The Smile That Apologised

Between Two Languages | When Pain Found Its Words.

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Afsana walked in first into the Out-Patient room. She had knocked first at the closed door, and then she strode in.

Bright. Cheerful. Confident. Trusting.

Her father followed. Tentative. Hesitant. Almost apologetic. It is a walk I have come to recognise over the years. The walk of someone entering a room where they perceive very little power – and know it. Where the people on the other side of the table hold the understanding, the words, and most hopefully, the answers. And sometimes, the absence of answers.

I stepped out as my medical team took over.

On paper, her life had been folded into a few short lines. Fourteen years old. A student in Mysuru. An atypical neurofibroma on the left side of her neck. Present now for eight years.

Eight years. More than half her life, lived alongside a swelling that would not leave her alone.

I found an empty seat in the waiting area outside and busied myself with my phone.

It was a typical weekday at the pediatric hospital, which is to say it was anything but quiet. The waiting area was overcrowded. Noisy. Chaotic. Every seat taken, every stretch of wall leaned against. The steel chairs creaked and screeched as they were pulled. The housekeeping staff valiantly trying to keep up with litter on the floor. The air punctured, every now and then, by a cry. Sometimes a wail. Everyone in that room seemed burdened with something.

A little while later, Afsana walked out alone and sat down a row of seats away from mine. Quite oblivious to my presence. Her father had stayed back inside, with our psychologist.

I watched her. She was somewhere far away, lost in her own thoughts. Her hands absently fiddled with her hair. Her eyes were fixed on a point on the floor, as though she might bore right through it if she stared long enough. She had a frayed hoodie on – despite the stifling warmth of the airless waiting room. And I wondered what a fourteen-year-old thinks about in moments like that. School, perhaps. Or, the pain. Or the conversation still going on behind that closed door. About her. Without her.

Then she suddenly caught my eye. Perhaps she had sensed my concerned eyes on her. Like we often do in a crowd.

Her face changed in an instant, lightening into a shy, self-conscious smile. The kind of smile a child offers an adult when she has been caught somewhere private. Almost an apology. A small effort to put the world back at ease.

I smiled back, walked over and sat down beside her.

I spoke to her in English. She answered in Kannada. And somewhere between the two languages, we found our way to a conversation that did not need any interpretation.

She talked about school. She talked about her favorite subject. And, she talked about her pain. She did not need much coaxing. She pointed to a spot on her neck, the place where it hurt the most, and tried to describe it to me. It felt like a pull, she said. And sometimes it was as though something was scratching. A kind of crawling. All over the swelling.

I asked her how she felt when that happened.

When the pain became unbearable, she said, she would feel a deep irritability. And anger. “And, then I try not to think about it”, she said.

She said it plainly. Without self-pity. As a matter of fact.

I have returned to that answer many times since. I wonder how often that anger would have been mistaken for something else. For a difficult child. For sulking. For a teenager being a teenager. I wonder how many adults would have seen the irritability and missed the pain beneath it. How often she may have been told to not make a big deal out of it.

We talked a while longer, until her father came out. Our clinical lead went downstairs to get her morphine prescription refilled; and Afsana went back in to spend some more time with our psychologist.

And that was all. A few minutes, on two hospital chairs, in the middle of a crowded weekday.

Those moments have stuck with me far longer than those few minutes. To replay and ponder – which is all what I can do.

I am not a doctor.

My training never included speaking with children – or anyone for that matter – with serious or life threatening illnesses.

And yet, almost every day, I find myself being in spaces – some physically, others virtually - sitting across from someone like Afsana. Someone whose body is failing before her mind has had the time to catch up. Someone whose treating physician made an implicit promise. Whose other caregivers repeated that promise. Whose palliative care physician – the one walking downstairs at that very moment to refill her morphine – embodies that promise.

And there I was, on a waiting-room chair, holding what that promise, at its heart, has always been reaching for. The promise to walk alongside.

There is an element of this promise that is as elegant as it is intriguing and challenging.

The promise of *Presence*. To not throw up one's hands. To not walk away. To not abandon.

To do what it takes. For however long it takes.

None of what we hold dear in our work in Palliative Care is really new. I have come to realise this slowly, over time spent in homes and hospital corridors.

Caring for the entire being, and not just the part of them that is failing. Easing a suffering that is not always of the body. Guarding a person's dignity, most of all when they can no longer guard it themselves. Holding the family close, because illness never happens to one person alone. Speaking honestly about what lies ahead, even when silence would feel easier. Believing that the quality of the days that remain matters as much as their number.

We give these things new names now. Frameworks. Principles. Goals of care. But underneath, they are the same old promise, carried forward. Not to leave.

For me, the allure of Palliative Care is that it allows for this 'wholeness' to be brought back into our definition of care. It is the allure of being listened to. To feel understood. To sense brotherhood. It has the power to re-open some very important doors.

And, this is the space I now inhabit.

When Afsana spoke to me of her anger, and the irritability that rises in her when the pain becomes too much, she was not describing a behaviour. Not something to be noted in a file. Coded. Corrected. She was handing me a small piece of her world; one she had carried - perhaps unspoken - for far too long. And she handed it over the way every child in distress should be allowed to. Openly. Without shame. Trusting that the person sitting beside her would hold it carefully, with understanding, and not look away.

In the days since this conversation, I have found myself going back to this. The image of Afsana on that steel chair, lost in thought, in the airless waiting room comes up in my mind. It is a vivid image. The colour of her hoodie. The tousled hair. The shy smile.

What unsettles me the most is that – I had almost missed the moment.

A phone in my hand, offered the easiest of escapes. It would have been so simple to look back down at it.

And I had – almost – done that.

I do not know whether Afsana will remember that conversation. I suspect she may not. It was a few minutes on a weekday, with a stranger who spoke to her in the wrong language.

But I remember it. Her description. Her words. The pull. The scratching. The anger she named so plainly. And that smile, offered almost as an apology, for being caught alone with her thoughts.

She should never have to apologise for that. None of them should.

Our part is simply to be available. Be present. And, to stay.

Names have been changed to protect privacy.

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