Words Matter: Use of Respectful Language in Oncology

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Abstract
During JADPRO Live Virtual 2020, Conference Chair Laura J. Zitella, MS, RN, ACNP-BC, AOCN®, spoke with Tatiana M. Prowell, MD, about overcoming implicit bias, the power of language, and creating a culture of respect in oncology for both patients and health-care professionals.

While cancer treatments continue to evolve at a rapid pace, the culture of medicine is rife with outdated norms that reinforce gender and racial disparities, explains Tatiana M. Prowell, MD, of Johns Hopkins Kimmel Comprehensive Cancer Center.

During JADPRO Live Virtual 2020, Conference Chair Laura J. Zitella, MS, RN, ACNP-BC, AOCN®, spoke with Tatiana M. Prowell, MD, about overcoming implicit bias, the power of language, and creating a culture of respect in oncology for patients and health-care professionals alike.

IMPLICIT BIAS

As Dr. Prowell reported, recent research has highlighted inconsistency in the forms of address used to introduce faculty. A review of 2 years of speaker introductions at the ASCO Annual Meeting showed significant differences in the likelihood of women vs. men to receive a professional form of address.

"It was disturbingly common how often women were introduced with a first name alone," said Dr. Prowell, who noted that approximately one in six women were introduced without such appropriate respect at this high-profile international conference. "I found this shocking."

Dr. Prowell observed that the issue is one of implicit bias, which refers to attitudes or associations that people have towards others without their conscious knowledge. The introductions of women without a professional title or by first name may not have been intentional, for example, but there was a substantial difference by gender, nevertheless.

According to Dr. Prowell, one of the big dangers of implicit bias is that it reinforces the disparities already present in medicine. To address this issue, Dr. Prowell and colleagues developed "The Language of Respect" guideline that aims to standardize these basic demonstrations of respect. All chairs, faculty, presenters, and panelists, including patients and advocates, who have a doctoral degree, for example, should be introduced and addressed as "Dr. Full Name" or "Dr. Last Name."

In addition to using standardization wherever possible, another way to overcome implicit bias is to diversify leadership.

"Having diverse groups of people evaluate candidates, review papers for publication, or decide who's going to be the keynote speaker at your conference can help protect against implicit bias by reducing the chance that many people hold the same bias," said Dr. Prowell.

PATIENT-CENTERED LANGUAGE

The way that health-care providers talk about patients is also problematic, said Dr. Prowell, who noted that, until recently, patients were not considered partners with clinicians.

"Now, patient advocates attend conferences and everyone is able to engage and comment equally on matters related to clinical trials or drug development or cancer care via social media, but the language of oncology still reflects a lack of parity between patients and clinicians," said Dr. Prowell.

According to Dr. Prowell, shorthand language was not developed with ill intent—it was about efficient communication—but when it was developed, no one envisioned that the patients would be listening to it. Given changes to the audience, said Dr. Prowell, health-care providers need language that's focused on clarity and respect. Referring to patients with genetically mutated disease as "mutants," for example, can sound disrespectful because patients are being equated to their disease.

"We shouldn't refer to patients by their disease," said Dr. Prowell. "We don't want to say 'breast cancer patients' or 'women who are metastatic' or 'women who are ER-positive' because women aren't any of these things. Patients can't metastasize, and women can't be ER-positive. We're really referring to their tumor."

The language of oncology is also loaded with terms that appear to blame patients when their cancer progresses.

"We frequently say that patients failed treatment when, in reality, the treatment failed them," said Dr. Prowell. "We also say 'screen failure' when we design trials that have eligibility criteria that are so restrictive that they exclude a lot of the patients we see every day in clinic. This is failure on our part, not the patient's."

These habits may feel ingrained, but there are opportunities to change, said Dr. Prowell, and some of these strategies are fairly straightforward.

"We can simply stop teaching this language to the people who are in training now, and in a generation, people won't talk like this anymore," said Dr. Prowell. "It may take a whole generation of people in medicine before we get to a place where people feel comfortable, but we have to be intentional about it."

PATIENT ADVOCACY

Dr. Prowell also underscored the important role played by patient advocates in improving diversity and inclusion.

"I tell individual investigators and companies that if they're not consulting patients or patient advocates at the design stage of trials or early in the drug-development life cycle, they are missing important insights that will come back to trouble them down the road," said Dr. Prowell.

Pharmaceutical companies and investigators are starting to heed this advice. Dr. Prowell noted that she has seen a shift over the years, albeit slowly, to incorporate the patient perspective in the design phase.

"More prominent inclusion of patients and patient advocates in clinical and drug-development processes has gotten a foothold now," said Dr. Prowell. "I've seen increasing numbers of companies, cancer centers, and cooperative groups embracing this approach."

DISPARITIES IN ACCESS TO CLINICAL TRIALS

Another challenge facing oncology is the disparity in access to clinical trials, which compromises the quality of data obtained. According to Dr. Prowell, if a drug is going to be approved and made available to the American public, health-care professionals need to be assured of its safety and efficacy for all patients.

"That's very important to me as a regulator, as a clinician, and as a consumer," Dr. Prowell said. "I want to make sure that we're doing everything we can to enable patients to be a part of clinical trials, and if they're eligible, to access those drugs at the earliest point possible."

One opportunity to improve access is to decentralize clinical trials. Although there's been reluctance to change the status quo, technological advances like wearable devices and telemedicine have provided resources to move beyond a centralized study design. The COVID-19 pandemic provided a push towards this direction.

"The pandemic has provided us with a few, small silver linings, and one of those is the recognition that we don't all have to go to a central place to get things done," she said.

Ultimately, creating a culture of respect will require more than just a change of language. Greater diversity in the selection process for advanced practitioners is needed too.

"We need to make sure that the people who are in charge of interviewing and selecting candidates to become advanced practitioners look like the diverse country and like the patients who we're taking care of," Dr. Prowell concluded. ●

Disclosure

Dr. Prowell and Ms. Zitella had no conflicts of interest to disclose.