Alternative Cancer Treatments and Survival Outcomes

Can alternative therapies cure cancer or cause harm? A conversation with Skyler Johnson, MD.

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Dr. Skyler Johnson is the lead author of a recent influential study, which investigated the survival outcomes for people who chose alternative cancer treatments only compared to conventional treatment. Not only is Johnson a radiation oncologist at Yale Cancer Center and a researcher, he understands how a cancer diagnosis is life-changing, as his wife was diagnosed with lymphoma while he was in medical school. This became a driving factor influencing his medical focus towards oncology. He is also personally motivated to write for his blog canceranswersmd.com, helping cancer patients have evidenced-based information.

He has noticed an alarming trend of patients choosing to forgo or delay cancer treatment that has been proven to prolong life or cure their cancer in favor of unproven alternative therapies. Often alternative therapies are thought of as healthy, nontoxic, and harmless. Is this true? Can alternative only therapies cure cancer or cause harm? If you take a look, you'll find there really isn't much scientific literature published on those who choose alternative therapies only. Knowing this, Dr. Johnson decided to investigate further and published one of the most comprehensive studies on the subject. I was fortunate enough to speak with him about his research and the motivation behind it. Here is our conversation, which has been edited for brevity and clarity.

Survivors' Table: Your recent publication is one of the few studies that looked at the survival rate of cancer patients who chose alternative therapy only for curable cancer stages compared to those that used conventional cancer treatment. Your research found those who choose alternative therapies only had a 2.5 times higher risk of death within 5 years of diagnosis. What initially prompted this research?

Dr Johnson: So there are a couple of first series studies done that show an increase risk of death, but they are relatively small so it's hard to extrapolate the information from them. Our study was trying to get the same data from the most common cancers in the best way we possibly could. It's the first study to look at multiple cancers and it's a little bit larger.

We were seeing patients in our own clinic making these decisions or considering them. When you went to the literature there was really nothing to help guide us to make an informed decision. Because you know unproven treatments have unknown outcomes and unknown risks. So it's hard

to have an informed decision about treatment recommendations with people who are considering alternative therapies because there is not much out there. It made it really challenging. That was the motivation to do a study like this. One of the real challenges are often the people who are a little bit skeptical about Western medicine are going to be skeptical of this data, but the hope is it will reach people who are on the fence.

Survivors' Table: Some interesting findings from your research is that alternative medicine only groups were more likely to be younger, female, have higher income, higher education, and more likely to live on the West or Pacific Coast. What do you think are some driving factors for these particular groups?

Dr. Johnson: Interestingly people on the West Coast are three times more likely to choose alternative therapies for their cancer. This geographic region is really fascinating, and it's something I'm really interested in studying closer. I want to investigate state by state and look at things like state legislation, where the Complementary and Alternative Medicine (CAM) schools are located, and the practitioners in those areas. There have been National Health Statistics surveys done in the past that include questionnaires about health practices and a subsection includes questions about CAM. Historically they have had to separate the Pacific region from other regions because there are so many people that use CAM's in this area. Their studies claim there are a large proportion of CAM practitioner schools because there is state legislation that favors them.

It's my suspicion this is likely the case for patients who are receiving alternative medicine for their cancer—there are large populations of people who favor traditional Chinese medicine for example or some other traditional healing therapies. Or there are a high proportion of these CAM practitioners and schools. The favorable legislation thing is fascinating as I don't know enough about the legal aspects of it, but it's something that really needs to be looked at because if there we can do something as a society to protect cancer patients it's probably along those avenues.

We're publishing a very similar study on patients who don't refuse conventional therapies, but are using unproven therapies with their conventional therapies. It's submitted and in review, and hopefully will be published in the next few months. I think there is a role for alternative practitioners though.

It's hard to know why specifically more educated people are choosing alternative therapies. Maybe there is an educational threshold where you have just enough education, you start to over estimate your knowledge, and think you know more than you actually do. But the higher income makes sense because most alternative therapies are not covered by insurance and it's likely people have to pay out of pocket for these services. So you've got to have some higher level of income in order to do these types of therapies.

Survivors' Table: During your research was there something you learned that surprised you?

Dr. Johnson: I was surprised the survival difference wasn't worse. If you look at all cancer groups combined at 5 years, 78% of cancer patients that used conventional therapies were alive, whereas around 55% of patients in the alternative medicine group were alive. Some people might look at

the data and say, “well the difference between 55% and 78% is not that large and I’m willing to avoid all of the nasty side effects of cancer therapies.” Despite for these curable cancers, treatments are much much better than they were in the olden days.

Some might look at the hazard ratio and say a 2.5 times greater risk of death is not that high and it’s a chance I’m willing to take. And what I think people need to realize is majority (70%) of the patients in this study were early stage cancers (stage 1-2) and the median follow up was only 5 years. And even then 25% of the patients in the study were prostate cancer patients, which after 10 years have no difference in survival when you just watch them as opposed to treating them aggressively.

There are a lot of reasons why the survival rate wasn’t worse. For example, if you look at cancer types individually and omit prostate cancer patients, the risk of death associated with breast cancer is greater than 5 times. With colorectal cancer it is greater than 4 times risk, for lung cancer it’s greater than 2 times, and for prostate cancer it’s almost no difference.

Alternative medicine groups also tend to be healthier as they are mostly younger, have higher education, and higher socioeconomic status. And it’s possible a lot of patients we see with alternative medicines initially in our study could have gotten conventional cancer care later on in the 5 years of the study. So for example a patient could have had stage 1 breast cancer and tried alternative medicine, then months later decided to get it treated. Maybe they were a stage 2 to 3 by then, which is still potentially a curable stage and still got it treated. But they still would have been looked at in our study as if they were alternative medicine only despite the fact they got both treatments. And it’s my opinion that survival is likely much worse than what we showed our study, especially if you looked at more aggressive cancers.

Photo by Katherine Hanlon on Unsplash

Survivors' Table: Why do you think patients choose alternative medicine over the advice of their doctors?

Dr. Johnson: So this is challenging because there's not a lot of information about this in the medical literature. We try to extrapolate what we know from the complementary medicine literature—which is unproven therapies used with conventional and alternative medicine (CAM). We think people chose CAM therapies because it aligns with their philosophical beliefs about how their cancer should be treated, and research does show this. There's also the desire to have self-autonomy. But I think it's important to note CAM is a multibillion dollar industry and it's one where patients pay more out of pocket for its use annually than they do for physicians office visits.

Its growth and popularity can be attributed to any number of these things. But I think in the alternative medicine setting—patients who totally refuse conventional cancer treatments in favor of alternative medicines—it's more likely there is some distrust in large medical institutions. Although there is not a lot of data to support this, that's our anecdotal evidence from the patients that actually come to us later on down the road when their cancer has progressed to incurable stages, because they used some other form of alternative treatment first.

But again, this is a really understudied population because they aren't traditionally being followed by an oncologist and are being seen by an alternative care practitioner. They don't often report what they have done or are considering doing to an oncologist.

When I hear of people who had a curable cancer stage and used things like black salve to treat their breast cancer. Then they come in with necrotic breast tissue and are no longer at a curable stage because the treatment didn't work. They say, "oh I was told what I was doing was working and my body was healing itself by expelling the cancer outside of my body"—those are the types of patients I genuinely lose sleep over. When your cancer fungates you're just advancing its stage to an incurable stage. It's unfortunate. I mean it's hard because you don't want to make people feel worse about their situation, but as a physician it's something that needs to be countered with increasing regularity.

Survivors' Table: Patients often say, "food is medicine". What does that mean to you?

Dr. Johnson: I think it means a couple of things. It's important that nutrition plays a really important role in health and usually the first recommendation or discussion with their primary care physicians is that nutrition is important, exercise is important, and these things will prevent complications later on down the road. But when people say food is medicine, it often and unfortunately is an over simplification that you can use diet to actually cure cancer and that's a bit concerning because there's no evidence to suggest it's true.

It is nice to hear because it tells you the patient is open and telling you things they are thinking. I think the real challenge we have as cancer doctors is patients often don't feel comfortable enough with us to explain what they are thinking in regards to CAM therapies. It's really challenging because often their choice to use CAM and alternative diets is really under reported, so we have a really hard time knowing what's going on, and that's to the determent of the patient.

Survivors' Table: Since pseudoscience often sounds like scientific information it can be hard to identify. What online resources do you guide people to—especially to evaluate questionable cancer cure all's?

Dr. Johnson: You may have seen my cancer CRAP's score blog post. So I like that a lot, but it's kind of silly and I made it off hand one day. I did this because it can be easier to identify misinformation and accurate information, but a lot of people don't know how to approach it. I wanted to just lay it out like here it is.

Now don't get me wrong I don't blame people because I've seen the misinformation out there, and it can be very convincing. I mean you can be given a life changing diagnosis, so you're faced with all of this fear and anxiety, and you didn't hear anything your oncologist told you because you just had so much going on in your mind. So you decide, well I'll just go online and read about it on the Internet.

When you see all of this misinformation online, I think the CRAP score is pretty helpful because if you are seeing big conspiracies out there, or sites asking for money, or doing other things that traditionally we would be skeptical of and some people may not be. If it's not the right source or a questionable source, even then you need to move on. There are also a lot of good resources that are primarily .edu or .gov. And that's usually what I advise patients to do, and it's a discussion I actively have with my patients.

I think it's important oncologists do that. It's probably something often overlooked because we are already giving patients so much information. I give them some resources to focus on because they are going to read a lot of things that are untrue. There are some things they can trust and I think patients tend to appreciate that.

Survivors' Table: Why do you think we should combat pseudoscience? Do you think people should be able to do what they want to do?

Dr. Johnson: So I'm a proponent of patient choice, and I think at times during a certain stage of disease and at a certain age, a focus on quality of life is better than a focus on aggressive treatment. That I believe strongly. I think pseudoscience needs to be combated though because people cannot make these decisions without informed consent. So in the case of alternative therapies without information of the risks and benefits, you cannot have informed consent. And that's ultimately what pseudoscience is…it's therapies that have been unproven or disproven.

Survivors' Table: What is one thing you wish people understood about the medical field?

Dr. Johnson: Something I wish they understood more is the fact that most providers by in large, with very very few exceptions, are genuinely good people, who care about their patients, and who want what's best for them. That's important for people to know because when physicians make recommendations, they don't make them because it's going to make the physicians life easier or that they want patients to do what they want them to do, but it's because they want what's best for their patient.

Survivors' Table: Is there anything we didn't talk about that you want to add?

Dr. Johnson: Out of everything we see from the CAM's, specialized diets are one of the top things. So it's really really important to have Registered Dietitians who are committed to the evidence. Pseudoscience happens in every field. The amount of information coming out in the '70s, '80s, '90s, and 2000s compared to now, is just insane. We're putting out more information in a matter of days, weeks, and months than we were in year time frames. It's almost nearly impossible to keep up with it all, unless you have governing bodies making sure people are looking at accurate evidence, so they can make a decision knowing all the risks and benefits.

For more information about Dr. Skyler Johnson, you can check out his blog and you can follow him on Twitter: @sky__john (includes 2 underscores).

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