

Most People Diagnosed with Cancer Seek Information Even Before Their Appointments

New research authored by Camille Stewart, MD, shows that cancer patients want information about treatments, therapies, and their providers.

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For many people who receive a cancer diagnosis, one of the first things they want is information – about the cancer itself, about treatment options, about side effects they may experience, about what it all means.

Patients navigate much uncertainty through their cancer journeys, so seeking information can be a means of gaining control on what may feel like constant steps into the unknown. However, while many patients arrive at appointments with their health care providers having sought information beforehand, not much has been known about where they got the information and the kind of information it is.

[Recently published research](#) shows that 74% of cancer patients surveyed sought information before a visit, and a large majority of those who searched for information got it from at least one non-validated source.

“As health care providers, we need to be asking ourselves whether we have the trust of our patients, and if we don’t, is it because we’re not providing them the information they’re seeking?” says [Camille Stewart, MD](#), study author and assistant professor of [surgical oncology](#) in the [University of Colorado School of Medicine](#). “We want to be the source for information and resources that patients know they can turn to.”

Building trust with patients

The research was based on an anonymous, seven-question survey given to new patients seen at the CU Cancer Center. A total of 405 people completed surveys that asked, among other things, whether they looked for information about their diagnosis prior to that day and to list the top three sources they used for information.

Of those who completed surveys, 57% sought information from doctors or medical providers, 36% from government or hospital websites, and 21% from friends or relatives. A majority of 77% noted that they trusted doctors or medical providers.

The survey also found that top subjects survey respondents would like more information about are cancer treatments, alternative or herbal therapies, surgery, the treatment team, and nutrition.

“I was happy to see that physicians remained a trusted resource and that hospital and government websites are also a trusted resource,” Stewart says. “There are so many sources where patients can get information, many which are not validated, so it’s important that we have that trust with patients.”

Being a source for information

For many health care providers, an ongoing challenge is understanding the wide range of sources, including social media, from which patients may draw information and supporting them in seeking sources of validated information. This might present a unique challenge for health care providers as patients seek information about alternative or herbal therapies, Stewart says.

“For a lot of complementary and alternative therapies, there just isn’t as much research,” she explains. “There haven’t been the same number of randomized controlled trials that there have been with drugs that require FDA approval, so we often don’t have the same level of evidence or data.”

A key takeaway of the survey results was the need to provide additional information for our patients, so that we can be a “one-stop shop” for information patients seek.

“The goal here is to provide resources that fit our patients’ needs,” Stewart says. “Patients may have different concerns and issues. Ideally, we build up our digital resources and ensure that those can be translated into paper resources for patients with differing levels of digital access. We need to be supporting patients in accessing the best validated information that is the most applicable to their needs and individual situations.”

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