What Should Public-Facing Science Communication (#scicomm) of Cancer Research Look Like?

A truly informed patient experiences improved quality and prolonged length of life because informed patients make better decisions.

April 5, 2017 By Adam Hayden

In this post, the first of two taking special interest in science communication (hashtag #scicomm), I offer my argument for the important role science communication #scicomm plays in sparking public interest in scientific inquiry, and closer to home, I make a case that #scicomm has a unique and vital role to play in educating our patient population to reinforce the notion of informed consent. A truly informed patient, I argue, experiences improved quality and prolonged length of life, not because they are science communicators, but because informed patients make better decisions with respect to benefits and risks of treatment. The onus, then, is on science communicators to consider what their role may be in describing origin theories of disease, e.g. cancer, in a way that empowers the public.

The disease of cancer is prevalent: perhaps not surprisingly, given our near universal experience of having been touched by cancer in some way, through the diagnosis of a loved one, grandmother, aunt, brother, cousin, and so on, or struggling with our own diagnosis, so it is that cancer is among the leading causes of death in the United States. Identifying preventable causes of the disease largely drives decades-long improvement in patient mortality statistics. The identification of preventable causes of cancer is of great benefit to public health, as it drives legislative action to protect a citizenry from increased risks while acting as responsible stewards of allocated healthcare dollars, taking on board the well-supported hypothesis that prevention is less costly than treatment. Beyond prevention, we may also wonder what researchers know of the nature of the disease itself. Knowing that limiting exposure to certain environmental carcinogens, for example, allows researchers to know something of cancer by way of preventable triggers, but a curious researcher, as we hope all are, should want to know something of cancer qua cancer, as we might employ the phrase in philosophy. Knowledge of cancer in virtue of its causes fails to penetrate deeply into the realm of inquiry, the space where our researchers and theoreticians operate.

Here is a story to help us. My oldest son may ask why the moon looks like a big circle one night but can look like only a sliver other times? I would not be incorrect to tell him it is because different portions of the moon are illuminated at different times, but this response is not very satisfying. Anyone with kids knows the natural follow-up question is, why? Why are different parts of the moon lit at different times? Now I may respond that the moon itself does not shine, but the light of the sun illuminates the moon. The illuminated portion of the moon appears a certain shape to an observer on earth given the relative positions of the sun and moon to earth. My son will likely lose track of the conversation at some point. If he is interested enough, he's had a snack recently, and the television is off, he may entertain me by paying attention while I build a model with a flashlight, his toys, and a ball to represent the lunar phases, but otherwise, he moves on and asks me the next night, why does the moon look like a big circle tonight?

Let's shift back to our topic. Why did my friend get cancer? Your friend got cancer because he smoked. While not technically incorrect, this answer is not very satisfying. A natural follow-up is to ask why? Why did smoking cause my friend to develop cancer? Now we are beginning to seek answers to the types of questions that motivate our researchers.

These stories help lay folk like you and me, "the public" or "the nonspecialist," those who have taken an interest in scientific questions, but who lack the requisite training, it helps us to engage more closely with academic researchers and their chief means of currency, the academic journal article. The answers provided to nonspecialists, like those I offer to my son, often are either unsatisfying given their nonspecificity and simplicity, or the responses are far too complex to be meaningful, and so nonspecialists are not allowed a seat at the table; no voice in the debate. Hence, we need models with flashlights, toys, and a ball. It is the responsibility of science communicators to build these models and to help nonspecialists along. Einstein reported that his earliest interest in seeking to understand the deep mysteries of the natural world was sparked as a child when he saw the needles of his father's compass move seemingly autonomously. What deep mysterious forces are moving these needles?

Like his father's compass did for Einstein is what I hope my conversations do for my three boys: spark their interest in understanding the natural world more deeply—whether that interest leads them to science, literature, theater, culinary arts, politics, machinery, craft, or engineering, there is not a single field or passion worth pursuing that does not benefit from a drive for deeper understanding of its "forces" that appear to the rest of us only as mysterious.

The burden on science communicators is great and the responsibility is one to take seriously because the models built by science communicators to help lay folks grasp deep concepts of the natural world by employing straightforward language, familiar concepts, and model building is not only an opportunity to help the public understand the power and priority of continuing to fund the sciences, but the public is also impacted in a deeply personal way as I may better come to know the hypothesized biological causes responsible for the development of my brain cancer, and I may find myself more genuinely invested in taking accountability for pursuing my treatment regimen if I better understand the mechanism of action by which my chemotherapy kills dividing cells by attacking their DNA, inhibiting mitosis (cell division), triggering cell death, or both.

Cancer mortality is declining, yes in some part to improved treatments, but largely mortality is lessened by identifying preventable causes of the disease. Prevention is good, going forward, but it is of little benefit to the 1.6 million Americans who received a cancer diagnoses in 2016. Effective treatment rests on a comprehensive and empirically tested theory of cancer's origin. Patients and their caregivers are right to expect safe and accessible treatment that seeks to maintain or improve quality of life and prolong a patient's life to the extent that is possible, while seeking to protect the first criteria. That is, my personal attitude toward treatment is that beyond some tolerable threshold, prolonging a patient's life should not irrevocably violate the quality of her life. This balance is subjective, arbitrary, and in every case that time allows, the topic is best discussed openly with friends, loved ones, medical teams, and other interested parties. No treatment allows a patient to evade death, but many available treatment options prohibit a patient's wish to die well.

The private and often taboo topics suggested in the final sentences of the previous paragraph are hidden beneath a guise that medical researchers and clinicians invoke with the phrase "informed consent": that patients or their elected healthcare representatives, after having been made fully aware of risks and side effects associated with a given treatment, may elect to receive or decline a therapy with their consent, even at great risk to their quality and quantity of life, up to and including hastened death. It is the patient's right, it is supposed, their autonomy, that a patient may choose to accept or deny treatment on the basis that the patient has been fully informed.

What I have said so far ties together researchers, clinicians, and patients in the following way: researchers benefit from intimate knowledge of pathology, clinicians tie their treatment recommendations to their understanding of the nature of the disease, and patients or their representatives consent to treatment on the condition that they be fully informed of the risks. Each of these parties are bound by their reliance on some working knowledge of the disease they either study, treat, or from which they suffer. Medical researchers and clinicians are licensed for their work after years of formal education, lab apprenticeship, or residency. The knowledge they have of their specialty warrants their expert status to make recommendations through research proposals, drug development, or clinical protocols. Patients consent to their recommendations on the presupposition that regulatory agencies and governing bodies maintain acceptable criteria of qualification and credentialing to place an acceptable degree of trust in these professionals.

A point I have made in public lecture and discourse is the following: medical professionals demonstrate their specialty knowledge and tacitly earn patient trust by trailing their names with such designations as MD, PhD, DO, RN, LPN, MSc, only to name a few, and with my asking for forgiveness for the many professionals whose abbreviated credentials do not appear on my list—their absence a sign of my ignorance, not your unimportance. I have received a craniotomy, eight MRIs, 30 sessions of proton beam radiotherapy, two CTs, tens of IVs, nearly 100 individual doses of chemotherapy, countless blood draws, routine vitals, and all I am is "state your name and date of birth." When do I earn my CPT, certified patient, credential? I don't, because I just made it up, and further because it flies in the face of the field of contemporary professional medicine whose aim is to treat patients and discharge them, not to celebrate them.

Should a patient be certified? Of course not, I am being rather absurd. Or am I? There are as many varieties of patients as there are diseses, and I am a patient, rather, I am a person who is driven deeply by inquiry to uncover the mysteries of the natural world. I stock my bookshelf full of medical school textbooks and popular medical science novels to intimately learn my disease. On March 29, 2017, I delivered two back-to-back lectures at Marian University College of Osteopathic Medicine (MU-COM) to mostly first and some third year medical students. Between lectures I was asked to make a slight modification from the first to second lecture by describing in slightly more technical details the characteristics of my type of brain cancer, glioblastoma. I mention this because while some may struggle to quickly find the words to describe the biological underpinnings of their disease, I have the opposite problem, that I must remind myself to trim back content before delivering an impromptu lecture on IDH mutations in high-grade glioma.

While I have not put in years of work as those serving on my medical team, and while I do not think that I set a reasonable baseline for what is or ought to be expected from patients, I do think that my hard work learning the competing theories of cancer's origin enables me to be more engaged in my personal healthcare, and I am happy when my oncologist rewards my hard work by allowing our appointments to stretch to an hour, sometimes 90 minutes, as we wander off in conversation about theories of cancer's origin or he reports about his experience at the recent conference he attended. "Precision Medicine" is the buzzword in cancer treatment these days, therapy that is made precise by targeting a patient's cancer's molecular markers, but this ability to identify my desire to share what I have learned, and my oncologist's willingness to engage in this discussion, is sort of old school precision medicine. It is therapy that is targeted to my needs. It celebrates the informed patient.

I do set a bar for an informed patient. I ask my readers to consider the gulf between my hard earned knowledge of my disease, and the average knowledge of a patient without desire, training, means, or ability, given socioeconomics, education, interests, cognitive impairment, or treatment side effect profile. If you have had a conversation with me about cancer or heard a talk I have delivered within the past several weeks, you know that I emphasize that patients learn to tell their own stories to identify what is most important to them to protect as integral pieces of their quality of life and that medical professionals learn story telling to better inform patients on the patient's terms, not the physician's.

Public-facing #scicomm is not (only) about sharpening the scientist's skills as expert communicator; it is not (only) about proving the worth of science writ large, or a specific domain of research within the broader sciences, it is not (only) to help the broad public constituency rally to disallow the disastrous cuts to science funding and frightening censure of science-driven federal administrations such as the EPA; no, the aims of #scicomm are to spark interest from our children, to empower people to seek deep mysteries of the natural world through embracing inquiry; most importantly, through my lens, #scicomm enables patients to become better informed about the nature of their diseases and mechanisms of their available therapies. In so doing, patients improve the quality and prolong the length of their lives. Next, they begin framing their own narratives to lift up the importance of science communication and motivate others to embrace inquiry and uncover the deep mysteries of the natural world.

Respectfully yours, Adam, CPT

[Note: If you are interested in hearing Adam deliver a public lecture on these themes and others, please join him for a public lecture hosted by the Religious Studies Department of IUPUI on the evening of April 19, 2017, 4pm. Light refreshments to be served beginning at 4pm. Lecture from 4:30pm-5:30pm. Topic: Well Wishes and Folks Theology: Religion in Interpreting Disease. The event to be held in room 409 of the IUPUI Campus Center located at 420 University Boulevard Indianapolis, IN 46202. For more information and to RSVP please click to open the Facebook event page.]

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