

Disclosure Day

By Kathryn A. Cantrell

October 1992- begin feeling weak, seventh birthday, don't want to play, always tired

"My advisor said I shouldn't disclose- that a hospital won't hire me if I tell them I had cancer, that I understand the process."

"That's absurd," my mother's voice drifts out of my phone. She's always this obvious. I'm applying to child life jobs across the country and enlisting her as my emotional support. Who knew a profession rich in play would be so conservative about sharing one's story?

"He thinks the hospital will fear I'll tell families about it- that I won't be as good at caring for the kids because I might make it about me," my voice shakes through the words, fearing that it might be a valid argument.

"You teach the patients how to disclose- why can't you do the same?" my mother always validates.

"Apparently it's unprofessional to share with others. I just won't say anything at the interview- keep it locked up. Maybe I'll tell them one day, if I get the job," I respond rationally.

"Tell them once they know how professional you are, once they understand you would never tell a family." And she's always wise.

"I don't want to be sappy," I respond, pushing down cancer's significance.

"It's your story, Katie, you have a right to tell it just like the kids you work with have the right to share theirs."

December 1992- visit Dr. Francis, diagnosis revealed, can't ride bike given at Christmas, pale, weak, grumpy

A pen sits at my right hand. It has sat and will continue to sit until this comes back. On my lap rest strewn, somewhat yellowed papers: notes, cards, letters, reminders. And at my left hand rests the timeline I made two days ago; the script is scribbled haphazardly, as though the words are disconnected from the person they belong to. It is an odd feeling, one of memories that don't fit in, memories replaced by a story heard too often. I stare at the dates in hopes that the list will come to life, speak, remind me of the senses behind it. Remind me of what hospital food really smelt like. What the stiff sheets felt like. Anything. At this point, I will even accept the recollection of pain.

The pictures recreate the most, their colors piecing together the world that engulfed me: hospital murals, graphic scrubs, mounds of stuffed animals. The images speak of the in-between moments, the days amid treatments and tests. But even in looking upon the cracked surface, scarred from fifteen years of fingering, tacking, pasting, taping, showing, hiding, the girl seems like a character, the receiver of my sympathy. Not myself.

Her scrawny arms are transparent, lucid, glass-like. And the veins inside show perfectly through like netting, webbing that weaves and dances in the layers of clearness. Just by touching her skin, she colors, becomes spotted with browns and purples, markings to track

affection or rough play. And upon looking toward her white face, one notices the clumps of blood that create circles to hug her eyes, wrapping them in an elegant, royal color.

She is playfully stern, as though disease is her ticket to childhood, or at least attention, and she is serious about using it. Following her, one can watch as she stares into mirrors and laughs at her new frailty, a laugh which signals an unawareness of the disease's full capacity. Today she paces in legs that wait to give out, knees that wait to break down, twig-like projections that jut from a torso that bulges, filled with prednisone.

January 1993- liver resection, two thirds removed, first round of chemo started, first hair loss

"The name of your virus is the Human Immunodeficiency Virus, or HIV, have you heard of it?" I state plainly, in an effort to remove value from my voice.

"Yea, I learned about it at school- it's contagious," she says as she blinks, searching my face for more information. She's 13 and despite being perinatally infected with HIV, is just now learning the name of her diagnosis. Both of her parents died from the virus.

"You're right, it can be contagious," I respond, "through sex, needles, and childbirth."

"Is that how I got it? Cause I haven't had sex," her eyes are bulging now.

"Yes, your HIV was passed onto you during birth," I wait for her to make the connections, to realize she has the same diagnosis that took her parents.

"I'm going to die?" her eyes swell up and it's clear she's pieced it together.

"The medicine will keep you healthy as long as you take it everyday," I place my hand on her shoulder and she leans into me. Disclosure day in the clinic is the hardest. But most often than not, it affords clarity to the adolescents and if they're information seeking, provides a starting point for their own health literacy. As a child life specialist working in an HIV clinic, it is my job to disclose and provide on-going psychosocial therapy.

"Can we just paint now?"

"Of course," I say, welcoming the redirection. A full assessment of her transition will come later. Right now, I need to provide a safe space for her to simply process.

February 1993- fighting pneumonia, chemo stalled, feeding tube inserted, respirator necessary, bed-ridden, three weeks comatose

It is Monday morning. Dr. Francis's voice can be heard down the hallway, it permeates through the ward. He begins to approach her room, walking with heavy feet, a head jutting forward and arms swinging madly. His dark mustache is his largest feature, too large for his frame, as he stands barely higher than the little girl. Wind seems to part the doors as he enters, as though his force intimidates the structures. Behind him are twelve students, eyes facing downward, staring at charts, anxiously awaiting his questions, hoping they'll be easy. They're never easy.

The girl laughs silently. She enjoys the play, seeing so many people see her. Watching their eyes as they search for her reflexes, their fingers as they struggle on her stomach, their eyebrows as they rise at her rarity. It's one of her favorite parts of the day, his eight o'clock (never a moment later) entrance.

His hands free themselves from pockets and they rise, floating over the crowd, conducting the scene. On cue, her parents place worried looks on their tired faces, the medical students remove pens from their breast pockets, and she sits, waiting for the performance. He first drills the father, asking about her appetite over the weekend. Then her mother, asking about the bowel movements. Then the child, asking about the pain. Then the students, asking about the protocol.

His eyes are dark, beady, anxious. He leaves minutes of silence after the questions, for dramatic build up. Finally, he speaks, sighing between words, saying, without interruption, that it is worse than we think, that more tests need to be run, that the pneumonia isn't backing down, that more fluids are needed, that the blood count is low, that the immune system is gone, that the chemo is only complicating matters, that the liver isn't healing, that there is internal bleeding, that...

Her eyes close. She is bored by the serious monologue, wants the action back.

He bows and leaves the room in a rush, pushing students out of his way, ignoring the tears from the parents, allowing the lights to fade on an empty, but still pounding, stage.

March 1993- chemo reinstated, renal failure, chemo failure, new protocol begun, vincristine this time

"What's it like there, surrounded by all the bald kids?" Dr. Francis's voice is still loud, but a bit heavier after twenty years.

"I dissociate, barely even notice, and just focus on the HIV clinic," I say, stoically.

"Katie, I don't believe you really can dissociate at a place like that," he states. He's often contentious with me. And since the death of my father, it seems the paternalism is only growing.

"Well, I've gotten pretty good at it over the years. Haven't shared it with a single person in ages," I say proudly, as if silence is a badge of honor and strength. Why does my profession, one that provides emotional support, desire stoicism?

"The illness story is too precious to keep locked up," his voice cracks and he sounds worried about me, about my coping twenty years later.

"I know," I respond, "that's what I tell the kids."

April 1993- protocol continued, signs of improvement

It is Wednesday. One hospital bed has been replaced by another. The child sits in her new home, observes, with eyes that seem heavier than normal the twisting, turning vines of the IVs, the blinking red eyes of the monitors, the up and down breathing of the respirator. Nurses move in and out in silent stalking steps, pressing buttons, replacing IV bags, checking vitals. They are different from the ones she had before; they are more serious, more stern, stoic, unaffected.

Her father walks in. His hands are behind his back, concealing a gift: a stuffed purple dragon that she's wanted for months. Slowly, he pulls it to his stomach and she responds by blinking twice, the way they taught her. Tears swell in his eyes and they fall forward, dance across his reddened cheeks and make his skin glisten. Nurse 1 juts in the room, grazes his chest in a hurried pace, runs through the routine, then leaves.

He places the dragon on the girl's lap and she fights to move her hand, feels only struggle through the paralysis and eventually gives up. He notices her wince, picks up her hand from the weight of tape, tangle of tubes, pain of bruises, and places it on the dragon's head. She blinks twice, the way they taught her. Nurse 2 gallops in, injects more fluids, tears off gloves, and disappears.

The machines work and breathe, animals on their own. The sounds of the room harp, move between mechanical and musical, as though, during some moments, they fight for life. She listens, loses herself in the clicks, ticks, and beeps, and struggles to ignore the heat of pain. Her eyes, though heavy, still dart, awaiting the next entrance, the next interruption, the next time someone will make her wake, make her blink, make her try.

May 1993- begin walking again, speech recovered, protocol continued

“Telling my partner will be the hardest part. I just know it. I’m scared he will leave me. I’m scared he’ll walk away and think I’m nasty,” his eyes are tearful, welling with fear.

“You think it will be difficult to tell him,” I reflect back, stoic like I’ve been taught, hoping he continues to share, hoping I have enough to fill out the assessment form.

“Of course! What will he think? He’ll say I’m easy, that I’m dirty, that I’m no good.” His voice sounds as if he’s in shock.

“You think he’ll see you differently, as someone unworthy?” I ask. The reflections are practiced, automatic.

“Yes, I think he’ll want to leave me, want to walk away,” his face looks as if he’s just considered the absence of his partner and what life would be like without him. He’s only twenty and yet his life has been turned upside down by the diagnosis. I shudder at the idea. To be so young and fear the loss of a partner because of stigma.

“You’re scared he’ll leave you,” I say.

“Yes, and then I’ll be alone with this terrible disease. I’ll be alone with no one to talk to.” My empathy swells at this statement. I am so lucky to have people who know my story and want to hear it.

“Would you like to rehearse the disclosure? So that you have an idea of what to say?” I move onto an intervention quickly. I tell myself that I’m doing it to motivate his disclosure but I know it’s just because I can’t bear to hear more about his potential loss.

“I guess. Yea. But I’m really scared, Katie.”

“Let’s work on it together, we have time.” It’s not true. His viral load is too high for time. If he doesn’t disclose soon, his body will disclose for him with boils, fevers, and weight loss.

June 1993- protocol continued, wheelchair no longer needed, blood count increasing

The dragon’s fur rumbles under her boney hand, and she can feel the purpled, leathered mound twitch at movement. She tries to push her down saying, “Shhh...they’ll hear you.” It doesn’t work –the dragon opens her mouth to a gape that trickles out sparks, drips of fumes, and finally, reveals a foghorn yawn. The stench of the fiery breath makes the little girl laugh in disgust.

The dragon responds: “I am Lucy, child.”

It is eight and in he comes, in a black suit this time. The girl acknowledges him, points her head toward the dragon, and allows him to explain the rest. His hands dance, orchestrating directions towards the door and thrusting his small body to the hallway. She follows in hurried steps, unsure of how much time they have.

The girl collapses onto Lucy’s back as they make it outside, plunges into her glittered fur, and grasps her arms around the neck. Lucy gallops, picks up speed, her fur matted by the rushing air, and finally lifts with the strength of her back legs toward the sky.

The girl uses each muscle in her face to shut her eyes, denying the distance between her and the ground. But her face eases as she feels the solidity of the body beneath her, the confidence of the fur and scales. Snot drains out of her nose like water, its thinness a result of the piercing air; she smiles as it runs towards her mouth and she can taste salt. She breathes in

large and heavy, then opens her eyes, takes in the view, and looks past Lucy's head to their destination.

July 1993- feeding tube removed, protocol continued, eating on own

"The youth are getting really good at sharing their stories. I'm seeing them advocate more and it's really rewarding," I say proudly as I share about the new illness narrative program we started in the clinic.

"That's lovely, sweetie. You know, you could learn a thing or two from them," my mother states plainly. She is always honest.

"What? By telling my story?" I say as if I don't know what she's referring to.

"When was the last time you talked about cancer? Honestly?" she asks.

"It's not a part of me anymore. The patients are- their HIV narratives are my life now, my own story is just a faded scar I barely notice," I say coldly, as if her experience as a caregiver were meaningless.

"You may not remember much but others do and for them, it's hard to see you repress it," she states slowly, as if she has to muster the courage to speak.

"I don't even know where to start," I say honestly. There's so much I can't recall.

"I'll bring pictures on my next trip and we'll make a timeline."

Sometimes she sounds like a child life specialist.

August 1993- protocol continued, eating normally

Finally, she takes a breath on her own and her parents rest their shoulders, but only slightly, for fear of getting their hopes up. Sleep has crusted on her lids so that expanding them, revealing her pupils, is impossible. Her mother sees the lids fight and takes a washcloth to the girl's face.

She moves to unwrap herself, awoken from a long sleep, so long she's forgotten how to budge her hands. It all surges at once, the need to remove the sheets, the gauze, the tangles that mummify her. Her fingers stir to unravel but only fall to her side from exhaustion; they twitch from weakness. Her neck strains to move her head from the suffocating pillows but only ends up cramping in pain. Each motion is stifled. Each body part restricted.

She relinquishes, falls back into the wrap, and tries to find comfort in confinement. She is dusty as her mother comes to hug her, a moldy breath, an aged tear. She is rusty as her father speaks to her, tells her how long she's been away; rickety eyes blink, and stiff cheeks rise. She looks towards the clock on the wall, sees it is eight and holds her breath.

In he comes, alone this time, with tears in his eyes and a body out of breath.

He simply says, "Good."

My pen collapses. My hand crumples from cramps. I still get cramps.

September 1993- protocol continued, improvements made, remission possible

"Each day I teach my patients about the importance of disclosure," I state plainly during a staff meeting, surrounded by twenty pairs of eyes, all on me.

"But I rarely disclose my own story or speak about my health," my voice cracks as I try to lean into it, "...twenty years ago I was diagnosed with embryonal sarcoma of the liver. I underwent a liver resection, two years of chemotherapy, and a lot of physical therapy. My memory is shot and I barely recall much. But for my mother, father, and physician, it was a stressful experience that shaped their lives. I need to honor it more and my first step in doing so is sharing this with you," I say as I pass around a photo of my bald head, shiny and pale.

Their eyes are comforting. I expected shock, signs of discomfort, rejection. Instead, I received warmth, validation, and appreciation for my experience. It was a successful disclosure and I know the patients I work with would be proud.

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