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Rethinking patient education in oncology in the age of precision medicine

by Laura Holmes Haddad

Everyone agrees that knowledge is power and, as a corollary, knowledgeable patients are key to the successful implementation of precision medicine. This is particularly true when applied to the implementation of precision medicine in the oncology space. While providers receive professional training and continuing education, patient education is often piecemeal – a combination of physician-provided information and other sources outside the medical setting. Addressing health literacy in the cancer community will be crucial to empower the patient for the successful, widespread adoption of precision medicine. The knowledge gaps and potential remedies are discussed here. >

A Fractured Approach to Patient Education

Education is a crucial pillar in the cancer care equation and that need is even greater now with advancements in cancer treatment. Educating patients goes beyond the primary goal of making informed medical decisions but must also include health literacy,¹ especially in light of precision medicine. For example, patients need to learn about healthy lifestyles and the ability to engage healthcare providers during examinations and regular check-ups.

diseases, and treatments is commonplace among patients but creates the potential for misinformation, incorrect self-diagnoses, and increased anxiety levels.

The NCI, for example, maintains a Dictionary of Cancer Terms that patients can access online. While the dictionary is easy to navigate, the definitions and explanations can be difficult to comprehend. Entering the word “brigatinib,” for example, results in this straightforward explanation but still leaves the patient with numerous questions:

Cancer patients cannot be expected to search the terms and medication around their particular cancer to clarify information provided in the clinical setting. This becomes even more complex when adding cutting-edge treatment options to treatment plans. A March 2016 ASCO report underscored this idea, declaring that *advancements in cancer treatment were irrelevant if the healthcare system was unable to get them to patients*. The report stated that “cancer care may be compromised due to the growing complexity of care delivery, inadequate healthcare access and affordability, and other external practice pressures.”² While these points are critically important, the focus is on the healthcare provider side, and seems not to take the patient side into account.

"ONE ATTEMPT TO ADDRESS PATIENT EMPOWERMENT IS THROUGH PATIENT-TO-PATIENT PEER EDUCATION"

To the average patient understanding a pathology report is a Herculean effort in and of itself, much less comprehending DNA sequencing and researching the benefits and disadvantages of this analytic tool. As precision medicine-driven diagnostics such as molecular testing become more widely available, a patient-centered education system becomes even more important for patients to gain full understanding and benefit.

One attempt to address patient empowerment is through patient-to-patient peer education. A health education company for patients called PatientsLikeMe.com was one of the first to address this. Founded in 2006 to meet



Laura Holmes Haddad

There is no shortage of resources for cancer patients to access. In addition to provider information, there are thousands of periodicals, books, and websites that offer general and disease-specific information. However, the sources vary widely in terms of accuracy and availability and are often targeted to medical professionals than patients. Indeed, the instinct to Google symptoms,

“A drug used to treat non-small cell lung cancer that has spread to other parts of the body and is anaplastic lymphoma kinase (ALK) positive. It is used in patients whose cancer has gotten worse during treatment with or who cannot take crizotinib (a type of anticancer drug). Brigatinib blocks certain proteins made by the ALK gene. Blocking these proteins may stop the growth and spread of cancer cells. Brigatinib is a type of tyrosine kinase inhibitor. Also called Alunbrig.” (Source: NCI)

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the needs of the ALS community, it was expanded to include more than 2,800 diseases. Patients create an account on the website and interact with other patients, sharing their health information and patient experience, including issues such as treatment options, medications, and symptoms. PatientsLikeMe is a for-profit company that shares the patient data with healthcare industry partners. A 2010 study looked at the educational benefits to patients using this approach.³ But as this is a peer-driven approach, viewpoints may be more subjective and a less than reliable option for consistent, unbiased information. In addition, PatientsLikeMe does not allow clinical trial listings to be posted on the website for recruitment purposes.

Patient Education and Clinical Trials: Mutually Beneficial

One glaring gap in patient education is in the clinical trial space. This is particularly true when examining clinical trial access and the current enrollment levels. Although more than 8,000 clinical trials are accepting participants, only an estimated 2-4% of newly diagnosed cancer patients participate in them.⁴ In fact, patients should be informed that not only could clinical trial participation offer a potentially lifesaving treatment option, it could also benefit cancer research, the drug investigator, and, hopefully, future patient populations.

A 2013 article indicated patient interest but a lack of provider communication in making patients aware of clinical trials.⁵ Education for providers must be targeted as well – if providers are unaware of trials, there is little chance that patients will fill that knowledge gap. The 2016 *CancerCare Patient Access and Education Report* found that “[r]egardless of where they were treated, only 12% to 18% of respondents to this survey felt adequately informed about clinical trial opportunities.”⁶

In “Inadequate Awareness of and Participation in Cancer Clinical Trials in the Community

Oncology Setting,” Mehmet Sitki Copur, MD, describes how most patients are treated in the community setting rather than an academic medical center and how this impacts access to trials: “Cancer-related clinical research and clinical trials have traditionally been conducted at well-established academic medical centers, while 85% of cancer patients are diagnosed and treated at local, community-based clinical practices.”*

And assuming a patient is informed about a clinical trial, eligibility and other details may create a major barrier to patient enrollment. In general, patients may face many “unknowns” about the trial itself that must be addressed. These include issues such as:

- Will travel to the trial site be required? If so, are travel and non-medical costs covered?
- What types of follow-up care are covered as part of the trial?
- Are the clinical costs covered under Medicaid?
- Financial and lifestyle considerations – e.g., can a patient take time off work, what is his/her current or previous medication history, child-care schedules, help from extended family and friends etc.

Financial considerations can be a significant hurdle for patient enrollment,⁷ particularly relevant for patients receiving coverage under Medicaid. As the American Bar Association noted in an article from their Health Research and Compliance sector, Medicaid coverage around clinical trials is “evolving.”⁸ Currently, clinical trial coverage for Medicaid patients depends on each state. ASCO’s Cancer.net webpage clearly states the limitations: “The ACA clinical trials coverage rule does not apply to Medicaid plans. Federal law does not require states to cover clinical trials through Medicaid. But some states have laws that require Medicaid to cover clinical trials.”⁹ Federal legislative efforts are imperative to ensure cancer patients can enroll

in a clinical trial regardless of the source of health insurance.

Nonprofits and Professional Organizations’ Role in Patient Education

Disease-specific nonprofits are one area that can provide substantial patient support and education in the clinical trial space. This information can help a patient determine their his/her eligibility for a trial. See, for example, the National Brain Tumor Society, which launched a Clinical Trial Finder on their website in 2017,¹⁰ and the Pancreatic Patient Action Network (PANCan), which has a disease-specific Clinical Trial Finder on their website.¹¹

Some nonprofits do cover the latest drug options for hereditary cancers, including the national nonprofit FORCE (Facing Our Risk of Cancer Empowered; facingourrisk.org). The National Coalition for Cancer Survivorship (NCCS; canceradvocacy.org) is another national nonprofit that has created significant resources for cancer survivors available on- and off-line. But there is no single comprehensive website or organization – government, nonprofit, or institutional – that offers education to cancer patients across all disease type.

There are hundreds of nonprofits in the U.S. devoted to patient-centered cancer services and most do provide educational resources either on their website and/or through printed materials. However, most of the materials do not reflect or include information about current research and treatment options, including clinical trials. One remedy could be to connect the nonprofits with the providers and institutions to create a more integrated, collaborative approach to educating cancer patients based on their specific disease type.

Professional organizations have also tried to fill the education gaps for patients. ASCO, for example, maintains a list of resources for clinical trials as well as detailed information ▶

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about insurance coverage for clinical trials. But few patients would think to access a professional organization for this information.

Another example is ClinicalTrials.gov.

Their website lists more than 140,000 trials in every state as well as foreign countries but it is difficult to comprehend and navigate.

Resources such as these are better utilized by providers and other support staff, such as patient and nurse navigators, as opposed to patients themselves.

Summary, Conclusions, Steps Forward!

In this decade of emerging cancer therapies, the need for patient education has never been greater, but the burden cannot lie only with the patient. And while there are myriad educational resources for patients, the access point for patients ultimately lies with the provider and institutions. Providers, including nurse navigators, genetic counselors, and clinical social workers, have the most patient interactions and opportunities to convey information to the patient. Connecting the nonprofits more efficiently and effectively to the provider setting would be one way to integrate educational services for patients. We summarize below our experience and research in the following lessons learned, observations, and recommendations.

Lessons Learned, Observations, and Recommendations:

- No single comprehensive website or organization – government, nonprofit, or institutional – offers education to cancer patients across all disease type.
- There is no shortage of resources for cancer patients to access. In addition to provider information, there are thousands of periodicals, books, and websites that offer general and disease-specific information.

- Sources vary widely in terms of accuracy and availability and are often targeted to medical professionals than patients.
- Nonprofits should be connected for:
 - more efficient and effective settings for the provider to integrate educational services for patients;
 - providers and institutions to create a more integrated, collaborative approach to educating cancer patients based on their specific disease type.
- Disease-specific nonprofits can provide substantial patient support and education in the clinical trial space.
- Federal legislative efforts are imperative to ensure cancer patients can enroll in a clinical trial regardless of the source of health insurance.
- Patient empowerment often occurs through patient-to-patient peer education but may vary in quality due to conflicting, subjective points of view.
- Providers and institutions are key access points to convey information to patients

Clearly, a paradigm shift is required for educational outreach to touch every stakeholder to ensure that providers, patients, and payers can make informed decisions about precision medicine-based diagnostics and treatment options. Once the healthcare system is motivated to expand their knowledge base to patients about these new options, the oncology community will reap the benefits of patient-focused advancements in cancer care. ■

Laura Holmes Haddad is a writer and speaker from California. A former cookbook editor, Laura's career focus shifted when she was diagnosed with Stage IV inflammatory breast cancer at the age of 37. After completing three years of treatment – including a Phase I extension clinical trial – she remains NED (no evidence of disease) and is committed to healthcare policy and patient advocacy work. Her speaking engagements have included the ACS Cancer Action Network, Pillpack.com, Young Survival Coalition, and Blue Shield of California. She has also been a guest on numerous radio programs and podcasts.

In addition, Laura is the author of *This is Cancer: Everything You Need to Know, from the Waiting Room to the Bedroom* (Hachette, 2016). Follow her on Twitter (@HolmesHaddad) or at lauraholmeshaddad.com.

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* **Article link:** Copur, MD, M. "Inadequate Awareness of and Participation in Cancer Clinical Trials in the Community Oncology Setting," *Oncology Journal*, February 15, 2019, Vol. 33, Issue 2. <https://www.cancernetwork.com/article/inadequate-awareness-and-participation-cancer-clinical-trials-community-oncology-setting>