

*Original Article*

# Prescribing Curiosity as an Antidote for Medicalized Discourse in Cancer Treatment

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## Abstract

This article explores how the language used in cancer, diagnosis, and treatment can shape and constrain patients' experiences, often limiting personal agency. By analyzing verbatim excerpts from conversations between the authors, it highlights how dominant discourses in the medical field, such as positive thinking and war metaphors, can impose, psychological burdens. The authors advocate for incorporating curiosity and flexibility in patient interactions to enhance agency and personalization of care. Through Emily's specific experiences with thyroid cancer, this article examines common ideas that can minimize agency and suggests ways to foster more supportive and individualized responses from medical professionals and caregivers.

## Keywords

cancer, personal agency, cancer & positivity, cancer treatment, cancer & counseling, curiosity & counseling, narrative counseling & cancer

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On January 25, 2019, Emily, one of the co-authors of this article, was formally diagnosed with thyroid cancer, confirming her fears that had been lurking as a possibility. Although she had wondered previously that something wasn't right with her thyroid, it wasn't until the official diagnosis that her personal fears transformed into medical confirmation. Emily's subsequent journey acts as the backbone of this article to engage conversational curiosity rather than absolutes. Paré (2013) states curiosity opens space for "co-research" for counselors and medical personnel to adopt a receptive stance joined in a "mutually supportive quest for preferred futures" (p. 258). We hope to provide counselors and medical personnel reflective opportunities to engage with curiosity with those receiving care.

Pulling from an interviewed transcript between the authors,<sup>1</sup> we unpack a few common ideas that minimize a person's agency when navigating oncology territories; in doing so, we endeavor to explore a person's agentic responses, befitting their lived preferences, historical abilities, and resources to respond to health changes. This is what we mean by a stance of curiosity; that is a move away from certainty that can overlook agency for those

at the center of treatment (Amundson, Stewart & Valentine, 1993). Anderson (1997) speaks about professionals inhabiting a stance of “not knowing” to increase curiosity and privilege clients’ knowledge rather than imposing expert accounts which risks colonizing clients’ experiences. Utilizing Emily's experiences, we are able to focus on common ideas that minimize agency for those navigating oncology territory. Instead, we will offer suggestions on how to incorporate professional curiosity with people who are living with life-threatening diagnoses and facing hard decisions. Our intent is to use an autoethnographic approach to consider how instances of common languages used to communicate cancer diagnosis and treatment options, can expand and simultaneously constrain, individual experiences. By using autoethnography, Emily's experiences and meanings are privileged that could otherwise be usurped by the ethnographically accounts when told by physicians, nurses, and social workers (Kleinman, 2013). An autoethnographic account claims marginalized stories by those most impacted whose descriptions might otherwise be subjugated. Autoethnography can “illustrate larger cultural values through the immediacy of personal stories” (Winslade, 2022, p. 111).

Our working hypothesis is that dominant discourses deployed during cancer treatment are often couched in that of pop psychology and lacks responsive flexibility potentially curtaining curiosity (Pare, 2013) and lays blame at the foot of those who have cancer. Or as McNamee (2015) states, “all problems we confront in contemporary society are traced to some personal failing or flaw within a modernist, individualist view” (pp. 375–376).

This becomes the training blueprints for medical professionals and patients alike to operate in socially acceptable domains. The term “discourse” roughly is referred to as everything that is spoken and written about how we should think, act, and feel, in cultural contexts. For example, we all are provided unwritten instruction how to perform gender, as it is a part of the air that we breathe. When discourses are taken up over time by institutions, they become invisible “regimes of truth” (Foucault, 1980, p. 131) that shape a person's ability to respond outside of what is expected lest they be seen as deviant. The diagnosis and treatment of cancer is no different; it is beholden to certain discursive rules that shape people's experiences and actions and how these are storied.

Like many who receive a cancer diagnosis, the words that accompany it lay a foundation that shapes the journey. If the person enters a trajectory of medical interventions including surgeries, radiation, and chemotherapies, there will be expectations that influences how they think, act, and feel about their health changes. This shift can be dramatic, altering a person reliance on their former physicality. Self-concepts of being able-bodied can be replaced and reduced to “cancer patient”. This unwelcome identity narrows possibilities of how one might live incorporating unfamiliar knowledges with the body they are living in.

In this brief piece we will speak to how ontological security is destabilized (Markham, 2021) when a potentially life-threatening diagnosis is confirmed and our world no longer has a sense of a familiar ground underneath our feet (Broyard, 1992). This change ushers in psychologized instructions, implicit and explicit, that become a part of the unwritten prescriptions alongside other medical treatment planning for a person living with cancer. In our conversations with those who have lived with cancer diagnoses, we wonder how dominant ideas infiltrate a person's responses and course of medical treatments which often comes with unquestioned taken-for-granted assumptions.

The standard of care or “best practices” could restrict a person's exploration of treatments or even opportunities to discuss options that best fit their life. The person with cancer becomes a project of the medical system (which might also mean a project of the insurance industry) as to what kinds of treatments are medically and socially acceptable (Lorde, 2020). We have witnessed the absence of curiosity by medical teams in fast-paced institutions that limit collaborative curiosity about what might work best for those receiving care. As

counselors, we both wish to enlist curiosity to give maximum agency possible for those at the center of challenging choices.

*Emily: When I was diagnosed, I was given very mixed messages. From the medical community, I've gotten the message that it's "the good cancer." That I shouldn't be worried. That they'd just take out the thyroid and I take medication and I would be fine. But you invoke the word cancer in any other arena and people panic about it. And at the same time, I've been getting the message that I should be hysterically worried and that I must be terrified.*

What sense can we make of "good cancer," and how might that position the stories circulated around it? There is a cancer hierarchy of lethality with some cancers being more "desirable" than others; that is, the treatable and nonlethal forms of illnesses that medical worlds can successfully wage war against with odds of certainty are "good." When a person is told this is good/treatable/survivable, then must we wonder about the impact of "goodness" with perhaps an implied suggestion that more years of health and life will be granted. This sense of security can easily vanish with the next CT scan or blood test.

Words impact where a future breath can be easily drawn, dramatically exhaled or even suffocated. In the face of medical shifts and the potential roller-coaster that is found between "good cancers" versus "bad cancers," how might we avoid distilling totalizing accounts of experience that accompany a diagnosis? This binary embeds the flip side of the goodness of cancer, of living with a sense that the floor could drop away at any moment where a metastatic growth changes the mathematical future equation. In most peoples' reality, "cancer" brings death into closer focus and shifts the imaginal trajectory of where a life might otherwise unfold. But to have more open spaces of in-between that live in liminality, a world of maybe might become a smoother ride with collaborative curiosity. Without this collaboration, cancer and death are the enemy, with medical teams evaluating who has better odds at life than others. The stage is set for the potential survivability which insists on positive thoughts for better outcomes, often to the point of suggesting that the cancer can feed on negative thoughts (Lane, 2023; Paturel, 2021).

The implications can be that a person's health and recovery is interconnected to their mental status (Ruthig, Holfeld & Hanson, 2012). And while this may have relevance and we will leave this debate to others, it is noteworthy to think through the ramifications of "positive thinking" and cancer diagnosis and treatment. If one is hopeful and creates positive thoughts, then it stands to reason that the cancer should recede, whereas a realist or a cynic is at fault when their cancer worsens. We wonder about the effects of scrutinizing the mentality of a person living with cancer and the potential blame for a worsening prognosis. Emily spoke of it this way:

Emily: But there's also an implied expectation for positive thinking.

Lorraine: So that if you think positively that will land you in one place other than someplace else?

Emily: Yes.

Lorraine: Where is that the expectations will land you if you think positively?

Emily: If you think positively, that's correlated with recovery...Interestingly, I've gotten, I've gotten that specific message from lots of different people including academic colleagues who've sent me, you know, "research has shown." That people who think positively in dealing with cancer have better outcomes.

There are many treatments that incorporate a mind/body connection, often found in humanistic and holistic movements. And while these may be very useful approaches for many, it can be confusing. At worst, people at

the heart of treatment can be held to account for the “failure” of their treatment or the spread of cancer cells rather than simply seeing it as biological changes.

Emily: I don't think any amount of positive thinking would have prevented the tall cell variant diagnosis, which is what has taken it from “highly curable” to “still survivable”. I was told that the cells are taller than they are wide. And they're known to behave more aggressively. They like to recur and come back.

Lorraine: And that shifted then the message from curability to survivability. When that message was given to you that shifted from this is curable to survivable, what were the expectations that changed about how you should be acting?

Emily: That was noted from the medical professionals in particular. Social system didn't change a whole lot. They were just kind of like: “Ok. So then we're still dealing with it and that's fine.” But according to the medical professionals, suddenly, I wasn't taking it seriously enough. Because the outcomes go from “surgery and then everything should be fine” to “okay, we need to follow up just in case and we need to, we need to behave aggressively.”

Lorraine: So at that point the expectation was that you shouldn't be so optimistic, but that you should be more serious?

Emily: I should be seriously optimistic at this point.

What might happen if medical professional were engaged in questions that inquire about the changes in meaning as entry points into a conversation, for example:

- What information would be helpful, if any, for you to know from your medical team about this shift?
- What do you imagine the implications of this shift might be for you as you take some time to digest this information?
- What information would be helpful for your support system to understand about this shift in seriousness?

## **Toxicity of Being Positive**

Cancer treatment seems is a mixed bag in how emotionality is addressed in pop psychology and medicine. The expressing fear or anger can be pushed to the shadows by an insistence on hope, positivity, and ultimately winning the war against the alien invasion that is cancer. Hope is couched in the desire to live, and while many people might opt for continued life, it perhaps limits responses. Hope could be explored to mean many things, for example, to be free from pain during treatment or a hope to live long enough for a special occasion. Hope might be generated from the experiences of exploring what values a person wants to live closely to as they are undergoing treatment and what might come next. While we acknowledge we are writing here in generalizations and recognize that not all medical people ascribe to this monochrome emotional definition of hope, the preponderance of treatment seems to fall back on remaining upbeat and hopeful that the treatment will be a success and cancer will soon be in the rearview mirror.

Lorraine: So these are the things that come with a cancer diagnosis? That you're supposed to manage it with positivity. You're supposed to fight in some fashion. You should be serious, but you should be

optimistic in your seriousness?

Emily: Yes. To clarify though, these are all messages that have been laid at my feet...Being told, “Well, you need to figure out how to fight...Because that's what you're supposed to do.” Whereas other people respond by saying like, “Do what you need to do.” But then I don't know what I need to do so that's equally unhelpful, even though it's intended with helpfulness.

Lorraine: Fighting seems antithetical to positive thinking sometimes. I can imagine that on top of difficult physical experience that at times this feels a little crazy making.

Emily: People seem to take liberties to impose how it [responding to cancer and treatment] should be done. if you're too negative, that's not just a really bad thing. According to the rules, it's pathologized. If you are feeling down, if you are feeling dark, if you are questioning survivability. Then it gets separated and compartmentalized as something that you need to speak to a psychiatrist about.

Questions that could explore meanings that we might suggest, could look like:

- If you aren't “fighting,” what would be a better way to describe your actions?
- How would you hope people would respond to the aspects of this that feel dark or isolating?
- If you were to talk with someone in similar circumstances, what advice might you offer?

## Getting “Back to Normal”

The emotional pathway that accompanies surgeries, radiation, and chemotherapy, has strong overriding goals. The more obvious goal is to not die. While that is a reasonable goal, it is something of an unwritten mandate for the medical profession even at the cost of quality of life. Cancer, and death, are the enemy and the medical personnel will do everything possible to not let cancer kill people. There are admirable aspects to this, such as having doctors and nurses who fight for your life; and yet, this creates other challenges when nuance might be compromised.

There is a secondary goal as well in the cancer treatments to support the aims of the first goal; that being, to commit to living which translates into being positive and find silver linings. There is little room for anger, fear, or sadness, as these feelings and their very presence could hasten an unsuccessful outcome. The admonishments are filled with positive thoughts, affirmations, and believing cancer is only a temporary malady that will be remedied.

There are implications to a requisite positive attitude. While we don't want to dismiss stories of strength, we wish to pry open space that allows wider responses to hard challenges. Without this spaciousness, feelings seen as “negative” are potentially forced underground. The ruminating fears of what could happen, or the anger at the illness, or the horrors of treatments, can be overlooked potentially leaving the person in a precarious state of isolation. Those living with cancer are often encouraged to return to “normal,” get back to an old life before cancer, and put this behind them. And while many people living with cancer might want to return to a former life, we mention it here as it could create prescriptive narratives suggesting people need to pull themselves up by the bootstraps to fight cancer and get back on their feet.

Lorraine: Do you think that are the expectations around being a patient that have been relayed to you either directly or indirectly about how you should be thinking or acting?

Emily: There's been an expectation of going back to life in general. I'll talk specifically around going back to work. With my surgeon, when I had the thyroidectomy. I got to work with one of his residents...

Emily: When I was in the hospital.—I told the doctor, “You know, I need a note for work. Because I'm off on medical leave.” I had to work with the resident [to get the note]. She gave me a note that said I should be able to return to work in 2 weeks... When it came to my recovery, I was under pressure to go back to work. And the “go back to” notion has kind of been prevalent the whole way along. Like hurry, hurry up and get back to work—to perform and engage the way that I had prior to the surgery. Get back to relationships, social relationships. Get back to physical activities.

Lorraine: To go back to a non-cancer state. You had this little blip on the radar. It's done. Please resume what we expect of you.

We question if there's ever a return to a noncancer normal. Even if a person has been declared in “remission,” the life-threatening potentiality lurks. It is one blood draw or CT scan away from a persons thoughts. We also wonder if there aren't other ways to hold space for emotions and hypothetical “what if's” that dread ushers in. How might speaking to how thoughts and feelings in one's relationship to their body, support an agentic response to cancer treatment. Perhaps a few questions in this vein might help:

- How could you imagine the conversation with the resident going better?
- For example, what might they have done or said that would have acknowledged that even in a return-to-work, your world is now different?
- Had they done this, what would have been the impact on you?

## Metaphors

All of us are in relationship with our bodies. We have stories about our bodies' capabilities, their appearance, about where we feel ease or distress in our connection to our body. When a diagnosis like cancer, or other life-altering diagnoses enter the picture, our relationship changes. People may feel more in touch with what their body is expressing, or betrayed by their body, or they find themselves needing to adjust to their body's capabilities. But changes to the stories and the physicalness that once were dominant will be reordered. These shifts can create chasms of possibilities, or despair, or both.

The stories that are brought forward in treatment discussions, could feel as though the agentic choices might be omitted from that of being “a healthy person” to that of becoming “a patient”. The hope is that these changing aspects can be transparently discussed to allow for multiple choice points for subsequent action and meanings. This is a shift from a one-sided story of hope and beating cancer at all costs; where the hard moments of treatment or changes in status can create potential into despair, like when your stomach drops out during gravitational plummets of a roller coaster.

We wonder about the use of metaphors, too and how in counseling, they can be a helpful way to open conversations. Our clients often might speak in terms of metaphors such as, “This feels like a closed door,” or “The bottom fell out from under my feet,” or even, “That was when I felt like I could take a full breath.” These metaphors can be a path to agency. People might speak about the ups and down in comparison to cancer treatment, like riding a roller coaster. While not literal, metaphors can be used to speak to an imaginal path toward clues that produce helpful meaning and actions. We might ask the following to use metaphors:

- Is the door locked or merely closed and if so, can you reopen it?
- Was this moment of breath useful to recall as you are making sense of this diagnosis and treatment?
- Are there lessons in the sensation of the up-and-down ride that you have found to be similar or different to your current medical situation?

## Fighting Metaphors

Unlike the above, there seems to be an abundance of war metaphors in oncology. People are fighting the good fight or battling the enemy of cancer. The rhetoric of war is so strong that it is often how people are storied in obituaries, being spoken about as having succumbed to their battle with cancer after a valiant effort and good fight. We do not begrudge these descriptions and appreciate how cancer can feel like a battle with one's body, the treatments, the medical profession, and the financial costs and insurance/reimbursement systems. Nevertheless, this language also poses antithetical reasoning to remaining positive and calm and peaceful. It positions people living with cancer potentially in a bifurcated reality of fight as hard as you can but do so with a good attitude. What happens a person wants to speak or think differently about their experiences?

Emily: I am tired. Like I've kind of been fighting with this [thyroid disease] for the past fifteen years. So, I'm not quite sure what they hope for me to muster at this point. Suddenly like, become a cancer patient with the will to survive and carry on...

Lorraine: Is the assumption that because of the diagnosis changing from thyroid disease to thyroid cancer that you should up the ante and you should then automatically fight more?

Emily: Yes. And my response is with what though? And adjusting to not having a thyroid that's functioning at all and being completely dependent on medication for that. It's not like I have a full tank from which to fight. This journey has emptied the tank. And now they drain the fumes... And they're [the medical team] like, "but, get going, step on the gas.". Like ok with what? And when I ask that it becomes now a psychiatric concern.

Lorraine: Do you have a sense of what would happen if there was room in these conversations where you might be asked, "Do you want to fight this?"

Emily: That would give me the space to explore that ambivalence.

When we place expectations that people should fight against cancer, we might need to think about how we equip them for what lies ahead, where and when the energy can be used best. Many treatment plans often include doing more of "healthy" activities, like working out, eating well, sleeping, and meditative events; however, this can perhaps place a burden on a person who is going to and from medical appointments and could be suffering from the effects of treatment. Asking a few questions along the way could be beneficial. Questions like the following:

- What would fighting cancer look like for you?
- What continues to fill your tank? And how could you get more of this?
- Who can help fill your tank or ease some of the tank drainage from you?

## Becoming a Patient

When a person enters a medical clinic, doctor's office, or hospital, or when they are diagnosed with a serious illness, their identity shifts. Outside of medical doors a person's identity might be defined in a myriad of ways important to them. It could include their profession and hobbies, their family, or values they have stood for. It is not unusual for these precious aspects of a person's life to be reduced to their new role of being a "patient" or as "having cancer." Not all medical professionals overlook these other aspects of a person's life, but there are certain protocols that limit the sharing of our humanity when we are involved with medical systems.

We become patient-ized in a series of acts that assert the authority of the medical world, from asking people to disrobe and vulnerably wait in paper "gowns," to the collection of "vitals" like weight and blood pressure, having an MD introduce themselves by their title (Dr....) while referring to the patient by their first name regardless of education or profession, or to characterizations written about a person in a chart. Patients are expected to follow unwritten rules that shape their performance and limit their responses.

Patients are expected to comply with prescriptions and medical instructions, have minimal questions (as that might be seen as an affront to medical expertise that is trying to save their life), have a cooperative attitude, and generally be deferential. Practices such as this have evolved to make matters easier and more efficient for medical personnel, but at a cost to the person receiving dignified care. If a patient behaves outside of these rules, they can be perceived as questioning a doctor's knowledge and authority or runs the risk of being seen as a difficult patient, something to be avoided when treatments, and potentially lifesaving measures, hangs in the balance.

Emily: —I use humor to go into an unavoidable situation...So it's like, yeah, ok. I'll come in and perform. I will perform patient in the physical sense...

Lorraine: Can you give me an example of this?

Emily: I walked into the operating room [instead of being wheeled in] and I am there with the nurses and they are saying, 'Ok.—you have a gown and pants, but you have to take the pants off. Ok, so do you want to take the pants off?' And I said, 'Ok, what if I want to leave my pants on?' And they said, 'Well, when you fall asleep, we'll just take your pants off after we give you the good drugs'. So I'm joking about, 'Ok. You're going to drug me and take my pants off. What kind of party is this?'

Lorraine: Are those places where you are refusing the identity of becoming a patient? You're refusing the identity of having your identity taken away?

There certainly are protocols that make medical procedures easier for the professionals involved but these events could sometimes happen without collaboration or explanation, potentially leaving the patient feeling more vulnerable. It is important to create an atmosphere where an inquiry about a person's needs and preferences can be honored, and the medical personnel can explain why something is needed in a particular fashion.

As we can read in the above excerpt, humor can diffuse situations where acquiescence is expected in becoming a more convenient patient. It can be risky too should it not be well-received or seen as refusal. Declining the invitation to only do things for the medical team and procedures is often a strategic move where a person hopes to join with their medical team on their behalf, for collaborative exchanges. Should a person appear confrontive or obstinate, they can face consequences that might even affect their treatment. The person receiving care needs to be accommodating, strategic, and warm to engender good working connections with those who are trying to rid them from disease. The difference in power between a patient and the medical

professionals requires people who need the care work diligently at creating the connections for increased collaborations. Emily offers one such example in her response to the awkward conversations she previously mentioned with the resident.

Emily: The surgeon was much more accommodating when I saw him to follow up... After sending a lengthy invitation letter for him to coach his resident differently.

Lorraine: Is that one of the ways that you have stepped into refusing some expectations? Sending notes to, say, "This is how she should have responded in an optimal situation, considering the experience of the patient." What was that like for you then to reach out to him with a little piece of information of "Hey, you might not know this, but..."

Emily: —It took me two hours to draft this email. After speaking with his receptionist about whether it's ok or not to give feedback...I also acknowledged that by saying anything at all, I run the risk of labeling myself as a difficult patient. And I referenced the Seinfeld episode where Elaine had been a difficult patient and then her medical file would follow her and then no doctors would work with her. And she ended up seeing a vet [for her medical care].

Much of refusing the role of "unquestioning patient" comes through how power relations with medical teams are navigated. For most people, this can be very difficult as doctors are to be revered for their education and professional knowledge. Unfortunately, doctors have occasionally reinforced practices that make it hard to penetrate the veil of power through a variety of ways, including the use of professional-speak language that is hard to make sense of without a medical degree, or the secrecy surrounding medical charts. It can take a concerted effort, particularly when a person is dealing with the emotional tenderness of serious illnesses, to find pathways to connect with the medical team. It is why medical advocacy sometimes suggests having a trusted person as supportive ally in the consultation room to help the patient remember the questions and to speak the hardest parts.

Emily: When I'm dealing with power relations and hierarchies. To know where I can ask, what I can ask... And what my best chances are...Like how I can package this as to be best received.

Lorraine: Are those acts that you think are different from how other patients might act?

Emily: Yes.

Lorraine: Ok.—How do you explain the difference that you do that?

Emily: I think this has to do with power relations. For example, the letters that I will write to medical professionals will come from my university email account. Which includes a signature, that says 'Emily Doyle, PhD, RPsych.' I invoke that [power] in the text.

I am someone who is fluent in being able to read medical journals and understand statistics. I talk about research. I can look that up and I can understand it.

What becomes more visible when we inquire about what actions people enlist to preserve a sense of themselves when undergoing treatments.

- What skills or knowledges have you used when communicating with your medical team that you have found useful?
- How have you learned these ways of communicating?
- What might you hope your medical team would come to notice and value about the way in which you have maintained a sense of yourself throughout this process?

## Right of Refusal

Refusing the practices that remove preferred identities and having this replaced with stories of being a patient or a cancer survivor can be tricky. It is the intentional stepping into a relationship with cancer that a person can live with rather than only an adversarial enemy, which according to Halberstam (2011) is seen as an agentic act to define ourselves in preferred ways. According to Halberstam, refusing to take up identities that are expected of us is a kind of “failure,” and opens to “offer more creative, cooperative, more surprising ways of being in the world” (Halberstam, 2011, p. 2).

This form of refusal however, needs an audience to stand alongside the new stories, which if the patient is lucky, would be the medical team. But often it means bringing others into the folding of the more agentic stories to support and strengthen those stories, where others can step forward to ease the isolation of cancer. The effect of this process can be finding new places of strength and meaning during life-changing events and gathering others to support agentic choices and stories.

Lorraine: How long have you been failing at being a cancer patient, you think?

Emily: Well, I've been failing at being a cancer patient since January 25th, I believe I've been failing at being a thyroid patient for the last 15 years.

Lorraine: Can we talk a little bit about how you have intentionally and unintentionally failed at being in a relationship with cancer?

Emily: Sure.

Lorraine: Do you have a sense of where you stepped into that place of saying, “Yeah, I might want to have a different relationship with cancer?”

Emily: I think that I started there. When I got the diagnosis, I spoke to the endocrinologist that I've been working with for the last number of years. Her response was “This is not something that you really need to worry about. Chances are you couldn't die from it, even if you tried to.”

Lorraine: Is this one of the ways that you refused that “I have cancer and I'm scared”?

Emily: Yes. I kept the other phrase in my mind that, you know, “I probably can't die from this, even if I try to.”

Lorraine: When you would intentionally adopt the message that you couldn't die from it, even if you tried, was there a comfort in refusing cancer's opportunity to speak otherwise to you?

Emily: I let people know what was happening for me. Rather than a message that lots of women get which is kind of the “suffer in silence.” Around so many different things. Instead, I chose to speak

up about it. I let people know. I let people know about the diagnosis.

Lorraine: In taking that stance where you're speaking against silence, are you also then invoking a resistance to patriarchal practice?

Emily: I think so.

Lorraine: Is there a theme about that? About failing at being in a relationship with cancer includes not being silent.

Emily: Yes.

Lorraine: And failing at being a patient means not acquiescing to power relationships that silence you. Are there other places where you have identified acts of resistance or failing at cancer's relationship with you?

Emily:: —There are several. One was when I went to the hospital for surgery. I had one of the nurses look at me when she took my blood pressure (which was a little elevated). We were going through a whole bunch of pre-surgery things. I had kind of chosen, ok what ground am I standing on when I go in. And—it was “I am the storm.” So from the parable—the devil whispers in your ear, “You cannot withstand the storm” and you whisper back “I am the storm.” But the nurse taking my blood pressure then said, “ah, there it is!”. Otherwise, she couldn't tell how nervous I was because I was performing “calm” as part of being the storm - like, I was the eye of the storm - but her expectation was that I would be performing something more obviously worried/anxious/nervous as a patient about to go into surgery.

Lorraine: Yeah. How did that affirm that place of you being “I am the storm?”

Emily: I guess I was performing “storm.” I refused to have the circumstance dictate what my interactions were going to be.

As Emily was performing the eye of the storm, which looks calm to observers, the nurse viewing her blood pressure results expressed validation of her expectation of nervousness, evidence by her comment of “ah, there it is!” when noting the higher than normal reading. The nurse's expectations of Emily's patient behavior subjugate what Emily had grounded herself in as helpful in that moment. Thus, feeling the effects of this parable could allow for a way of acting that has congruence with Emily's life. This strength could have a history that we can inquire about, such as its birthplace or other circumstances when it was present. We can ask:

- Has this sense of being the storm been with you before?
- Do you have a sense of what kind of storm you are? A gentle one or something else from that?
- How are you imagining this storm will assist you in the coming months with the treatments and surgery recovery?

## What Could be Different?

We have written here about many of the ways in which a cancer diagnosis and treatment position a person with limited choices or where larger practices impose expectations and remove agency by speaking about one person's experiences with one particular form of cancer. But this is not the only experience. There are always

exceptions and some medical personnel who engage differently. There are those who listen and create flexibility in consultation, but these seem to be the exception and not the rule.

Lorraine: So how often in that—just speaking about the expectations around cancer—how often are people saying, “Are you discovering what works for you and making inquiry along that path?”

Emily: Very few. I’ve had one really positive interaction. With a nurse that works with the endocrinologist who specializes in oncology... Like she specializes in thyroid cancer. She was excellent.

It is important to explore these options further to learn what can be helpful for people at the center of the diagnosis and treatment. In what Emily recounts, it was perhaps less of what the nurse said and more about her willingness to share openly and be transparently human and vulnerable.

Lorraine: What did the nurse ask that was useful for you? Do you remember?

Emily: —I had at first actually refused the follow-up treatment. She asked what I was going to do instead. She encouraged me to do something. And was open to different possibilities...

Emily: I don’t remember her exact words. But it was along the lines of “You need to pick a path that works for you, but you need to pick a path, you need to do something, and be active...”

Emily: Then, she sat back and took a breath, and decided to disclose that she was living in a relationship with leukemia. She had discontinued the medical science and the chemotherapy in favor of alternate treatments and was doing well.

Her disclosure gave context. She put herself there and suggested I consider going forward with the medical treatments for x and y reason and to investigate complementary alternative treatments. If she was making the decision for her, that is what she would look at. That was actually the most helpful.

She answered my questions from how she knew it in a personal way.

There is a tender human connection that happens here that opens space for a different kind of conversation between Emily and this nurse where curiosity and humanity holds emergent stories of identity with reverence. In the next section we will speak more to what else can be offered to support agency for the person at the center of the diagnosis and treatment.

Connection doesn’t require self-disclosure or a shared identity in relation to cancer. What it does require is acknowledgement of the personhood of the patient. In the example above, Emily’s request for a particular type of response was accommodated, but connection could also have been fostered with genuine curiosity about the challenges faced in making treatment decisions; thus:

- What, if anything, might make your decisions about treatment options easier to engage in?
- What, if anything, might make your decisions about treatment options more difficult to engage in?
- What is most important for me to understand about you as the person who is making decisions?

## **Where Does This Transport Us to?**

As counselors, our role is to open space for different possibilities in the face of challenges. We have the skills and training to remain curious, refuse the role of the expert, and inquire about how people are making meaning and what their preferences are. Even in “informed consent” conversations, we can be curious about the implications of treatment choices (Paré, 2013). It can be hard for counselors to stand against ideas that can be such taken-for-granted assumptions, like those we have noted throughout this article. There can be pressure for efficiency that joins with the power of medical world. We might have expertise about options and even medical procedures, but we do not hold the expertise as to what options and actions might mean for a person. When counselors or medical professionals let go of an expert stance with those who consult us and honor that they know what is best for their lives, then we can engage co-research to discover what is the most helpful.

There are a few ideas that might be useful. First, we should note that we are both trained in narrative counseling and postmodern approaches to counseling, and while this isn't a treatise on narrative work, it does inform how we think and speak with people. As such, we often find ourselves thinking more relationally than individually. We believe we are in relationship with everything—with one another, our bodies, our medical diagnoses, and our thoughts and emotions. This might sound a bit foreign but it opens conversations to speak about the emotional and physical facts of these things, for example, the effects of living in a relationship with cancer. We can inquire about the intricate dance between the person and the cancer. It could be conversations where we explore where cancer feels like it has the upper hand or perhaps where the person feels like they have the upper hand. We are not suggesting engaging battle metaphors to vanquish the cancer but propose a focus on an ever-shifting relationship and internal dialogue with cancer. Counselors can make visible where these dialogues engage, in the quiet or in the shadows, and in so doing, perhaps, create new possibilities where difficult choices can happen.

Narrative counseling describes this process as “externalizing” (White, 2007) where the problem (in this case, cancer) can be spoken about as if it is living outside of oneself, and we are in relationship with it. Or as White (2007) noted, the problem is the problem; the person is not the problem. This way of speaking allows for the problem to be linguistically separated and the person to speak almost as if the problem can be addressed in the third person. The person can then note where hidden implications are that the problem brought into the person's life; where the person has created acts of resistance to the problem's influence and tactics.

One of the many benefits in speaking in this narrative fashion is that it allows the person to claim stories that engage with options, strength and communities of concern. For many without these externalized conversations, the diagnosis can feel all-encompassing so that it occludes other aspects of achievement and values of one's life. This practice creates a zooming back out of the camera lens as a stand against what cancer, and medicalized practices, can take from a person's identity.

## **Audience-Ship**

Anyone who has experienced the hardship of cancer, or simply of life, knows that going it alone is a hard road. Preferred ways of being and places of identity that connect us to life projects and purpose need an audience. These could be living people who are surrounding the person. Listeners can reinforce the stories that support the person during treatments and medical appointments and the resulting life-stopping inconveniences. Friends and family members can assist to stand against stories where agency is diminished. In a perfect world, medical professionals too become possible witnesses and could speak how the person has moved them or taught them new ways of interacting. These are but a few of the questions that could highlight the reinforcing of preferred stories for people that might be helpful:

- What have they appreciated about how the person (the person living with cancer) has handled these challenges?
- Have there been responses and strength that didn't surprise them knowing the person they have witnessed?
- What have they have found inspirational that they have seen from their person?

## Conclusion

We have written about one person's experiences being formally diagnosed with thyroid cancer and some of the types of comments she heard during her treatment in hopes to examine ways in which this positioned her. It is our hope that in doing so, and in providing examples of inquiries, that others living with similar experiences might find solid ground to stand on when ontological security is destabilized by a life-threatening diagnosis. We would further hope that those involved in the medical profession or counseling profession can engage their own curiosities so that we can all sit in places of shared humanity.

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## Note

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