Bystanders: Terminal Illnesses Through the Eyes of Loved Ones

Ella Waked

Abstract

This ethnography explores the lived experiences of three individuals in Lebanon who have witnessed a loved one go through the final stages of a terminal illness. Using drawing on a range of qualitative sources – my own lived experience, available scholarship on end-of-life journeys, and in-depth interviews with three relatives of terminally ill patients in my acquaintance – the research focuses on preemptive grief and the various emotional and moral dilemmas that surround it. The first part highlights the emotions that this experience brings out, with a particular emphasis on hopelessness. The second part discusses survivor's guilt and the weight of living in the absence of someone deeply cherished who, in the "survivor's" eyes, deserved to live. The third and final section addresses the ethically complex and profoundly emotional question of euthanasia or mercy killing, investigating the internal conflict between love, compassion, and moral, cultural and religious values. Through these main themes, this ethnography seeks to highlight the dimensions of witnessing someone else's end-of-life journey.

Keywords: terminal illness, Lebanon, grief, survivor's guilt, mercy killing

Introduction

I had a friend in high school whose mother died in a car crash. We were 14, she was driving at night, going back to her family, and suddenly she was gone. I don't remember the details of what happened, but I know that something broke in my friend that day, and by the time we lost contact after graduation, he was still trying to put it back together. I never thought there would come a day when I would envy that friend.

The grief that comes with the loss of a loved one is something we all go through sooner or later, whether we like it or not. Death comes for us all in the end, in different ways and at different points in our lives, sometimes expectedly and sometimes by surprise, but unarguably and inevitably. Does knowing that death is near make the grieving process more bearable? Or does the anticipation just prolong the suffering, making us start mourning even before the person has passed? Illnesses are painful, they're tiring and all-consuming, expensive, and endless. Terminal illnesses? The ones where you know that no matter what anyone does, the patient is on a direct flight, with a one-way ticket to meet the Creator? Those are even more painful. The stories we hear about those patients are ones of hope and perseverance, of making the best out of the little time they have, of

learning to accept their own mortality and greeting death like an old friend at the end of the road. The reality is much harsher. The reality is that if someone you love is going through such an illness, they take you with them on the journey, only to drop you off at the last stop before the terminal. And while their story ends, the ones who witnessed their pain and struggles live on, and they too have a story to tell.

Very little exists in terms of Terminal-Illness writing in the Arab world, and even less includes the perspective and input of the outsiders, people who aren't ill themselves. Three main works helped enhance this project and should thus be highlighted. To begin with, Shahd AlShammari[1] tackles issues of illness, disability, and identity in her autobiographical book *Head Above Water: Reflections on Illness* (2022). Throughout that book, AlShammari discusses her life with Multiple Sclerosis,[2] a chronic but not terminal illness, as a Kuwaiti-Palestinian woman, author, and academic living in the Arab world. Despite this memoir not being specifically about a terminal illness, it contributes immensely to the literature pertaining to illness-writing in the Arab world (Breteau, 2023). In addition, *The Man in the Mirror: Reflections on Dementia Caregiving in Lebanon* by Nayiri Baboudjian Bouchakjian (2023), a Syrian educator, writer and storyteller who grew up in Lebanon, is a paper that deals with the author's autobiographical journey caring for a dementia patient, her father. The paper goes through the entire illness journey, from diagnosis to grieving after the patient's death and deals with themes of preemptive grief and loss. Finally, an essential part of the literature regarding terminal-illness writing and end-of-life writing is With the *End in Mind: Dying, Death, and Wisdom in an Age of Denial* (2017) by Kathryn Mannix. While not set anywhere near the Arab setting, it does offer unique insight into the dying process. Written from Mannix's experiences throughout her long career in Palliative Care,[3] the book advises approaching death with understanding and openness rather than fear, breaking the taboo and preparing oneself for the experience that is watching someone slip away.

The present work seeks to answer three main research questions, each in a separate section through a combination of interpretive personal experience, critical commentary, and interviews with three relatives of terminally ill patients collected over a three-month period, from February till May 2025. This ethnography narrates all its stories in first person to highlight the emotional intensity of each lived experience and better connect it to the reader. First, how does witnessing a loved one's terminal illness affect one's emotional and mental wellbeing? This question is tackled in the section *Emotions*, with the main finding being the ways that people of different ages deal with hopelessness and helplessness. Second, can one suffer from survivor's guilt if they were never put in a near-death situation themselves? The section Guilt finds that, indeed, any trauma involving the encounter or witnessing of death, especially of a loved one, can lead to the development of survivor's guilt. Third, are there instances where dying is the better alternative, and should euthanasia, the deliberate and painless killing of a patient suffering from a terminal and incurable illness or injury (Merriam-Webster), ever be considered as an option? Keeping in mind that mercy killings are unlawful and strictly prohibited in Lebanon, the section titled *Pain* attempts to put the impossibility of such a choice into perspective.

Emotions

Solutions

It was a Sunday afternoon and my family, instead of gathering at my grandparents' house as we would usually do, had decided to spend time together at the hospital where *jeddo* was staying.

I was around eleven at the time, and my cousins and I were all frustrated at being left out in the corridor. We wanted to know what the adults were talking about, we wanted to play, we wanted to go home, but most of all we were all worried about *jeddo*. Our parents had sat us down one day and explained to us that *jeddo* was very sick, that he wouldn't be with us for much longer, that he was going to die soon, but that it was okay because he would be with the angels in heaven. They answered all our questions, even when I asked if that meant he would stop coughing so much.

Out in the corridor, amid the chatter from my cousins, one distinct sound was heard from *jeddo*'s hospital room. All the time we'd been there, that was the only sound that had really passed through the closed door. It was horrible, this hacking, heaving, cough, the kind of cough that makes you think that person is going to cough up their organs, the kind of cough that was absolutely terrifying to me, especially since I knew that my grandfather was the one coughing up a storm. For the first time all day, my cousins didn't say a word. You could have heard a pin drop in that eerie hospital corridor as we all struggled to grasp the reality of what we had just heard.

That was *jeddo*'s cough. This cough that sounded like he could not breathe at all, that was *jeddo*. That sound, the sound of someone dying in pain, that was *jeddo*.

And I couldn't take it, and I couldn't understand it, or maybe I couldn't bring myself to understand it, because that just couldn't be true. *jeddo* had a cough before the hospital, he had a cough almost all my life, but it was never this bad, never this scary.

All my life, I had been raised to find the solution to my problems, to find ways around the obstacles life threw at me, and so that was what I did. In that creepily silent hospital corridor, I gathered my cousins and told them we were going to play a new game; we were going to come up with a solution to make *jeddo* feel better.

So, we brainstormed until the adults were done and it was time to go home. Maybe if we brought him sweets, that would make him happy? Maybe we could play a game of cards with him, and that would distract him from the pain? Maybe, if we worked really, really hard, we could entertain him in some way? Or maybe the doctors just need to give him a different medicine or change something in his treatment. Maybe the machine wasn't working properly and that was why he coughed so much. When it was time to go home, they still wouldn't let us in the room.

That night, I lay awake in bed, trying really hard to think up a solution. There had to be something we could do, because everything had a solution, right? Slowly, it started sinking in. Slowly, it came to me, dawned on me like the rosy morning that was creeping through my window, that for the first time, there was no solution, nothing anyone could do. For the first time in my life, I knew what it felt to lose hope.

Doctors' Apathy

I will never forget the words my father's doctor said to me when he fell into a coma.

"You know, there's only a 2% chance he's going to wake up, so don't hold on to it."

Logically, yes, we knew. We'd done our research; we had prepared ourselves for the worst. Logically, we knew he wouldn't be the same, if he even woke up at all. Logically, we knew we shouldn't hope. But it is easy to think logically when pondering a hypothetical, much

easier than when one is hit with the onslaught of emotions being in that situation brings. Despite our preparation, all logic flew out the window when the dreaded scenario actually happened.

She looked at me, a fifteen-year-old whose father was lying in a hospital bed unresponsive and wanted me not to hope he would wake up.

How could she tell me not to hope when hope was all that was keeping me from completely falling apart? How could she tell me not to hope when all I wanted was to know he could hear me?

My mom and I spent hours in that hospital room, holding his calloused, scarily cold hand, talking to him, hoping that he wasn't in pain and that he knew how much we loved – love – him.

How could that doctor tell us not to hope when my dad's heart rhythm would fluctuate whenever he heard my name? How could she tell us not to hope when I swore I could feel him squeeze my hand on more than one occasion, when he held on to it so tight one time and wouldn't let go.

But it wasn't about me, and it wasn't about my dad, it was about her being right. It was about proving her point.

"It's just brain activity," she would say. "It doesn't mean anything."

The words hurt, but her tone cut deeper. Even if she was right, even if it had been nothing, couldn't she be gentler? Couldn't she see that I needed to know that my father was still in there somewhere?

But still we hoped, because how could we not?

For nineteen days, I would go to the hospital straight after school and sit by his bedside. For nineteen days, I would talk to him about my day, about teenage gossip and other random stories, things I would have told him if he was awake. For nineteen days I told him all the things I didn't tell him when he was awake. I told him that I would take care of my mom. I told him that we would be okay, no matter what, that we were strong like that. For nineteen days, I told him I loved him and that he could let go, even when I hoped he wouldn't.

Every day, I hoped he would wake up and crack a stupid joke, one that would have made me roll my eyes before laughing along. Every day, I hoped he would get to be at my high school graduation. Every day I hoped he would get to walk me down the aisle at my wedding. Every day I hoped he would get to hold my future children. And every day, the doctor told me not to hope, and I tried, but the hope wouldn't go away.

Not Today

I will never forget the last few months of my aunt's life. I was 19, and had just figured out what I wanted to do with my life, when I was suddenly thrown into the role of at-home-nurse. I say thrown, but really, no one actually forced me. It seemed almost natural for me to take care of her, especially with how much I loved her and after all she had done for my siblings and me.

One of the most memorable instances from that time was a day in mid-September. By that time, what had first started out as breast cancer had spread to her ribs and back and brain and lungs. She was extremely weak, so she spent most of her day in bed, only getting up for meals and that one show she adored watching.

It was a Friday morning, my other aunts were at work, my grandmother was in the living room watching TV, I was sitting in my grandmother's bed, the bed next to my aunt's, attending my online classes, when I heard her cough. It started as a normal cough, but then it didn't stop. She coughed and coughed and coughed, and it only took me half a second to be by her side but once there I was at a complete loss as to what to do. She was coughing her lungs out, struggling to breathe and there was absolutely nothing I could do except stand there frozen, and try to offer moral support. But what good does moral support actually do when the entire body of the person you love is seizing with a soul-wrenching cough, when they're turning blue from the lack of air and yet can't seem to stop coughing long enough to take even the briefest of inhales? What good does moral support do when the person you love is suffocating? What good does moral support do? And yet there was nothing else I could offer, so moral support would have to do.

The entire episode lasted only a couple of minutes, but felt like actual years. As the coughing finally died down and she struggled to get air back into her lungs, my aunt looked up at me and smiled her most radiant smile. "*I'm okay*!" she panted out. And I could finally release the breath I had been holding for the past few minutes.

I'm okay. Such a simple phrase. A phrase you'd expect from a child who had just fallen on the playground or from someone who had knocked over a pan or walked into a wall, not from someone in the final stages of a terminal illness. But in that moment, she was.

I'm okay. That's all I could allow myself to think about as I sat back down on my grandmother's bed and tuned back into my online class, the professor's voice once again the only sound in the room. *I'm okay*. That's all I could think about as I looked towards my aunt once more only to see she had fallen asleep, her breaths even, her face the perfect image of serenity. *I'm okay*.

And that's what she was. Maybe not in the long run, or physically, or mentally, maybe not in the way we usually mean it, but right then, right there, in that specific moment, it was a reminder that it was not yet her time. Right then and there, it was her way of staring death in the face, tall (or as much as one can be while only being 4'9) and proud and unafraid, and telling it "Not today."

Reflection 1 – An Emotional Rollercoaster

These stories, all the stories in this collection, focus on the final stages of terminal illnesses, on the point in the loved one's life when there is nothing anyone can do to make everything better. This first section was meant to tackle the emotional and mental effects that witnessing a loved one go through that can have on a person. Writing this, I find myself with more questions, while still answering questions I haven't even thought to ask. The three people whose stories are told above witnessed the death of a loved one at different stages of life – pre-adolescence, adolescence, and young-adulthood. While they may have gone through very different experiences, understood the situation in very different ways, and felt different emotions through it all, one common ground among all three experiences is the hopelessness of it all, the realization that there is nothing to be done, nothing anyone can do.

For a ten or eleven-year-old raised with the "be proactive instead of crying about it" mentality, that was a new feeling, a realization so to speak, that sometimes there is nothing you can do but hope for the best. Even then, it was pretty clear to the narrator of this piece that his grandfather wasn't going to get better. Children don't really have the ability to gauge the importance or severity of certain situations and, as can clearly be seen in this piece, they just want to fix things, naively believing that everything can be fixed. The United Nations Children's Fund (UNICEF) has listed frequent concern for others and changes in sleeping habits as commonly observed signs of distress in children aged between 7 and 12 years old, which can be observed in this particular story. For the narrator, this experience was a sort of coming-of-age experience, a step away from childhood innocence and into the harsh reality that is real life. I believe it was good parenting on his family's part that made him cope so well with that realization, and he seemed to agree. During our interview, he mentioned multiple times how his family had sat him down and explained the situation to him, prepared him for the fact that his grandfather would not get better and would soon not be with them anymore. He praised the way his parents handled the situation overall. When discussing difficult situations with children, the best thing one can do is be open and honest with them about what's going on without conveying hopelessness (National Parent Teacher Association). In this case, it is apparent that the situation was well-handled.

The second story offers a different perspective. Here we have a teenager who has already been disenchanted with life, who has lost her childhood sense of wonder, who has grasped the unfairness of existence, but who still wants to cling to hope. From our conversation, I could tell that she knew, even then, that she wasn't really expecting her father to wake up. She hoped he would, yes, but she also knew he wouldn't be the same, that he would have complications. Her struggle was between rationality and emotions, between knowing that the chances of her father waking up were slim to none and hoping that he would, in spite of it all, because she couldn't bear to let go of him just yet. Her struggle was made even worse by the medical professional's cold, matter-of-fact attitude and overall detachment from the situation. When we talked, the narrator's main focus was on how this doctor's attitude made the experience even worse for her. She emphasized the idea that bedside manner is important in the medical field, not just when addressing patients but also when talking to their families. Language, especially in the medical field, can affect the relationship between the patient and the healthcare workers in charge of their treatment, but also convey an unintentional oppression or subjugation of the patient (Cox & Fritz, 2022). This inadvertently can be seen by the family of the patient as the doctors not caring properly for their loved one, thus affecting the way that the family views the healthcare system in general and adding more stress to an already trying situation. Several hospitals who have palliative care services also provide bereavement programs for the patients' loved ones, providing support during and after this incredibly hard period, because they understand the impact that illness has on the patient's entourage. The way the family is treated by professionals can really affect the way they view their loved one's illness and eventual death and one experience, good or bad, can affect their view of the medical field in general. In *With the End in Mind* (2017), Mannix illustrates the importance of the medical professionals offering honest and, most importantly, compassionate answers to both the patients and their families about the situation but also what to expect. It is telling that, when asked about her experience with her father's illness, this is the first thing she wanted to talk about, the point she most wanted to get across.

The third story is my own experience; one I have struggled to try to come to terms with for years. I think in this particular incident two things stick out. One, the fact that the patient is the one providing comfort and reassurance to the loved one instead of the more traditionally or commonly witnessed scenario – the other way around. This, I think further

highlights just how hard witnessing someone's illness can be. Two, the helplessness of not being able to do anything but be there is again a recurring theme in all three narratives. In this case, even though the narrator is older – nineteen years old – there is still no solution, no way to fix things, and no real illusion that the loved one is going to get better. In a study conducted on the effects of illness on patients' families, helplessness was mentioned by family members across the study, regardless of whether they were primary caregivers of not (Wittenberg et al., 2013).

These three narratives, overall, capture the essence of what it feels like to witness someone slowly dying, knowing there is nothing you, or anyone, can do about it, and that they are never going to get better. No matter how many emotions surge through you when you're in that situation—hope, fear, grief—the emotional rollercoaster always leads back to the same destination: helplessness.

Guilt

He Should Have Been Here

After my dad died, it was just my mom and me, struggling to deal with his passing, missing him every day, but at least we had each other. For us, that was good; most days, that was enough.

At the same time, however, I found myself clinging to the faintest traces of my dad in my life. I stole his jackets, wore them even when they were five sizes too big for me. I befriended people who had the same interests he did, or a similar sense of humor. I tried to remember our conversations, the advice he gave me, his opinion on different matters, his smile, his laugh, praying I would never forget any part of him.

And then my mom got sick, and it was just the two of us, so of course I went with her to doctors' appointments and hospital stays and treatment sessions. I did it all and I did it without complaint because I could not imagine my mom going through any of it without me being by her side. But through it all, I could not help but think that my dad should have been here. My dad would have helped her better, my dad would have known what to do, my dad would have been better at this than me.

Throughout my mom's sickness, I could not help but feel an unexplainable sense of guilt; instead of having my dad by her side, she had me. And sometimes, I could not help but feel that if someone had to die, it should have been me. How useful was I really to anyone, to my mom in particular? How much smoother would things have gone if my dad was the one helping her through her illness?

On the really bad days, the days when life had no meaning and no purpose, the days when I really wanted to die, that was when the guilt was the strongest. My dad had so much more to do, so much more to give, and here I was, useless and hopeless, wanting to die anyway, so why couldn't it have been me?

But those were the cards we had been dealt, and at the end of the day, I just had to deal with it. Life is unfair, I understood that much, and I just had to pick off the pieces and move on, because my mom needed someone, and that someone was me.

After my dad died, it was just my mom and me against the world, even though I wished he was the one by her side when she needed him most.

Switching Places

I spent a lot of time at my aunt's bedside in the last month before she passed. During that time, I got to witness her bad days, her better days and her worst days. During that time, I got to witness the slew of visitors that wanted the chance to talk to her one last time.

Friends, family, coworkers, people who hadn't visited in years came by, knowing she wasn't long for this world. Every time, the visitors would talk and joke and reminisce, and she couldn't talk much, or at all in the end, but she smiled, she nodded, she contributed as much as she could.

It was in these moments, as I saw the relief and pure love on these visitors' faces, that I started really understanding the impact my aunt had on everyone around her. To me, she had always been a source of comfort, but I had always believed it was because of our relation, because she was my godmother, because she took care of me when my mother wouldn't. In those moments, I saw that same air of comfort reflected in each and every visitor's face, and I realized, maybe it wasn't me, maybe it was just who she was.

These visitors would only acknowledge my presence at the very start and very end of their visits. For the most part, I was but a fly on the wall, witnessing these small windows of familiarity and peace amidst the chaos that was my aunt's illness.

One would expect a dying patient's visitors to be the ones trying to comfort, but for my aunt it was the opposite. She was the one reassuring them.

"Everything is going to be fine, don't worry," she would say in that soothing voice of hers. "I'm good, I'm okay, whatever happens is going to be okay."

And the visitors, every time, would leave the room crying, but smiling. As they left, every one of them, they would all say the same words to me. "Your aunt is an angel."

And I believed them. And the more visits I witnessed, the more I believed in the unfairness of it all. The more visits I witnessed, the more I believed she still had a purpose on this earth. And the more I thought of her purpose, the more I started thinking of mine. What was I doing with my life? What impact did I have on the people around me? Was I making any difference at all?

The more questions I asked, the more questions I had, the more I realized that my life, until that point, had been meaningless. Why then did I get to live on, with no purpose and no impact, when my aunt, with all her goodness, was slowly being taken away? Why end a life so full when there are so many empty ones around?

More than anything, I wanted to switch places with her, to die so she'd get to live, but it just wasn't possible. Her fate was to die, and mine was to live on and maybe try and make an impact so my life wouldn't stay meaningless forever.

Reflection 2 – Survivor's Guilt

Bistas and Grewal (2023) state survivor's guilt is particular to people who "have encountered or witnessed death and managed to survive the experience." This statement counters the widely accepted, and yet untrue, belief that survivor's guilt can only be experienced when the person was themselves in danger; witnessing it happen is enough. The two pieces above deal with this exact theme: survivor's guilt – the feeling of being left behind while someone more deserving is taken – when one was never in any

danger themselves. In *He Should Have Been Here*, the narrator grapples with feelings of inadequacy, of feeling like her father's absence is an injustice, not only to her but also to her mother. In *Switching Places*, the inadequacy is also present, although it takes a different form. Where in the former it had a physical manifestation in the form of situations where the narrator felt her father would have known better or acted better, it had a more abstract manifestation in the latter, with the narrator comparing her outlook on life to her aunt's – and her impact on life to her aunt's. Bistas and Grewal (2023) also mentions that survivor's guilt is often associated with feelings of unfairness and responsibility, something that is clear in the two stories above. Regardless of the way it shows itself in one's daily life, the guilt that comes from coming out alive from a traumatic experience that others did not survive, especially when the deceased is one we cared for in life, is a very real effect of witnessing a loved one's terminal illness.

Pain

Five Days

It took five days for my uncle to die. It took just five days for the life-loving, cheerful man we all loved spending time with to leave this earth.

On day one, he was in a lot of pain, so my aunt drove him to the hospital.

On day two, they did some tests. He was still in excruciating pain despite the medicine they were giving him, but he plastered a smile on his face when we went to visit. His kids were pretty young at the time, so everyone's main priority was to make sure they did not panic. And so, we hid our fears, hid our anxieties, and tried to reassure ourselves and the kids that everything would be just fine, that their dad would be back home in no time. But in that sterile hospital room, we all knew we were lying to ourselves.

On day three, he was diagnosed with liver cancer. The prognosis wasn't good, the doctors thought his days were numbered, and they told us that. It was at that point, with us kids out of the room, that the adults had their debate about giving him a merciful death. My sister, being older, was allowed to stay, and she told me what happened afterwards. Ten years after Uncle's death, I forgot the exact details, forgot whether it was because we're a conservative family or because my uncle wanted to spend as much time with his loved ones as he was allowed to, but they decided against it in the end.

On day four, the bleeding started. We went to visit him, the whole family, all the cousins, but we kids were kicked out of the room when it started. I only heard about it later from my sister. She told me my uncle bled from everywhere, every opening, every pore; it was horrible, or so I was told.

On day five, he was gone. My cousins were staying with us while their dad was in the hospital and their mom was by his side and my sister and I had to keep them entertained so they wouldn't dwell on the situation too much. Thankfully, we weren't the ones to break the news to them. My parents took them aside and tried to be as gentle as possible, as gentle as one could possibly be when telling a child they would never see their father again. Meanwhile, in the other room, my sister and I grieved the loss of our uncle, someone who had an unending love for life and was taken from us far too soon.

Let Her Die

My aunt's cancer metastasized to practically every part of her body. It was in her kidneys, it was in her bones, it was in her spine, it was in her brain and in her lungs. It was everywhere, and the symptoms just kept getting worse.

She got really thin, a paper-thin skin on twig-like bones. She got really weak, barely able to sit up for more than a couple of minutes at a time, let alone stand or walk. She had this horrible, horrible cough when she already couldn't breathe without the help of a machine.

Every day I was with her, every night I slept in the room next to hers, and I would listen to her ragged breathing, listen to her moans of pain, listen to that terrible, horrible cough. Every day, I would look at my aunt, barely a shadow of the woman she once was.

Every night, I would think, "Please, let her die. Please, let it end. Please, let her rest. Please, just let her die."

And every morning, I would go back to her bedside and feel guilty, feel selfish for wanting her to die only so I could stop watching it happen.

Every morning, I would remember that there were people who loved her so much, they couldn't bear the thought of letting her go. Every morning, I would watch my grandmother hold her dying daughter's hand, pray with her, pray for her. Every morning, I watched my other aunt brush her sister's hair and tell her stories of when they were kids. Every morning, I remembered what losing my aunt would mean, not just for me, but for everyone who was still clinging on to the few days they had left.

Every morning, I felt like the most horrible person for wishing death upon someone I loved so much. But then night would fall and the electricity would go out and we would all rush to switch out the machine for the old-fashioned oxygen tank and the whole thing would take less than a minute but that was enough for her to not be able to breathe, for her liquid-filled lungs to completely lose the ability to expand as she struggled to take in even the smallest amount of air.

Some nights, most nights, I was the first to reach her, so I would be the one switching out the tubes. In those moments, I could not allow myself to think of anything but what to do next. On the few nights when someone else was faster, I just stood there, my mind completely blank except for the phrase, "please let it end."

Those nights, I would stay just long enough to make sure the switch was successful before rushing back to my room, unable to stay around my family knowing I was having such selfish thoughts. On and on it went, a constant loop, every single day, until I finally got my wish and my aunt passed away.

Pulling the Plug

When a patient falls into a coma, especially one who has battled illness for a long time, doctors pull the family aside. Their voices are gentle, measured, but the question they ask is anything but soft.

"Do you want to pull the plug?"

Machines hum, monitors beep, the room thick with the scent of antiseptic and something else, something stale, unmoving. Keeping someone alive like this, suspended between life and death, is a cruel kind of purgatory. Hope flickers, fragile and desperate, but reality stands firm.

We never would have pulled that plug.

My dad's one wish throughout his illness was to die before he had to rely on anyone. He had always been a man of quiet strength, one who carried his burdens alone. In the end,

he got his wish. Had he woken up, he wouldn't have been the same. His hands, once steady and sure, would tremble. His voice, once full of warmth and command, would thin into something unrecognizable. His sharp mind, the one that had guided me through childhood, might have dulled beyond repair. Had he woken up, he would have wished he hadn't. So, he didn't.

The universe, or maybe he himself, granted my dad his wish when we were too desperate to cling on to hope to do so. Had he not died when he did, we would have continued as we had for those nineteen days, caught in the cruel rhythm of waiting, of whispered prayers and hollow reassurances.

There were days when I hesitated outside his hospital room, my fingers tightening around the door handle. Not today. Please, not today. I still need him. Inside, I would watch the slow, mechanical rise and fall of his chest, listen to the unnatural cadence of a body kept alive by machines. Wake up, Dad. Just wake up.

Other days, I would sit in the stiff hospital chair, my gaze tracing the wires and tubes that connected him to the world he could no longer reach. I would picture what waking up would mean, the complications, the endless therapy, the struggle, the suffering. Give him peace, I would think. Let him go.

And in the end, peace is what he got. On his own terms. The way he had always wanted.

I don't blame the families who choose to pull the plug. I admire their strength. Letting go, recognizing that keeping someone tethered to life means prolonging their suffering, takes a kind of courage I'm not sure I possess.

My mom and I? We never would have pulled that plug. We would have stayed in that room, caught in an endless loop of beeping monitors and hushed voices. As if we, too, were hooked to those machines.

We never would have moved on. Never would have grieved. Even now, eight years later, I still find myself listening for his voice, still expecting to see him walk through the door, still telling myself he's just on an extended work trip. Pulling the plug would have meant saying goodbye. We weren't ready for that. Maybe we never would have been.

Reflection 3 – Mercy or Hope

When is it merciful to let someone die? When is it ethical to let someone die? Is prolonging the life of one who is suffering an act of love or an act of cruelty? Is death a sentence or a mercy? The three stories in this section attempt to put this dilemma into perspective, not necessarily to try and come up with an objective answer, but to highlight the impossibility of such a choice.

In *Five Days*, the family is faced with the question of euthanasia after the uncle's terminal diagnosis. The fact that it was even considered an option in Lebanon, a country where "laws strictly prohibit mercy killing" (Zouheiry, 2022), especially when the narrator himself admits that his family is a more conservative one, is interesting, to say the least. Ultimately, the choice to stay alive was the patient's own decision in this case, even when it resulted in his final days being filled with pain. Nevertheless, the suffering that his uncle had to endure haunts the memory of the narrator, even when the entire ordeal lasted a relatively short period of time. Kolmetz (2024) discusses the reality that witnessing someone else's trauma is

a trauma in and of itself, what the author calls secondary trauma. Additionally, the Center for Substance Abuse Treatment (2014) reinforces that trauma can impact an individual either subtly or outright, but always destructively. Another oddity regarding the family's consideration of euthanasia is that the uncle was gone really quickly, when compared to other terminal illness journeys which can last several years. Thus, even if they were still struggling with the decision or debating the merits of mercy killing, the choice was taken out of their hands.

Let Her Die presents a more internalized version of this dilemma. The narrator, witnessing her aunt's excruciating decline, repeatedly wishes for her death, not out of malice, but out of love. The profound guilt that follows is one she would struggle to rationalize until years later; how can someone wish for the death of someone they care for so deeply? And yet, isn't that wish, in this case, the most compassionate response to unbearable suffering? Isn't it, in a way, a wish not for the person to cease to exist, but for their suffering to end? Multiple accounts of people who have witnessed a loved one's struggle with illness have shown that wishing for an end to the suffering, both of the patient and of the caregiver, is a common response to that situation – Lauren Dykovitz (2023) even calls the thought, or wish, selfless. This story forces us to consider and acknowledge the uncomfortable, some may say horrible, truth about terminal illness: sometimes, survival is not mercy, it is torment.

Pulling the Plug takes this debate one step further. The narrator and her mother's inability, or refusal, to let go is deeply human. We desperately cling to the things we love, even when we know that letting go may be the kinder option. Denial is the first stage of grief, and for the people witnessing a loved one's terminal illness, the grieving process begins before the patient is even gone: "You grieve for them during the disease and then you grieve for them again when they pass away" (Arrigo, as cited in Dementia Australia, 2023). To the narrator, letting go would be accepting that her father was never coming back, something she was not ready for at the time, something she admits that she would never have been ready for. On the one hand, for a lot of people, pulling the plug feels like giving up, like making death a choice rather than an inevitability, but on the other hand, is keeping someone alive through machines really preserving their life, or merely delaying their death?

Studies have shown that, even in cases where the patient had been going through an illness for a while, very few patients actually discuss their wishes and preferences with their families (El Baradei, 2022). This all revolves around the taboo that exists around the topic of death and dying, something that both Dr. Mannix (2017) discusses in her book and tries to destigmatize. Talking about one's wishes in such a case, especially when diagnosed with a terminal illness, would alleviate guilt and responsibility from the family as well as prevent conflict between the family's wishes and the doctors' professional advice. The narrator of this piece recognizes years later that her father may have preferred to die than to have to live fully dependent on others. In the end, the choice was taken out of the family's hands, just like in the first narrative of this section, by the father passing away. The narrator reflects on the timing of her father's death as them being "less unfortunate," since protocol would have required medical professionals to open up his trachea on the 21st day of his coma, which would have resulted in a slew of other complications had he eventually woken up after that. Nasir Bhatti lists the short-term and long-term complications that might arise after a Tracheostomy, some of which are immediate and others might only be witnessed years after the procedure.

Across all three narratives, and in life in general, there is no "correct" answer to this debate. Euthanasia and mercy killing are deeply personal and ethically complex issues, tangled in legal, cultural, religious, and emotional factors. What these stories make painfully clear is that letting go is sometimes the hardest and most loving thing one can do, but that doesn't make the loss any less agonizing.

Conclusion

This work is not about any specific terminal illness. It is not about any particular people or situations. This work is an attempt at explaining what it's like to witness a loved one go through the final stages of a terminal illness, something that, ultimately, one cannot hope to summarize in a few pages. The questions asked are not ones that have any specific objective answers, at least none that can be found in one person's lifetime. At the end of the day, watching someone we love slowly fade away and die, especially after a struggle with illness, is an experience that is both deeply personal and yet universal in many ways. My only hope, at the end of this journey, is to have done right by the people whose stories I am retelling and that whoever reads this piece gains something from it, if only the tiniest bit of comfort that they are not alone, no matter how unique their situation.

Ella Waked
BA Student, English, Lebanese American University (LAU)
ella.waked@lau.edu

ENDNOTES

1. Shahd AlShammari is also the author of *Notes on the Flesh* (2017) and *Confetti and Ashes* (2025). AlShammari teaches literature and has written numerous short stories, as well as creative nonfiction. Her research areas include illness narratives and disability studies (AlShammari, n.d.).
2. Multiple sclerosis is an autoimmune chronic disease of the central nervous system wherein the myelin sheaths of the nerve cells are attacked and destroyed, damaging the nerves and disrupting signals to and from the brain (Johns Hopkins Medicine).
3. Palliative Care is an area of medicine that aims to improve the lifestyle quality of patients and families coping with challenges caused by a terminal illness (World Health Organization, 2020).

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