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Uncertainty and Competing Priorities in Shared Clinical Decision-Making

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Let's face it, sometimes even our most carefully considered and skillfully delivered recommendations or care plans are not adopted by our patients. This phenomenon has been variously, and often pejoratively, referred to as “noncompliance” or “nonadherence.”¹ In this issue of *Journal of Patient-Centered Research and Reviews*, four articles specifically touch on the subject of patient uncertainty or competing priorities that can affect medical decision-making.

Grant and colleagues, in their study of patients with heart failure during the first month following a related hospitalization, reported that some individuals felt uncertainty over their health status and wanted reassurance regarding safe limits to daily activity.² They also noted that patient priorities changed over the weeks following discharge.²

Similarly Hagan et al, in their novel Twitter chat regarding the needs of women treated for ovarian cancer, discovered uncertainty was common among the patient participants.³ The authors end their work by advising clinicians: “This vulnerable time in patients’ lives is our opportunity to demonstrate our understanding of their needs and concerns.”³

The qualitative study of women with breast atypia by Goff and colleagues found that interviewed women “varied in the extent to which they wished to actively

participate in decisions” regarding treatment.⁴ Their subjects also self-reported that they had to handle uncertainty regarding increased risk of invasive cancer developing after a diagnosis of atypical hyperplasia or lobular carcinoma in situ.⁴



Finally, in their exploration of what outcomes matter most to hysterectomy patients, Bossick et al concluded that their collective data “suggest a need for increased education and empowerment in the decision-making process.”⁵ Several of the included participant quotes implied issues of uncertainty surrounding hysterectomy decisions.⁵

It might be tempting to write off these concerns of uncertainty as merely a byproduct of poor patient-provider communication. Yet absolute certainty in medicine is difficult to achieve. Before any communication can be improved, one must be reasonably confident regarding the information he or she intends to relate.

Among novice and experienced clinicians alike, diagnostic and therapeutic uncertainty is an important issue.^{6,7} It may well be true that there is a general intolerance of uncertainty among some physicians, leading to difficulties in patient care.⁷ In fact, there is evidence from over 30 years ago that “only rarely (did) clinical uncertainty present management problems for the doctor.”⁸ It may have been rarely identified and likely posed little problem due to the doctor being “in

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a position of control” in medical encounters, whereas the patient was “dependent” or passive.⁸

However, a recent mixed-methods study involving 385 videotaped patient encounters observed that physicians expressed uncertainty in a fair proportion (12%) of topics discussed in the visits (compared to 20% among patients).⁹ This same study indicated that for both physicians and patients the amount of expressed uncertainty varied by topic (mental health topics had the most), and that physicians expressed more uncertainty with patient-initiated topics compared to general biomedical topics.⁹ Patient uncertainty is to be anticipated in many chronic conditions, or even incidental findings, especially if the etiology is unknown and/or there is a lack of consensus regarding specific treatment and predictable outcome.^{10,11} For at least some diseases, like prostate cancer, the degree of uncertainty may vary by ethnic group, age, and educational level.¹² Unsurprisingly, uncertainty and the “perception of danger” decreases satisfaction with treatment outcome.¹²

Recently, Davies and colleagues interviewed persons who had been living with an incidental thyroid lesion that was known or suspected to be malignant for a mean of 3 years.¹¹ These individuals expressed uncertainty or questioned the advice they had been given to intervene to remove or reduce the threat of cancer. Their experiences included anxiety, “secret keeping,” isolation, shame, and ostracization.¹¹ Similar to the findings of Bossick et al regarding hysterectomy choices,⁵ Dahlerus and colleagues, in their qualitative study of patients with advanced chronic kidney disease, found that these individuals wished more input into dialysis decisions.¹³ Some had fear and lack of conveyed knowledge, if not explicit uncertainty.¹³

Patient priorities at the time of medical decision-making often have an impact on those decisions. I am reminded of a small project family medicine residents performed in our teaching clinics. Based on their knowledge of the patient’s medical history, the physicians were to indicate their greatest fear or concern regarding the patient’s health before entering the room. Not sharing their concerns, the physician then asked the 94 patients (82% of whom had at least 1 chronic disease) what was their greatest fear regarding their health. Patient-

physician concordance was a mere 44% (and only 32% in those with hypertension). Thus, patients may often prioritize their chief concerns differently than we do (Quiroz EM, Kram JJ, Bernhard KA, Ledesma M, Rosner K, Baumgardner DJ, unpublished data, 2014). Others have observed that patients with chronic disease and clinicians may differ regarding priorities and that such discordance may affect the patient-clinician relationship.¹⁴ Not surprisingly, these patient priorities can change over time.^{14,15}

Mangin and colleagues noted that person-focused care, as opposed to disease-focused care or even patient-centered care, includes “the additional dimension of care over time, which in the context of multimorbidity is both essential and requires priority setting as well as preferences for care.”¹⁶ These authors found a dearth of tools to assess patient priorities in the primary care setting. The single useful article identified, in my opinion, shows promise as a fairly quick and simple tool to start patient priority conversations during an office encounter.¹⁷ This report, by Fried et al, describes a 100-point visual analogue scale on which patients are asked to rank four possible outcomes: maintaining independence, staying alive, reducing or eliminating pain, and reducing or eliminating other symptoms.¹⁷ Test-retest reliability, however, was fair to poor (which could, in part, represent changing patient priorities).

Tinetti et al also took up the issue of fragmented, disease-oriented care in patients with multimorbidity.¹⁸ They recommend a “refocus of care ... to patient-priority-directed care,” in which patient outcome goals are solicited and an examination of the burden/benefit ratio is undertaken; the authors did acknowledge the multiple challenges and complexity of this dramatic paradigm shift.¹⁸

It has recently been suggested that our electronic health records (EHR) be redesigned to focus on goal-directed, rather than problem-focused, health care.¹⁹ Perhaps with such redesigned EHR, simple office tools like that proposed by Fried and colleagues,¹⁷ and the will to practice shared decision-making (a model “based on *choice, option* and *decision talk*”²⁰), clinicians can at least approach person-focused care at its best. This evolution will naturally incorporate many of Rosner’s proposed solutions to “noncompliance,”¹

and likely assist both patient and clinician in facing the uncertainty that often unavoidably occurs during the ever-developing processes of diagnosis and treatment.

One way of addressing uncertainty in medicine is to view the patient-provider exchange as a two-way street. Patients can serve as teachers, as Becker and Seeman point out in their essay within this issue,²¹ one of myriad reasons why they deserve our greatest care and respect. No doubt they can teach us much about handling uncertainty and their competing priorities. We must ask and listen.

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