforded to individual decisions even if they are not based on scientific evidence. Such supplemented decision aids may increase patient satisfaction with the process in preference-sensitive decisions.

The gap between the science of medicine and the uncertainty of day-to-day life is a space within which both doctor and patient should learn to be comfortable. Acknowledging the presence of uncertainty as an element of SDM may help physicians and patients feel more at home there.

Acknowledgments: *This study had no sources of funding.*

Conflict of Interest: *The author declares that there are no conflicts of interest.*

Corresponding Author: *Zackary Berger, MD, PhD; Johns Hopkins Outpatient Center, 601 N Caroline St Suite 7143, Baltimore, MD 21287, USA (e-mail: zberger1@jhmi.edu).*

REFERENCES

1. **Elwyn G, Laitner S, Coulter A, Walker E, Watson P, Thomson R.** Implementing shared decision making in the NHS. BMJ. 2010;341:c5146.
2. **Stacey D, Légaré F, Col NF, et al.** Decision aids for people facing health treatment or screening decisions. Cochrane Database of Syst Rev. 2014;Issue 1. Art. No.:CD001431. doi:10.1002/14651858.CD001431.pub4.
3. **Elwyn G, Frosch D, Thomson R, et al.** Shared decision making: a model for clinical practice. J Gen Intern Med. 2012;27(10):1361–7.
4. **Joseph-Williams N, Elwyn G, Edwards A.** Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. Patient Educ Couns. 2014;94(3):291–309.
5. **Fox RC.** The evolution of medical uncertainty. Milbank Q. 1980;58(1):1–49.
6. **Geller G, Faden RR, Levine DM.** Tolerance for ambiguity among medical students: implications for their selection, training and practice. Soc Sci Med. 1990;31(5):619–624.
7. **Han PK, Klein WM, Arora NK.** Varieties of uncertainty in health care: a conceptual taxonomy. Med Decis Making. 2011;31(6):828–38.
8. **Kirkegaard P, Risør MB, Edwards A, et al.** Speaking of risk, managing uncertainty: decision-making about cholesterol-reducing treatment in general practice. Qual Prim Care. 2012;20(4):245–52.
9. **Politi MC, Street RL Jr.** The importance of communication in collaborative decision making: facilitating shared mind and the management of uncertainty. J Eval Clin Pract. 2011;17(4):579–84.
10. ABIM Physician Charter. Accessed August 25, 2014, at http://www.abimfoundation.org/en/Professionalism/Physician-Charter/Principles-of-the-Charter.aspx.
11. **Légaré F, Thompson-Leduc P.** Twelve myths about shared decision making. Patient Educ Couns. 2014. doi:10.1016/j.pec.2014.06.014.
12. **Olsman E, Leget C, Onwuteaka-Philipsen B, et al.** Should palliative care patients' hope be truthful, helpful or valuable? An interpretative synthesis of literature describing healthcare professionals' perspectives on hope of palliative care patients. Palliat Med. 2014;28(1):59–70.
13. **Elwyn G, Edwards A, Kinnersley P.** Shared decision-making in primary care: the neglected second half of the consultation. Br J Gen Pract. 1999;49(443):477–82.
14. **Epstein RM, Gramling RE.** What is shared in shared decision making? Complex decisions when the evidence is unclear. Med Care Res Rev. 2013;70(1 Suppl):94S–112S.
15. **Elwyn G, Edwards A, Kinnersley P, Grol R.** Shared decision making and the concept of equipoise: the competences of involving patients in healthcare choices. Br J Gen Pract. 2000;50:892–9.
16. **Towle A, Godolphin W, Grams G, Lamarre A.** Putting informed and shared decision making into practice. Health Expect. 2006;9:321–32.
17. **Rogers W, Ballantyne A.** Towards a practical definition of professional behaviour. J Med Ethics. 2010;36(4):250–4.
18. **Edwards A, Elwyn G.** Shared Decision-Making in Health Care: Achieving Evidence-Based Patient Choice. New York: Oxford University Press; 2009.
19. ABIM Charter. http://www.abimfoundation.org/Professionalism/~/media/F8B71F15DE8B486599F13E662603F25D.ashx. Accessed August 26, 2014.
20. **Power TE, Swartzman LC, Robinson JW.** Cognitive-emotional decision making (CEDM): a framework of patient medical decision making. Patient Educ Couns. 2011;83(2):163–9.
21. **Gandhi TK, Sittig DF, Franklin M, et al.** Communication breakdown in the outpatient referral process. J Gen Intern Med. 2000;15(9):626–31.
22. **Quill TE, Brody H.** Physician recommendations and patient autonomy: finding a balance between physician power and patient choice. Ann Intern Med. 1996;125(9):763–769.
23. **Barsky AJ III.** Hidden reasons some patients visit doctors. Ann Intern Med. 1981;94(4_Part_1):492–498.
24. **Salkeld G, Ryan M, Short L.** The veil of experience: do consumers prefer what they know best? Health Econ. 2000;9(3):267–270.
25. **Elwyn G, O'Connor A, Stacey D, et al.**, on behalf of the International Patient Decision Aids Standards (IPDAS) Collaboration. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. Br Med J. 2006;333(7565):417.
26. **Keirns CC, Goold S.** Patient-centered care and preference-sensitive decision making. JAMA. 2009;302(16):1805–1806. doi:10.1001/jama.2009.1550.
27. **Graber ML, Franklin N, Gordon R.** Diagnostic error in internal medicine. Arch Intern Med. 2005;165(13):1493–9.
28. **Lenzer J, Hoffman JR, Furberg CD, et al.**; Guideline Panel Review Working Group. Ensuring the integrity of clinical practice guidelines: a tool for protecting patients. BMJ. 2013;347:f5535.