

Commentary

The Radiation Therapist and the Patient: Epiphanies, Stories, and Social Media

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Introduction

What follows is an unconventional piece of writing for an academic journal. It is a co-written account of the beginning of a relationship between a radiation therapist (RT) (Amanda) and a patient undergoing treatment for breast cancer (Sue). Sue and Amanda met on Twitter, a social media platform that is arguably neutral; a place where patients and health care professionals rarely mingle. How this initial contact carried through to the “real world” is the story that follows.

Narrative inquiry (NI) is “the study of the ways humans experience the world” [1]. Using narratives in health care is not new, there are numerous examples of patient stories, health care professional stories, and health care professional-as-patient stories in many formats. Authors who use autoethnography (a type of NI) “retrospectively and selectively write about epiphanies that stem from, or are made possible by, being part of a culture and/or by possessing a particular cultural identity” [2]. They can offer a unique insider’s perspective to better understand a specific environment, such as health care.

What follows is Sue and Amanda’s attempt to co-construct the epiphanies (or significant moments) they had, together and separately, during Sue’s course of radiation therapy treatment. Their cultural identities (patient and RT) were very different, but each learned from the other. We leave you to draw your own conclusions about the two stories, where they intersect, and what they might reveal about the place of social media in patient support and interaction with health care professionals, and the roles and expectations that we each carry as “patient” and “provider.”

Amanda

I have been working in radiation therapy, in Canada and abroad, for over 30 years and am the Provincial Professional Practice and Academic Leader for Radiation

Therapy at the British Columbia Cancer Agency (BCCA). I’m also a researcher, with an interest in what now is being called patient experience. Therapists are a hybrid of technical expertise coupled with a hugely important affective role. We support people who may be emotionally and physically devastated by a recent cancer diagnosis. I have always wondered about the relationship we have with patients. How do we define it? How can we improve it? How do patients see it? I am also midway through a doctorate in education at University of British Columbia where I will be using storytelling—NI—to look at how lesbian, gay, and bisexual RTs deal with coming out at work.

I came across Sue on Twitter last year. I have a son with a disability and so does she. She is a BC parent advocate and blogger with an honest and politically savvy style that I liked. I commented on one of her tweets and started to follow her, just one of many accounts that I follow. Earlier this year, her tweets and blogs started to explore a new area. Sue had been diagnosed with breast cancer and was frankly communicating what it was like to navigate the somewhat broken cancer care system as she went through staging appointments, biopsies and, eventually, radiotherapy.

Of course I took an interest! She was being treated at BCCA and I was intrigued what she would make of it. Her first post (“Susan Gets Radiated”) was a bit of a shocker—but should be required reading for all RTs. One line struck me—“there’s no peace here” [3]. I remember reading it at home, in the evening, a cup of tea next to me. I felt a sense of sadness that this was how we were seen and guilt that we let her down. I have been around the block, and I know that first day is usually tough. Patients are disoriented, nervous—they might be upset because they have had a hard time finding a parking spot or still reeling from a recent diagnosis. We thrust leaflets at them, but they have no idea what to expect. I read her blog with this in mind but holy moly, I wanted to fix it!

I thought about what to do for a day or so. In the meantime, the blog was retweeted by another staff member at BCCA (I did not retweet it). I talked to a few people,

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including some working at the centre where Sue was being treated. I was reminded that first-day feedback should be taken with a grain of salt—you know patients (people said), they don't really get it until at least halfway through. There were two rough groups of opinions. One was that the blog was essentially a private space and that we should respect Sue's privacy and allow her to express herself without any interference. The second was that we should (in essence) treat this like any other "feedback" from patients. The trouble is, our usual feedback mechanisms are clunky and a bit archaic. We have a comments box and an evaluation survey. Closing the loop on any actionable items from patients usually involves a phone call or meeting with a manager to assure the patients they have been heard and that we are doing something. A BCCA employee reading a patient's blog is a grey area.

I have to be honest as well and say that I did not want to get in trouble at work. I am a big fan of social media (Twitter and blogging, particularly) and most health care organisations approach it as a risk management issue. Do not post this, do not say that. It makes health care professionals really, really wary of interacting with patients. This is a shame, as we know there could be a lot of advantages to more open interactions. We have a lot to learn from patients (and maybe vice versa).

In the end, I sent the link to Sue's blog to the management at the centre. After a lot of reflection, I thought the learning opportunities of reading the blog outweighed the potential repercussions. After all, I said to myself, she shouldn't be shocked to realise her words had some kind of impact. Hopefully a positive one? I wasn't the only person who had read it—and was I not obligated to take action? All this rationalisation did cover up a creeping feeling that maybe starting up the grinding wheels of "patient feedback" wasn't the best way to go forward. But I couldn't think of another option that somewhat fit with "how we do things around here."

So, the blog was shared with the RTs who treated Sue. That was not my intention and would not have happened if it had been submitted through a more traditional feedback mechanism, like a comment card (unless there was an error). I also heard that Sue received a phone call to meet with the Clinical Manager to talk about her experience. I guessed it was part apology and partly as a further learning opportunity for the centre. Job done, then. I could rest easy knowing it was all taken care of.

I then flew to the UK for a conference. It was fun, and busy, and I was having a great time. I woke up one morning in my Manchester hotel room with the permanently dripping shower and opened up my iPad. I read Sue's new blog ("I am a patient and I have had an experience") and felt sick. She wrote "my blog is public, but it feels creepy that my blog is being monitored in this way... I felt reported." She pointed out the numerous ways patients want to give ideas and opinions beyond comment cards and surveys and how they are routinely discounted and labelled as "difficult." Oh God, I thought, what have I done?

Ironically, my talk at the conference was on coming out. As I got ready for my day I thought "I have to come out to her!" I wandered around the poster section. The prize winner was titled "The radiotherapy conversation in the digital age" about Twitter and patient experience that concluded that there was minimal two-way communication between patient and health care professionals and that this needed to change [4]. It is a sign, I thought, and I sat down under the poster and privately messaged Sue on Twitter.

She was incredibly gracious. She said "my writing IS meant to be for teaching, so I am happy you shared it. It is meant to be shared!" I was hugely relieved; we chatted and agreed to meet for coffee (which turned into lunch) when I got back.

A few days later, Sue shared her blog post based on the letter she gave to the therapists on her last day (Figure 1) [5]. I tweeted it and posted it on the Facebook page "World Wide Radiation Therapy" and it got a lot of attention. It was heartening, and this (I thought) is the typical story we tell ourselves based on the cards we get, the boxes of chocolates. We do make a difference—but we don't always get it right. It's important to read through the whole blog, from the too-loud waiting room TV always tuned to CNN (why not a nature channel?) and the effort Sue had to make to establish a relationship with a cold-appearing therapist (shouldn't we be doing most of the work?). The unconventional nature of this kind of feedback surely makes it more accessible to all of us. She is an "n of one" (as Sue would say) but don't we

You have helped me these past four weeks. Thank you. I always presumed competence, but it was your kindness and humanity that set you apart.

Here are the small things that meant the world to me:

1. Eye contact, introductions and smiles.
2. The offer of a warm blanket.
3. Chit chat – about the weather, colour of my nail polish, my family, plans for the day.
4. Helping me on and off the table.
5. Covering me up as much as possible.
6. Telling me what you were doing as you went along. (This lessened anxiety, a lot).
7. Your respectful treatment of my husband and son when they came in.
8. Being open to answering my questions. Prompting me to ask questions. Saying, 'what questions do you have' instead of 'do you have any questions'
9. A reassuring hand on me.
10. Not appearing rushed, even if you were.
11. Your demonstrated compassion: empathy for fatigue, burning, itching, how crappy this whole experience is.

I am grateful for all those so-called little things. I think medicine can cure (sometimes) but it is the love that actually heals us patients. Please keep doing these things, even if the system tells you otherwise. They matter.

Figure 1. An open letter to radiation therapists (09.06.17).

recognise the issues she writes about and feel deep down that these stories are not really that unique?

Our lunch was great, Sue was bubbling with stories, ideas, and suggestions. She told me how terrified she was on her first day, she had to hold her breath for treatment (an immobilisation technique that protects the heart), and she said “It’s hard to do when you are scared, hard to get the breathing right.” She described how the therapists talked over her head in the treatment room, the incomprehensible numbers, and how it would have been easier if someone had explained to her in more detail what was happening. I sat there thinking of all the times we have argued for more time on the first day to talk to patients, to explain the process. Time that gets whittled down and down as budgets tighten and waiting lists grow. This is not a criticism of her treatment team, it is the system we work within where we are forced to lose almost everything not directly measurable. Sue made a comment over her noodles that her dental hygienist takes the time to explain every time she goes there, step by step, and it helps minimise her anxiety. Ouch, I thought! Likewise, the remark that the whole skin care thing was a costly and confusing issue, with trips to various places to buy expensive (and unnecessary!) lotions and creams. As a chair of the provincial skin care group—ouch again!

We parted with hugs on the corner by the cancer centre as I went back for another meeting. I thought a lot about our lunch over the next few days and about how and why we had connected. I think Twitter is a great equaliser, but there is still a profound divide between patients and health care professionals. I agree with Sue that if more of us talked over noodles, the divide would be less. But as we are both bloggers, writers, advocates for change, we wanted to do a bit more. This co-written account is our attempt to show it can be done and that first contact has precipitated a chain reaction that I know will continue to spark changes for a long time.

Sue

I am a regular person—a mom of three with an emptying nest who is married to an IT guy and lives in a suburb on Canada’s west coast. I also happen to be a writer. I write to give myself a voice. I write to make sense of random events, to help myself heal, and to tell stories to make change in the world. (Also, writers write. That’s who I am and what I do).

“Preach from your scars, not your open wounds,” says Nadia Bolz-Weber [6]. My work that has been published in magazines, newspapers, and journals is written from my scars. But contrary to Bolz-Weber’s advice, my writing on my personal blog for the past 9 years comes directly from my wounds.

Up until this year, my posts have been focused on being a mom. It is a jumble of talk about health care, education, and motherhood. Being the mom of a kid with a disability pops up a lot, as my youngest son has Down syndrome.

On February 6, 2017, that all changed. This was the day I was diagnosed with breast cancer. I suddenly became a patient. This turned my whole world upside down. I had been humbled in life before, but cancer has exposed me and made me feel especially vulnerable. I kept writing on my blog, but tentatively at

first—a book review, a story about my cat, a post examining the agony of waiting for cancer treatment.

As I acquired more experiences as a cancer patient in the hospital, I started to become braver with my writing. Because my paid work life (writers need a day job, too) has led me to family-centred care consultant positions at children’s hospitals the past 8 years, I could not help but look at every encounter at the cancer centre through my patient experience lens.

I’m guessing that this happens with clinicians, too, when they become patients. In fact, a book like neurosurgeon Paul Kalanithi’s cancer memoir ‘When Breath Becomes Air’; beautifully illustrates this [7]. As a patient, he says, “...yet now, I felt that to understand my direct experiences, I would have to translate them back into language.”

Now, I am not Paul Kalanithi, but I still needed to write. I was so raw that cancer things tumbled out in my blog from gaping, fresh wounds.

I wrote about a spectacularly awful experience in day surgery when I had my partial mastectomy called “Number 51.” [8] I had been called by a number, not a name, was not allowed to have my husband at my side and almost passed out from the trauma of an unседated fine-wire insertion in my breast. I shared this post on Twitter, and it received a lively response, including emails from two nursing professors who asked permission to share my essay with their students. I said, “of course, yes.” I knew from my work in children’s hospitals that patient and family storytelling is a powerful agent for change. Could some good come out of my cancer experience to motivate positive movement in the health care world?

I also wrote about my first day at radiation treatment called, “Susan Gets Radiated” [3]. I would like to think it was a highly constructive piece about how it feels to show up for cancer treatment; others might term it a highly critical piece instead. Everything is perspective.

In Susan Gets Radiated, I recounted how I was scolded by the young RT for interrupting his work at the desk, how unfriendly the RTs were, and how terrifying the experience was holding my breath underneath the whirring radiation machine. For the staff, it was clearly just another day at work. For me, it was one of the worst days of my life. So I wrote about it.

A few days later, I received an unexpected message on my voice mail from a manager at the cancer centre. Someone had passed on my blog post, he said. He would like to talk to me about my complaint.

I felt rattled by the unexpected phone call. I am of course aware that my blog is public and that everybody can read it. But I had not filed a complaint with the hospital. I had merely told my story online, without identifying staff or the name of the hospital, but clearly it wasn’t hard to figure out. It felt creepy, like someone was monitoring my blog. The call felt invasive.

I dutifully met with the manager before one of my radiation appointments, bringing my husband with me for moral support. I was right in the middle of my 20 days of treatment and was terrified the staff would be reprimanded and this would taint the rest of my treatment. I have no idea if my

words affected my treatment in any way—whether positively or negatively. I tried to be pleasant and constructive in all my comments to the manager, emphasising how difficult the very first appointment was for me. Alas, I could tell that to the manager I was just a “difficult patient” with a “complaint” and that nothing would end up changing. I left feeling defeated. It felt as if he had just checked me off his “to do” list. I even followed up and sent him a link my favourite video about patient experience, from Cleveland Clinic [9]. I asked if I could meet with the cancer agency’s Vice President of Patient Experience, but I never heard back.

I then received a direct message from an RT I followed on Twitter—someone local, who, from her tweets, I could tell had a passion for the patient experience—that’s why I followed her. This was Amanda Bolderston, and this is where our stories intersect.

Amanda said she was the person who had passed on my blog to the manager. She said she was sorry if this made it worse for me. I felt terrible, she felt terrible—a typical Canadian reaction—but I appreciated that she broke through the red tape and fear of appearing “unprofessional” to reach out to me.

In retrospect, I wish Amanda had been in touch with me first to ask if I wanted to be contacted. A quick message to me through Twitter would have done the trick. The key here is that I wish I had the choice to pass on my feedback to the manager—or not. So much of being a patient means abdicating control, so any time choice can be offered to us as patients is a bonus. I like to say, wondering what the best thing is for patients? The answer is simple: Just ask us!

I suggested that Amanda and I meet for coffee, which turned into lunch. In July, we met for ramen near the cancer centre. She was lovely and wise, open to listening to my rambling stories, railing against permanent radiation tattoos and confusing skin care recommendations. Most importantly, I learned about some of her own challenges working within a bureaucratic organisation. We walked back together to the cancer centre and departed with a hug.

The best part of our time together was realising that we also had lots in common other than radiation therapy—we were both mothers, speakers at conferences, and had a keen interest in improving the patient experience but were not sure how. I think this article is a start.

Health care is all about trust. Meeting Amanda for lunch was a great equaliser. We were no longer the “professional” and the “patient.” She was Amanda and I was Sue, and we were just two women getting to know each other over noodle soup. It was infinitely more human to meet to break bread together than for Amanda to invite me to her office at the hospital for a meeting. The restaurant was neutral ground, and the setting was conducive to getting to know each other as people, not roles.

As Don Berwick, President Emeritus and Senior Fellow, Institute for Healthcare Improvement, says about health care, “to become a healer, you must do something even more difficult than putting your white coat on. You must take your white

coat off. ...when you take off that white coat in the sacred presence of those for whom you will care—in the sacred presence of people just like you—when you take off that white coat, and, tower not over them, but join those you serve, you become a healer in a world of fear and fragmentation.” [10] This is the secret to true patient-centred care.

I strongly believe that innovation happens at kitchen tables and coffee shops, not boardroom tables. Social media is a piece of that, for Twitter and Facebook are where the people reside. This is particularly true for those of us patients who are stuck at home not well or sitting alone in waiting rooms—social media keeps us company during those lonely times. I would never have met Amanda without Twitter. Social media should not be feared. It is just another way to connect and communicate with each other.

I believe that Amanda demonstrated leadership by taking a leap and contacting me. First she broke through the vast unspoken patient-professional barrier by following me on Twitter. Then, she reached out to me directly to message me when the sharing of my blog went sideways. And then, she met me in person. (And now we wrote this article together).

She was the first clinician who was genuinely curious about my experience with radiation. I tip my hat to health professionals who take a risk and reach out to patients through unconventional channels. I think clinicians often hide behind the cloak of professionalism in an attempt to shield their hearts, in a misguided attempt to avoid burnout. But us patients are desperate to connect as human beings when we are in vulnerable positions. Consider allowing patients a glimpse into your own heart.

This is how the great health care revolution will begin—through holding space for one another and taking the time to understand our different perspectives. Social media is a part of that, and it is not going away anytime soon. Let us embrace it instead of fearing it. Let us vow to embrace each other more, too.

Footnotes

Competing interests: The authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

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