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LIVED EXPERIENCE

Hidden struggles in cancer treatment: A brief taste of loss

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'The wound is the place where the light enters you'. – Rumi

A fleeting loss

It was a typical evening. I sat in front of the television with caramel popcorn, prepared to watch a programme. During the meal, I recalled that only weeks earlier, I had lost my sense of taste entirely.

The onset was abrupt. Strong antibiotics prescribed after a postoperative complication led to an immediate and complete absence of taste, rather than a mere reduction. For someone who frequently engages with food, reviews restaurants and enjoys cooking, this change significantly affected my daily routine. Eating became a habitual task, and over 2 weeks, I unintentionally lost seven kilograms as food no longer held any appeal.

This shift extended beyond the physical experience. I started avoiding social occasions that involved meals and reduced my participation in discussions about food. This lack of involvement brought about unexpected isolation, highlighting how illness can affect daily life not just through discomfort or limitations, but also by diminishing enjoyable experiences.

I had not received prior notice about this possible side effect. While it would not have changed my treatment decision, the warning might have lessened its impact. This brief episode offered a perspective into what some patients with conditions like metastatic breast cancer may encounter regularly, as their treatments often involve ongoing side effects that are constant aspects of life.

When 'manageable' is not manageable

In oncology, we often sanitise side effects with phrases like 'manageable' or 'well tolerated'. But tolerable for whom?

Loss of taste for a chef is not 'mild'. It is an assault on identity. Neuropathy for an artisan is not just tingling or numbness; it is the loss of craft, livelihood and dignity. Grade 2 diarrhoea might seem acceptable when captured in trial protocols, but on the morning of a daughter's school recital or a career-defining meeting, it is anything but. Toxicity grading tables, although essential, cannot fully capture the emotional, social and existential weight of side effects [1].

One of my patients, a seamstress, embodied this truth. Chemotherapy-induced neuropathy made her fingertips numb, turning once nimble stitches into clumsy efforts. For her, this was not a 'side effect'; it was the collapse of a livelihood built over decades and a loss of identity, as the business had been passed down through many generations.

Another, a middle-aged professional, experienced 'manageable' diarrhoea on targeted therapy. She coped at home, but on the morning she was due to present at a national conference, her first significant speaking opportunity, she found it difficult to leave the bathroom. She ended up being able to go ahead with the presentation, but the anxiety of the near thought of cancelling lingered long after the episode resolved.

And then there was the young mother who feared fatigue above all else. For her, the ability to stay awake through her son's school play meant more than marginal gains in median progression-free survival. She chose a less aggressive treatment, not because she feared death, but because she feared missing life.

The language of oncology

The language we use in oncology often betrays a clinical detachment. Words such as 'manageable', 'tolerated' or 'acceptable' flatten human experience into sterile categories. They serve a purpose in research, but they risk obscuring the profound impact of toxicity in real lives.

For example, when we describe neuropathy as 'grade 2', we imply it is a minor inconvenience. Yet for a pianist, sculptor or seamstress, that same neuropathy represents the end of a vocation. When we note 'alopecia, grade 1', we may overlook the reality that for some women, hair is not cosmetic but symbolic, a connection to identity, femininity or spirituality.

Language shapes perception. If clinicians repeatedly hear that a side effect is 'well tolerated', we may unconsciously internalise the idea that it is insignificant. As Say and Thomson [2] observed, the challenge for doctors lies in recognising and incorporating patient preferences into treatment decisions, even when these diverge from our assumptions.

Loss of control

One of the most painful aspects of illness is the erosion of control. My brief taste loss reminded me how helpless it feels when something central to your identity is snatched away overnight. For my patients, the loss of control is often more profound and more enduring.

I recall a young man in his 30s, diagnosed with metastatic breast cancer. His overriding concern was fertility. He wanted the chance to father a child. Yet the treatments most likely to prolong his life carried a high risk of infertility. On paper, the decision seemed obvious: prolong survival. But for him, the possibility of future fatherhood mattered more than additional months tethered to hospital visits.

Another patient, an older woman, had one wish: to live long enough to attend her granddaughter's wedding. She refused aggressive interventions that might hospitalise her in the weeks leading up to the ceremony. She achieved her goal, walking proudly down the aisle with her granddaughter before dying peacefully weeks later. For her, that was victory.

Quality of life versus quantity of life

These encounters remind me of the words of my mentor, Professor Ian Tannock: '*When treating metastatic disease, only two things matter: helping people live longer, or improving their quality of life. Ideally, both'*.

Yet in practice, the priorities of patients and clinicians often diverge. Oncologists tend to prioritise survival, while patients often seek dignity, control, and normalcy [2]. Extending life at the cost of relentless suffering is not always the gift we imagine it to be.

I recall vividly a woman who dreaded losing her hair more than anything else. I knew of a drug with stronger efficacy but inevitable alopecia. We sat together, weighed the evidence, and she chose to preserve her hair, even if it meant fewer months of life. That was her choice, her value, her life.

These moments reinforce that shared decision-making is not a procedural formality. It is the heart of compassionate oncology [3]. Behind every toxicity grade is a person with their own fears, responsibilities and identity. Our job is not to impose our medical logic but to make space for their truth.

Listening to what matters

My fleeting taste loss was a small hardship, but it reawakened lessons my patients have taught me for years. What may appear trivial to a clinician can feel catastrophic to the person living it. Insomnia, changes in appearance, and dry mouth can all become the 'last straw' when layered upon the larger traumas of anticancer treatment.

As an oncology trainee, there was a patient post-mastectomy, who came for an appointment. We asked how she was, and she replied, 'Fine' My consultant at the time refused to let that pass. He told her that he could check her wounds, but that wouldn't be good doctoring. He sat, unhurried, and listened. That moment of presence and compassion moved her deeply, and years later, it still moves me. It taught me that our role is not only to deliver treatment but to create space for patients to voice what they fear, mourn, and value most.

Listening is not a luxury; it is a clinical necessity. Patients who feel heard are more likely to trust, adhere to and endure treatment. Those who feel dismissed may disengage or abandon treatment altogether.

Beyond survival curves

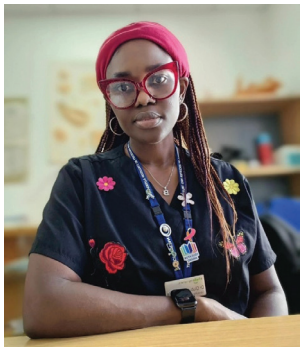
Medicine, especially oncology, privileges survival curves, hazard ratios and measurable outcomes. They matter; they guide practice and inform progress. But survival at the cost of misery is rarely the gift we imagine it to be. Extending life only matters if the life extended still feels like living.

Patient-reported outcomes, such as the PRO-CTCAE tool, are beginning to bridge this gap, capturing toxicities from the patient's perspective [4]. Yet until these measures are fully integrated into both research and practice, the lived reality of side effects risks being under-recognised.

My brief encounter with 'taste blindness' taught me something statistics never could: that even the most negligible side effect can unravel identity, joy and dignity. For patients living with cancer, these experiences are not side notes; they are the text itself.

Because living longer is only meaningful if life itself still feels worth living.

Short biography



Dr Olubukola Ayodele is a Breast Oncologist with international experience across Nigeria, the Republic of Ireland, Canada and the United Kingdom. She has developed innovative services for patients with metastatic breast cancer and is a passionate advocate for equity and patient-centred care in oncology.

Dedication

'People will forget what you said, people will forget what you did, but people will never forget how you made them feel'. – Maya Angelou.

I dedicate this piece to my patients, past and present, who have taught me that behind every toxicity grade lies a story, a fear and a hope. Your courage, honesty and trust continue to shape the doctor I strive to be.

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