Don't Just Check the Box: Capture the Patient's Story to Define Meaningful Goals of Care

written by Thomas Dent, M.D. | February 15, 2018

What does Shared Decision-Making between doctor and patient really look like? I spent four decades as a primary care physician, as well as 27 years teaching medical students and residents. Looking back on my treatment of patients, I now question whether my management was driven by what the patient wanted—or by what I wanted for the patient.

Certainly, I wanted to do what was in the best interest of the patient, and I sincerely hope that our interests were often well aligned. In certain specific cases, I acted against the stated desires of the patient, a necessary call (discussed below). Most often, however, I could have better elucidated the desires and capabilities of my patients. They were often passive participants in goal-setting.

Why do I now believe that patients must be the primary authors of their goals? Because patients bear the bulk of responsibility for acting on these goals. They are the only ones who

can make necessary lifestyle changes as well as follow any therapeutic plan that I formulate.

In my practice, I believed patients would do most of what I defined as their therapy; where I was unsure, I would try to identify barriers. But I did not start the conversation with questions about the patients' desires or goals. Rather, I would ask how the patient was doing with a problem from a previous visit. This would immediately limit responses. The patient's life occurred outside of the examination room, and there were multiple factors affecting the patient that I didn't always know.

As a result, I realize now that I was in the dark about meeting the patient's expectations. Diagnostic testing or referrals to find answers for poor outcomes was potentially wasteful and even misleading, absent an understanding of what the patient wanted and was willing to accept.

I share these reflections because the time has come for a shift in priorities in the exam room.

Defining Patient Goals Is Messy but Essential

The process of defining goals is more complex than we clinicians may want to admit. I would often not state a goal as mine, but defer to guidelines. Let's say a patient asked if a blood pressure reading was okay. I would explain if it was above or below a guideline. If high, I would then place this in context of associated risks. What's tricky here is the fact that high blood pressure is often asymptomatic; so it's unlikely that a patient would arrive at the necessary goal of lowering blood pressure unless he or she had experiences with prior therapy.

When a symptom or outcome was more obvious, however, a patient might ask to discover the cause. "Just knowing" is important and often a point of agreement between patient and physician. But this type of goal setting didn't work when the patient had mental health issues that were the source of the symptoms, and she or he would not accept the diagnosis, as a result.

Over time, my and my patients' expressed goals would change. New conditions arose and, sometimes, old ones resolved. Treatment side effects would affect priorities, as would marginal improvement in outcomes. When patients stopped smoking, lost weight or stopped drinking, I felt I was at least partially responsible. However, when patients reverted to these behaviors (as very often happened), I also felt responsible. I owned the goals and outcomes because I had created and pushed them. But in reality, for new behaviors to become long lasting, healthy habits, the patient must own the goal and steps to reach it. I could help with medications or referrals, but the patient's home or social life trumped my efforts.

Some of the most important input I received for creating and meeting goals for the patient came from individuals close to him or her. They often revealed goals that the patient had but could not or had not articulated.

Even with the best of intentions, however, I didn't always have time to address goal-setting, The ability to meet goals during a single office visit was limited. Persistence over long periods of time worked best, but wasn't always easy to accomplish. There was no well-organized process to capture goals and measure success in follow-ups. Visits would often be consumed by urgent concerns. And, because I was the one who created the goals, the work was on me—when it should have been a shared responsibility.

So, what were some of the goals I set, and were they actually meaningful to the patient? Some goals involved intermediate outcomes (BP, weight, HgbA1C). These goals are often quality measures for primary care physicians, more physician-centric than patient-centric. Therefore, patients had little investment in meeting them.

Other cases necessitated that I be directive in establishing goals: protecting vulnerable children, working with patients acting under the influence of alcohol or other mind-altering medications, or treating people who were otherwise incompetent. These instances require physicians to create interventions with family members or other people important to the patient, and who might provide insight and leverage to help the patient.

Achieve Better Results by Engaging Patients in Goal-Setting

All this experience has taught me that the patient—and physician—will achieve better results if the patient sets the goals. So why are physicians still not likely to ask patients about their goals at the outset of treatment?

At a very basic level, patient-set goals may differ dramatically from physician-set goals. The underlying reasons for a patient's goal may well be complex and require a nuanced discovery process by the physician—one that is time consuming and difficult to pursue within the constraints of office caseload and revenue requirements.

This is not to argue against a shift in the exam room dynamic, however. A discussion that reveals a patient's personal circumstances, such as poverty or loneliness, may have a profound impact on how the care team might act, with dramatic benefit for the patient. After years of taking hypertensive medications, for example, a patient might put "lower my blood pressure" on a list of goals, but the true desire is to avoid a stroke or other vascular event in order to

maintain independence—mobility, cognition and self-care.

Likewise, without probing more deeply into a patient's circumstances, the physician could miss subtle changes to cognition that the patient chooses not to mention because of hopelessness or fear and denial. Patients may set goals that don't make sense unless the care team understands personal deadlines, such as attending a son's wedding. Physicians may err on the side of setting low-bar goals based on patients' age, and miss their true ability or passion for running or other sports.

Ask Key Questions to Help Identify Patient Goals

To help patients articulate these goals, we need a different approach to the discovery process. It starts with asking broad questions to draw out the patient's opinions, preferences and beliefs. The patient and/or family need information about the patient's health status and options to create an appropriate context for making decisions. Questions like the following can elicit the patient's overall goals for health and treatment:

> What do you want to be able to do or achieve, related to your health?
> What is the most important and meaningful goal for you as a person, which will make life better (more enjoyable or more fulfilling) physically, emotionally or spiritually?
> What do you think is needed to meet these goals?
> What is the most effective treatment you have experienced or step you have taken to improve your health in the past?

This is, admittedly, a tall order. Physicians are disinclined to ask such questions because patient-set goals require action beyond the competence and comfort level of many physicians, such as delving into social and family dynamics. In addition, physicians may have to create clinical interventions to achieve the patient's goals, and that requires time that exceeds most primary care office visits.

Meaningful goals are often messy and time consuming to develop. Walking carefully through potential adverse outcomes for any given intervention is necessary for patients to understand and watch for inherent risks. Interventions to meet goals should also utilize the patient's social support system as much as possible (with the patient's permission) as a means of identifying barriers and understanding the patient's motivation. Ultimately, patients must be engaged and motivated in order to create meaningful goals that they will actually strive to meet.

How Organizations Can Help Physicians Facilitate Better Outcomes Through Patient Goal-Setting

Given limits on physician time and resources, their organizations must play a key role in helping them elicit patient goals and introduce Shared Decision-Making. The organization has five essential tasks:

1. Create a method to allow documentation and tracking of patient goals.

Physicians need an easy method of documenting and tracking patient goals for further discussions and goal modification. This documentation and tracking should be discussed and implemented as part of the organization's support structure for physicians.

In documenting meaningful goals, organizations should consider how much input the patient should have in memorializing his or her healthcare wishes. Desires, fears and prioritization of health choices must be accurately reflected, time stamped and tracked. This includes the trade-offs that the patient is willing to make.

While "documentation" is usually structured and boxed, it is important for Shared Decision-Making to obtain unstructured responses to the above questions. We can't put words in the patient's mouth or limit responses. This is in keeping with the goal of having patient-centered Shared Decision-Making and reflects the goal of creating a unique story for each patient.

2. Help physicians develop the motivational and guidance skills they need to elicit patient goals.

The AMA has recently promoted a process of asking patients "What Matters to You?" This is an admirable program to uncover the social determinants of health. As healthcare professionals begin to use this approach, the entire goal-setting process will need restructuring. It is my belief that the more detailed approach I delineated above will capture a richer and more nuanced picture of what matters most to a patient—a more complete story.

Motivational skills grow from empathy and understanding the patient as a person. Identifying approaches and techniques that have resulted in observable improvements in goal results will enable clinicians to recognize the factors used in their practice or organization that contributed to success.

3. Measure results of patient outcomes related to goals, including capture of patient-reported results.

We often assume that measurement of results must fall upon physicians and data harvested from their input. But there is a strong case to be made for asking patients how they did. First, it provides a touch point to reconnect on goals and assess progress. It also provides an opportunity to give physicians useful feedback, via measurements such as the following, using descriptors for each response on a scale.

Patient obtained feedback:

- Whether they are able to meet or work toward their goals;
- How effective the health care team has been in helping them reach their goals.

Data from visit analytics:

- Visit and contact adherence for chronic condition management (frequency and regularity of contact between office and patient, including visit and telehealth contacts);
- Change in attribution for Medicare patients (i.e. whether or not the patient was assigned to the clinician based on the amount of primary care services).

4. Facilitate needed time for goal-setting and further discussion through appointments focused on Shared Decision-Making.

To create this environment requires substantial time and physician training. Organizations that seek to implement true Shared Decision-Making—in which the patient, not the physician, really sets the goals—must restructure productivity goals and expectations for office visits.

The pay-off for the patient and organization promise to be significant. By capturing patients' desires, fears and aspirations to formulate goals, the patient and physician form an important bond. Paying attention to the unique patient story will uncover factors leading to poor health or, at least, lack of improvement. Creating a loyal cadre of patients who value clinicians who ask detailed questions and take time to listen will distinguish these institutions.

5. Utilize care teams with diverse skills, such as including community health workers.

A health care team comprised of a range of providers augments the physician's ability to understand the patient's goals. More providers will ultimately spend more time with the patient; other skills and insights can illuminate the patient's circumstances. Team knowledge of the family, community and available resources can help to refine goals and support the patient's efforts to achieve them.

Patients may be more open to sharing deeper concerns with some health care workers than they are with physicians because patients view them as more accessible. Home care workers can provide dramatic insights into the patient's life outside the office. This is also true for physicians who provide home visits. Community health workers are often an underutilized resource for clinicians to enhance their understanding of the patient's community and his or her role in it.

The Patient's Real Story Is More Than a Medical Record

The patient's story is so much more than what gets captured in a medical record. It is fluid and requires the patient's oversight and tending. At the same time, the patient may not have considered all of her or his goals, and the physician can help identify the appropriate path. The patient should expect responsiveness, encouragement and kind understanding from the health care team. Clinicians must begin to look where they haven't always looked to fully address their patients' desires and needs. This includes asking what transcendent goals the patient might have. Helping others has a therapeutic value that should not be ignored.

I wish I could go back and ask my patients more about their personal goals. I believe this would have improved their wellbeing. I encourage clinicians to learn from my experience and invest the time and effort needed to fully understand patients' goals as a critical step toward real Shared Decision-Making.

Founded as ICLOPS in 2002, Roji Health Intelligence guides health care systems, providers and patients on the path to better health through Solutions that help providers improve their value and succeed in Risk. Roji Health Intelligence is a CMS Qualified Clinical Data Registry.

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