

How Health Literacy Affects Equitable Care in Advanced Prostate Cancer

Health literacy is an emerging determinant that can have a profound impact on the patient experience, especially in aPC.



To address this pressing topic, Dany Habr, MD, Oncology Chief Medical Affairs Officer at Pfizer, Daniel George, MD, Director of Genitourinary Oncology at Duke Cancer Institute and Hendrik Van Poppel, MD, PhD, Professor Emeritus of Urology at KU Leuven and Chairman of the EAU Policy Office provide their unique perspectives on the importance of health literacy in aPC.

Health inequity is a complex problem. Socioeconomic differences, racial discrimination, age and gender-related biases, educational level and countless other forces work against equitable healthcare. To resolve these issues, we must start by identifying the underlying causes. One hidden barrier to equitable care is poor health literacy.

What is health literacy?

Health literacy is a person's ability to access, understand and act on information to make decisions regarding their own health or the health of their loved ones. It can present in various forms, such as a person's knowledge of a disease's warning signs or a patient's ability to follow their provider's guidance. Being health literate means understanding health information to manage or overcome conditions effectively, and at a high level, it can even help prevent health problems from arising altogether.¹

People with low health literacy are less likely to communicate effectively with their healthcare providers (HCPs) and, in turn, may have a more difficult care journey.² The effects of low health literacy cannot be understated – insufficient patient education has been associated with more frequent HCP office and emergency room visits, along with increased expenditures, as opposed to those with higher health literacy.³

Health literacy's impact on aPC

Prostate cancer is asymptomatic in its curable stages and often first detected by a routine check-up or cancer screening.⁴ Only once the disease has progressed to an advanced stage do symptoms typically arise. **“Early detection of prostate cancer is one of the most critical steps in treating and overcoming the disease,”** says Dany Habr, MD, Oncology Chief Medical Affairs Officer at Pfizer. **“Proactive screening for prostate cancer, however, can be overlooked by those with low health literacy.”**

For patients diagnosed with advanced prostate cancer (aPC) or whose disease is progressing to an advanced stage, conversations with HCPs can become increasingly complex. And it's not getting easier for patients — over the past 30 years, more treatment options have become available, which may make the decision-making process even more difficult. High health literacy enables patients to actively engage with their care teams and appropriately act on medical information that may otherwise be difficult to understand.

As with all cancers, prostate cancer also takes a significant mental and emotional toll on patients and their loved ones. **“Cancer is a particularly scary and anxiety-inducing diagnosis,”** says Daniel George, MD, Director of Genitourinary Oncology at Duke Cancer Institute. **“How a patient and their family members initially react to a cancer diagnosis can be adversely affected by low health literacy. Over time, low health literacy can take a toll on their mental and physical well-being.”**

Why might someone have low health literacy?

The complexity of health systems can be overwhelming for patients. Understanding advanced medical terminology can be difficult for anyone. Many factors can drive low health literacy, varying by country, region or community. These factors often fall into two categories:

1. Challenges in understanding information.

- **An individual's educational background**, prior exposure to medical terminology, or listening, comprehension or problem-solving skills may impact their ability to effectively communicate with providers and navigate their healthcare system.
- **Language barriers** and the availability of translation services can impact the accurate communication of health information.
- **Cultural beliefs, norms, or traditions** can influence how medical information is perceived and understood.
- **Mistrust** in institutions that people feel unrepresented in or disenfranchised from can influence how an individual interprets or shares health information.
- **Misinformation**, overwhelming **volume**, or **untrustworthy** information — particularly from online sources — can greatly affect an individual's health literacy.
- **Financial and health system literacy**, along with fear of perceived or real costs associated with healthcare, can be an independent deterrent.

2. Challenges in seeking out or accessing information.

- **Geographic barriers**, such as living in less-developed, rural or underprivileged settings, may limit access to essential health resources.
 - Limiting factors include transportation, Internet connectivity and familiarity with technology, among others.
- **Low-income** patients may not have access to preventative screenings, high-quality care, or reliable health information.

- Racial, ethnic, gender or age **discrimination** can impact the availability and quality of health resources.
- **Social or cultural stigma** may discourage individuals in some communities from seeking medical care or discussing certain health conditions.

In his experience, Hendrik Van Poppel, MD, PhD, Professor Emeritus of Urology at KU Leuven and Chairman of the EAU Policy Office, has observed that some patients, particularly men, are not as engaged in preventative health. “The typical sentiment is, ‘I feel fine, so why assume anything is wrong?’” Van Poppel states. “Men tend to not prioritize their health over other responsibilities – and that can very much affect their level of health literacy and interest in their health, particularly concerning their prostate.”

Improving patient interactions through shared decision-making

Individual providers can play a critical role in driving meaningful change in patients’ health literacy. As the first “line of intervention” against prostate cancer, general practitioners (GPs) and primary care physicians (PCPs) are the strongest influences in promoting preventative care and proactive screening, unless there is an established screening program already in place. Often, when patients have an established relationship with a GP or PCP – it is here that health literacy can be fostered.

For patients diagnosed with aPC, urologists, oncologists, psychologists, nurses and other health professionals must take on the role of educator. Like any educator, it’s a provider’s responsibility to effectively communicate medical information and ensure that the patient fully understands it. The ability to evaluate a patient’s “level” of health literacy is an important initial step, and adjusting the level of communication based on that assessment is crucial.

As Daniel George, MD, explains: **“The first 10 minutes of our first interaction with a patient is a critical time. It’s then that we need to assess the patient’s engagement and understanding of our conversation. I’ve found that simply stopping early on to ask a patient to repeat or summarize what was discussed is a useful way to assess their understanding.”**

By informing patients about their condition and the treatment journey ahead, providers can facilitate **shared decision-making**, in which patients actively make choices about their health alongside their providers. Treating and living with aPC can be long and arduous – it’s up to HCPs to establish trust, offer continuous guidance and help build up a patient’s health literacy.

The role of industry & policymakers

On a larger scale, tackling the issue of health literacy begins with awareness and education.

“Empowering and partnering with advocacy groups and educational institutions can be the key to promoting health literacy in entire communities and patient populations,” says Professor Van Poppel. But for an awareness campaign to be effective, it must be culturally appropriate and tailored to the specific needs of diverse target groups. Successful awareness efforts are powerful – and their impact on oncology is evident. For example, lung cancer mortality rates are steadily decreasing in several European countries – partially attributed to awareness and education efforts encouraging people to quit or not start smoking, along with effective tobacco control policies.⁵

Access to credible health information also remains a significant barrier to equity in health literacy, and both policymakers and industry leaders serve as gateways to education. Deterring misinformation is a vital aspect of patient and provider education, and policymakers can play a crucial role in the distribution

of credible health resources, while also policing misleading sources of information. Further, drug developers have responsibilities in providing patients and HCPs with clinical and treatment information that is consistent with the most up-to-date guidelines and presented in an understandable language. Pfizer is also making a difference through its publication of plain language study results which are intended to explain information about its clinical trial findings in an easier to understand way for people of all educational levels.⁶

“We’re all in this together,” says Dany Habr, MD. **“All of us, from academia to pharmaceutical companies, have a role in fighting misinformation and helping guide patients through their care journey with accessible, accurate information.”**

Industry leaders are also hubs of innovation in technology, some of which bring opportunities in addressing health literacy. Artificial intelligence can provide patients with health information tailored to their specific needs and conditions while offering capabilities to help translate complex medical terminology into plain language. Meanwhile, innovations in health access have emerged through solutions like telehealth, wherein providers can communicate with patients remotely.

“Tools like telehealth are not only great for accessing patients, but changing the patient-provider dynamic,” says Dr. George. **“Meeting with a doctor in a clinic can be intimidating. With the rise of telehealth, we’re beginning to meet patients on their turf, and it’s changing the healthcare experience in a positive way.”**

Looking toward meaningful change

Partnership across all stakeholders, from industry to providers to policymakers, creates our best chance to improve patient health literacy and, in turn, reduce inequities in aPC and beyond. The foundation of this partnership is established through one-on-one visits with providers. Provider understanding and emphasis on improving health literacy of their patients can lead to better patient interactions and treatment acceptance. By empowering HCPs to help patients build their health literacy, patients are in turn empowered to make more informed health decisions.

Beyond the individual provider, change can also come from partnerships at the organizational level. No one company or patient advocacy group can solve a problem as broad as disparities in health literacy alone. Whether it’s collaboration on awareness campaigns or providing resources and support to patient populations who need it most, it takes all of us to chip away at the drivers of health inequity. These efforts can directly impact patient outcomes – and that’s what we’re here to do.

Daniel George, MD, is an internationally recognized clinical researcher and thought leader in GU malignancies. Dan is a Professor of Medicine and Surgery, Divisions of Medical Oncology and Urology, at Duke University School of Medicine in the US. He also holds appointments in the Duke Clinical Research Institute and the Duke Cancer Institute where he is the Director of Genitourinary (GU) Oncology.

Dany Habr, MD, is the Chief Medical Affairs Officer at Pfizer Oncology, overseeing the oncology portfolio and medical organization. He has co-authored 43 manuscripts and more than 80 abstracts in the fields of hematology-oncology and health equity and has presented at major medical conferences.

Hendrik Van Poppel, MD, PhD, is Professor Emeritus of Urology at KU Leuven in Belgium and Chairman of the EAU Policy Office. He is the first author of more than 200 papers on uro-oncology and a co-author of more than 350 others. Prior to his current roles, Hendrik was the Director of the European School of Urology and Adjunct-Secretary General of the European Association of Urology (EAU) responsible for Education.

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