

Reflections on Communication and Hope

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As I prepare to leave my position as Coordinator of the Communication in Cancer Care Research Programme, there are so many patient stories that stay with me and want to be written about. Many of them come from my “quotable quotes” file – those memorable words that I heard from patients that expressed something powerful, even if I didn’t quite know what that was at the time. They were words that demanded further thinking and reflection, and stories whose profound messages deserve a voice.

Many negative stories stay with me. But although they remain with me most, they were not the only ones I heard. Patients often described incredibly caring interactions with their health care providers, wonderful people who clearly cared about ensuring that the human connection between patient and provider was part of the healing journey no matter what the journey’s outcome. Many of those same clinicians were involved in communication initiatives within their own institutions, trying to expand their insights into approaches that could make a difference for all. It is also the case that some of the patients I interviewed were not particularly concerned about communication; they got whatever they needed from their physicians and others on their cancer care teams and they were content.

It should also be stated here that this research focused on patient perspectives; I know that I normally heard only one side of the story – what patients heard and remembered and were affected by. And so I recognize that much was going on and no one narrative or research report could ever hope to capture it all. But the stories that still haunt me the most, and demand a space in this reflection, are those that stand out because they were all about invalidation and hopelessness.

1.

What I have learned is that patients for whom communication and hope are important suffer tremendously when they encounter health care providers who trample on their hope, dismiss it, question it and sometimes destroy it. These are the words of a 37 year old woman with Non-Hodgkins Lymphoma:

The times when I felt the most powerless, the most ill, the most defeated have not been when I’ve been undergoing treatment or have been sick but when a doctor or a healthcare professional puts me in this position with poor communication and makes me feel totally vulnerable and helpless and powerless to do anything. And it’s happened

when, in that instance I just described or in little instances with nurses or caregivers or booking staff. It's not the disease, it's the communication and it happens over and over again. And when I feel empowered it's because I've been given hope or I've been given, you know, a good transaction with communication and we move forward and we're all on the same team. But when it falls apart and there's no hope offered, I think that's when I feel sick physically, mentally, all these things. Even though you might think there isn't any hope, surely you know that giving hope to someone is a better quality of life -- even if they were dying -- than hopelessness.

This young woman also so clearly explains what is wrong with what I have come to think of as an "insistence on death" that some health care providers seem determined to perpetuate:

I think most patients, if they have a serious diagnosis or a diagnosis at all, are very realistic about what that means. Your mind immediately, when you're told that information, goes to the deepest darkest place and the contemplation of your own death. I don't have a problem figuring that out. What's more difficult for me is continually having hope in light of that. So that's what I need help with from a doctor. Not, "Well this is very grave". I know that. Most patients do. If you tell them anything involved with the diagnosis, we go there automatically. So it's your job, as a doctor, to instill hope, however small. That's the part that's a challenge, I think, for most patients to keep that up continuously in light of, you know, bad news or, or bad prognosticators. So I don't understand why they feel it's their duty to keep reinforcing that this may not go well, this may not turn out how you want it to. Don't you think I've gone there? Don't you think I've, I've considered that possibility? That's why I'm coming to you to get help with this!

But she also spoke of "good transactions" as did so many other cancer patients over these years. An example of a good transaction with communication comes from a 51 year old woman with a very long history of metastatic cancer whose oncologist knew how to communicate with respect and compassion:

He was the sort of guy that, you know, he came to [the hospital] when I was after surgery and would sit on the edge of my bed. And he would like always give me news in a way that would be bad news, but he'd always reframe it in a way that still said that we have something to fight it and we have something to do. This isn't "All that we have to offer you is, is nothing." So it was always reframed in that positive frame. And I find the doctors and people who interact with me who can do that, can give me some hope. Because that's what you need is that lifeline of hope. And if nobody's extending it you don't grab it, you know. And luckily, I had it within myself to grab it for myself but I also knew that I had to surround myself with care.

In contrast, a poor transaction is some version of this: “...`Well, you know, this is not what we had wanted to find, and people in your position they usually like to go on a trip or something.’ Now that tells you straight off that he’s given up on you”. Other versions of this are “this will get you in the end” and “this will have a bad outcome” repeated over and over again.

I asked another woman with a recurrence of kidney cancer what was wrong with a doctor speaking and acting as if things were “all over”, if they probably were? She said:

Because I’m still breathing [my emphasis]. And they don’t know from one day to the next. Yes, there’s cancer research going on and, yes,.....but, you know. There are treatments, there are options and a person’s own attitude towards living. And their life and their health plays a huge role in the person’s wellbeing and the person’s ability to fight their own disease. And when you’re handed a death sentence with no hope, no options, no nothing, you give up. What the hell’s the point of fighting?

I asked one of these women what the difference was for her between the first, second and the present time in treatment with regard to her communication needs and preferences when receiving her diagnoses and prognoses. She said:

You know, I don’t think anything changed. I’d still want the same thing. I still don’t want people giving up on me. My husband has just ordered me a whole lot of buttons from Monty Python’s Flying Circus which says “I’m not dead yet” [laughter]. And I’m, I’m intending to wear these to all my doctor’s appointments. And I shall even give them one each.



Discussions about hope and the multidimensional role of hope in the lives of many patients have been hijacked or derailed by discussions about informed consent in the literature and in practice I think. Among health care providers who communicate poorly, informed consent seems to be the excuse they use to let themselves off the hook for not communicating with respect and compassion when they give a diagnosis or prognosis of cancer; they “hit people over the head”, so to speak, over and over to remind them they are going to die eventually. Somehow they forget that they are talking with a living human being. They seem not to know, despite the literature, that hope is not always about a positive outcome (cure, remission, another treatment) but is very often about relationships, understanding something, being valuable, planning for the next reachable goal, or existential peace. One woman I interviewed suggested that health care providers should:

Consider that the person that they're telling is a person with a family and with a life and with hope of growing old. Yes, the disease is horrible and, yes, we have to be told. But please don't tell me I've got six months to live when you don't even know what kind of cancer I have, you know. Don't go giving me my death sentence before you know exactly what my death sentence is. And if you don't know exactly what it is, you know, don't say it. Say this is what I've got and, you know, but treat me like I'm a human being. I was treated like I was a, a worthless piece of meat.

In contrast, this same woman relayed this positive interaction with a nurse: *"She treated me like I was a person that had, that wanted to live, you know, that I had the right to live even though, you know, I have cancer. She treated me like I had the right to live."* When asked if she could say more, she said, *"You know, she asked me about my kids, my family, um, what my goals were, my long, you know, if I'd had long term goals or what my short term goals were like I had, I had the right to have goals."*

"I'm not dead yet." Why do so many patients have to remind their health care providers of this? There are many answers to this I think: the residue of family dynamics, the fact that physicians are trained to cure, not care and if they can't cure, some may not care either. This is the worst way of putting it but more benignly, it is also because of poor or no available helpful mentors, individual personalities, the ongoing experience of having patients die and the need to develop some way of coping with these cumulative losses without having the time or opportunity to do so, and perhaps their own projected hopelessness.



Sometimes, when health care providers are not hopeful or optimistic, their patients help them out by being assertive. I've encountered many articulate study participants who knew themselves well and knew what kinds of information and support they wanted from their health care providers as they went through their frightening cancer treatments and appointments. These assertive patients communicated their preferences clearly to their health care providers. What shocked me so often was hearing how often their stated preferences were ignored. As a former counselor, I have worked with ill and injured people one-to-one and coordinated research in which listening, discerning and genuinely respecting what people say is not only paramount but also central to learning about their needs and providing them (or helping them provide themselves) with appropriate support. So it always surprised me to hear that health care providers were not doing that especially when communication preferences were communicated so clearly. I wondered: "What part of that did they not understand?" Health care providers are intelligent, learn quickly and have to be discerning in many contexts. Why is this one so hard? One 65 year old woman with an advanced rare type of cancer told me

that however often she indicated her preference for optimism in word and tone to her specialist, he either didn't pick up the cue or did, and ignored it:

When I said, "Look I feel really good, I have got lots of years left", he said, "Well this will get you in the end..." It has been therapeutic [to tell other people what he said] because I actually then started to make myself wrong for not being able to accept what he has to say, because he is the doctor, he is the expert. What right do I have to feel any optimism, which is how it transpired. Go home and get yourself organized here. Obviously what you imagine and how you feel isn't real, you better start throwing out things.

I think that what this specialist should have done is validate her feelings of optimism and work with them instead of making her feel wrong for being hopeful. I know I am not there in that physician's shoes, and I know I am only hearing half of the story, but the feelings persist of an urgency to ensure that more patients are not left feeling this way.

IV.

What is the corollary of the statement "*I am not dead yet!*"? I think it is "*I am currently a living breathing person and as such, I am deserving of proper integrated professional care and communication.*" This is the perspective of a palliative approach in nursing, which is an emerging initiative in current provincial health care. The idea is to apply a "palliative approach" to all care of all patients across the life span. A palliative approach treats the whole living person, that is their emotional, spiritual, intellectual as well as physical selves. It considers and "promotes quality of life along the illness trajectory, across the lifespan, and with a focus on both the dying person and those who are significant to him or her" (Stajduhar, 2011; Beckstrand & Kirchoff, 2005; Coyle, 2006). The central concepts in palliative care are dignity, hope, comfort, quality of life, knowing the patient, teamwork, suffering, and care and caring (Seymour, 2004). Ironically, a palliative approach in nursing is not different from high quality professional care that all health care providers are supposed to be able to provide to their patients and families any and all times.

Because the imperative of informed consent has often trumped respectful, compassionate, genuine communication, many well-meaning health care providers simply do not know how to convey hope when providing serious diagnostic or prognostic information; they are not taught or do not learn what to say. Study participants have taught me that hope can be conveyed to them by demeanor, language, gestures, focusing on the future as well as the present, tone, clarifying something they didn't understand, sincerity, honesty, thoroughness, professionalism, time and eye contact. One of the most important ways that hope is conveyed is through "presence". The surgeon in the example of the woman with metastatic breast cancer who said

“people in your position usually like to go on a trip or something” conveys an obvious linguistic detachment from the human being he is. But it is more than linguistic detachment and more than detachment from himself. He has separated his humanness from hers by putting it this way --“people in your position” Putting it this way tells her that he is not going to be with her emotionally or professionally as she dies.

The following are statements I have heard either from patients who felt supported by their health care professionals in understanding that hope is never wrong, or they are statements they wish had been uttered:

“Continue doing whatever you can to keep yourself healthy and we will do what we can do to keep looking for whatever might be done”.

“I hope this works”.

“You know, I hope this prolongs your life.”

“You have every reason to hope”.

“There are long term survivors”.

“This is a very serious cancer. And I am going to be here with you every step of the way, no matter what happens.”

There are ways of being with people through the most difficult times in their lives that make a difference, that show humanity, that are honest, that are compassionate, and that take the risk of showing caring. All cancer patients deserve this.

Val Oglov is a social worker by background with extensive experience in the psychosocial oncology research field. From 2007 to 2013, she coordinated the Cancer Care Communication Project at the UBC School of Nursing, working with a wonderful team of investigators, project staff, graduate student/trainees, clinical partners and - of course – cancer patients. For many cancer patients across BC, she was the face of the project, providing an ear to the full range of emotions and experiences that living with, through and beyond cancer represents. The ripple effect of her work with the project will continue to be felt in the reports, publications, presentations and knowledge translation activities of all who have been involved in this inspirational team.

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