When treating patients, 'our core goal is to enable their goals' - *Atul Gawande, MD*

CHICAGO — When treating patients with serious illnesses or at the end of life, the goal of clinicians should to be help draw out and then enact patients' goals related to their well-being, satisfaction and affordability of treatment, ***Atul Gawande, MD,*** said during the opening ceremony of ASCO Annual Meeting.

"The bottom line is that we should imagine with them their life worth living, and then use our medical capability to enable [that life]," *Gawande*, general and endocrine surgeon at Brigham and Women's Hospital, professor at Harvard School of Public Health and Samuel O. Their professor of surgery at Harvard Medical School, and author of *Complications, Better, The Checklist Manifesto* and *Being Mortal: Medicine and What Matters in the End,* among other books, said during his guest speaker's address.

This practice may differ from what is taught in medical school, *Gawande* said.

"The way I'd practiced and learned to think about my goals [as a clinician] was to give patients options for their best health, independence and survival," he said. "Give them the facts of their situation, their options, and the risks-benefits and pros-cons, and then give them their choices."

However, *Gawande* said, patients inevitably will respond to this information by asking, "What would you do, doctor?"

"In medical school, I learned to say, these aren't decisions for me to make. Only you know you, and there is no wrong answer here.

"But, I always felt I was abandoning them," he said.

Beyond treatment vs. no treatment

When treating patients with terminal illnesses, the pivotal moment often comes when patients are tasked with the choice of whether to continue treatment or choose palliative or hospice care. Often, patients may see this as a choice between "continuing to fight" or "giving up," *Gawande* said.

"What strikes me about that moment is that ... these are the specific moments that we all struggle with, as clinicians, as family members, and also as societies and professions," he said. "What do we do in this moment? What do we think of as great care? What is actually our goal?

"I found over and over that it was unclear," he added. "I learned about a lot of things in medical school and residency, but mortality wasn't one of them. I knew how to fix many things, but for the unfixable, what does it mean to be great at doing this work?"

To answer these questions, *Gawande* embarked on a mission to interview a range of clinicians — from surgeons to medical oncologists, hospitalists, palliative care providers and hospice nurses — and over 200 families and patients.

The journey began by interviewing *Temel and colleagues* about their research — published in 2010 in *The New England Journal of Medicine* — that investigated the role of early palliative care in patients with stage IV lung cancer.

That analysis included 151 patients randomly assigned to undergo usual oncology care or palliative care initiated at diagnosis.

Palliative care this early in the treatment trajectory might cause patients and clinicians alike to think, "it's too early, we still have options," *Gawande* said.

But, the results showed that not only were the patients assigned earlier palliative care less likely to receive chemotherapy within the last 2 months of life, and 90% less likely in their final 2 weeks of life, but they also had less suffering. They spent more time at home and less time in the hospital, incurring fewer costs for chemotherapy.

"And the real kicker was, they lived 25% longer," *Gawande* said.

"I'd thought that the trade-off between serving the quality of people's lives and serving the quantity of people's lives was fixed," he added. "We had to make choices. And here, this would suggest that you could serve people by reducing their suffering, improving their quality of life, and not reducing their quality of life — perhaps even improving it."

However, a model in which palliative care clinicians aim to serve patients' quality of life, and medical clinicians aim to serve patients' quantity of life, "seems crazy," *Gawande* added.

"I wanted to do both," he said.

During his interviews, *Gawande* learned that the most powerful thing palliative care clinicians did was ask patients what their priorities were.

"When we don't ask, the care we provide is out of alignment with people's priorities," he said. "The result of that, is suffering."

From his interviews with patients and their families, *Gawande* learned that patients have goals beyond survival, and these goals differ from person to person.

To enable clinicians to understand these individualized goals, *Gawande* and colleagues developed a conversation guide. The guide includes questions such as, "What is your understanding of where you are with your illness, and how much information would you like about what is ahead of you?" "What are your goals for your health situation?" "What are your biggest fears and worries?" and "What life-extending treatments are you and aren't you willing to undergo?"

Gawande and colleagues studied the impact of this conversation guide among a group of 91 oncologists at Dana-Farber Cancer Institute. Fifty percent underwent an intervention that included training in goal-oriented discussions and coaching and support, with system reminders if conversations were not had or documented.

Results showed that goals-of-care discussion came about 5 months earlier as a result of the intervention. Ninety percent of patients discussed their values and morals, and patients were more likely to have discussed their prognosis and had greater illness understanding.

The intervention doubled the likelihood for documenting patients' preferences for life-sustaining treatment and cut by about half severe to moderate anxiety and depression among patients.

"It seems like our goal is very simple: People's health and independence," *Gawande* said. "When that's not possible, it seems like we're lost ... and people are coming to us with very large questions.

"We haven't thought of this as our core goal, to enable their goals," he added. "In order to do that, we need to ask them about their goals for health, family and financially, and then make choices and actually recommend to them what from your experience gives them the best chance of achieving those goals."

Thus, this goes beyond presenting patients with their options and asking them to choose on their own, as *Gawande* was taught to do in medical school. This presented a "completely different way" of approaching these conversations, he said.

"This is not just about anyone approaching the end of life. This is about the way we work as clinicians," he said. "It is about any serious illness: We set a goal, and we make a plan and make sure it is executed and we are all the while optimizing well-being, satisfaction and affordability."

'Fight for one good day'

Gawande also spent time shadowing a hospice nurse, during which he learned that hospice goals of care are much different than what he had assumed.

"I thought their goal was to let nature take its course," he said.

Instead, the hospice provider he was shadowing replied by saying, "Medicine's goal is to sacrifice people's time now for possible time later. My goal is to use the same medical capabilities to give people their best possible day today, regardless of the consequences for tomorrow."

"It was almost Zen," *Gawande* said of this nurse's words. "Let's just focus on having your best possible day."

During his lecture, *Gawande* shared the personal anecdote of his daughter(*Hunter)'s piano teacher, Peg, who underwent a year of treatment for rhabdomyosarcoma, leaving the hospital with an excellent prognosis.

However, she soon developed myelodysplastic syndrome as a result of this treatment. Later, when the therapy for her myelodysplastic syndrome had stopped working, her doctors also discovered that her rhabdomyosarcoma had returned and had spread throughout her pelvis and liver.

She called *Gawande* and told him that her doctors had given her a choice between fighting or giving up, and asked what she should do.

Gawande ran through the conversation guide to help ascertain Peg's goals. Then, he asked a question prompted by his time shadowing the hospice nurse.

"It seems like it's been a while since you've had a good day," he said. "Is that worth hoping for, worth fighting for? The question isn't do we do something or do nothing, do we fight or give up. The question is, what are we fighting for? Maybe we could fight for one good day."

His recommendation to Peg was to return home on hospice care, which she did 2 days later.

To *Gawande's* surprise, Peg soon called again to ask whether she could resume teaching his daughter, Hunter, piano lessons. After arranging the logistical and care needs for Peg at home, her hospice nurse enabled Peg to have time to again teach piano to her students, what her "good day" looked like.

"That is something that we never would have known was even possible," *Gawande* said. "We weren't even striving for it, we weren't asking whether it could be achieved. The key thing to understand about who we are is that in this moment, when genomics are exploding, the choices are multiplying ... it's going to require richer conversations with patients about their goals for quality and quantity of life, about what living a good day really means and making it possible."

As Peg became sicker, she held a final two concerts to say goodbye to her patients and offer them advice.

To Hunter, Peg gave a book of music, and told her she was special.

"I tell you this because, today, Hunter is now in her second year of Berklee College of Music in a career as a musician, because of these moments," *Gawande* said. "These are critical to what you [as clinicians] make possible. Having a richer sense of what we are, what our goals are, and how we achieve them every day for our patient's outcome, for their experience working with us, and for their affordability, is essential. I thank you for everything you are seeking out to do to make these moments possible."

- Report by Alexandra Todak – June, 2019