The Legitimacy of the Patient Story: The Unofficial Autoethnography

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PERSONAL NARRATIVE

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ABSTRACT

While communication is the foundation of patient experience, survey data and comments are the primary source of results. The focus on data, though meaningful, reduces humans to text on reports. With a focus of autoethnography in both her baccalaureate and post-graduate studies, the author, (a fulltime patient experience professional) shares her professional focus on the value of the data and comments, esteeming it all as valuable research given by the only people who can report patient experience – patients. She compares her stance regarding patient experience before and after receiving a diagnosis of breast cancer. The author shares how the experience as a patient with a life-threatening illness impacted her professional beliefs, including demonstrating purposeful, personal concern for patients, valuing patient experience data and comments, and encouraging others to do the same.

Keywords: Patient experience, Cancer, Patient comments, Compassion

1. Introduction

My academic focus in both my baccalaureate and post-graduate studies was autoethnography, so, my subsequent professional focus of patient experience has been centered on patients’ stories and comments, esteeming them as valuable research given by the only people who can report on patient experience – patients. The bulk of relevant knowledge that we glean, as patient experience professionals, is found only through the collective voice of those who are part of a culture that we, hopefully, only intermittently visit. The voice that can tell the navigational story of illness and health care belongs solely to the patient. In January 2023, I was diagnosed with aggressive and invasive, triple negative breast cancer. My beliefs as a patient experience professional collided with in-depth and ongoing patient experience encounters as I fought a potentially life-ending illness. What follows is what I have learned, and hope that others can learn without undergoing the experiences I have lived.

Patient experience professionals strive to identify the voices that speak out, to internalize the passion they impart, and to understand their message – one that is crafted only within the active experience of receiving health care services. We use their concerted voice as our guide, learning from what only they can teach. We implement improvements, not through clever campaigns, trainings, or mission statements, but by heeding what these precious researchers tell us about the services we provide, while we simultaneously and desperately hope to never undergo these services or experiences ourselves.

These unofficial researchers are invaluable and unpaid, transparently telling us what is right and what is wrong. Their methodology is perfect and their position unwanted. They sit half-naked in cold rooms and wait; they undergo painful and frightening tests and procedures; and they listen to health care professionals disseminate information that profoundly impacts,
if not alters the course, and even length of their lives. And we, the patient experience professionals, are charged with the responsibility of making those life events better.

It seems obvious that consulting our patients’ research is the most efficient means to that end. Therefore, we cannot limit the grit of their experience to watered down synopses of “the biggest bang for the buck” in improvement efforts. Nor can we reduce their petitions to momentary self-appeasement found in a strategically selected goal for percentile ranking. The patient story is profound, priceless, and honorable, and must be regarded as such if we are to call ourselves those who strive to improve the patient experience. Yet, the sheer volume of stories we receive, paired with the ease of digital streamlining survey results, makes reducing human experience into data far too easy, and we often find ourselves erroneously focused on numbers instead of the humans that those numbers represent.

Prior to my diagnosis, my posture as a patient experience professional had been founded on the premise that the Latin root of our English word, “patient” means “one who suffers.” I beseeched all in my sphere of influence to meet patients in a sacred space that acknowledges patient suffering, regardless of whether suffering is discernable. In an instant, my diagnosis drafted me begrudgingly into joining the ranks of the priceless and weary patient experience researchers that I had so highly esteemed in my profession. From the first moment, sitting stunned on a sofa in a patient consultation room, listening to a health care staff member explain how aggressive the cancer was, and that there would be chemotherapy, radiation, and surgery, I immediately understood that “suffering” was a painfully accurate descriptor.

I had never experienced the level of fear I felt in those first moments. The fear only worsened in the weeks and months that followed. Cancer did not invoke the fear. Treatment did. The fear was neither unfounded nor unrealized. Treatment was brutal.

What I now understand in greater depth is that health care worker’s perceptible words and actions must clearly communicate genuine care for their patient. We have, for too long, focused on mere attempts to alter the patient’s perception of their care. The difference may seem like semantics, but it is far greater. For example, “my pleasure,” has become the rote response that is expected, delivered, but not always genuine, along with countless other customer service niceties that are uttered in relatively low stakes realms, such as fast-food service. Even in fast-food service, customers are resistant to rote communication that is perceived as disingenuous. The realm of health care, however, is one of high stakes, where patients place their lives in the hands of health care workers – from registration to radiation, blood draws to biopsies, EKGs to chemo, complications, surgery, side effects, and emotional crises. In such a realm, simply saying things to control patient’s perception of their care is hollow, because here, the patient, who is, by definition, suffering, is desperately searching for evidence that their life is of value to the people providing their high stakes care.

While we may believe that caring about the clinical outcomes of our patients is enough, patients cannot believe that we can or will carefully treat their illness or injury if our concern for them as a fellow human is not perceptible. When we truly try to understand our clientele, we can see that they bring an invisible entirety of their history, all the current details of their life, and the sum of their hopes for the future with them into every space they share with us. I understand this more than ever now, as I was the stereotypical, movie-of-the-week, “touchy-feely” example of a 50-something female cancer patient, who, when told of my scheduled treatment plan, and how difficult the final doses of chemotherapy would be, responded with, “But my daughter is getting married that week – 1200 miles away! How will I make it there in that condition?”

I needed a physician and a team that understood that there was an entire life revolving around and weaving in and out of the schedule and plan they were building. My perception of the care they provided far exceeded how easily they scheduled those appointments, and even the outcome of them. It involved the tenor in which they discussed my hair loss, how well they exceeded how easily they scheduled those appointments, and even the outcome of them. It involved the tenor in which they discussed my hair loss, how well they explained what each terrifying procedure would actually feel like, and how seriously they listened on the day I thought chemo was killing me.

Patients’ perception of their care is a human metric, and the interpretation of perception of care will always be void of true meaning when we filter out the humanity and reduce the laboriously reported patient input to “data.” The temptation to view patient insights as numeric is real, but, when patient experience scores decline or improve, it is a direct reflection on us. We are measured. Experience is not a standalone noun that we can philosophize over from afar. It is a reliable measurement of how we have treated other humans in the sacred space of health care. That weight may seem more easily carried when depersonalized,
yet when the weight of the responsibility of human life is offloaded, so are the intrinsic rewards that accompany it. Most contemporary research regarding compassion and health care supports the idea that owning the weight of the humanity and responding with compassion changes the experience for the better for the patients and delivers more rewards for the health care providers, including wellbeing, professional satisfaction, and even longevity. Yet the temptation to establish an invisible boundary and immerse ourselves only in the tasks remains.

Patients’ perception of care is intrinsically tied to every health care worker’s perceptible demonstration of caring. When I, as a patient, place the delicate scales of life and death to precariously balance in another human’s hands, sensing some credible evidence that the entrusted person actually cares about me as a fellow human is mandatory, or I know I can, at any point, be reduced to a statistic – one of those “cases” that just went poorly; one of the “wrong numbers entered” that just slipped through the cracks; one of the phone calls that we “just forgot to return,” - the results of which can be life altering – medically or otherwise. The otherwise matters, because we are treating people who entrust us with the entirety of their life each time they enter a health care space.

Navigating life and death is high stakes. There is no small detail we miss or neglect that will not impact a human life, thereby negatively impacting that human’s perception of our care for them. We must get the caring part right – every time. Patients cannot absorb the additional fear that accompanies the burden of wondering if their health care workers care about them as a person with a life in which every detail profoundly matters. The fear they have carried into our presence is already too overwhelming. I know this all too well. Compounding the suffering of a patient through a blasé attitude or mediocre communication regarding matters of life and death is truly nothing short of cruel. It is not “good clinical care” when a patient cannot perceive it as care at all, because when care cannot be perceived, it is interpreted as an utter indifference to one’s very life.

I am fortunate. I had a good outcome. I am doubly blessed: the trauma of my treatment will serve as a steppingstone to better understand and advocate for patient experience, because I was able to view cancer treatment through the eyes of a Certified Patient Experience Professional. I now live in the season of recovery that brings snapshot refreshers every three months, as I again, sit half-naked on that table, waiting to hear what they saw on the latest image, and as I labor through the diligent rehabilitation required to reverse the damage that treatment did to my body. My previously treasured waist-length hair has finally barely begun to cover my ears, and my body is permanently disfigured. Both the physical and emotional suffering are real and remain. Suffering persists and haunts, long after even a good report.

Cancer and treatment have not changed my belief that health care workers must intentionally meet patients in a sacred space where we vow to acknowledge that all patients, by definition, are, in some manner, suffering. Cancer and treatment have galvanized that belief. Cancer and treatment have also reinforced the high esteem in which I hold patients who have been forced into research that no one would do voluntarily.

I am fully persuaded that we, as those who endeavor to understand and improve patient experience, must hold the patient story in the highest regard, faithfully collecting it, studying it, and believing it. We must ensure its messages are not lost, overlooked, or wasted. They are too costly and far too painfully obtained to be reduced to percents and percentiles, hollowly labeled as, “slipping” or “trending up.”

I understand the extreme privilege that most health care workers enjoy in garnering patient experience information without experiencing the painful indoctrination into its research cohort. As such, we must remain true to those who entrust us with their care and with their subsequent, transparent interpretation of that care. It is my sincere wish, and the entire purpose of this narrative, to persuade my fellow patient experience professionals, and my fellow health care workers, to learn these deep, painful truths without enduring the pain of the insider information that comes from sitting in the chemo chair, or on the cancer consultation couch, or waiting half-naked for the latest results. The easiest way to manage the patients’ perception of their care as caring, is simply to allow yourself to genuinely care about them. It doesn’t require a bad diagnosis to remember the importance of treating humans. Their value is intrinsic, as are the rewards we receive when we treat them with genuine concern, compassion, and respect.

May we stave off the reflex of defensiveness, and rather be willing to change in response to each poor comment we read or hear, knowing we have been given a freely offered lesson that someone else paid dearly for in unnecessary suffering, of which our very purpose is to reduce. May we celebrate every good comment, and every measure we improve, for when we approach our metrics as a yardstick for reducing
human suffering, our work becomes important on a global, existential, and moral scale. This is our calling, and we are indebted to those who are coaching us, correcting us, and beseeching us to listen and respond.

Let us always be willing to learn from the wisdom our patients impart. It is the medicine we cannot prescribe, the cure we cannot outsource, and the key to reducing suffering. Even when death cannot be avoided, human suffering can be reduced.

May we recommit to advocacy. May we find expedient and effective ways to convince those in our spheres of influence that it is mandatory to meet patients in that awful, yet sacred space, acknowledging and honoring their suffering, so that we never miss even the smallest opportunity to reduce it. May we esteem our surveyed sufferers, so that their knowledge is documented, valued, and hearkened. May we do so with deep gratitude as we are permitted to be recipients of such collective insight, and may we celebrate each day we are spared the fear-filled mandate of being a contributor to that same, precious, and arduously obtained information.

My hope is that this article, in some way, achieves what autoethnographies are created to do - educate those outside of the culture and effect positive change for those inside. May the suffering of those in this unwanted cohort be reduced by a reignited compassion in the health care workers they look to for genuine caring in the health care services they provide.