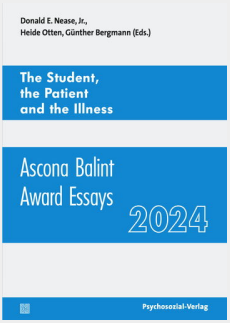
Dikshya Parajuli

As Much an Art as It Is a Science



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As Much an Art as It Is a Science

Dikshya Parajuli

"Inferior STEMI, 87 y/o female. Metastatic cancer, recent aortic dissection. Do not resuscitate, for palliative cares only" cubicle three's ambulance notes read.

I was on my emergency medicine placement as a final year medical student. I strolled over to cubicle three, where an elderly female who I'll refer to as Edna met my gaze with glassy eyes and a tired smile. Her emaciated body was surrounded by doctors and several nurses. She had been discharged from hospital back to her rest home for end-of-life cares only three days prior. With widespread breast cancer metastases, she was on huge doses of opioids and had been under the care of hospice for some time. After an episode of unrelenting chest pain that morning, Edna had decided it was all too much and had asked to return to hospital for what would inevitably be her final days.

When questioned by the doctor as to why she wanted to die in hospital and not her own space, Edna replied: *"I feel more safe dying here. I will get better care here".* She spoke with poise and certainty. Tinged with the acceptance of a life well lived, she possessed no denial in the futility of further medical treatment. Although her organs were failing, her desire to maintain dignity over the body that remained was still burning fiercely. She wanted to die with dignity. In a place she felt safe. *Safe to die.*

A nurse walked in with a vital signs monitor, and immediately turned around on hearing the doctor say *"no observations, she's palliative".* The doctors words and the nurses actions appeared so devoid of emotion.

One by one, everyone left.

A room that seconds prior had been full of minds skilled and dedicated to *save lives* was abruptly empty, leaving only a dying patient and a medical student behind.

Edna's enfeebled skeleton was visibly exhausted. As she lay there in tremendous discomfort, the weight of her suffering became palpable. The knowledge I was armed with on the clinical aspects of her presentation felt not only inapplicable, but brutally irrelevant to the visceral nature of her suffering. Medical school had taught me about many ways to keep a patient alive, but very little about how to comfort them as they die. I felt idealistic, inexperienced and unprepared for the strength of my own emotions.

Edna's desire for someone's emotional presence was obvious. As her youth filled eyes turned to me, uncertainty engulfed my mind. For a moment, I wondered if I even belonged in the room. A familiar feeling of unease took hold, as if I was suddenly swimming in waters out of my depth. I had spent the last several years learning the intricacies of human biology, disease and pathology. I had worked hard to develop my clinical competence and confidence. I had a lot of theoretical knowledge. However, when face-to-face with a dying soul for whose illness an obvious panacea did not exist, I felt *helpless*. I longed to swim back to shallower water.

"Not a very exciting one is it?" one of the ED doctors asked me as I walked over to prepare a cup of tea. Determined to not let him see the tears that I was fighting back, I nodded and with tea in my hands, I walked back to Edna's room. Though I felt like there was little I could do for Edna, the thought of leaving her alone in that cubicle ached me. My presence emerged as the only solace I could offer her. I handed her the warm drink and accompanied her as I waited for her palliative care team to take over care. Maybe I was merely treading water, but I felt driven by a naïve urge to extend empathy and a desire to diminish discomfort.

Whilst we waited, Edna drank her tea and shared with me her wishes and worries. In that time, I saw Edna's fear turn into trust – trust that although her illness could not be reversed and her life could not be saved, she *could* and *would* be cared for here. An unspoken bond had formed between us, instilling a sense of trust and vulnerability that transcended the limitations of clinical interventions. I realised then that even as a medical student, I was and could continue becoming someone who belonged in the room.

Eventually, an orderly from the patient transfer services came to transfer Edna to the west wing of the medical ward. The place where comfort cares would be initiated for her. A place where death would neither be hastened *nor* postponed, where she would get the dignified ending she so deeply desired.

Over the next few days, I continued to visit Edna. I soon learnt that apart from her palliative care team, I was her only regular visitor.

Each time I entered her room, her glistening eyes would turn to me, be-

seeching me as to whether I had any time to lend her. Any length of undivided empathetic presence was enough to make her smile. On days I had time, I would sit down to her level, and I would listen. On days I didn't, I would pop in, say hello, top up her water, open her window; do *anything* to remind her that she had not been forgotten.

And each time I left, I would close the curtains that separated her from the chaos of the medical ward. Though flimsy and fragile, the curtains preserved Edna's dignity. *Dignity is all she wanted,* I would remind myself.

Just as the flowers on her windowsill that slowly began to wilt, Edna grew weaker and weaker with each passing day; her wrinkles becoming more defined, her breathing becoming more laboured. Her medical progress notes validated my observations that every organ in her body was slowly withdrawing *bit by bit* from life. Watching Edna dwindle amidst a backdrop of withering flowers served as a sobering reminder that death is an inevitable part of every life cycle. Someday, we all approach an end. No matter how resisted and refused, death is the most certain thing in *all* of life.

Each sunset does *not* bring the promise of a new dawn.

Everything, including life itself, is temporary.

Over the days I visited Edna, mortality became less of an abstract concept and more of a defined and truthful reality.

Some consultants treat ward rounds like an authoritative and ritualistic task; towering over patients, reciting questions on autopilot and hurriedly running off to their next review. The patient meek or mute, trusting the doctor wholeheartedly, ready to bear whatever suffering was necessary.

Edna's palliative care doctor on the other hand, was the opposite. By weaving together strands of empathy, expertise and experience, she treated her time with Edna not as a compulsory task, but rather an opportunity to forge a relationship founded on understanding. She listened and acknowledged, and by doing so she made Edna feel seen and heard. She found out what was important to Edna and fought hard to respect her wishes. It was as if she deeply understood that although she would not save Edna's life, by virtue of her actions alone, she *could* become a conduit for healing. She was simply incredible.

As I watched her truly care for Edna, I could not help but reflect on how throughout my entire academic career, I had been trained to value objective performance. Grades, numbers and percentages had equated to progress and the promise that I could be a good doctor. However, in the face of Edna's insurmountable suffering, the skill that appeared to matter the most was the very one that had never been assessed or taught objectively; *empathy*. At this realisation, med-

ical school felt like a dress rehearsal for the real responsibility that lay ahead in my future as a doctor.

On one of my morning visits, Edna whispered *"Can you spare me a little longer today, dear?"*

My emotions, which had already begun retreating inwards at noticing how much weaker she looked, were acutely wrenched back into the present. Her desire for someone's emotional presence was tangible. I looked down at my clipboard; a long list of uncompleted academic tasks glanced back at me. However, the only thing that felt right in that moment was to sit by Edna's side. As a student, I had something that her doctors did not. *I had time*. And there *were* things I could learn, even from a dying patient.

I smiled, sat down and turned away my clipboard.

That day, Edna recounted a vibrant timeline of her life's events. From college, to family, love, parenthood, illness and age, I learnt many things about the magnificent tapestry that had been her life; the rich and royal hue with which her 87 years had been woven. The lucidity of her recollections served as a poignant reminder that patients at the end of life *are still living*. Whilst a component of their individuality becomes lost the minute we exchange their clothes for a hospital gown, and their name for a room number; they are still individuals with stories, identities *and* emotions.

As I listened to Edna, I found myself questioning who I was to witness her at this moment, *the most fragile and vulnerable she had been in all of her life.* I recalled a quote from Dr Paul Kalanithi's book *When Breath Becomes Air; "All of medicine, not just cadaver dissections, trespasses into sacred spheres".* In that moment, I felt like I had finally grasped the essence of Dr Kalanithi's message. Perhaps this is what was meant to be taught in the *hidden curriculum* mentioned repeatedly in medical school.

I genuinely think Edna realised how truly privileged I felt to be in her presence and to give her the gift of my time, and I think she also understood that she was giving me a lot too. It was as if she already knew that although this was the end of her, it was only the beginning for me. The beginning of a career in service and I think she could see that I was determined to learn how to serve well.

I visited Edna again the day before my two week vacation. A sense of vacuity settled into my stomach as I realised then that it was my time to say goodbye – *goodbye, forever.* Despite knowing all too well that it would likely be the last time I would ever see her, I could not bring myself to tell her this.

A kaleidoscope of emotions crept in and took root within – sadness, guilt, fear and frustration. Unsure of how to navigate the balance between being pro-

fessional and being human, I loitered next to Edna like a shadow. Visible, but not fully present. Paralysed by the thought that I might say or do something wrong. Never before had I farewelled a dying patient. Abruptly, I was in uncharted waters, in unfamiliar territory. However, this was a first like no other. I found myself wondering if there was room for humanism and empathy in this stoic profession that by default fosters distance and emotional detachment. As my mind searched for answers, I felt tears well up in my eyes, and slowly drift into my respirator mask. A subtle expression of connection that inherently felt bold, an expression of what it means to be human. Unable to hold Edna's gaze, I turned to face the window, her withering flowers framing the periphery of my blurry vision.

I said goodbye like any other day, daring hard to not lull my words with a sense of finality. I remember wishing that day that I could have been half as strong-willed and composed as Edna had appeared.

I never saw Edna again.

On my first day back after my vacation, I made my way up to the west wing of the medical ward where I had walked many times to visit Edna. I probably could have walked that route in my sleep. However, this time, the room label outside Edna's room had a new name on it. My shock initially became confusion, and then turned into discomfort. Her absence became acutely apparent.

A nurse who had regularly cared for Edna walked past and confirmed for me what I already knew deep down. I learnt from her that Edna had died two days ago. She told me that Edna had been comfortable at the time of her passing and right throughout, she had received care that aligned with her values, guided by a doctor whose only goal was to respect these. All of her wishes had been honoured. *"It was the dignified death that Edna had wanted all along"* The nurse said softly.

Upon hearing this, the pangs of sadness and guilt I felt slowly lifted and I found myself smiling.

In medical school, we have been reminded time and time again by our professors, tutors and lecturers that our best teachers will *always* be our patients. I have never once doubted this, for knowledge delivered to me about suffering and illness has paled in comparison to the lessons I have gained from directly witnessing, comforting and caring for patients. Edna reaffirmed this understanding in every aspect.

My encounter with Edna was deeply moving and served as a raw illustration of nuances of the human condition; life, emotion, identity and death. Confronted with the fragility of life and bearing witness to the suffering of a dying woman whose fate that could not be changed, I found myself searching deeply for ways to alleviate her suffering but realised that time and empathy were the only things

I could offer. The profound connection I built with Edna has forever coloured how I view the purpose of my profession; medicine is more than just the privilege of saving lives, it is also the privilege of attenuating pain and suffering even when lives cannot be saved.

Witnessing the joy my visits brought Edna shattered an illusion I had naïvely and unconsciously crafted as a medical student; that caring for patients meant solely *fixing* problems. After all, as doctors we are trained to fix and solve. Our identities are formed on our ability to cure. The corollary, therefore, is that a failure to *cure*, is a failure to *care*. However, Edna taught me that patients are not merely broken objects that require fixing and death is not always a failure. Nor is death always a battle, at least not one that we can always win.

Through the act of holding space for empathy and compassion for Edna, I realised how transformative these values can be when helping patients navigate the difficult terrain of emotions presented by illness. When I had first met Edna in the emergency room, the interactions between her and healthcare providers in the department had appeared to lack emotion. In a field where exposure to pain and suffering forms the crux of virtually every encounter, it is not surprising that healthcare professionals sometimes subconsciously engage in a degree of emotional desensitisation. Perhaps a means of self-protection, detachment helps us to not feel too deeply for patients who are hurting, and especially those who *cannot* be healed.

However, complete emotional disengagement, particularly when interacting with those at the end of life, diminishes our ability to care and is contrary to our promise to *do no harm.* In such a sacred space, expressing anything other than compassion *feels* inhumane. And this *is* okay – as long as we have processes by which to let go of this emotional residue and mitigate compassion exhaustion.

We owe empathy to those whose health is entrusted to us. Whilst they live, whilst they suffer *and* whilst they die.

The physician-patient relationship is a unique one and interactions between the two tread on a delicate tightrope – an intricate juxtaposition of science *and* art, of opportunity *and* obligation, of professionalism *and* humanity. I am constantly awed by the vulnerability and trust patients endow upon physicians. In palliative medicine, the connection we get to form with patients feels even more raw; in this space, connection has the potential to alleviate suffering in ways that pills and ventilators *cannot*.

In the realm of end-of-life care, both fortes and deficiencies of clinicians become exaggerated. Throughout my clinical years, I have seen many times where a patient's death has brought clinicians a deep and palpable sense of defeat, despite

their death being expected *and* inevitable. The heaviest burden of the clinician's deficiency in these cases fell on those whose lives and identities were already under threat; for it was the patient who was subjected to further suffering and undignified interventions for minimal gain in their quality or quantity of life. A diminished ability to accept death and dying as meaningful aspects of life sometimes drive clinicians to cure-driven interventions and futile prolongation of life. Though modern medicine is captivating, powerful and has tremendous capacity to heal, at times it also strives for life *at all costs*.

I cannot help but wonder what difference might have been made to those patients' lives if their clinician's had recognised that their role was not to *fight* fate, but simply to improve the quality of their patients' lives, for as long as their lives existed. In those moments, I remember wishing desperately that they could have had a death like Edna's.

On the contrary, I have also had the privilege of witnessing doctors deliver timely, high-quality and holistic care to palliative patients; care that was directly concordant with patient values *and* priorities. These physicians treated their patients as people, and not merely problems to be solved. They cared for their patients deeply, even when giving them life-altering diagnoses. They stood by their patients' side as they came to make sense of their illness, reshaped their identities and made difficult decisions about what kind of life was worth living. They were empathetic, eloquent and passionate to do right by those they were caring for. Edna's palliative care doctor did all of these things.

These doctors showed me that engaging in our own humanity in service of our patients is not only possible *but necessary*.

They fuelled my desire to learn not only how to *fix,* but also how to *care*. They taught me that compassion does not need to be dispensed frugally out of fear of blurring the boundaries of the physician-patient relationship and that being good at this work does not require the suppression of our humanity, but rather the expansion of it.

During my time in paediatrics, I had a few days of placement in the regional neonatal intensive care unit (NICU). End of life discussions took on a different moral lens when they were not about 87 year old individuals who were rendered a life-limiting diagnosis, but rather cherished premature infants who were at the *beginning* of life. The neonatologists at the unit however delivered exemplary care; they guided families through difficult shared decision-making and they navigated the ethical dilemmas of futile care with equipoise and moral clarity. I was simply in awe of them. *How did they know which lives could be saved, which lives couldn't and which lives shouldn't? Like me, did they too take home the suffering and*

sadness exuded by families who had lost a loved one too soon? Surrounded by tens of infant incubators, each attempting to provide a budding life with a second womb, I would often find myself questioning whether I would ever learn to lead and live with such responsibility, or if I was even cut out for the tremendous responsibility of medicine. My time in the NICU left me pondering many questions, but it left me certain of one fact; that doing this profession the justice it deserves would require more than only clinical excellence. If medicine truly is a moral endeavour and its goal is to truly care for people – then I needed to develop more than just my knowledge. As such, learning how to balance the science and art of this sacred profession has become not merely an aspiration for me, but an imperative.

Every time I reflect on what I have learnt from these incredible clinicians, I feel a deep sense of respect and appreciation for my future colleagues in medicine and a newfound motivation to grow into a doctor who one day can care for patients exactly as I have seen them do.

Palliative medicine has led me to the end of many lives and in doing so has uniquely highlighted the power of informed choice. Some patients will consent to any intervention or drug, if it gives them any chance of a longer life. Others think instantly about what kind of life is worth living for them, and will forgo quantity for quality. As clinicians, we may have the knowledge and expertise to manage illnesses, but it is not up to us to single-handedly make decisions about what level of care is enough. We may not always be able to save our patients lives, but we can and should ask questions to understand our patients wishes, values and priorities for care. Nathan reminded me of this.

Nathan was a 25 year old male I met on the same emergency rotation I had met Edna. He had a rare form of epithelioid sarcoma with pleural metastases and bilateral pneumothoraces. At a very early stage in his cancer journey, Nathan had been offered surgery and radiation therapy – both of which he had declined due to religious beliefs. His past admission notes were complex – with strands of ethics, illness and self-determination interwoven to create tension between the principles of beneficence and autonomy. However, it was deemed that Nathan had full decision-making capacity and that he understood the consequences of his choices. As such, his ultimate right to refuse treatment was respected. Now, the ceiling of treatment for Nathan was palliative – health professionals caring for him would do everything to keep him comfortable, but would not actively treat his illness or aggressively manage him if he was to become more unwell. And this was exactly the kind of care that aligned with Nathan's wishes, values and beliefs. This is all Nathan wanted.

I once heard him listlessly explain to a healthcare assistant who had ques-

tioned his choices whilst nursing his wounds, *"My life is not truly mine without me, and with this cancer, I am not me".*

When I first was introduced to Nathan's story, I was initially taken aback by how someone so young had chosen to forgo beneficial treatment and allow cancer to invade his body. In the context of young Nathan's inevitable death, I could not help but think about the vastness of the chasm between the life he may have had if he had consented to cancer treatment, and the life he would soon no longer have because of his choices. The vastness of this chasm served as a powerful reminder to me that whilst patients have the right to life, they also have the right to be autonomous and make decisions about what kind of care they wish to receive. Healthcare providers have a duty to do everything they can to provide beneficent care and to first*, do no harm*, but competent, fully informed patients, *can* refuse standard medical care. Nathan reminded me that there is more to living than just being *alive*.

As doctors we are the doers, the ones who act; as patients, we are simply done and acted upon. When we are the ones who act, we may have an idea of what it is like to be a patient, but most of the time, we do not know what it is *really* like. I personally came to first grapple with this realisation only a few months ago when I too traversed the line from being on the side where one acts, to being on the side where one is acted *upon*.

Earlier this year, my ten year old younger sister was abruptly ill with an acute abdomen and required two emergency surgeries back to back in the span of a few days. At the time, I was miles from home and in the midst of a busy medical rotation. However, on hearing the news, I requested urgent leave and caught the next flight home. Little did I realise at the time that this would be one of the most difficult times in my life as a sibling, and one of the most *transformative* as a student doctor.

Throughout my years at medical school, I had made trips to the operating room and watched the induction of general anaesthesia at least a hundred times. I could recite the intricate details of the stages of *induction, maintenance* and *emergence.* However, when I walked my sister in for her emergency laparotomy, I was now on the other side of the operating table, the other side of the anaesthetist's needle and the consent documents. In that space, every word and every action of the medical practitioners surrounding me seemed to carry with it a different mountain of significance. The power imbalance between the patient, and the doctor has never been so evident.

How little do we understand the ordeals we subject our patients to? I found myself wondering. I recalled learning in third year medical humanities that the

English word *patient* originally stemmed from the Latin term *patiens,* meaning *"the one who suffers and endures".* The present particle of the verb, *patior,* translated into *"I am suffering".* This time, it was my sister and I who were suffering, and it felt visceral. I ached to my core.

As a student in the operating room, I was very calm and level headed. As a family member of a patient, I was fearful and weak. As I watched the sedative drugs take effect over my sister, my heart trembled with each beat. My eyes could no longer see clear through the dusk of tears that flowed unrestrained. The last thing my sister asked me before succumbing to the unopposed effect of propofol was *"Sis, will the surgery hurt?".*

I was then ushered out of the operating room. The two hours whilst I waited for her to come out of her operation felt like a lifetime. In those moments, the remainder of the world ceased to exist in my fragile recollection. My vast existential worries, deadlines and tasks became infinitesimal. Time passed slowly as I waited for her to come out of her operation.

I spent the next three weeks by her bedside, attending to her every need. Feeding her, braiding her hair, helping her as she relearned how to walk and play again. As a medical student, I was trained to view suffering through a professional lens; I was trained to cure. However, when faced with a loved one's illness, I naturally assumed my role of a caregiver; entwined with heartfelt emotions – fear, hope, love and deep yearning for recovery.

Thankfully my sister was okay. She continued to make triumphs in her recovery in every aspect and after 24 days in hospital, she was on her way back home; her laparotomy and laparoscopy surgical sites appearing insignificant in the grand scheme of the suffering she had endured. She is now healthy, happy and is healing at home and I feel blessed beyond belief to have her with me. What I learnt from my experience as a family member watching a loved one navigate the challenges of illness will always be an unshakable part of my foundation, informing a myriad of future learning and a relentless drive to serve others with compassion as a medical practitioner.

Although I was constantly surrounded by stories of suffering in my academic life, it was when suffering infiltrated into my personal life that the tenuousness and fragility of life became profoundly obvious. In that brutally painful period of my life, I too drowned in the labyrinth of emotions I had seen patients and their families navigate amidst illness many times before. It was in that space that I came to understand through direct experience that firstly, that privilege and responsibility go hand in hand and secondly, illness evokes some of the darkest days a patient and their families will ever see.

Illness and death are certain in life for no one is exempt from humanity's ultimate destination. However as doctors, we have the opportunity of honouring and respecting these processes, and transforming something that is unavoidably painful and devastating into a meaningful life event. We may even be able to plant seeds of empowerment. In this space, we hold immense power to alleviate fear, suffering and pain that patients and their families experience. What an immense privilege this is.

Processing my encounter with Edna has given me the opportunity to reflect on many thought-provoking patient interactions I have encountered as a medical student. Undoubtedly, witnessing patients at their most weakest and vulnerable comes with emotional costs. There were days where I do not know where to even begin unpacking the complex emotions born out from my time on placement. There were times where I too took home the turmoil I see patients and their families face. There were moments of uncertainty, fear and confusion I found myself reliving.

However, through such experiences, I have discovered a shared vulnerability that unifies me to patients I have learned from and cared for; whose beautiful, sometimes painful narratives I have had the privilege of immersing myself into. Such challenges have also offered me the opportunity to cultivate a repertoire of strategies to cope with the challenges of this work, which I will no doubt use in my future as a junior doctor. I have learnt to ask for advice from my seniors when in need, to take time to debrief, cherish my time with loved ones and to look after my own wellbeing. In doing so, I am learning how to care for myself better, whilst I learn how to care for others.

Through the mundanity and intensity of it all, I have not once questioned why I chose this career or whether it would be worth it. Medicine; rich with its complex emotions and responsibilities, is *absolutely* what I want to do. Encounters with patients like Edna humbly remind me of this.

Even months later, I still find myself wondering about Edna. On the day she arrived into the emergency room, she knew that she likely had days to maybe weeks to live. She was constantly aware of her mortality, but she did not seem to fear it once. She taught me a little about dying, but a lot more about living.

Months later and I continue to feel immense gratitude for all that she taught me during her final days. Because of Edna, I have in fact truly come to appreciate patients, their experiences of illness and stories of suffering as both windows *and* mirrors. Windows to better understand intrinsic aspects of the human condition; biology, mortality and suffering, mirrors to provide a platform for deep moral reflection and a glimpse of the moral dimension of our sacred profession. Patients give us the unique privilege of both *seeing out* and *seeing in;* they offer new understandings, whilst offering reflections.

I will always remember Edna. I'll remember how her aged skin starkly contrasted her eternal youth-filled eyes. I'll remember how she shared the most special parts of her humble life story with me; for me to learn from and to cherish. I'll remember her vulnerability, her integrity and above all; her desire for dignity.

Thank you Edna for being both a window *and* a mirror. You deepened my understanding of the science and art of medicine, and you also gave deeper meaning to my own sense of place within it.

I see you in every 87 year old I have seen since, in every dying patient who does not have family at their bedside and in every palliative individual who faces death with strength. It has been months since I first met you, but I have still not stopped learning from you.

Because of you, I now find myself taking more time with my patients, seeking to understand the experience of their illness, not just their symptoms.

I aim to listen, without rushing.

I allow my patients to teach me to *see out* and *see in.*

I err increasingly, on the side of *compassion*.

I try really hard to not become too emotionally detached that I lose touch with humanity, and not too emotionally involved that I lose my ability to assess objectively.

I embrace the notion that caring extends beyond curing.

I slow down and make time for patients so they too, like you, feel seen and heard.

These actions, though small, are helping me to build a humanistic perspective into my craft of doctoring. As I progress further on in my medical journey and closer to becoming a doctor, actions that seek to achieve humanisation feel equally as important as clinical aptitude.

In learning that this work is sacred, and is as much art as it is science, I feel humbled and honoured by the opportunity to pursue a career in caring and aspire to do right by those whose health is placed upon my hands.

Caring for patients, particularly in the face of overwhelming suffering and at the end of life can be painful and raw, and it is a *huge* privilege. Thank you, Edna, sincerely, for letting me be a part of your ending, and for shining a new light to the power of empathy and the art that is medicine.

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