

The Beautiful Place

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There is a place in Minnesota, a magical place, where everyone is beautiful. It's not the moonlight, which scatters across obsidian northern lakes and filters down through tall, leafy trees into fractals of glimmer. It's not the sounds, of the loon or of the sweet humid night breeze or of the quiet lapping of lake water against sand and smooth pebbled stone, trailing wayward bits of sea grass. It's the shadowy figures, darting joyously, deviously between trees. It's the two figures silhouetted against the night, rocking on a wood-slatted swing facing the darkened, sleeping lake. It's the heads tilting together and the shoulders encircled by a bandaged arm. It's the laughter punctuating the love song drifting out from inside a wooden cabin after lights-out.

I think skin is beautiful, and before I came to Teen Camp Discovery I thought this was why I wanted to be a dermatologist. My interest was not in "beautiful" skin of the youthful, dewy variety appearing radiant throughout magazine ads and billboards, but in skin in all its variety. I love the geography of skin, the way disease and injury carve new landscapes, cutaneous terrains of fissures and crusts alive with a subterranean life of flowing blood and dividing cells, surfacing in myriad ways. Learning the vocabulary of this specialty is a split education in the mellifluous and the decidedly grounded; impossible Latin diagnoses trip clumsily off the novitiate tongue as we students must also learn to describe lesions in hearty, geologic terms: erosion, scale, crust. It is a world in which one can lose oneself. But in a cabin in the Minnesota woods I was instructed in the far more rewarding terrain that lies within.

The mission of Teen Camp Discovery is simple: to provide a weeklong camp experience for 50 or so teenagers with serious skin disorders. The campers' skin conditions range in severity, rarity, and visibility, from epidermolysis bullosa (EB) to vitiligo, lamellar ichthyosis to psoriasis. Campers in wheelchairs are welcomed alongside avid athletes. Together they spend a week laughing, swimming, fishing, horseback riding, dancing, eating ice cream, flirting, looking at the stars, painting their toenails. Campers slip out of skins that in the outside world cause them nothing but fear and pain, isolation and rejection. Ugliness evaporates. Campers sometimes forget, I am told, that they are different. For a fleeting week they leave a cruel world behind, a world that judges from the outside in.

My education in the deception of outward appearances and the cruelty in their judgments came along with a crash course in Britney Spears. I learned about both of these seemingly irreconcilable worlds from 6 girls with EB, 5 campers, and a counselor, bunking together in one cabin. The EB sorority house was littered with the detritus of American adolescence: wardrobes of bubble gum-colored sparkled tops and slinky pants, lip gloss and glittery eye shadow, and stacks and stacks of compact discs.

One did not have to look far to realize that this was a soundtrack to a parallel existence, that these girls could never be a part of the glamorous world of teen pop, of beautiful, glittering flesh. These girls were different and were living in a world whose value system would never include them. A motorized wheelchair with a sticker reading "It's rude to stare" stood sentry by the door. There were pumps for overnight tube feeds on stands by many of the beds and cases of Ensure slid under beds. Each camper had at least 2 huge wheeled suitcases with them, but only half of one suitcase was filled with clothes. They came with teddy bears snuggled in yards and yards of Kerlix gauze, tubes of Bactroban, sterile needles for lancing blisters, syringes for pushing medications, spare G-tubes, vials of eyedrops, and bottles of medications. Everything was inventoried, neatly labeled, packed just so by parents anxious at the thought of their children, such fragile, vulnerable girls, leaving home, often for the first time.

Conversations were studded with a jarring vocabulary. Words like "sepsis" and "stricture" that can't be found in the lyrics of Britney Spears. Talk frequently turned to EB: the annual conference, friends and online support groups, and techniques for coping. I don't know what this sorority talked about together in private when the lights went off. I do know they guarded each other's privacy and supported each other

through daily pain, sharing coping and distraction techniques. They did what friends do. They worried together about a cabin mate who kept postponing a dressing change out of fear. Almost everyone had lost someone—a sibling or a friend—to the disease, and sepsis was a reality. And they offered those outside their inner circle selected glimpses into their world with stories of physical and emotional pain, insults suffered at school, parents whose love and support turned to tears and self-blame, and the cruelty of strangers and kindness of friends.

In the evenings a crew of nurses, residents, dermatologists, and others helped everyone settle in for the night. Days for this crew were full of tightly scheduled bandage changes that often lasted several hours and were excruciatingly painful for the campers and exhaustingly intense for their caregivers. As a novice medical student, I assisted in distribution of medications campwide, but after the last of the nightly medications were distributed, I would head over to the EB girls' cabin. Together we, campers and staff, lingered over bedtime rituals, talking, listening to music, singing, and spinning in impromptu dance parties.

Each girl was differently affected, and I quickly became better at knowing how and when to help. For some, the blistering and scarring of their disease had left them with almost no use of their fingers, while others retained much use and only needed help carrying or moving large items or working particularly tricky zippers and snaps. Several of the girls with EB changed their own dressings in perfectly choreographed, daily practiced routines adapted to their particular functional abilities and limitations.

Early one evening following an afternoon spent at the waterfront, I helped one of the campers change her soggy bandages. We had been swimming, and she had splashed me mercilessly. She wore navy blue tights under her bathing suit to keep her bandages in place, but every so often an end of gauze untucked itself and trailed her in the water. We had laughed together at her fashion statement.

I imagined her classmates on a trip to the beach. I thought of the bikinis, the attention to blemishes and tans, and our cultural dance between flashy self-presentation and excruciating, brutal self-consciousness. Not just the adolescent fixation, but the judgmental perfectionism and self-absorption we cultivate as we strive toward the beautiful. I hated myself for my part in a culture that would not invite this laughing, splashing, blue-suited girl to its beach party, leaving her sitting out, spectating, afraid of her own skin.

The dressing change was a slow process, and she worked methodically, purposefully, like an athlete dressing for a game or a dancer preparing backstage. There was beauty in how spare her movements were as she wrapped herself in her stretchy armor. Behind this economy of movement, this choreography of spiraling gauze executed with scarred, crippled hands, were years of painful practice and repetition. Despite the beauty and artfulness with which she executed her task, I imagined she might give anything to never have to do it again. She didn't need my help, but she gave me small tasks and narrated the steps of her daily ritual. She showed me exactly how to prepare sections of gauze for her to use, how to open packages and lay them out next to her, just so. She laughed at me when I got things wrong, when I tore the corners of packages as I struggled to open them, when I misaligned the gauze stacks, or when I clumsily let a roll tumble to the floor.

At one point she looked up from her wrapping. "Sometimes I wonder," she said, then paused. "What do you, the others, really think of us? Of the way we look?"

I didn't see the erosions, blisters, and scarring, though this was on the outside. I didn't think about "perfect" or "flawed" skin. I didn't think about skin at all. "I think you're beautiful," I said.

A few nights later, near the end of camp, the EB girls and the evening crew danced to the theme song from Titanic. Céline Dion crooned on "repeat" as we twirled and swayed in our bare and bandaged limbs, on 2 legs and 2 wheels, embracing, laughing, and silently crying.

We must have looked strange from the outside, from the world beyond the darkened woods, from the world of the normal people, the beautiful people, with their chemical peels and sclerotherapy.

We were not beautiful people. Our outsides had lesions and blemishes, our skins were a rugged, violent, ugly terrain. But for those moments we were beautiful. This is what beauty is. It is here. It is 6 girls, wrapped in bandages, dancing in a cabin in the woods.